A ‘Magical Mystery Tour’ That ‘Makes Your Brain Hurt’

Understanding parents’ experiences of help-seeking for a child who has ADHD / difficulties with attention, concentration, impulsivity and / or hyperactivity: A mixed-methods study.

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I, Alexandra Wall, confirm that the work presented in this thesis is my own. Where information has been derived from other sources, I confirm that this has been indicated in the thesis.

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Abstract

Increased prevalence of Attention-deficit hyperactivity disorder (ADHD) diagnoses in children and young people have led to questions about how best to support this group. Recent media coverage of what has been termed a 'SEND crisis' and discussions at policy level around how local authorities can sustainably deliver effective support to children and young people with Special Educational Needs and Disabilities (SEND), have focussed attention on the difficulties that some families have experienced when trying to access support from professionals. A review of the Educational Psychologist (EP) workforce by the Department for Education highlighted an important role for EPs in mediating between health services, families and schools, but noted how growing public awareness around neurodiversity has led to an increase in requests for support, with insufficient resources to meet demand.

This study aimed to explore parents' experiences of seeking help for their child's difficulties related to ADHD in order to suggest how EPs can provide the best support. Taking a mixed-methods approach to understanding parents' help-seeking, through the critical lenses of critical realism and pragmatism, this study used insights from qualitative data obtained through fourteen semi-structured interviews that, when taken together with broader survey findings from a sample of forty parents, highlight how EPs can ensure their support is appropriate, helpful, and an effective use of resources. Results from a reflexive thematic analysis were explored within ecosystemic frameworks and found that family, environmental, and wider systemic factors shape both children's difficulties and parental challenges in seeking support. An ADHD diagnosis is viewed by parents as aiding understanding and access to help, but obtaining this diagnosis is challenging, with unclear entry points, long waits, and unequal access. Being listened to by empathetic professionals was described as vital. These findings add to a body of literature on parental help-seeking, and may be used by local authorities to help design, commission and deliver more effective services for children and families affected by ADHD or related difficulties.

Impact Statement

This qualitatively-driven, mixed methods study explored the experiences of parents seeking help for their child's difficulties related to ADHD. Survey responses were used to indicate general patterns of service use and parents' levels of satisfaction in their engagement with professionals. Following this, a reflexive thematic analysis of in-depth interview data was conducted in order to develop storied illustrations of parents' experiences. My findings suggest that family, environmental, and systemic factors shape both children's difficulties and parental challenges in seeking support. An ADHD diagnosis is viewed by parents as aiding understanding and access to help, but obtaining this diagnosis is challenging and stressful, with unclear entry points, long waits, and unequal access. These findings have implications for further research, professional practice and policy.

Firstly, the study has indicated some key areas for further research. Although this study adds a robust reflexive thematic analysis that adheres closely to Braun and Clarke's frameworks (2006; 2022) further quantitative studies with large-scale samples could investigate interactions between cultural, social, and economic factors, and how these shape parents' help-seeking pathways, particularly in marginalised or underrepresented populations. Longitudinal studies could examine how experiences evolve pre- and post-diagnosis, and how these relate to treatment outcomes. Given the themes raised by this study related to labelling, further qualitative research into children's own experiences of their diagnosis and how labels affect self-concept, identity formation, and engagement in learning would also be valuable. Furthermore, this study has indicated scope for pilot studies into a novel 'active waiting' intervention (e.g., remote monitoring apps) to support parents and their children whilst they await ADHD assessment.

As well as benefits to the research community, this research can benefit my own and others' professional practice. It underscores the important role that EPs can play in bridging gaps between families, schools, and health services, by providing holistic assessment of a child's needs as well as supporting families to navigate these different systems. Professional practice frameworks should empower EPs to take a role in supporting systemic change, promoting equitable access, and challenging reductive narratives around ADHD and behaviour whilst maintaining the ability to listen to and validate parents' voices. Disseminating my findings amongst my own local authority, as well as a wider network of professionals in other EP services through my trainee EP cohort, will help to spread this study's key message around the importance of valuing parents' views and preferences.

Finally, this study has possible implications for policymakers, which are of particular relevance considering the current scrutiny that Local Authority SEND provision is under. This study has found that parents are not always receiving accessible information as they should be under the Children and Families Act, 2014, and therefore policymakers should address the need for families to be provided with information including maps for support pathways and decision-making tools for intervention and treatment. Ideally, there should be national guidance on coordinated, transparent pathways for ADHD-related help-seeking, co-developed with families and professionals, with EPs involved in their design and dissemination in order to endorse a broader biopsychosocial understanding of ADHD that extends a medical model. For EPs to be involved in this consultative work, in addition to providing the early intervention that may reduce the need for formalised assessments, consideration will also need to be given to increasing capacity within the EP workforce.

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Definition of Key Terms

ADHD: Attention deficit hyperactivity disorder

The British Psychological Society (BPS)'s Division of Educational and Child Psychology defines ADHD as: "a diagnosis, typically given by psychiatrists or paediatricians, to children and young people whose behaviour appears to be inappropriately impulsive, overactive and/or inattentive for their age, and which may present barriers to their learning and social functioning."

(Division of Child and Educational Psychology (DECP), 2022a, p.1)

Note that, whilst some use the term Attention Deficit Disorder (ADD) when behaviours include inattention and impulsivity but without hyperactivity, in this thesis I have used the term 'ADHD' across these varied presentations.

Help-seeking

The process of help-seeking has been defined as: "the active search for resources that are relevant for the resolution of [a] problem."

(Zartaloudi & Madianos, 2010, p. 662)

Note that, in line with a neurodivergence-affirmative perspective (e.g., Sonuga-Barke & Thapar, 2021), in this thesis, the 'problem' is not necessarily located within the child, but can be related to aspects of a child's environment which require adjustment to allow the child to thrive.

SEND: Special Educational Needs and Disabilities

The SEND Code of Practice states: "A child or young person has SEN if they have a learning difficulty or disability which calls for special educational provision to be made for him or her."

(Department for Education (DfE) & Department of Health (DoH), 2015)

1. Introduction

1.1. Research overview and context

In this mixed-methods study, I have explored parents’ help-seeking experiences for a child who either has a diagnosis of Attention-deficit hyperactivity disorder (ADHD) or experiences difficulties associated with this condition. I have considered patterns in help-seeking experiences across forty families, with a nested sample of fourteen parents providing further elaboration in the qualitative phase. I have considered the possible impact on parents and their children of differences in help-seeking experiences that may be mediated by factors such as socioeconomic status. As a mixed methods project, I have described broader trends that were indicated by survey responses and explored these in depth during semi-structured interviews and a subsequent thematic analysis of data.

This research has been undertaken to fulfil the requirements of the doctoral training course in Educational, Child and Adolescent Psychology (‘DEdPsy’) at the UCL Institute of Education, and as such has been conducted with an eventual goal of detailing how educational psychologists (EPs) are able to offer more effective support to families and schools. This study adds to a body of literature on parents' experiences of gaining support for a child with ADHD or related difficulties within a help-seeking framework, and adds a particular focus on interactions with EPs.

The thesis is organised as follows:

Chapter 1 introduces the study's focus and provides a rationale for the research by outlining key legislation across education and health, and the background to ADHD including diagnosis, prevalence, treatments, and the aetiology of the condition. It considers parents’ experiences, and looks at the respective roles of schools and EPs, set within the current context, and linking to my own previous research. Finally, I outline the help-seeking frameworks that have influenced this study.

Chapter 2 contains a review of the literature that examines in more detail how parents have been shown to seek help for their child at different stages of the help-seeking process.

Chapter 3 details and justifies the research methodology, covering the chosen paradigm, considerations of quality, research design, participant information, data collection and analysis methods, and ethical considerations.

Chapter 4 presents the research findings, with results from the quantitative phase presented first, followed by a thematic analysis of interview data from the qualitative phase.

Chapter 5 discusses my research findings in relation to existing studies and the legislative context, before addressing the study's limitations and providing recommendations for EP practice and future research.

Note on terminology: I have used the word 'parents' in this study to indicate any person with parental responsibility. The recruitment materials and survey used the wording 'parents/carers', with the intention of being as inclusive as possible and to engage possible participants who self-refer in ways other than 'parent'. In the event, all participants indicated that their relationship to the child was either 'mother', 'father' or 'parent'.

1.2. Relevant legislation and guidelines

The aim of this study was to improve ways of working that are in line with legislation specific to EP work, primarily the statutory guidance in the Special educational needs and disability (SEND) code of practice: 0 to 25 years (Department for Education & Department for Health, 2015) which outlines the legal responsibilities of Local Authorities (LAs) schools and health services under the Children and Families Act 2014. In addition to the code of practice, given the nature of ADHD as a medical diagnosis and the crossover between health and education in the assessment and treatment of ADHD in children, guidelines for health professionals – namely the National Institute for Health and Care Excellence (NICE) Guidelines – are also relevant to the study.

The SEND code of practice explains processes for the new Education, Health, and Care (EHC) plans that were introduced in the Children and Families Act 2014 in order to provide additional resources for children whose special educational needs require support above what is ordinarily available in schools. There is one specific reference to ADHD under the 'Social emotional and mental health difficulties' area of need, but the code is largely more general in its explication of how person-centred approaches can be applied across the range of SEND. Importantly for this study due to its focus on parental help-seeking, the code emphasises the importance of parents' rights to active involvement in decision-making for their child's educational provision, and insists that they be provided with accessible information regarding services that can support their child, as well as highlighting the need for integration and multi-agency working across different services.

NICE clinical guidelines are evidence-based recommendations for those working within the National Health Service (NHS) in England and Wales, in order to ensure appropriate treatment and care. The most recent guidelines for the diagnosis and management of ADHD were published in March 2018 and updated in September 2019. The following recommendations are particularly pertinent to this study: (a) training programmes on the diagnosis and management of ADHD should be developed by specialist teams for (amongst others) education providers (1.1.7); (b) ‘Referral from the community to secondary care may involve health, education and social care professionals (for example, GPs, paediatricians, educational psychologists, SENCOs, social workers) and care pathways can vary locally’ (1.2.5); (c) when recommended to parent training programmes, parents should be reassured that this does not imply ‘bad parenting’ (1.4.11); (d) the importance of a holistic treatment plan that takes into account the preferences of the child and their parents (1.5); and, (e) medication should only be offered to children over 5 years old if symptoms are still causing significant impairment following environmental modifications (1.5.13). These guidelines are an important backdrop to the study in considering whether or not they align with parents’ experiences in practice, and will be referred to throughout.

1.3. Background to ADHD in children

Children who have been diagnosed with ADHD typically demonstrate a pattern of behaviours including inattention, impulsivity and hyperactivity (Russell et al., 2022). In England, clinical diagnosis is usually made when children display six or more symptoms (NHS, 2021) from a list of eighteen criteria as set out in the fifth edition of the American Psychiatric Association’s *Diagnostic and Statistical Manual of Mental Disorders* (DSM-V, 2013) which are deemed to be “excessive for the person's age or level of overall development” (NICE, 2019, 2.1) and occur across two or more settings (generally home and school) for at least six months. Although some strengths, such as the ability to hyperfocus, have been observed in those diagnosed with the condition (Hupfeld et al., 2019) there is also an association between ADHD and negative outcomes both at school, including academic underachievement and increased likelihood of exclusion (Loe & Feldman, 2007; Parker et al., 2015), and later in life for the 30% - 60% of children whose symptoms persist into adulthood (Caye et al., 2016). There is a high degree of comorbidity with other neurodevelopmental conditions, and a second diagnosis of autism alongside ADHD is not uncommon (Fibert & Relton, 2020).

ADHD as a diagnosed condition is estimated to affect approximately 5% of children globally (Sayal et al., 2018), although, as symptoms exist on a continuum, it has been suggested that a further 5% have difficulties which do not meet the threshold for diagnosis (Sayal et al., 2018). It is one of the most commonly diagnosed psychiatric disorders in childhood, with more boys than girls receiving a diagnosis (Singh, 2012). The prevalence of ADHD continues to rise, attributed to changing diagnostic criteria as well as increased awareness in both medical professionals and the public (Abdelnour et al., 2022). Trends across popular social media demonstrate rising views of content with the hashtag ‘adhd’, currently standing at 33 billion views on TikTok over the last three years (see Appendix 1.1), with much of this content inaccurate or misleading (Yeung et al., 2022).

As awareness of the condition increases, and demand within the National Health Services (NHS) grows, clinical services have become overstretched, leading to long waiting lists for children awaiting assessment (Valentine et al., 2024). Some of those seeking help who have financial resources to do so are turning to private healthcare providers (Wall, 2023), however a BBC *Panorama* documentary exposing the practices of some private ADHD clinics (15 May 2023) suggested that diagnoses obtained through such services are often the result of inadequate clinical assessment, conducted online and not by healthcare professionals with adequate training (Khan, 2023). Whilst this documentary focussed on adult experiences, my own research (explained further in 1.9. below) revealed how some parents (according to the EPs who had worked with them), frustrated by long waiting lists for NHS paediatric mental health services, were turning to private clinics to seek help for their child's difficulties, with some even travelling abroad in order to obtain a diagnosis for their child (Wall, 2023).

1.4. Aetiology

Different aetiological orientations draw on opposing explanatory models for the causes of ADHD, with the three main models being the biomedical, the sociocultural, and the biopsychosocial (Flack, 2018). The biomedical model asserts that abnormalities such as differences in levels of neurotransmitters in the prefrontal cortex affect executive functioning, leading to the difficulties we associate with ADHD (e.g., Lambek et al., 2011) and proponents cite the high level of heritability for ADHD traits (see, for example, twin studies; Nikolas & Burt, 2010). However, there is currently no biomarker that can be used for diagnosis (Abdelnour et al., 2022) and a lack of surety over the aetiology of the condition has fuelled debate, with those favouring a sociocultural explanation questioning medicalised formulations of behaviour. One vocal proponent of the sociocultural model is Sami Timimi (2005, 2015, 2017, 2021) who questions the validity of ADHD as a construct, arguing it is a 'pseudo-diagnosis' reliant on subjective interpretation, which "cannot explain behaviours or experiences as there are only symptoms that are descriptions (not explanations)" (Timimi & Timimi, 2022, p. 17). Exponents of the sociocultural discourse express concern that children are being prescribed psychotropic medication due to non-conformity with social norms and we should be working to understand behaviour rather than medicating it (Visser & Jehan, 2009). A wide range of non-biological factors that may influence ADHD-type presentations in children have been identified, such as parenting styles (Deault, 2010), sleep disturbance (Becker, 2020) and late birthdate in relation to school cohort (Whitely et al., 2019). Furthermore, the cumulative effect of adverse childhood experiences on ADHD diagnosis has been noted (Banerjee et al., 2007; Klein et al., 2015) and associations made with socioeconomic disadvantage (Russell et al., 2014). Children with a history of developmental trauma may also be more at risk of developing negative self-beliefs as a result of receiving a diagnosis (Rostill & Myatt, 2005).

At the least, ADHD may be regarded as a ‘delicate diagnosis’ which may be ‘difficult’ due to fluctuating, subjective symptoms, ‘disputed’ in terms of medical validity and ‘desired’ by powerful advocates (see McCartney et al., 2022, for a detailed discussion) or those otherwise struggling to access resources and support (Wall, 2023). Many EPs value the biopsychosocial model as a middle way in which to understand the complex and varied influences on children’s ADHD-type presentations. This model acknowledges the interacting and overlapping nature of the different components – biological (including genetics and atypical brain function), psychological (including aspects of mental health) and social (and environmental, including parenting and classroom practices) - that affect an individual’s health and wellbeing. The model fits well into the context of EP work, which will be discussed further in section 1.8. By considering difficulties through this multi-modal lens, the biopsychosocial model addresses the limitations of the more singular perspectives and allows for more holistic support (Engel, 1977) respecting the different, complementary roles of environmental modifications and medical interventions where necessary.

1.5. Treatment options and parental preferences

Treatments for ADHD in children aim to manage symptoms (Fibert & Relton, 2020) and comprise either pharmacological or non-pharmacological approaches (Hill & Turner, 2016). Pharmacological approaches include the use of stimulant medications such as methylphenidate, whereas non-pharmacological approaches include environmental modifications (the recommended first-line treatment in NICE guidelines), parent-training programmes and therapeutic approaches such as cognitive behavioural therapy (Coghill, 2004). Prescription rates of methylphenidate continue to rise, with the Care Quality Commission reporting an 8% increase in their last report (2021). Although randomised controlled trials have demonstrated the effectiveness of commonly-prescribed stimulants in ameliorating ADHD-related symptoms in the short-term by supporting a child's ability to focus on tasks (Cortese et al., 2018), contrasting evidence indicates that any positive effects on academic outcomes may diminish as medication use is continued into adolescence (Posner et al., 2020) with one possible explanation being poor medication-adherence in this group (Charach & Fernandez, 2013). Furthermore, while we do not yet fully know the risks of long-term stimulant-use (Sayal et al., 2018), there is convincing evidence indicating a range of negative side-effects, including changes to growth (Poulton, 2005) and weight (Cortese, 2020). Possible associations have also been made between stimulant use and cardiovascular problems (e.g., Martinez-Raga, 2013).

As children do not generally make decisions about their own mental health treatment (Graves, 2017), it is their caregivers – predominantly parents - who mediate the experience of seeking help by advocating for their child (Tamm et al., 2023) and making choices about treatments. Strong motivators for parents initiating and continuing with pharmacological treatments for their child include concerns about academic progress and perceptions of growing social isolation (Ahmed et al., 2017). In their study of Australian parents, Ahmed and colleagues found that symptom improvement - often noticed very quickly - led to parents continuing with treatment, but where parents chose to cease or modify drug regimens (for example, by not giving their child medication at the weekends or during holidays) it was because of concerns about side effects, such as appetite suppression, stunted growth or possible future drug addiction. The authors concluded that parents need ongoing advice and reassurance regarding their child's medication, but that they are not always empowered to make decisions in this way. This is despite supposed shifts towards shared decision-making healthcare, away from paternalism (Hayes et al., 2023).

Similarly, in England and Wales, despite NICE guidelines (2019) stating that parents' and children's preferences regarding treatment should be taken into account, there is evidence to suggest that such discussions are not always taking place (e.g., Hill & Turner, 2016). A wide range of non-pharmacological and psychosocial treatments – which may be more acceptable to parents (Brinkman & Epstein, 2011) - have been proposed, including: modifications to the classroom environment (DECP, 2022a), cognitive behavioural therapy (Moore et al., 2018) and parent training (Glasser & Easley, 2016). However, in a U.K. study of parents' preferences (Town et al., 2016), over 64% of respondents said their child had taken stimulant medications despite the same proportion expressing preference for non-pharmacological treatments, leading the authors to call for a decision-making aid to be provided to parents at the point of treatment-selection. This is an especially helpful recommendation given the difficulty in finding good-quality information online, when search engines may highlight results sponsored by pharmaceutical companies over an impartial NHS information site (McCartney et al., 2022).

1.6. Parents’ experiences

As stated, parents are typically the voice of their child and so advocate for them in healthcare and education matters (Boshoff et al., 2016). Therefore, in this section, I will consider parents’ experiences in relation to having a child with ADHD or related difficulties. I will define parent advocacy and introduce how different parent characteristics and experiences can affect the nature of how parents advocate for their child. I will consider how parents are affected by the experience of parenting a child with ADHD and consider reasons suggested by previous research for why parents might seek help – and advocate – for a child with attentional or hyperactivity difficulties. Finally, I will introduce the help-seeking frameworks that have provided the theoretical basis for this study.

1.6.1. Parent advocacy: What, how and why?

From a philosophical standpoint, such as that of intersectionalists Harry and Ocasio-Stoutenburg (2021) speaking in relation to black children with disabilities, parent advocacy can be as fundamental as, ‘a desire to have one’s child matter in the eyes of other human beings’. Most definitions incorporate concepts that pertain to parents’ efforts to support their child’s development and wellbeing through obtaining support, raising concerns on behalf of a child and, in some cases, advocating for change on behalf of the larger group to which the child belongs (e.g., Boshoff et al., 2016). Trainor (2010) proposes four different types in relation to how parents advocate: (1) intuitive, whereby parents use their own instinctive knowledge of their child to advocate for support; (2) disability expert, where the parent uses their knowledge of the condition or disability; (3) strategists, who refer to their rights in order to secure access to services (which in England might include the legislation outlined above in 1.2., and other relevant legal protections such as those included in the Equality Act 2010); and (4) agents of systemic change, who campaign for changes that will benefit all children in the group their child is part of.

Previous research suggests that the nature of parent advocacy can be impacted by parent characteristics, for example, parents who have more knowledge or work in the field are more likely to advocate (Burke et al, 2018) by taking the ‘disability expert’ role. Attempts to secure support and services can take significant time and energy, and not all parents have such resources, with research suggesting that parents of lower socioeconomic status can be limited by factors such as a lack of financial resources or more inflexible work arrangements (Lalvani, 2012). As differences in parent advocacy (that may be mediated by factors such as socioeconomic status) can lead to further inequalities and impact child outcomes (e.g., Lareau, 2018), from a social justice perspective this is an important consideration for EP practitioner research such as this.

1.6.2. Parental stress

Both the experience of parenting a neurodivergent child and the processes of obtaining help for that child can be linked to higher levels of stress (e.g., Boshoff et al., 2016). Whilst the predominant reason why parents choose to advocate for their child is in order to create a better future for their child (e.g., King et al., 2009) it has been suggested that the act of advocating in the early phases of diagnosis can also bring a sense of control to what is an otherwise uncertain and difficult experience (Boshoff et al., 2016).

Previous qualitative research has demonstrated high levels of stress for parents who have a child with a diagnosis of ADHD: Corcoran and others (2017) conducted a meta-synthesis of 73 studies of parents' lived experience of having a child with ADHD and found that parents across the studies were describing the emotional burden of parenting a child with ADHD, feelings of isolation and helplessness, and challenges that overspilled into their own wellbeing, relationships and jobs. The authors concluded that parents need more support and validation of their experiences. A meta-analysis of 44 quantitative studies (Theule et al., 2013) suggested that the level of stress may differ according to contextual factors (such as parental relationship status, with single parents experiencing higher levels of stress) as well as the particular nature of the child's presentation. Whilst it has been suggested that parental stress may be a cause rather than consequence of a child's ADHD diagnosis (e.g., Deater-Deckard, 1998; Haack et al., 2016) qualitative studies have highlighted many of the day-to-day challenges for families in which a child has been diagnosed with ADHD. For example, Ringer and others (2020) explored the long-term processes involved in Swedish parents' meaning-making in relation to their child receiving an ADHD diagnosis and, through semi-structured interviews with twelve parents, heard of the difficulties that they experienced with everyday routines such as getting ready for school, and managing demands from others such as teachers or other parents, as well as difficulties for the parents when attempting to implement their own personal values regarding child-rearing. The authors identified further conceptual categories to capture how parents adapt in order to cope with their challenges, describing a diagnosis as “a kind of mediating factor” (p. 382) whereby parents are given a “clear threshold to a new way of interpreting their child's behaviours and needs” (p. 384). The authors found that, for their homogenous sample of highly-educated parents, a diagnosis removed ambiguity by framing the child's difficulty as a biological inability, making it easier for the parents to understand the behaviour and thus manage it (see also Kendall, 2016). Furthermore, this view of the child was less threatening to parents' views of themselves and enabled them to regulate previously-held emotions of shame. Indeed, to consider, specifically, the role of the mother in choosing – or consenting – to seek a diagnosis of ADHD for their child, is to consider the multiple and conflicting socially-constructed discourses affecting that role (DiQuinzio, 1999). Legacies of harmful psychoanalytic theories, such as Bettelheim's (1967) 'refrigerator mothers' causing autism in their children, reverberate in far more recent research pointing, for example, to a bidirectional relationship between a child's AHDH and "impaired mothering" (Chang & Gau, 2017). With mothers commonly held responsible for the well-being of their children, having an ADHD diagnosis can redirect the responsibility for a child's difficulties away from the mother (Lindley, 2013) which is especially helpful when society's support resources will only be deployed, "when it has been established, by the scientific or medical community, that it is not the mothers' way of behaving that has led their children to be different" (Lindley, 2013, p. 13). Therefore, it is unsurprising that mothers often pursue medical explanations for their child's attentional difficulties and hyperactivity (Malacrida, 2001) and are willing to challenge professionals who dispute ADHD as an explanation for the behaviour (Norris & Lloyd, 2000).

Such stigma can have a significant impact on parents' own levels of wellbeing. In an exploratory study with Australian parents, Leitch and colleagues (2019) found that high levels of stress experienced by parents were a product of their child's behaviour and social difficulties plus the stigmatizing attitudes of others, plus the families' unmet support needs. The authors' qualitative study, illustrated with rich narrative descriptions throughout, conceptualises parents' experiences of home feeling like a 'warzone' at times, capturing the emotive and challenging nature of the topic. Whilst the study is limited insofar as the participants had already self-identified as experiencing high levels of stress, the findings led the team of researchers to design and implement a pilot and feasibility study for a mindful parenting intervention (Leitch et al., 2023). The authors reported positive outcomes for all parents in the study, suggesting they had found aspects of the course helpful. Although the proposed delivery format of face-to-face retreats may not always be practically viable for families, and would require significant resources, the parents commented on the value of developing social connections at these events. Short follow-up exercises conducted at home using either a paper manual or a phone App supported parents to become more aware of their thoughts, feelings and behaviours, and 'respond rather than react' to children's challenging behaviours. The authors note there were differences in the preferences or participants, suggesting, importantly the need for interventions to be flexible, responsive and personalised. Whilst some participant characteristics were collected, demographic data related to ethnicity and class were not collected for this small sample, therefore cultural attitudes and beliefs may have affected the acceptability of the intervention.

1.7. Role of schools in the diagnosis and management of ADHD in children

As noted in 1.2. above, although the exact nature of involvement is dependent on local referral pathways, schools have a key role in supporting parents when they seek help for their child who has difficulties with attention, concentration and/or hyperactivity. Furthermore, given how these challenges can impact children's ability to access the curriculum (e.g., a meta-analysis suggested a comorbidity rate of 45% between ADHD and a 'learning disability; DuPaul, 2012), as well as their social and emotional wellbeing at school, schools are further obliged under the SEND code of practice (2015) to explore with parents how their child can be best supported in their education and implement school-based interventions. However, teachers do not always feel well-equipped to fulfil their obligations in this area, due to a lack of timely, accessible and effective training (Ward et al., 2021) despite reporting that children with ADHD can be more stressful to teach (Greene et al., 2002). Additionally, it has also been suggested (via sociocultural explanations for ADHD) that the school environment itself may be contributing to children's attentional difficulties. In 2016, a systematic review of qualitative research into the influence of school environments on ADHD symptoms concluded that classroom expectations on children to sit still and be quiet can trigger or aggravate symptoms (Gwernan-Jones et al., 2016). Indeed, those who work directly with children have long voiced concerns about school environments being overly focussed on improving examination results at the expense of children's wellbeing (Fisher, 2022) with teacher expectations of children sitting still and quietly for long periods in the classroom being unfair and unrealistic (Prosser, 2008). One study in the United States (where different policies in different states enable comparison) has even indicated that higher levels of accountability in schools correlate with increases in ADHD diagnoses (Carr, 2015). A sociocultural perspective might conclude that such diagnoses are facilitating the 'pharmaceutical suppression of behaviour[s]' that are bothersome to teachers (Graham, 2008). At the very least, these findings suggest that the wider political systems influencing education can determine how behaviours are perceived and labelled.

1.8. Role of Educational Psychologists

Whilst EPs working in England do not generally have a role in the formal assessment and diagnosis of ADHD in children and young people (Hill & Turner, 2016), they do have an important part to play in supporting schools and families with evaluating children’s additional needs within both the school and home systems (DECP, 2022b), implementing appropriate interventions (DECP, 2022a) and collaborating across different stakeholders and services to develop solutions that benefit children (Atfield et al., 2023). Whilst a medical model of disability may see ADHD as a deficit that needs to be treated and corrected (with medication), EPs tend to work within social constructionist frameworks in which “differences are not viewed as deficits” (DECP, 2022a; p.3) and, rather than seeing the child themselves as needing correction, instead, EPs attempt to identify disabling societal barriers, and support the development of adaptations. Whereas the medical model of disability is based on ‘neuronormative assumptions’ (Hartman et al., 2024), proponents of a ‘neurodiversity affirmative’ approach reframes individual difference, and shifts the focus to what needs to be changed in order to support an individuals’ need.

Addressing members of the British Psychological Society’s (BPS) Division of Educational and Child Psychology (DECP) at a conference in 1976, Hargreaves argued that children only become ‘maladjusted’ when they are labelled as such. Following this argument, once a child is categorised as having a biological ‘disorder’ such as ADHD and problems have been positioned within the child, the systems around the child – primarily the school and family - are no longer responsible for making adaptations to the environment. Furthermore, the child may “begin to believe such (deficit) accounts of their personhood and perhaps subtly imbibe, accentuate, or assume the characteristics of the attributed diagnosis” (Billington, 2021, p. 8, explaining Hacking’s concept of ‘classificatory looping’ (1995)). The EP’s role, then, is to “look to the labelling process rather than at the labelled product” ((1976, p. 6) which involves asking, as Osborne (2003) suggests, ‘who owns the problem?’

Research suggests that the ‘problem’, as located within a child and identified as possible ADHD, is often initially owned by teachers rather than parents (Ringer et al., 2020). With pressures from performance targets (as noted above) and budgetary constraints (Done & Andrews, 2020), schools may become reliant on identifying children as having special educational needs so as to acquire additional resources (Weale & McIntyre, 2018). This can lead to protracted collecting of ‘evidence’ of the child’s problems, thereby reinforcing the deficit account (Frederickson and Cline, 2015). Previous research has found that EPs tend to hold more inclusive attitudes regarding ADHD, and greater knowledge of the condition than other education professionals (Toye et al., 2019; Wiener, 2020), highlighting the necessary role of EPs in supporting children and families where difficulties related to ADHD have been identified.

Working with parents is an important competency for EP practice, as set out by the British Psychological Society (BPS) and professional standards that must be met for registration with the Health and Care Professions Council (HCPC; 2016); for example, competency 1.7 refers to “working in partnership with parents and carers” and 6.8 highlights the importance of “promoting collaboration and partnership between parents, school and community agencies”. Of the five main areas of EP work as outlined by Fallon and colleagues (2010), three - assessment, intervention and consultation - are likely to involve at least some direct contact with parents, although consultation is the only of these that routinely involves parents as a significant part of the process, and is generally mediated by the child’s school (and rarely a service that parents can independently access, as noted by McGuiggan, 2021). Described by Dowling and Osborne (2003) as a process in which EPs support parents and teachers to mobilise resources and make their own decisions about what needs to be done next (p. 67) consultation draws on a range of psychological frameworks and often applies solutions-focussed approaches (Lutz & Berg, 2002) which assume that (unless shown otherwise) all parents want to positively impact their child's life and are doing the best they can, given their circumstances and the resources at their disposal.

In an extensive review of the EP workforce commissioned by the Department for Education, in which parent and carer views of the EP role were considered alongside those of Principal EPs, Maingrade EPs and other stakeholders (such as school staff) in a multi-informant mixed methods design, Atfield and colleagues (2023) collated examples of effective working between EPs and parents. The research team observed EPs in consultation with parents, giving 'specific hints and tips that could work alongside existing strategies' (2023, p. 62), as well as direct input through interventions such as 'Circle of Adults' (whereby the team of adults around a child come together to reflect and problem-solve) and Video Interactive Guidance (VIG) which celebrates and reinforces positive examples of parenting. More generally, using non-judgemental, strengths-based approaches to support parents in understanding their child's needs, and developing their resilience and parenting skills were seen as important outcomes of EP work. However, while many EPs could share examples of where they had shared such advice and guidance with parents, and there were pockets of effective work where parents and carers forums had worked closely with the LA EP service to develop better awareness (p. 72), not all parents fully understood the EP role. Furthermore, although case studies suggested an important role for EPs in mediating between health services, families and schools, and families felt that EPs had listened to and empowered them where they had been previously let down by other services, challenging relationships between schools and families were found to be possible barriers to EP work (p.90). Principal EPs also noted that increased awareness around neurodiversity had led to an increase in requests for support for autism and ADHD, but there were insufficient resources to meet demand.

When children and families seeking support for ADHD-type difficulties come into contact with LA services, they may interact with professionals who align with either a medicalised or sociocultural approach, and as there is still no nationally-recognised protocol for multi-professional identification of ADHD in CYP, the service they receive can vary significantly both within and between geographical regions (Hill & Turner, 2016; Wall, 2023). Some LAs are currently attempting to better meet the needs of children and families by standardising their approach to child neurodiversity; for example, in Hampshire and the Isle of Wight, the Portsmouth ND Profiling tool (Ginns, 2024) is being developed in order to allow different professionals to pursue a needs-led (rather than diagnosis-led) approach to assessing how children present according to nine dimensions including energy levels, attention skills and impulse control, and what accommodations should be made through a “whole-system, ‘everybody’s business’ approach to meeting need” (Ginns, 2024, p. 35). Whilst in Portsmouth, parents were interviewed to obtain their views of the diagnosis process, further research, across different LAs, is needed to fully understand the current trajectories of help-seeking when families pursue diagnoses of ADHD for their children.

1.8.1. Previous EP research in this area

Whilst mainly focussed on child experiences of ADHD, Emma Flack’s (2018) thesis submitted for the Doctorate in Professional Educational, Child and Adolescent Psychology, notes that six of the eight parents surveyed as part of the multi-informant study had some experience of working with an EP in connection with their child’s ADHD, and had found their input useful due to the EP’s knowledge of ADHD and child development, and the strategies they shared. However, “the only issue raised was not seeing them enough” (2018, p.105). Therefore, despite EPs having the appropriate skills, knowledge and professional frameworks to support children and families, barriers to practice as outlined in Atfield et al.’s (2023) review and also underlined by Flack’s (2018) respondents may mean that not all parents are receiving the support that they need.

In his doctoral thesis, Paul Codling (2022), a trainee EP, used interpretative phenomenological analysis to explore the lived experiences of children with a diagnosis of ADHD along with their parents, and through a process of interviewing parent-child dyads about their experiences was able to propose ways that EPs could support children and their families. Codling’s proposed strategies included work at an exosystemic level, through liaison and expertise-sharing with other professionals in education and health settings, and also at a microsystemic level with children, such as direct emotional support and more personalised strategies around executive functioning and also for parents, including signposting further services and providing help with managing their child’s ‘emotional dysregulation’ (2022, p. 145). However, as Codling’s qualitative research was conducted with a small sample, and his conclusions about possible implications for EPs are an indirect product of the research rather than central to the research questions, the current study builds on Codling’s work with a wider sample and more targeted exploration of parents’ experiences with professionals, including EPs, within a help-seeking framework. This allows me to propose new ways of working with parents in Section 5, Discussion.

1.9. Year 1 research project

The current study also builds on my own previous research. In the first year of the DEdPsy programme, I undertook research (Wall, 2023) exploring how EPs view their role in the identification and intervention of ADHD and considering how views may have changed since Hill and Turner conducted a similar study in 2016. I investigated how non-pharmacological interventions are being used across schools and explored EP perceptions of best practice in this area, in addition to considering the possible impact of the Covid-19 pandemic which had occurred in the intervening years since the original research. Interviewees provided rich detail about how, when EPs are facilitated to support schools with preventative work, or with evidence-based, non-pharmacological interventions, their role can be transformative for children and their families. Survey data suggested that EPs are most commonly involved in supporting education settings to develop and implement modifications to classroom environments and create a positive social and emotional climate at school, but are less-commonly involved in interventions using approaches based on Cognitive Behavioural Therapy. Many participants referred to waiting times for health services, which some felt had been exacerbated by the pandemic, and suggested that an advantage of using EPs to support school interventions is that they can be put in place whilst children wait for a diagnosis. However, many participants reported that barriers such as funding or workforce capacity can limit this type of work. Numerous participants had worked with children who had not received adequate post-diagnostic support and lacked understanding of their diagnoses, and a key finding from this study was that seeking the views of children and young people, and advocating for them thereafter, are important facets of the EP role that would benefit from being more formally integrated into assessment protocols, with EPs given a central rather than peripheral role. Whilst the research questions did not cover aspects of parental help-seeking, the EPs who I interviewed in this study sometimes speculated about parents' views and experiences, and it was this that I wished to explore further. These unanswered questions have led me to seek the experiences of parents directly in the current study.

1.10. The current 'SEND crisis'

Since I conducted the earlier piece of research, the current situation in schools and LAs in relation to SEND provision has come under the media spotlight as councils face deficits due to growing demand for EHC plans. In September of last year (2024), an open letter with signatories including the Association of Educational Psychologists, the British Psychological Society's Division of Educational and Child Psychology and the National Association of Principal Educational Psychologists in addition to several charities, addressed the Secretary of State for Education to outline the issues currently faced by the education sector amidst a 'widely acknowledged' SEND crisis. It cited the 72% increase in EHCPs since 2019 alongside rising numbers of tribunal appeals and called for a comprehensive review of the system, insisting SEND be seen as an integral part of the wider education system rather than a 'bolt-on'. The letter notes that current ineffective approaches to SEND provision have led to different parts of the system – schools, parents, LA staff and children – blaming one another, with parents often, "blamed for being 'pushy' or 'demanding' when what they are doing is advocating within a system which was not designed with their children in mind […resulting in] huge emotional impacts". In recent months, the government has responded to the growing financial crisis with the promise of reforms. These are due to be set out in a white paper later this year and are expected to focus on improving state provision over costly private specialist schools, but parent interest groups, such as ‘Special Needs Jungle’, have expressed concerns about the potential for diluted SEND provision (Butler et al, 2025). I will discuss how my research might be considered in this current context in section 5.

1.11. Help-seeking and Illness Career Trajectories

The literature on help-seeking – which has been defined as “the active search for resources that are relevant for the resolution of [a] problem” (Zartaloudi & Madianos, 2010, p. 662) – provides a useful framework for understanding the ways that parents seek help for their child’s difficulties. Goldsmith and others’ (1988) help-seeking model, which draws on earlier proposals from Anderson and Newman’s model (1973), explicates the stages along a health-seeking pathway as shown in fig. 1. As Srebnik and colleagues (1996) emphasise, parental help-seeking for their child’s mental health problems is rarely a single decision but many smaller decisions which are embedded in a network of social interactions, therefore the framework groups these into four distinct phases.

[image redacted for copyright reasons]

Fig. 1: Stages of help-seeking, as proposed by Goldsmith et al. (1988)

Whilst the third and fourth stages are sometimes seen as a single stage in help-seeking models (e.g., Power et al., 2005), because ADHD is regarded as a chronic condition (Dreyer et al., 2010), the ADHD help-seeking process is viewed as having a distinct and long-term ‘maintenance’ phase, which can be affected by factors such as time demands and service ease-of-access.

Related to help-seeking frameworks, the concept of ‘patient’ and ‘illness career’ trajectories have their roots in sociological theory and concern the sequences of events and junctures in the course of a disease (in the case of a ‘patient’ trajectory) or, in an ‘illness career’, the “formal and informal social networks as an interactive process of meaning and action” across time (Pescosolido, 2014, p.1171). In their qualitative exploration of the role of familial sociocultural context on American families’ decisions to seek medical help, Leslie and colleagues (2007) modified Pescosolido’s (1991) ‘nonspecific illness career model’ to discern six stages of ADHD help-seeking, adapted here in fig. 2 using language more common in the UK.

[image redacted for copyright reasons]

Fig. 2: Stages of ADHD help-seeking, adapted from Leslie et al. (2007)

Whilst a theoretical perspective of labelling (as discussed above in 1.8., in which a behaviour only becomes a problem once it is labelled as such; Hargreaves, 1976) may dispute Leslie’s conception of the ‘problem onset’ as distinguishable from an adult defining the problem (stage 1 and 2 respectively in fig. 2), the framework otherwise offers an effective way to demarcate separate stages of the help-seeking process and the influencing factors that interact at each stage. Power and colleagues’ (2005) model further details cultural and familial factors that affect whether help is sought (see fig. 3).

[image redacted for copyright reasons]

Fig. 3: Cultural and familial factors affecting each stage of help-seeking, Power et al. (2005)

In choosing to use help-seeking frameworks for this study, it is important to acknowledge concerns that have been raised by members of the disability and neurodivergent rights communities regarding some of the implicit assumptions of such frameworks. The term ‘help-seeking’ has been seen by some as reinforcing power dynamics in which an individual is dependent on an ‘expert’ helper to ‘fix’ their problems, thereby framing difficulties – which may be more accurately positioned as systemic failures and societal exclusion – as individual deficits (see Brinkman et al., 2023, for a wider discussion regarding discourses on disability). In recognising the potentially pathologising assumptions of such frameworks, and applying them with critical awareness and a neurodivergence-affirmative perspective, I focus on processes of help-seeking in terms of systemic responsiveness to parents’ attempts to navigate appropriate support for their child. The parent is positioned as the expert on their child, and help is viewed as a collaborative process between different members of systems within which the child develops.

1.12. Ecosystemic frameworks

Both Power et al.'s and Leslie's help-seeking models fit well with an ecological approach that draws on Bronfenbrenner's (1977) ecosystems theory of human development. In this model, a child is perceived to be at the centre of, and influenced by, different systems, from those in the immediate home and school environments (the microsystem) through the exosystem, which might comprise the wider community, mass media, a parent's work environment and local government, and then wider macrosystemic influences which include sociocultural norms, political and economic systems. These different systems are perceived as changing across time (the chronosystem) and as being interconnected with one another through the mesosystem (such as the interaction between home and school). The location of the EP within a child's systems will depend upon their level of direct interaction with that child; if they are in regular contact then they may join other professionals (such as teachers and GPs) in the microsystem, but if they are working more distally – for example, as part of an LA EPS providing services to local schools such as training or consultation – they would be better situated in the exosystem.

Although Bronfenbrenner did later update his theories of development to add more significance to the role of children's individual personal characteristics in shaping their development (known as the 'bioecological' model; Bronfenbrenner & Morris, 2006), the earlier ecosystemic model remains most useful for this study which is designed to develop an understanding of the wider contextual factors affecting parents' experiences and decision-making, rather than focussing on the child. Specific areas related to each level of Bronfenbrenner's model, as related to the aims of this study are as follows:

- Child: What are the child's characteristics in relation to biological and genetic factors, skills and temperament?
- Microsystem: What is the nature of the home environment? How does the family's resources affect the child's experiences? What is the nature of the school and classroom environment?
- Mesosystem: What is the nature of the relationships between child and school staff, and parents and school staff / other professionals? What is the nature of the EP role in relation to these interactions?
- Exosystem: How are mental health services and other community services experienced? How does the EP role fit in?
- Macrosystem: How do social attitudes towards ADHD affect the child and parents? How are they impacted by funding for schools and mental health services?
- Chronosystem: How is the help-seeking trajectory experienced by families over time?

Bronfenbrenner's model has informed the design of data collection instruments (survey and interview schedule) and subsequent thematic analysis (where coding was more deductive). The vocabulary of this model has also been integrated into my discussion of results.

1.13. Summary

In this section, I have introduced the context for the present study. I have provided an overview of the condition of ADHD, its prevalence, aetiology and current treatments. I have indicated how both parents and schools are in a bidirectional relationship with children who exhibit these difficulties in that they are affected by them whilst also likely influencing them. I have also considered exosystemic and macrosystemic influences, placing the EP within these systems, and considering key legislation. The following section will review the literature as it pertains specifically to the help-seeking experiences of parents.

2. Literature Review

Given the vast body of literature concerning debates around ADHD, and in order to ensure that my review of literature was as representative of previous research as possible (Goldacre, 2012), I took a systematic approach to searching for peer-reviewed articles on parental help-seeking in relation to their child's ADHD, across the following databases: ERIC (EBSCO), ERIC (ProQuest), Child Development and Adolescent Studies, the British Education Index, Scopus, Embase and APA PsycINFO. I used key words that included combinations of relevant terms for three main conceptual areas: “help seeking” AND “parent” OR “carer” OR “mother” OR “father” AND “adhd” OR “attention deficit hyperactivity disorder” OR “attention deficit disorder”. To ensure the quality of literature for review, I only included peer-reviewed articles from academic journals; other types of literature, such as grey literature, book chapters and theses have been included where relevant in the introduction chapter of this thesis. Further inclusion and exclusion criteria can be found in Appendix 2.1, and an overview of the selected articles (n = 19) is included in Appendix 2.2.

The following review considers previous literature according to the different stages of the help-seeking process, integrating the authors' findings in relation to factors that affect the nature of parental help-seeking, what barriers parents face, and what is helpful to them. Studies on specific populations are highlighted to support the development of a culturally-sensitive approach in my own research.

2.1. Initial stages of help-seeking; parental knowledge and problem recognition

Studies into the early stages of help-seeking have tended to assume a position of concern about the psychological, social and academic impairments that can result from unmet mental health needs in children. As parental readiness to seek help for their child’s problems is viewed as crucial in remedying this, previous research has focused on what parental characteristics are significant and how these affect the help-seeking pathways for children with difficulties related to ADHD.

The key role of problem perception (that is, parents observing the child’s symptoms and deeming them problematic) is emphasised by Thurston and colleagues (2014) and it has been demonstrated that parental knowledge of ADHD is strongly predictive of an interest in seeking help (Davidson et al., 2022). To assess the role of parental knowledge – also referred to as ‘mental health literacy’ - researchers commonly use randomly-assigned vignettes describing different behaviours and ask participants to report how they would respond if this was their child (Davidson et al., 2022; Jackson et al., 2023; Thurston et al., 2018). Using this method to evaluate Canadian parents’ ‘mental health literacy’ skills, Davidson and colleagues (2022) found several factors were associated with stronger mental health literacy skills, as operationalised through more accurate detection of ADHD symptoms. The factors were: being a mother; having mental health experience, and; having higher levels of parental self-efficacy. Further studies confirm that accurate labelling leads to help-seeking: In another study using vignettes illustrating symptoms of known clinical disorders including ADHD, Jackson et al. (2023) note that when parents (in this study, parents of pre-schoolers) use accurate diagnostic labels to describe children’s behaviours, they are more likely to recommend help-seeking. Whilst, as in Davidson and colleagues’ study, the parents’ responses to vignettes were hypothetical rather than based on their own experiences, the finding that labelling and help-seeking were positively associated even for parents of very young children, suggests that the lens through which parents view a child’s difficulties will affect the subsequent help-seeking trajectory.

Parents' attributions about the stability and causes of ADHD have also been found to influence their help-seeking decisions. Johnston and others (2020) note that parents' problem recognition is dependent on their appraisal of the problem according to beliefs they have about its aetiology and stability; in their review of previous literature, the authors find that parents are more likely to seek help for their child's difficulties if, in addition to the problem being severe and a burden on the parent, they believe the problem is due to biological causes (and use diagnostic labels to describe the problem). However, they are less likely to seek help if they think the problem will go away on its own. Differences in parent's attributions and the subsequent likelihood of initiating help-seeking steps may also occur according to the race and gender of the child; in their sample, Bussing and colleagues (2005) found different characterisations of children's presentations, with Black African American girls viewed as 'misbehaving' whilst White boys were perceived in line with an 'indisposed child' trope, and as such more likely to be taken to the doctor.

In summary, recognising that a child has a problem and labelling it in ways concurrent with diagnostic descriptions is seen amongst much of this literature as the gateway to seeking help (e.g., Thurston et al., 2018) and parent and child characteristics can both contribute to different patterns in help-seeking. However, it should be noted that, whilst these studies used quantitative methods to draw such inferences, the qualitative studies within this review (Clarke, 2013; Cormier, 2012; Graves, 2017) suggest a messier route into help-seeking. Clarke (2013) for example draws on sociocultural perspectives of ADHD in her exploration of how Canadian mothers initially try to normalise behaviours privately before seeking help with professionals, suggesting that parental knowledge and attributions are flexible and fluid, and can change throughout the help-seeking process.

2.2. Deciding to seek help: Sources of support

In the study by Davidson and colleagues (2022) discussed above, problem recognition was found to be linked to greater intention to seek help from most sources, except friends and family. Parental knowledge, attributions of ADHD and other demographic characteristics can predict *where* parents choose to seek help (Bazier et al., 2024). Thurston and colleagues (2018) have, like Bussing and colleagues (2005), suggested differences according to race, with African American families relying on informal support, including church networks, while White parents are more inclined to use self-help resources. Whilst these findings may be context-specific to the US where the studies took place, they highlight the importance of maintaining a broad and open perspective on possible sources that parents may use to seek help for their child.

Parents who recognise problems do not always choose to seek help from primary care (i.e., GPs) leading to possible under-identification and under-management of the difficulties (Sayal, 2006). Parents often contact education professionals rather than healthcare providers, with a lack of GP engagement being a major barrier. In Sayal and colleagues' (2006) comparison of child data from the 1999 British Child and Adolescent Mental Health Survey, contact rates with services were examined for children with ADHD, with only a third of children found to have received evidence-based treatment from specialist services. The authors concluded that the main barrier to care is a lack of presentation of problems to GPs by parents. However, this 'responsiveness' of services – the association between children being referred to specialist services only when their parents directly asked for it – emphasises the significant advocacy role that parents have in ensuring their child accesses professional support even when using a free-at-the-point-of-need service. Sayal and colleagues' study also highlights the important role of education staff in supporting the identification and intervention of ADHD-related difficulties, as parents may be more likely to speak to teachers about their concerns than their child's GP, who themselves may suggest alternative pathways to parents, knowing that waiting lists for Child and Adolescent Mental Health Services (CAMHS) are so long. Other studies have indicated possible uncertainty amongst parents regarding health professionals: Amongst participants in Davidson and colleagues' study (2022), there was a scepticism of more specialist mental health services and allied professionals including psychologists and psychiatrists and a preference for seeking help from their primary health care provider, however, it is important to note that this may be reflective of the study's community sample, only 15.6% of whom indicated they actually had a child who had experienced a mental health problem. Therefore, it may be that when parents are more closely involved in the process and their responses are based on personal experience rather than hypothetical responses to fictional vignettes, they may be more open to such sources of support.

Certainly, the process of seeking care often requires perseverance due to waiting times and referrals between services. Clarke's (2013) qualitative study illustrates parents' frustrations with being referred from service to service, and the long waiting times in between. This corresponds to more recent literature on experiences in the UK (e.g., Valentine et al., 2024) as well as widespread media coverage such as that by the BBC regarding waits of two or more years for diagnostic assessments in Surrey (Bish & Norman, 2024). Parents not knowing where to go for help – and feeling like professionals did not listen when they did ask for help – has been noted in studies in the UK also (e.g., Sayal et al., 2015). In Bazier and others' recent study (2024), a distinction is made between the formal services that parents may go to for help in the United States – for example, a psychiatrist or a psychologist – and informal sources such as friends and family, or online sources. Using Raviv et al.’s (2003) parent help-seeking questionnaire, the authors explored the role of parental knowledge of ADHD and their attributions of their child’s behaviour as predictors in the help-seeking process, focussing at the stage of service selection, following a decision to seek help. Stability attributions (believing the behaviour is likely to continue into the future) were found to predict interest in informal services and attributions of higher child control predicted interest in medication. Survey responses in Davidson and colleagues’ (2022) study suggested that, when seeking help from professionals, parents expressed a preference for written information (such as a leaflet) which the authors propose may be indicative of a need for more reliable, streamlined sources of information for parents, online or otherwise. When parents seek information online, it has been acknowledged that the web-based sources that are often turned to are not always reliable or suitable, and Scholze and colleagues’ (2023) study asked two focus groups of parents to share their views on what would improve such information. Participants indicated a preference for destigmatizing content (such as real-life stories of overcoming the challenges associated with ADHD) and clear (video-supported) guides on recognising problematic behaviours, alongside evidence-based strategies, and authors used the findings to inform the creation of a website (see Appendix 2.3). When noting in their study the importance of parents being provided with reliable information and signposting regarding a range of evidence-based interventions, Bazier and colleagues (2024) found that while psychologists often do this, medical professionals may not.

Sayal et al. (2015) conducted a longitudinal study of children in England in order to assess child, parent and sociodemographic factors that influence (specialist mental, or general) health service use and found that child symptom severity and parental mental health problems were independently associated with greater service use. Identifying possible barriers, the authors found that the most common barrier was parents not having adequate information about who could help or feeling like professionals did not listen when they asked for help. Interestingly, in their list of results regarding where caregivers seek help, there is no mention of EPs; instead, the sources of support (listed here from most commonly cited by service users to least) were: Class teacher; family; friends; GP/primary care; internet; accident and emergency; self-help group; telephone helpline; voluntary agency; private / alternative therapist. As even 63% of non-users of specialist services still sought help from the child's class teacher, it is possible that, in some instances, an EP may be working indirectly through the teacher, but the closed questions of the survey did not allow for this to be shared.

2.3. Treatment selection and use

The nature of symptoms displayed by children may affect the type of treatments and interventions that parents seek. Tamm and others (2023) investigated the likelihood of parents seeking one of the three main treatment modalities; classroom behaviour management approaches (which might include reward systems or teacher adaptations), behavioural parent training and pharmacological treatment. They found that caregivers of children with greater externalising symptoms were more likely to seek classroom behaviour management while greater difficulty with attention was associated with seeking pharmacological treatment. Importantly, caregivers who agreed with their child's ADHD diagnosis, and who had more knowledge about ADHD, were more likely to seek behavioural parent training, suggesting an important role for professionals in supporting caregivers in understanding the condition in order to improve uptake of this non-pharmacological treatment.

Ultimately, it seems parents respond by "doing what helps most," (Cormier, 2012) with many initially resisting medication but eventually opting for it due to a lack of alternatives. In her Grounded Theory study, Cormier (2012) found that ‘coming to terms with the need for medication’ was seen as a central task of this stage of a parents’ help-seeking journey, with participants citing a lack of guidance from professionals and a feeling that other non-pharmacological approaches had not worked as reasons why they decided to move to medication. Clarke (2013) drew similar conclusions from her qualitative interviews; Parents move to medication when struggles become too much to manage. In the UK context, recalling Hill and Turner’s (2016) study, some parents may also be forced into opting for medication because it is the *only* treatment that is available to their child.

In a UK-wide survey of treatments in use by children with ADHD to which 175 families responded, Fibert and Relton (2020) found that two-thirds of children were using a mainstream ADHD medication such as Ritalin, a third of families had received behaviour-focussed therapy and almost three quarters of parents had received parenting classes. Caregivers who agreed with their child’s diagnosis, and who had more knowledge, were more likely to seek parent training; highlighting an important role for professionals in supporting caregivers’ understanding (Tamm et al., 2023). In addition to NICE recommended treatments, ‘non-mainstream’ treatments, defined by the authors as those identified (and usually funded) by parents rather than recommended by doctors, were also considered and 45% of families reported using such treatments; amongst these, ‘homeopathy’ and ‘nutrition’ were common, and a long list of such treatments from reflexology to Cannabidiol oil demonstrates the wide range of treatments parents are willing to try to help ameliorate their child's difficulties. Whilst more research is needed in order to establish the effectiveness of such treatment, and in order to ascertain how many of these treatments are being funded for privately by parents, the findings of this survey reinforce the need to remain open-minded regarding where and how parents seek help for their child's ADHD.

Adherence to clinical recommendations has been found to vary. For example, in Dreyer et al.'s (2010) quantitative study into parental adherence to clinical recommendations for their child following evaluation in an ADHD clinic, it was found that whilst parents were likely to follow through on over 80% of recommendations, they were least likely to engage in recommendations for psychological services such as therapeutic support for the child or training for themselves. The authors suggest that possible reasons for this may be greater time demands on parents, or their discomfort and unfamiliarity with psychological (rather than medical) services. Whilst this study was conducted in the United States, where healthcare systems are different to the UK, a recent study in this country into the feasibility of a self-help parenting programme assumes a similar premise that the time-demands of in-person workshops can deter parents: In their small scale randomised control trial (RCT) of New Forest Parenting Programme (which include self-help materials such as behaviour management strategies, and games to target self-regulatory and cognitive needs), Daley and colleagues (2021) found that the programme could provide a more accessible way for parents to increase their parenting efficacy and improve their child's social performance at school. Parents in the treatment arm also made fewer negative comments towards their child after the intervention than those in the control group. The authors propose that self-help approaches can sidestep barriers posed by in-person parenting programmes such as cost, psychological barriers for attendees such as perceived stigma, or practical ones such as childcare.

2.4. Barriers to accessing support

In their review of previous literature on parental help-seeking, Johnston and others (2020) found evidence for "*perceptual, structural and financial barriers*" (p. 226) that affect the process (and subsequent outcomes for children) including those related to parents' previous experiences with professionals and their understanding of available services. Further common barriers include lack of information, professionals not listening, and financial barriers (e.g., Clarke, 2013). Previous research – including that cited above regarding gender and race biases at assessment stage (Bussing et al., 2003) - has suggested that there may be between-cultural differences in help-seeking practices as well as within-culture differences, and these may be in part due to barriers such as limited access to culturally-competent practitioners (Kappi & Martel, 2022).

In Graves' (2017) Grounded Theory study exploring the help-seeking of participants who identified as African-American/Black single mothers on low income in the US, the author argues that, despite being more vulnerable to mental health disorders, African American children living in poverty are least likely to seek or receive formal help. Through her interviews with eleven mothers, Graves generates a help-seeking theory to explain possible 'filters of influence' on the process. Graves notes that these influential factors either impeded the help-seeking process, or propelled the mothers faster towards accessing treatment. In line with other studies cited above, the filters included the mothers' beliefs, knowledge and experiences of mental health treatment, their informal support networks, relationships with professionals and sense of competence in managing their child's behaviour (linking to Davidson et al.'s (2022) focus on parental self-efficacy). These findings, helpfully presented across the sequence of help-seeking stages, raise questions regarding the way that such filters of influence may arise in a UK sample of parents, and how relationships with EPs specifically can be considered in this framework.

2.5. Summary

Based on the literature reviewed here, factors that contribute to help-seeking behaviours can be found that relate to child characteristics (e.g., the severity of the problem) and parent characteristics (e.g., parental skills, beliefs and understanding) as well as factors involved in the mesosystem (family interactions with different professionals and services) and broader macrosystemic influences. Regarding service selection and utilisation, parents are using a wide range of services – including those that may be regarded as non-mainstream– but may be less-likely to follow up on recommendations to seek support from psychological services. Whilst Sayal and colleagues have considered parents' help-seeking in the UK context from the perspective of health services, the same has not been undertaken with the additional focus of education services. Furthermore, parents' experiences in relation, specifically, to the EP role, are not explored, suggesting this study can add to current understandings in this area. As the majority of the literature reviewed here draws on quantitative data, this study builds on previous work by providing rich illustrations of the help-seeking experiences of parents amidst the backdrop of a 'SEND crisis'

2.6. Research Questions

Following a review of the current literature, in the present study I sought to answer the following questions:

1. How do parents describe their experiences of help-seeking for a child who has difficulties with attention, concentration, impulsivity and/or hyperactivity?
2. How do parents describe their involvement and interactions with different professionals in relation to their child’s difficulties?
3. How, according to parents, might educational psychologists best support children and their families who experience these difficulties?

The following section will outline my methodological approach to answering these questions.

3. Methodology

3.1. Introduction

In this study, I aimed to explore the help-seeking experiences of parents of a child with ADHD or related difficulties. In this chapter, I outline my paradigmatic position as a researcher and reflexive stance, noting important ways that these influenced my methodological approach. I explain why a mixed methods research design was appropriate for achieving the aims of the project, and outline how I collected data through an online survey and semi-structured interviews. I describe procedures related to participant recruitment and data analysis, and the steps that I took to strengthen the quality of the research. Demographic information regarding the survey sample is included, as well as a separate summary of interview participant characteristics. Finally, ethical considerations are discussed.

3.2. Research paradigm

A paradigm can be defined as a “basic set of beliefs that guide action” (Guba, 1990) which also encompasses the practices, assumptions and values within which the researcher undertakes scientific practice (Braun & Clarke, 2013), thereby revealing ontological and epistemological positions. Oppositional approaches to research in the social sciences might be viewed along a spectrum, with positivism at one end (characterised by an assumption that reality is objective and observable, and that the only legitimate knowledge is that which is obtained by quantitative, experimental methodologies, in which variables are controlled and bias removed; see Ashworth, 2003) and interpretivism and constructivism at the other (where humans are conceptualised as operating “within a subjective, interpreted world” in which multiple realities are constructed; Braun & Clarke., 2013, p. 7). As clarity regarding this study’s situation in the ‘paradigmatic landscape’ (Deforge & Shaw,

2011) was necessary for developing coherence in the project and ensuring rigour (Guba et al., 1994), here I will explain my paradigmatic position, which drew from both critical realism and pragmatism.

The two paradigms of critical realism and pragmatism share a middle-ground approach to epistemology which uses reasonable judgements about the nature of knowledge (acknowledged to be fallible; see Bernstein, 1989) in order to inform our understanding and, in the case of pragmatism, as a basis for action (Elder-Vass, 2022). Ontologically, there is neither a reduction of the world to universal laws, nor complete abandonment of the notion that there are ‘patterns’ of reality, separate to the self, that can be viewed by a researcher, albeit partially and imperfectly, and thus “provide a foundation for knowledge” (Braun & Clarke., 2013, p.27). Commonly used in mixed methods research, where there may be philosophical ‘inconsistencies’ (Weaver, 2018) between the different phases, pragmatism devalues ontological positions (Kivinen & Piiroinen, 2004) in favour of a focus on ‘what works’ (Weaver, 2018). Pragmatism’s purpose of having practical application in the real world (despite the nature of that ‘real world’ being contested amongst pragmatists themselves; see Kivinen & Piiroinen, 2004) aligns with my own position as a researcher-practitioner, particularly as my key motivator in becoming an EP is to support helpful change in the everyday lives of children, families and communities. Furthermore, the commitment to dialogue with different perspectives, and a willingness to learn from these (linked especially to the postmodern pragmatism of Rorty as described by Johnson and others, 2017) resonates with my own values and beliefs. However, where this study deviates from pragmatism is in relation to the role of social structures; Elder-Vass (2022, p.262) notes that “pragmatists distrust and discourage invocations of structural power in social explanations, whereas realism encourages them”. Given the importance to EP practice of having an ecosystemic understanding of a child embedded within ever-widening systems, from family, school, peers and community out to the media, government and wider society (Bronfenbrenner, 2005), acknowledging the social structures that children and families are operating within, and their potential causal powers, is paramount. Margaret Archer’s (2003) conceptualisation of how structure, agency and culture shape outcomes is helpful: ‘Actors’ are viewed as making decisions about which actions to take within particular contexts, amongst cultural norms and pre-existing structural conditions such as social exclusion (related to race, socioeconomic status, gender) and resource scarcity, all of which influence both the actions that are taken, and the outcomes of these. This conceptualisation is pertinent to this study, given its focus on the unevenness of parental help-seeking experiences within a social context in which resources are not equally distributed.

In recognising the strengths and limitations of these two related paradigms, I acknowledge my position as ‘bricoleur’, blending tools and approaches that are available and fitting to the project (see Lincoln, 2001). Through this position, I have addressed my research aims through what Kincheloe names “synergistic interaction” (2011, p.181) – that is, combining two approaches in a way that means the sum is greater than the parts - between critical realism and pragmatism. Data have been collected, analysed and discussed with the understanding that they are mediated versions of reality (see Braun & Clarke, 2022) and socially-located, but can nevertheless offer valuable insights on ‘what works’ (and what does not) in the material world.

3.2.1. Reflexivity

Recognising myself as part of the research process, and understanding that my experiences and values have necessarily influenced the research findings, is an important component of the critical realist paradigm (Edwards & Holland, 2013) and a necessary element of the chosen analytic approach of Reflexive Thematic Analysis (TA; Braun & Clarke, 2006). Such reflexivity has helped to ensure the quality and transparency of the research (Yardley, 2008). Therefore, it is important to acknowledge my positioning as a trainee educational psychologist, who has also previously worked for over a decade as a teacher and, more recently, as a teaching assistant in an alternative provision 'hub' for children with social, emotional and mental health (SEMH) needs, whose diagnoses of ADHD were a significant part of their identity. These experiences have contributed to my own perspective of ADHD, which best fits the biopsychosocial model: It is my view that features of our society and school systems are sometimes not conducive to healthy child development, and that there is more that we could do to support children and parents before prescribing medication. However, I have also worked with children whose functionality in the classroom was greatly enhanced by these medications, and whose teachers say they would never have completed their GCSEs without them.

My identity as a mother of an eight-year-old boy has supported me in developing rapport with participants and enabled me to empathise more readily with some of the everyday pressures of parenting. Whilst this identity produces an insider perspective on cultures pertaining to parenting, Suzuki and colleagues (2007) remind us that our "multiplicity of identities [mean] that we are always both insiders and outsiders" (Suzuki et al., 2007, p. 300) and we should continually be attending to both what is similar, and what is different, between ourselves as researchers and our participants. I am aware that there may have been aspects of my privilege – I am White, financially secure and studying for a professional doctorate – that created power imbalances with my participants. Throughout the interviews, I endeavoured to remain open to hearing participants' experiences outside of my own framework by using the 'social graces' (Burnham, 2018) in questioning; Burnham suggests using questions that support the process of bringing 'forth the invisible' by being explicit about some of the aspects of society and culture that can influence people's experiences. An example of how I achieved this can be seen in the interview schedule in Appendix 3.2.

One interview participant specifically asked me to share whether or not I myself was a parent of a 'neurodivergent child', as she felt that she was only willing to share certain aspects of her experience with someone who could fully relate to these from personal experience. This led to important reflections for me regarding the assumptions of what it means to be a researcher, and whether having a personal stake in the outcome (or, occupying the demographic group being sampled) is more important than having developed the necessary skills to be an empathic listener (Laub, 1995). I considered Stein and Mankowski's (2004, p. 24)) perspective:

> *"Witnessing in qualitative research is not about the personal needs of the researcher, his or her level of self-disclosure, or desire for mutuality […] Rather, witnessing involves the transformation of the researcher from dispassionate scientist to impassioned listener and human being."*

In responding to the participant's voiced concerns, I acknowledged that whilst there were limits to the level of self-disclosure I was prepared to make, her consent to participate in the study was voluntary, and she too should only share what she felt totally comfortable with. In doing so, I hoped to emphasise “equity in [the] power relationship” (Hall & Callery, 2001, p. 266) between researcher and participant. It is important to note that this participant’s initial resistance has likely shaped the outcomes of the project, particularly in my thinking about how the study can be of benefit to the community.

3.3. Research design

The research questions I addressed in this study were:

1. How do parents describe their experiences of help-seeking for a child who has difficulties with attention, concentration, impulsivity and/or hyperactivity?
2. How do parents describe their involvement and interactions with different professionals in relation to their child’s difficulties?
3. How, according to parents, might educational psychologists (EPs) best support children and their families who experience these difficulties?

I chose to use a mixed methods design for this study in order to draw on the benefits of both quantitative and qualitative approaches to research (see Weaver, 2018). The survey data obtained from the quantitative phase enabled me to identify general patterns in the help-seeking experiences of parents, whereas the semi-structured interview data facilitated a more in-depth exploration of parents’ descriptions of their involvement and interactions with different professionals (Braun & Clarke, 2013). Combining methods in this way also meant that survey results could be illustrated and elaborated on, providing a more complete picture (McCartan & Robson, 2016).

Creswell (2003) suggests answering four key questions when designing a mixed methods study, covering: (1) the sequence of data collection; (2) the priority given to each phase; (3) when the data will be integrated; and (4) what theoretical perspective is taken (for the final point, see 3.2 Research paradigm). Initially, I hoped to use the survey in order to identify interesting phenomena to explore in more depth during the interview stage through purposive sampling of cases (Plano Clark & Ivankova, 2016), however, time practicalities and the need to respond quickly when accepting participant offers to interview (see 3.5 Participants) prevented a sequential design, and instead I used a concurrent triangulation design (Creswell, 2003) in which both qualitative and quantitative methods were used in parallel. I began collecting quantitative data via an online survey in early July 2024 and conducted my first interview two weeks later. I have described this as a ‘qualitatively-driven’ mixed methods study, as it is the rich interview data that are most helpful in addressing my research questions and will be most influential in my professional practice as an EP. Results from the two phases are presented separately in Chapter 4 and are then integrated at the discussion stage, where I consider how the two phases have jointly contributed to my understanding of the topic; see Figure 4 for a procedural diagram.

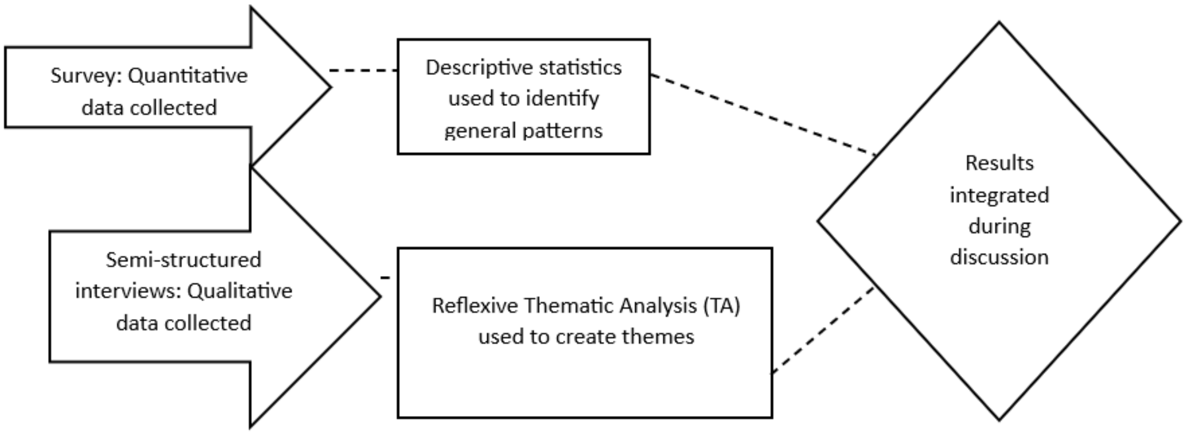


Fig. 4 Procedural diagram of mixed methods research design

3.3.1. Data collection tools

The initial quantitative phase comprised a short online questionnaire containing a series of closed questions inviting a range of responses on a Likert rating scale in order to gain a broad view of parents' help-seeking behaviour and their interaction with different professionals, as well as open questions which allowed parents to share any information that did not fit into the given prompts (see Appendix 3.1 for a copy of the survey questions). Reflecting on the relative merits of open-ended and closed questions, Fibert and Relton (2020) noted that a prompt list may support parents to remember services and treatments that they would otherwise forget or not consider relevant to the question. Therefore, such lists were used at the survey stage to gain an overview of the services that families have accessed, with an option for 'other'. The majority of questions were written to fit the needs of this study, but for two questions the wording was taken or adapted from established sources; firstly, to establish suitability for the study, participants had to confirm that their child experienced difficulties beyond what might normally be expected of a young child, and wording from the parent interview of the Development and Well-Being Assessment (DAWBA; Goodman et al., 2000) was used for this. Secondly, the item related to barriers that parents have experienced in relation to help-seeking was taken from the 'Need for Help' Questionnaire (Douma, Dekker & Koot, 2006; see Appendix 3.1. for the full list of survey questions and credited sources). At the end of the survey, I asked participants to share their ethnic group and household disposable income. In deciding which demographic information to obtain, it was necessary to balance the need to gain enough useful information to identify possible patterns in the nature of parental help-seeking, without cluttering a short questionnaire and putting busy parents off; therefore, whilst I collected information on household income and ethnicity (which have both been implicated in the literature on uneven help-seeking experiences; see Chapter 2, Literature Review), I did not collect geographical information or school-type in the survey, which prevents me from considering how these variables affect help-seeking experiences and differential access to resources and support. As questions about income can be sensitive, I emphasised that parents were able to skip the question, as well as adding an option for respondents to indicate they would prefer not to share this information (see Appendix 3.1). Given the substantial time commitment required by the qualitative phase of this project, it was not feasible to conduct a formal pilot study of the survey. However, in order to check the survey instrument's ease of use and comprehensibility (see Van Teijlingen & Hundley, 2001), I used an informal piloting approach. In addition to my research supervisors, a small group of friends and family members – one of whom is a parent of a child with SEND – completed the survey and provided feedback on the clarity of the questions and the overall flow. This led to some minor adjustments including clarity around who was invited to participate, 'debugging' where pop-ups required an answer from participants (despite all questions being optional) and changes to the order of questions. This provided sufficient preliminary validation to proceed confidently with the main data collection.

The qualitative phase of data collection explored individual lived experiences in order to better understand the decisions that parents make for their children. A focus on each participant's narrative – that is, the "story or account that the individual tells about themselves, currently or in the past, or about events or people that they have experienced" (Breakwell, 2012, p. 403) facilitated a deeper temporal understanding of events and interactions with professionals that led to parents seeking help. I used a semi-structured interview schedule (see Appendix 3.2) which included the main areas to be covered in order to gather relevant data, as well as prompt questions which were used as necessary. The exploratory nature of this phase meant a more open style of questioning was appropriate, with enough structure allowing for comparison of responses to a common set of themes between the different interviews (Suzuki et al., 2007). Because of the conversational nature of such interviews, they required skill in transitioning between topics and encouraging elaboration – skills that I have developed through my EP training. The interview schedule was designed according to the specific aims of this study, but drew on items from an established instrument, the Family Stress and Coping Interview (Minnes & Nachshen, 1997) which has proven reliability and validity and was designed in collaboration with families (Nachshen et al., 2003), as well as questions shared in previous studies on help-seeking (e.g., Power et al., 2005) and Flack's (2018) thesis which explored parents' experiences in relation to their child's ADHD diagnosis.

All interviews were carried out over the video-chat platform, Microsoft Teams, using my university account. Prior to joining the online meeting, participants gave their written consent for interviews to be recorded and transcribed by emailing either an electronically-signed version of the consent form or a scan of the printed version. I clarified details and answered participants' questions via email communication before the interview date (see Lobe et al., 2020). Although qualitative research interviews have traditionally been conducted face-to-face, it is becoming increasingly common to use online video conferencing software (such as Zoom or Microsoft Teams) due to its cost-efficiency and convenience (Gray et al., 2020). Indeed, using this technology allowed me to respond quickly to offers of participation, without the need to make expensive travel arrangements. Furthermore, it has been noted that the experience of creating rapport can be quicker with online rather than face-to-face interviews (Deakin & Wakefield, 2013) and participants may be more comfortable speaking about personal topics (Gray et al., 2020). There was one instance of a participant's unstable internet connection causing a pause in the interview, but this was temporary and did not significantly impact the flow of the interview (see Seitz, 2016). Whilst unlikely, it is possible that a very small number of participants were deterred from taking part in the study due to logistical issues such as lack of access to a private internet connection, possibly linking to the skew in sample towards higher income families.

3.4. Ensuring quality: Trustworthiness and transferability

Assessing quality in mixed methods research is complicated by the paradigmatic differences in perspectives on what makes for credible findings in quantitative and qualitative research (Plano Clark & Ivankova, 2016). Whilst I have emphasised the standards and terminology associated with qualitative research because of the higher status I have allocated to this phase of the study, I have also considered Teddlie and Tashakkori's (2003) additional approach to evaluating mixed methods research using the concept of 'inference quality'. This assesses whether conclusions drawn from mixed methods research are sufficiently robust to apply to similar settings or contexts, and are therefore relevant. They suggest looking for inconsistencies between the two sets of findings and considering these within the context of theory or previous research. Given that my survey sample is small and not representative of a national sample of parents (see 3.5 Participants) I have used descriptive statistics to indicate possible patterns (and avenues for future research) and to consider alongside qualitative data in making inferences that are consistent with both phases.

I have chosen Reflexive Thematic Analysis (TA) as developed by Braun and Clarke (2006) as this study’s central method and have drawn on these researchers’ characteristics of what makes a ‘good’ TA (Braun & Clarke, 2022) in order to ensure the quality of my research. An explicit description of the steps I took in creating themes is covered below (3.6. Data analysis) and analytic themes are supported throughout with data extracts from across the dataset to ensure a good fit between data and analytic claims. Incorporating direct quotations has ensured that participants' words are central to the themes (Patton, 2002).

A reflexive approach accepts that bias is inherent in the choices that we make in how we interpret data, and I kept a reflective journal throughout the data collection and analysis phases to interrogate my personal responses (Braun & Clarke, 2022, p. 19). I also sought a review of my coding and themes from my research supervisors, and used this feedback to check how individual positionality may have affected my interpretation of the data (Braun & Clarke, 2013). To support transferability of findings from this study to the real-life contexts of my readers (see Mertova & Webster, 2020), I have tried to include sufficient contextual details of time, place and context to support the necessary comparisons to consider applicability of findings to their own unique contexts, without jeopardising my participants’ rights to anonymity. It is important to acknowledge that there is wide variation in patterns of EP service delivery nationally and the data in this study only relate to the particular contexts that participants accessed, therefore they may not be generalisable to the wider EP profession.

Whilst this study’s qualitative weighting means that it has not sought to be representative of a whole population, as Dillon (2011) states, personal experiences are nonetheless, “limited, moulded, defined and delimited by the broader and social context. They feel personal, and their details are personal, but their broad texture and character, and especially the limits within which these evolve, are largely systemic." (2011, p. 141). It is the systemic nature of the experiences that will support me, as a trainee EP, to understand how I can best support children, young people and their families who are experiencing difficulties. 'Theoretical' generalisability (Reissman, 2008) means that findings may be useful in other contexts with similarities, and may be able to shed light on some of the ways that current systems and processes are enabling or hindering families in their search for support. These insights can therefore be used by LAs to help design and commission more effective services for children and families.

3.5. Participants

This section details how participants were identified, recruited and selected, and considers the limitations of using social media to access participants. I incorporate demographic information for the survey sample, as well as relevant details about the interview participants. I discuss the composition of the sample and explore issues of representation, as well as outlining the steps I took to widen participation.

To be eligible for the study, participants were required to confirm they have parental responsibility for a child aged between 6 and 12, who either has a diagnosis of ADHD, or who has been identified as having difficulties related to such a diagnosis. Whilst NICE (2018) guidelines dictate that ADHD should be considered in all age groups, I made the decision to limit my sample to parents of a child in the middle period of childhood for the following reasons: I wanted to consider how schools responded to the child's difficulties and parents' concerns (thereby excluding very young children); I hoped to explore how parents were advised around treatments, including ADHD medications (which do not have a marketing authorisation for children aged 5 years or under in the UK; NICE, 2019); finally, I capped the age range at 12, as adolescence can be a time of additional conflict and negotiation between parents and their child (e.g., Noller & Callan, 2015) and I wanted to limit the possibilities of such experiences adding unwanted variability in the dataset.

Participants were recruited via the snowball method of convenience sampling (Goodman, 1961). Parents were contacted through my own personal and professional networks via social media (primarily WhatsApp and X) and email. Before using social media as part of my recruitment strategy, I considered Gelinas and others' (2017) recommendations for ethical use and ensured that I was fully transparent when sharing information about the study online. The initial message (or online post) included a brief explanation and a link to the questionnaire, which then contained full information and a consent form. There was an option at the end of the survey to volunteer for the interview phase by inputting contact details. These participants then shared details of the project with their own acquaintances, thereby improving the number of respondents. To widen participation further, eye-catching posters advertising the research (which displayed a QR code to scan; see Appendix 3.3) were also placed in children's centres and CAMHS clinics across South-East London. To maximise variation in the data, efforts were made to enrol both mothers and fathers, and parents with a child who has a diagnosis of ADHD as well as parents who have a child who is awaiting assessment or who has been identified either by the parent or others as having difficulties associated with an ADHD-type presentation.

Whist incentives may encourage participation (Singer & Kulka, 2002) I chose not to offer them due to the possible ethical complications with ensuring freely-given consent (see Head, 2009, for a discussion). Studies that have explored participants' reasons for volunteering suggest various possibilities including the personal gain of finding the interview a therapeutic experience and helping the furthering of scientific knowledge (Stein & Mankowski, 2004). Reviewing my participants, I have identified two that I sense were motivated by their own interest in educational psychology and the possibility of applying for a place on the doctorate. However, neither participant expressed any suggestion that their participation was transactional and they expected to receive support from me in return.

Although online recruitment methods have been shown to increase participation rates (Christensen et al., 2017) it is important to note that recruitment by social media may result in a different participant sample to those recruited directly; in their exploration of young cancer survivors' experiences, Benedict and others (2019) found that the group recruited online were more likely to have higher levels of negative perceptions. As I recruited using both 'online' and 'offline' strategies, and do not know which participants are in either group, I should be cautious in my interpretations, and consider that it is possible my participants represent a group that have particularly strong views or have had especially challenging experiences.

As early data indicated a skew in the sample towards the higher income brackets, with the majority of respondents identifying as White, I took further steps to attract participants beyond the 'usual suspects' (Braun & Clarke, 2013). Braun and Clarke note that the dominance of White, middle-class, heterosexual people in Western academia, together with the use of snowball sampling (as used in this study) can lead to this common problem (2013, p. 58). In trying to gain the views of more ‘difficult to reach’ participants, I employed the suggested strategies by Braun and Clarke (2013, p. 60) by sharing in university parent groups, leaving flyers in specific locations where target participants were likely to be, posting in Facebook groups, and flagging at my LA EPS team meeting and with schools in which I work. Finally, I emailed the details of my study to 50 primary schools involved in the Teach First programme (which works with schools in low-income areas), but this strategy did not result in any additional survey participants.

When I ceased data collection in December 2024, a total of 57 participants had started the survey. 17 incomplete responses, defined as those which had not been continued after the initial screening questions in sections 1 and 2 of the survey (see Appendix 3.1), were excluded from the analysis. The resulting sample consisted of 40 parents each living with at least one child who fitted the criteria of the study. 93% of the parents are mothers and 81% identify as White.

Table 1

Sample demographics (N = 40)

		(n) (%)
Age range child (years)	6-7	10 (25)
	8-9	16 (40)
	10-12	14 (35)
Parent relationship to child	Mother	37 (93)
	Father	3 (7)
Sex child	Boy	25 (63)
	Girl	15 (37)
Child’s diagnosis status (may be more than one)	Has diagnosis of ADHD	27 (68)
	Has been referred for assessment	15 (38)
	Parent feels there are difficulties	10 (25)
	Others think there are difficulties	1 (2)

Description of concern	Inattention	12 (30)
	Hyperactivity	7 (18)
	Both	20 (50)
	Neither	1 (2)
Ethnic group of parent (of total n = 37)	Asian	2 (5)
	Black / African / Caribbean	1 (3)
	Mixed / multiple groups	1 (3)
	White	30 (81)
	Other	3 (8)
	Other	3 (8)
Annual household income range (of total n = 37)	Less than £20,000	3 (8)
	£20,000 - £39,999	3 (8)
	£40,000 - £59,999	5 (14)
	£60,000 – £99,999	9 (24)
	£100,000 or more	13 (35)
	Prefer not to say	4 (11)

In a UK representative sample, we would expect a similar distribution of ethnicity groups (81.7% white; https://www.gov.uk/, 2022) but a different distribution in relation to household income, with the national median annual net disposable household income for a couple with two children under 14 being much lower than the sample at £45,400 (https://www.gov.uk/, 2024). Whilst it is evident that my sample population is skewed towards the higher income, there is an argument that qualitative research with privileged groups can still contribute to enabling social change by illuminating inequalities (Prilleltensky & Nelson, 1997) and this is something that I explore further in following chapters. It is also important to note that, despite the skew, during the qualitative phase, data were collected from a variety of participants who offered insights into lived experiences across the income distribution (as can be seen in Table 2).

To recruit interview participants, I used a ‘nested’ sampling method whereby the qualitative sample was a smaller subset of the quantitative (Onwuegbuzie &

Collins, 2007). I initially planned to analyse survey responses for typologies and then use these to support participant selection for the qualitative phase, with criterion sampling ensuring that both typical and extreme cases were selected. Due to time constraints and the need for prompt responses to participant availability (see 3.5 Participants), this was not feasible; instead, I contacted each volunteer shortly after receiving their survey response, and interviewed all of those who consented. Initial survey responses did not suggest a need to make changes to the (already flexible) interview schedule, so in order not to lose potential interview participants who shared contact details early on in the survey time window, I began interviewing in the Summer, and therefore collected both quantitative and qualitative data concurrently.

A total of fourteen volunteers participated in an interview; an overview of their characteristics and brief relevant details related to their help-seeking experiences is presented in Table 2.

Table 2
Interview participant information

No.	*Child info. Sex / age Diagnosis (Y/N)*	*Ethnicity*	*Income (£k)*	*Pen Portrait*
1	F 8-9 Y	White	60-99	A mother whose daughter has diagnosis of ADHD which was obtained privately. Following medical advice, she chose to treat her daughter with medication.
2	M 10-12 Y	Black / African / Caribbean	40-59	A mother who spoke about her positive experiences with professionals when getting help for her son who has a dual diagnosis of autism and ADHD, and takes medication. She spoke about difficulties related to living conditions during Covid lockdowns and problems with lack of medication stock.

3	F 8-9 Y	White	60-99	A mother whose daughter is adopted. Whilst she has had some negative experiences with professionals, her daughter's school have been supportive.
4	F 10-12 Y	White	Prefer not to say	A mother who identifies as neurodivergent. Her daughter has experienced anxiety and has received support from a clinical psychologist. The family has paid for assessments for autism, ADHD and a cognitive assessment.
5	F 8-9 Y	White	100+	A mother who was living abroad when she initially sought a diagnosis for her child. She has since moved back to the UK and is navigating the NHS system.
6	F 8-9 Y	White	60-99	A mother of three daughters. She describes her daughters' school as being proactive with strategies, but has not seen an EP. She is frustrated that no holistic support other than medication has been offered.
7	M 8-9 N	White	60-99	A mother who notes the very negative impact on family life of her son's difficulties. He does not yet have a diagnosis but has been referred for assessment.
8	M 10-12 Y	White Child is mixed race	60-99	A mother who has four children who she describes as neurodivergent. She educated her son at home for a period as she felt his needs were not met at school.
9	M 8-9 Y	White	Less than 20K	A mother who is a single parent to her son. She partially links her son's presentation to adverse childhood experiences including her substance addiction during pregnancy, and the family has had social care involvement.
10	M 6-7 Y	White Child is mixed race	60-99	An adoptive mother who works with children. Her son has an EHCP and has had involvement from an EP. He takes melatonin for sleep.
11	M 10-12 Y	White	Prefer not to say	A mother who describes her family as neurodiverse. Her son is educated out of school on an EOTAS package.

12	F 6-7 N	Mixed / Multiple ethnic groups	100+	A mother who is currently seeking a private assessment of her daughter’s difficulties due to long NHS waiting lists. She is a school SENCo.
13	M 8-9 N	White	20-39	A father who is currently seeking a diagnosis for his son but wonders if one would be necessary if schools were more accommodating.
14	M 6-7 N	White	60-99	A mother who feels a strong connection to the community of parents of neurodivergent children. She has had negative experiences with professionals including an EP.

3.6. Data analysis

3.6.1. Data analysis: quantitative phase

Survey data were analysed using descriptive statistics using the computer software SPSS.

3.6.2. Data analysis: qualitative phase

I decided to use a Reflexive Thematic Analysis (TA) as the qualitative methodology for this project, ruling out other theoretically informed frameworks on the basis that TA was better-suited the aims of my study. In particular, I considered the relative merits of phenomenological approaches (IPA) and Grounded Theory (GT) before dismissing these in preference of TA.

IPA involves close engagement with the subjective viewpoints of a very small number of participants and focuses on the unique features of each account (Burns & Peacock, 2019) and whilst this microanalysis would have been valuable for providing deep insights into the reasons why three or four parents have sought support for their children’s difficulties, I felt that gathering a wider range of views and looking at the patterning across a larger dataset would better support me in developing an understanding that was applicable to professional practice.

Like TA, GT has a similar emphasis on reflexivity, and the ultimate purpose of producing a substantive theory links well to the help-seeking frameworks that are central to my research questions. However, the member-checking that is integral to GT was not feasible in this project as time restrictions meant it was not possible to integrate such feedback in a meaningful way. TA does not see such participant validation as necessary for credibility, given the explicit acknowledgement of researcher interpretation. Furthermore, GT's requirement to produce a new theory to explain a phenomenon (Corbin & Strauss, 2014) was less flexible than TA, which accommodates deductive orientations to data analysis as well as inductive (Braun & Clarke, 2022) and has allowed me to draw on ideas across existing research in both psychological and sociological disciplines.

I undertook the analysis following Braun and Clarke's (2006) framework which abbreviates a complex and recursive process into the following six steps:

1. Transcription
2. Familiarisation with data
3. Coding
4. Creating initial themes
5. Reviewing themes
6. Defining and naming themes

Interviews were conducted on Microsoft Teams and were recorded and transcribed using that software. I began by checking transcripts for accuracy through re-watching recordings whilst reading through a printed copy of each anonymised transcript and correcting any errors. This allowed me to familiarise myself with the data and begin an exploratory and data-driven coding process, in line with an inductive approach (Braun & Clarke, 2016). The process of coding can be defined as “exploring the […] patterning of meaning from the dataset, developing codes, and applying code labels to specific segments of each data item” (Braun and Clarke, 2022, p. 53). I coded all transcripts a total of three times in a systematic approach, in which I adjusted the order of coding in order to ensure I did not always code Transcript 1 first (and Transcript 14 last) which could result in an unevenly-coded data set (Braun and Clarke, 2022, p. 71). For the first two coding ‘runs’, I used the computer assisted qualitative data analysis software (QDAS) programme, NVivo (see Appendix 3.4. for an example screenshot of a coded segment of transcript). Whilst some have noted that such software can potentially distance the researcher from the dataset (e.g., Hinchcliffe et al., 1997; Seidel, 1991) such concerns have usually been voiced as a means to caution against uncritical and absolutist use of such software, and can be mitigated through ‘stepping away’ from the computer screen and re-engaging with data in a different way (Jackson et al., 2018). Therefore, my final coding run and subsequent creation of themes was conducted manually with hand-written cards (see Appendix 3.5).

I identified 29 codes in the first coding run, from which I created a codebook and shared it for review during supervision. This first set of codes were largely semantic (that is, explicitly stated ideas) and not sufficiently discriminatory (e.g., the code labels did not capture whether a meaning was positive or negative or whether something was being explored in terms of its absence or presence). Therefore, I went through all data extracts under each code and devised new code labels that had more specificity and better captured underlying meanings (see Appendix 3.6). Using this list, I re-coded all transcripts using NVivo, adding and deleting codes as necessary. For the final coding run, in which I moved away from screen-based coding and used a manual process, I focussed on reducing and refining the code labels in order that they could stand alone in their representation of the data extract; e.g., one initial code label, '*things that help,* was amended to, '*being listened to and guided helps'*. Alongside this coding process, I recorded personal reflections to support the construction of themes and maintain reflexivity.

In order to consider how codes might be clustered around fundamental observations in the data that address the research aims (Braun & Clarke, 2016), I created a separate hand-written card for each code and sorted these into different piles. Each pile was united by a central concept, and distinct from the concept of another pile, which meant letting some codes 'go' (Braun & Clarke, 2013, p.234). Following this process (which can be seen in the three photographs in Appendix 3.5.), I had created six themes. In the final phase, I reviewed these themes for coherence and richness, and tested their quality by writing out their definitions. I then designed theme names in a way that has been designed to capture their essence (Braun & Clarke, 2022, p. 112).

3.7. Ethical Considerations

This study received ethical approval from the university ethics board, adhering to the UCL Code of Conduct for Research (Lamb & Morawska, 2023) and the research was conducted in accordance with the guidelines of the British Psychological Society (The British Psychological Society, 2014). Three main areas of ethical consideration are discussed in more detail here: informed consent and anonymity, protection from harm, and representational ethics.

3.7.1. Informed Consent and Anonymity

Informed consent for voluntary participation is central to ethical conduct in research, and involves ensuring that participants have a full understanding of the purpose of the study and their role in it (Bhutta, 2004). To this end, an information sheet (see Appendix 3.7) was shared with potential survey participants prior to them beginning the survey, and participants were required to signal their informed consent by checking a box before they were able to respond to any other items. The introduction to the survey reminded participants that they could skip any questions that they did not want to answer and that they were free to withdraw consent at any time prior to submission.

For volunteers who were invited to take part in the interview stage, a consent form was sent by email, which they were required to sign and return prior to the interview (see Appendix 3.8). Before recording started, I reminded participants of the conditions of their freely-given consent, and emphasised that they could skip any questions they did not want to answer, suggesting a few phrases that they may choose to use in order to do so. The option of making ‘off-the-record’ statements (see Suzuki et al., 2007) was taken by several participants, and the content of these was not included or alluded to in the results, although, as noted by Suzuki and colleagues (2007) this information may have shaped how I interpreted what I subsequently heard ‘on-the-record’.

In order to protect anonymity, all names were removed in transcripts. Personal information included in the participant descriptions has been reduced to generalised, non-identifiable demographic information. Audio recordings of interviews have been saved on a single password-protected computer and will be deleted once the study has been completed.

3.7.2. Protection from harm

As geographical information was not collected in the survey, I asked participants to share this verbally at the beginning of interviews, in order that Local Authorities could be contacted in the event of a safeguarding concern arising during the interview. I informed participants via the consent form and again verbally at the beginning of interviews that this was the only instance in which anonymity would be broken. I discussed the content of interviews with my supervisors in order to reflect on this important aspect of my role as a researcher. No safeguarding concerns arose.

As I asked parents to discuss and reflect on something very personal that they may or may not have previously examined (Smith, 2011), there was a possibility that this could possibly result in distress. Participants were reassured they could withdraw from the study at any point up until data analysis began, and were able to skip any questions they feel uncomfortable with. At the end of each interview, I debriefed each participant. I was prepared to signpost appropriate services, but this was not required.

3.7.3. Representational Ethics

The concept of ‘interpretive authority’, which can be defined as ‘the power to analyse and represent people and their lives’ (O'Connell, 2016, p.148) is an important one to consider as a qualitative researcher. Whilst advocacy goals of research might speak of ‘giving voice’ to participants, in selecting which data to collect, analyse and report, I have controlled the version of that voice that is represented in this study (see Swauger, 2011), and therefore have had an ethical responsibility to do so empathetically and respectfully. To maintain a heightened awareness of this responsibility, I have made use of a reflexive journal as well as both peer and formal supervision. Importantly, I have tried to do as Braun and Clarke (2022, p. 215) suggest, and, "focus […] on the idea and what it can tell us about the wider meanings" rather than the participant themselves. One way that I have chosen to do this is through representing participants in a simple alphanumerical form (P1, P2, P3 etc.) rather than by a pseudonym (see Heaton, 2022).

3.8. Summary

This study used a qualitatively-driven mixed methods design to gather the help-seeking experiences of parents who have a child with ADHD-related difficulties. Together, data obtained from an online survey and semi-structured interviews have enabled me to identify the sources of support accessed by parents, and explore the nature of their help-seeking experiences in more depth. In this chapter, I have outlined how I recruited parents of children aged 6-12 years old through social media and community outreach, and discussed the steps I have taken to ensuring the quality of the research. I have described my data collection tools and procedures, and detailed the process of thematic analysis.

The results of descriptive statistics and thematic analysis are presented in the next chapter, followed by a discussion of possibilities for strengthening and developing the EP role in relation to parents' help-seeking journeys for a child with difficulties related to ADHD.

4. Results

4.1. Introduction

This chapter presents results from the two separate phases of data collection. Quantitative data from survey responses are analysed and presented first, followed by the results of a reflexive thematic analysis of semi-structured interview data. Finally, I present a summary of findings from across the two phases.

Data were analysed in relation to the following three research questions, with discussion directly related to each question presented in the next chapter:

1. How do parents describe their experiences of help-seeking for a child who has difficulties with attention, concentration, impulsivity and/or hyperactivity?
2. How do parents describe their involvement and interactions with different professionals in relation to their child's difficulties?
3. How, according to parents, might educational psychologists best support children and their families who experience these difficulties?

4.2. Quantitative Data

For the purposes of this report, a cut-off point was designated at 31st December 2024 and data were drawn off the database for the following analysis. Responses from a total of 40 complete questionnaires were analysed using descriptive statistics. Table 3 shows where parents chose to seek help for their child's difficulties related to ADHD. Sources which parents went to at the start of the help-seeking process are shown in the first column, and sources that they have been to at any stage since are shown in the second.

Table 3

Where Parents Seek Information for Help with their Child's Difficulties

Source	Frequency (n) (%)	
	Went to first	Been to since
Teacher	18 (45)	15 (38)
School SENCo	14 (35)	27 (68)
GP	12 (30)	10 (25)
CAMHS / Psychiatrist / Clinical Psychologist	11 (28)	17 (43)
Family member or friend	9 (23)	7 (18)
EP	7 (18)	15 (38)
Paediatrician or specialist health service	5 (13)	10 (25)
Social Media / Online sources	4 (10)	16 (40)
Books / leaflets	4 (10)	15 (38)
Speech and Language Therapist	4 (10)	10 (25)
Teaching assistant or other school SEN staff	3 (8)	11 (28)
Self-help group or charity helpline	3 (8)	9 (23)
Someone from social services	2 (5)	2 (5)
Someone else in the community e.g., faith group	0 (0)	1 (3)

These results indicate the central role of the school SENCo – and class teacher - both in initial stages of help-seeking and afterwards. Social networks – particularly those in the wider community outside immediate friends and family – are relied on less than might be expected. Almost half of all respondents (19) had sought help from an EP either in the initial stages or since, or at both times. Results suggest that help is sought across both health and education services, as well as more informal sources such as books and social media (the latter particularly so after the first sources had already been consulted). 45% of the parents who responded to this questionnaire had paid for one or more of these services; a breakdown of which families – according to household income bracket – have paid for services, and the nature of these services, is shown in Table 4:

Table 4

Which Families have paid for Services by Income Bracket

		Less than £20,000	£20,000 - £39,999	£40,000 - £59,999	£60,000 - £99,999	£100,000 or more	Prefer not to say
Did you have to pay for any of these services?	**% Yes**	33	67	20	33	54	75
	(of total n)	(3)	(3)	(5)	(9)	(13)	(4)
If so, what? e.g.		Counselling	Books Private assessment	None given	Play therapist Private Assessment	Private assessment	Private assessment

The one participant in the lowest income bracket who paid for private counselling explained further during the interview phase that paying for this service meant she had to make sacrifices elsewhere (such as her son’s extra-curricular clubs). Contrastingly, in the highest income bracket, a participant noted that she had paid for a private assessment as her, “daughter was referred by her SENCo for an NHS diagnosis […] however this has over a two year waiting period”. The theme of mobilising resources to circumnavigate difficulties in the system is explored further in 4.3 Qualitative Data: Thematic Analysis.

Parents also shared which treatments their child had received; these results are displayed in Table 5:

Table 5

Treatments Respondent’s Child has Received (Child may receive more than one)

Treatment	Frequency (n) (%)
Special education services	13 (33)
Medication	12 (30)
Behavioural therapy	5 (13)

Counselling	5 (13)
Diet and lifestyle changes	5 (13)
Alternative therapies (e.g., acupuncture, homeopathy)	3 (8)
Other	8 (20)

Of the 26 children who have a formal diagnosis of ADHD, 12 are taking medication. The majority of these (n = 7) are in the older age range (10-12 years) with three in the 8-9 years age range and two in the youngest (6-7 years). Fewer children than might be expected are receiving psychological interventions such as behavioural therapy or counselling. Only half of parents who responded to the questionnaire are either ‘somewhat’ or ‘extremely’ satisfied with their child’s treatment (see Table 6):

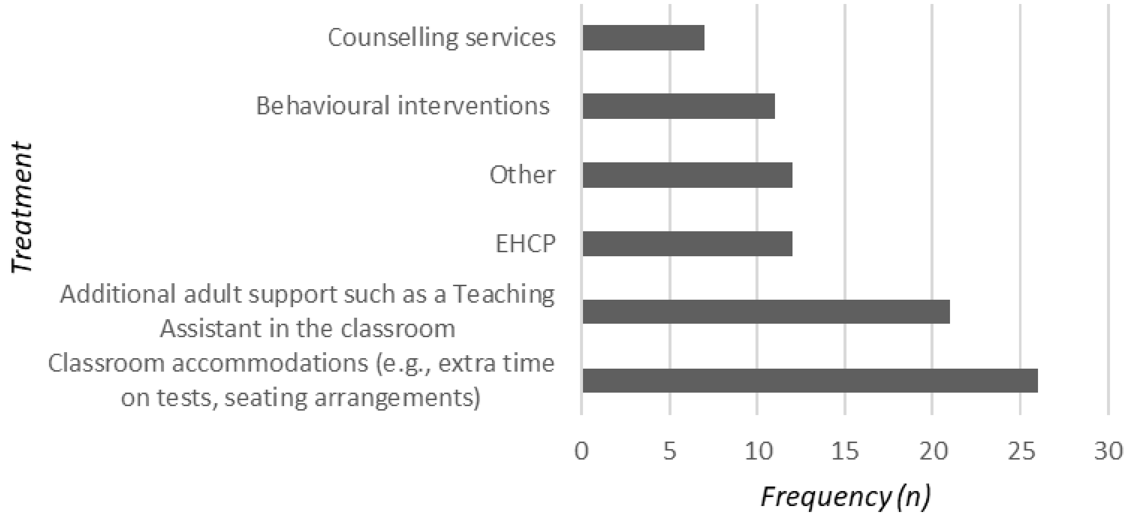
Table 6

Parents’ Levels of Satisfaction with Child’s Treatment

	Frequency	%
Extremely dissatisfied	1	3
Somewhat dissatisfied	7	22
Neither satisfied nor dissatisfied	8	25
Somewhat satisfied	13	41
Extremely satisfied	3	9

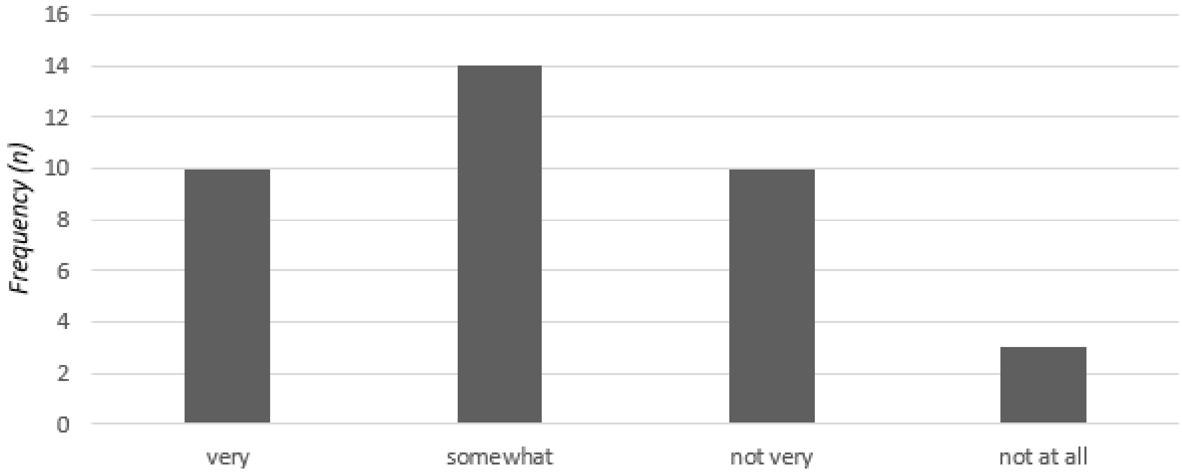
Challenges that parents have faced when accessing treatment included long waiting times (n=27 parents, 68%), availability of specialists (n=19, 48%), stigma or lack of understanding (n=14, 35%) and cost (n=13, 33%). Other challenges that parents added to this list were “unsure where to go”, “lack of communication” and “reluctance of school to consider ADHD”. In school, just over half of the children referred to in participants’ responses were receiving classroom accommodations (26) or additional adult support (21), with twelve of these children having an EHCP. However, psychological interventions such as counselling services (7) and behavioural interventions (11) were some of the less-commonly received forms of support (see Figure 5):

Fig. 5: School-based support received by child according to respondent



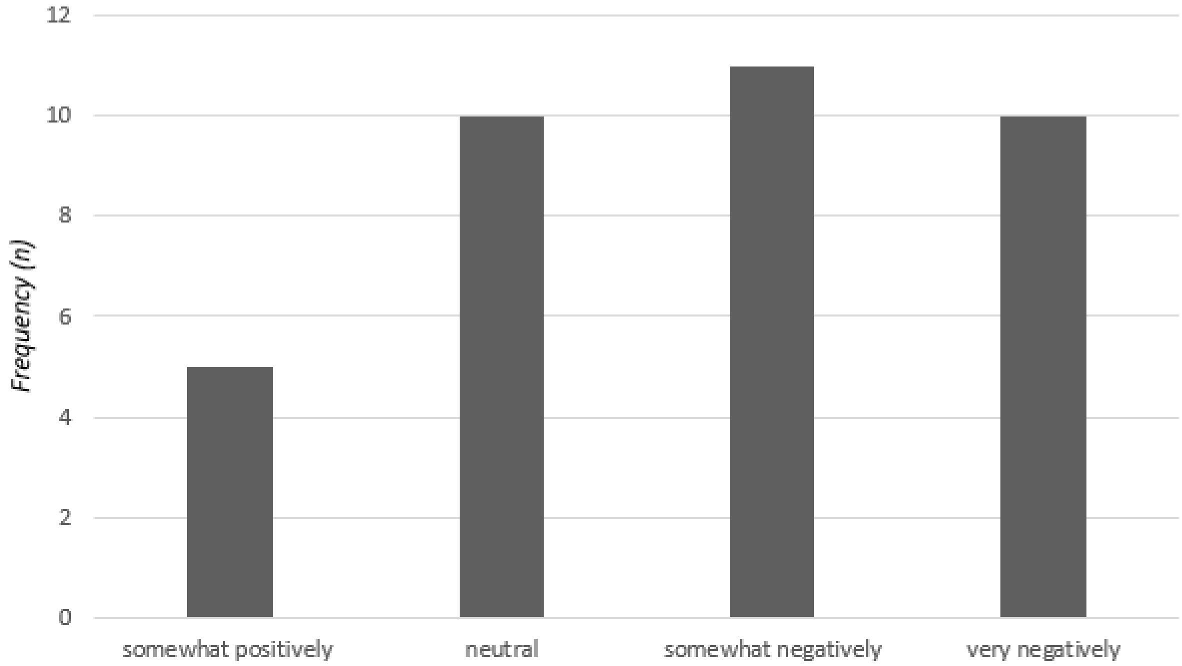
The proportion of parents who felt that their child’s school had been ‘somewhat’ or ‘very’ supportive was fairly high at 65% (see Figure 6).

Fig. 6: How supportive has your child’s school been in managing their ADHD / related difficulties?



58% of respondents perceived their child's difficulties related to ADHD as impacting somewhat or very negatively on family life (see Figure 7), yet the number of parents themselves accessing support groups or counselling was low (8 and 6 respectively).

Fig. 7: How has your child's ADHD or related difficulties affected your family's day-to-day life?



Other sources of support accessed by parents are shown in Table 7, with the most-frequently accessed form of support being parent-training programmes.

Table 7

Sources of support that parent has accessed

Source	Frequency (n) (%)
Parent training programmes	14 (35)
Educational resources	13 (33)
Online communities	10 (25)
Support groups	8 (20)
Counselling	6 (15)
Other (e.g.):	11 (28)
Medication for anxiety	
Helplines	

The two barriers to support most frequently cited as a significant barrier to support (see Table 8) were ‘Steps to seek help were overwhelming’ and ‘Too busy / competing priorities’. These barriers will be explored further in 4.3 Qualitative Data: Thematic Analysis.

Table 8

Barriers to Accessing Support

Barrier	Frequency (n) (%)		
	Not at all a barrier	Somewhat a barrier	A significant barrier
Not knowing where to find help	7 (18)	19 (48)	10 (25)
Too busy / competing priorities	10 (25)	14 (35)	13 (33)
Steps to seek help were overwhelming	10 (25)	13 (33)	13 (33)
Negative experiences with professional help	13 (33)	11 (28)	11 (28)
Having difficulty describing the problem	21 (53)	11 (28)	4 (10)

Fear of labels / stigma	20 (50)	9 (23)	6 (15)
Believed the problem was not serious	18 (45)	7 (18)	11 (28)
Fear of being a burden	25 (63)	6 (15)	5 (13)

Other barriers to support as noted by respondents in the free text boxes included: “Lack of funding in schools to support my son or disbelief in his diagnosis (his primary school were unsupportive until CAMHS confirmed his diagnosis)” and “A lack of advocates or support for neurodivergent parents trying to navigate the politics of the system”.

In summary, these results highlight parents’ reliance on schools as well as health services for ADHD support as well as significant challenges related to accessing help in the initial stages of help-seeking. The financial burden of seeking support was indicated for some families, along with mixed satisfaction with current treatments. These descriptive statistics have indicated patterns of service use by parents in their help-seeking, and their satisfaction with these services. The following analysis of qualitative data will explore parents’ experiences in depth and consider how aspects of a family’s context interact with different systems, whilst elaborating on how the EP role can fit in to parents’ processes of help-seeking for their child.

4.3. Qualitative Data: Thematic Analysis

Fourteen interview participants, primarily mothers, shared their help-seeking experiences in interviews that were, on average, 45 minutes long; see previous chapter for further details regarding participant characteristics and analysis procedures. The following six themes were created following a reflexive thematic analysis of interview data: *Unique problems need unique solutions; The ADHD label offers benefits; Navigating complex systems is hard; Stuck in limbo whilst things get* *worse; Mobilising resources works (sometimes);* and, *Banging a drum but not always heard.* The characteristics of each theme are briefly summarised in Table 9.

Table 9

Theme Summary Table

Theme	**Characteristics**
Unique problems need unique solutions	Child's difficulties that prompted parent to seek help, and aspects of home and school contexts that might contribute. The importance of holistic support.
The ADHD label offers benefits	The utility of the ADHD diagnosis for helping parents and others understand their child's difficulties, and access additional resources and support.
Navigating complex systems is hard	Parents' difficulties in co-ordinating different systems of health and education. The importance of good social support networks and helpful professionals; the additional strain when these are unavailable.
Stuck in limbo whilst things get worse	Stretched services with long waiting lists. Parents' concerns that waiting will cause harm. Ideas for active, rather than inactive, waiting.
Mobilising resources works (sometimes)	Choosing to circumnavigate waiting lists by getting private assessments can result in quicker treatment, but does not remove all barriers.
Banging a drum but not always heard	Parent voice not always valued; having to fight to have concerns taken seriously. Importance of being listened to.

4.3.1. Theme 1: Unique problems need unique solutions

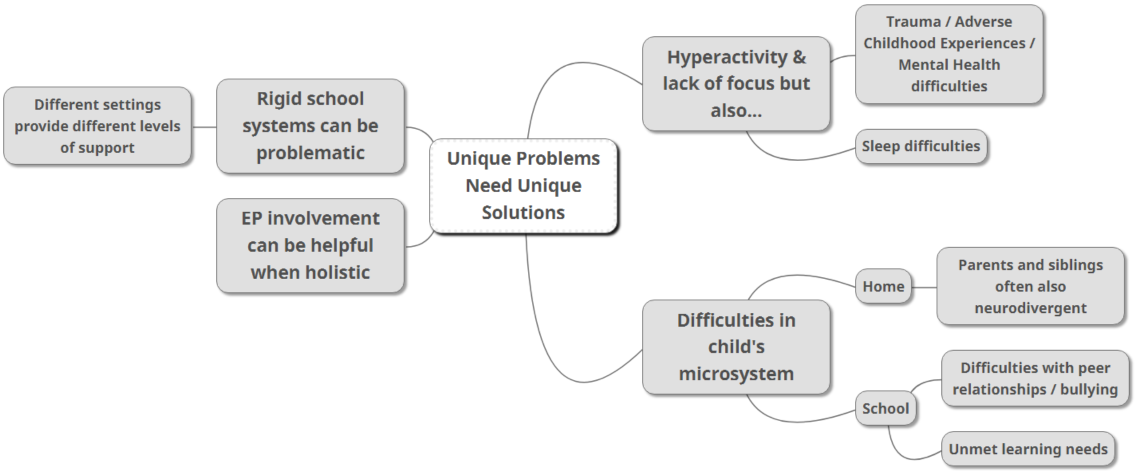


Fig. 8: Thematic Map: Theme 1

Across the fourteen interviews, the difficulties that prompted parents to seek help were varied. There were many descriptions of behaviours that are more typically regarded as symptomatic of ADHD such as hyperactivity ("*extremely high power, literally bouncing off of the walls*"; P2) or difficulties in focussing ("*if there's a tree out the window […] that's sort of blowing the wind, she'll be […] distracted by that*"; P7). However, parents also described problems that are not as easily captured under the ADHD label, such as difficulties with sensory processing ("*there were things around her touch, so she would not like to press on things"*: P5). Some children whose parents took part in the study (such as P1 and P12) also had co-existing physical health needs which impacted on their difficulties. Other participants' children were experiencing further mental health difficulties, including anxiety (P4), and panic attacks and a vomiting phobia (P6) and many of the parents talked about their child having significant difficulties with sleep.

Parents from different types of families took part in the research, and the differences of each became part of the help-seeking story they shared. Two separate parents had adopted their child, and speculated about their child's early experiences as contributing to their difficulties: P3 shared that she felt "*it's maybe a bit more complicated than just ADHD"* and P10 noted that her son's *"birth mother didn't access any antenatal care at all. And we don't know the health of that pregnancy. So it's fair to say from day one we always had concerns*". Another parent explained that she was using drugs before she was aware of her pregnancy and shared her belief that, "*I'm sure me using must also have a huge part in [his behavioural difficulties]*" (P9). She was also living in temporary accommodation with her son in his early years, having left a difficult relationship with the child's father.

The uniqueness of each 'problem' that initiated the help-seeking process was reinforced by the complex interplay between different aspects of the child's microsystem – home and school – that could be seen in each transcript. At home, parents described busy lives in which there were often several children in the family with additional needs, and parents who also regarded themselves as 'neurodiverse'. Some participants shared how they felt this influences the parent-child relationship: "*As a neurodiverse parent with a neurodiverse child, we're at loggerheads because I'm like, boom, boom, boom, boom, boom*" (P7). Experiences during the pandemic were sometimes raised to further illustrate the difficulties of family life. P2 explained how the combination of living conditions and homeschooling her son during the pandemic exacerbated difficulties:

> "*at the time I lived in a one bedroom flat. So the space was tiny. We had no [space] we had a little balcony, but at the time, with cars, [and my son's'] lack of awareness, it just wasn't something that, you know, he could access. So we*

didn't really have much outdoor space. We did have a park, but for children who have autism and ADHD, especially during the lockdown time where there's very busy crowds and noise, it was just very, very difficult."

For other parents, it was the experience of homeschooling that revealed the extent of their child's difficulties and led them to seek help; for example, P3 shared that her child was having "*massive tantrums*" due to being overwhelmed by the work being set, and P6 shared that, "*it was just a battle to try and get it to 30-40 minutes at a time for the virtual lessons. And we tried various things. We tried her sat next to us on the calls, and we'd constantly be trying to get her attention back on to the call."*

The school system was described by some as one in which their child's difficulties were acknowledged and accommodated for, and by others as one in which problems were exacerbated. Where schools were described as more flexible and accommodating, examples included offering different options for seating and activities (P10). P1 explained that, "*even before we got the diagnosis, but whilst we were sort of talking about ADHD, they did things like move her to a desk so that she was facing the front of the class so that she couldn't see the trees that kept on distracting her*" and P3's daughter also had "*little interventions like having a timer*" prior to receiving a formal diagnosis. P2's son, who has an EHCP, has a place in his school's resource base, which means, "*he is allowed that freedom […] that time to exert his energy. You know, they have lots of equipment available, you know, so he does soft play a lot of the time*".

In contrast, several parents described rigid school systems in which their child struggled. P11 spoke of the impact of uniform policies on her son's sensory processing needs and explained that he "*could not cope with his shirt tucked in* *because it was on his waist, so he was getting behavioural sanctions because he was untucking his shirt, whereas in a uniform situation where they're wearing polo shirts and sweatshirts, there would have been no behavioural problems*". In this description, it is the situation (rather than the child) that is regarded as causing the problem, as the parent considers how the same child would present differently in a school with a different uniform policy. Similarly, P1 intimated at the psychological impact of behaviourist classroom management approaches on her daughter:

> *"They always seem to have to line up at school […] she was quite often on the orange, and that was bothering her a lot, so they have this […] sort of system of like you either on the gold, the green, the orange or the red […] there was a long period of time where she would be coming home from school being like 'I was on the orange again'."*

Likewise, P13 expressed his frustration with his son's school's lack of flexibility and reasonable adjustment:

> *"from the beginning of year three at the age of seven, the expectation was that they'd write in their diary every single day, how much they'd read and a reflection on what they'd read. [son] couldn't write a sentence down. And so we said obviously he won't be doing that. We'll do it. We missed it once, and he was given detention and made to miss his Break, which obviously when he needs to be moving, that isn't a brilliant thing."*

This father, who himself works within education, later shared his view that, ""*if the system was better equipped and there was better understanding within schools, [my son] wouldn't have crossed the radar, I don't think*".

Other difficulties related to the school context which became part of the fuller picture of each child’s needs included unmet learning needs (for example, P10, P13, P3 and P6 all described their child as having literacy difficulties or a dyslexia diagnosis: “*it's like a jolly combination of dyslexia, but then not being able to focus”:* P3) and difficulties with peers at school, including incidences of bullying (mentioned by P4 and P6) or a difficulty in maintaining close, positive relationships with other children (e.g., P9).

Given the wide range of interacting factors that contribute to a child’s presentation as having ADHD-type difficulties, it is unsurprising that, where parents (or their child) had seen an EP, one of the things they found most helpful was the EP’s skill in understanding the uniqueness of the child, and the disparate nature of his or her difficulties. P10 shared, “*I felt they were really holistic. And you know that actually that she captured everything that wasn't just the ADHD*”. Yet there was still a sense in other interviews that the problem was being centralised within the child and approached from the medicalised perspective:

> P4: “*we went to take her to the new school and we sat down with the deputy head. And we said we do have some concerns that she might have neurodiversity because we've got a family history […] She said, ‘it's funny you say that because as soon as I just observed her, I thought, I think she might be ADHD. Just by her presentation’. And it was kind of at that point really we thought, right, we've got to get her diagnosed.”*

In summary, this theme captures how parents described seeking help for their children due to a diverse range of difficulties, partly but not wholly linked to ADHD-related symptoms. Other difficulties included sensory processing issues, co-existing health conditions, mental health struggles, and school-related challenges, with experiences varying based on family dynamics, and the level of support within school systems.

4.3.2. Theme 2: The ADHD label offers benefits

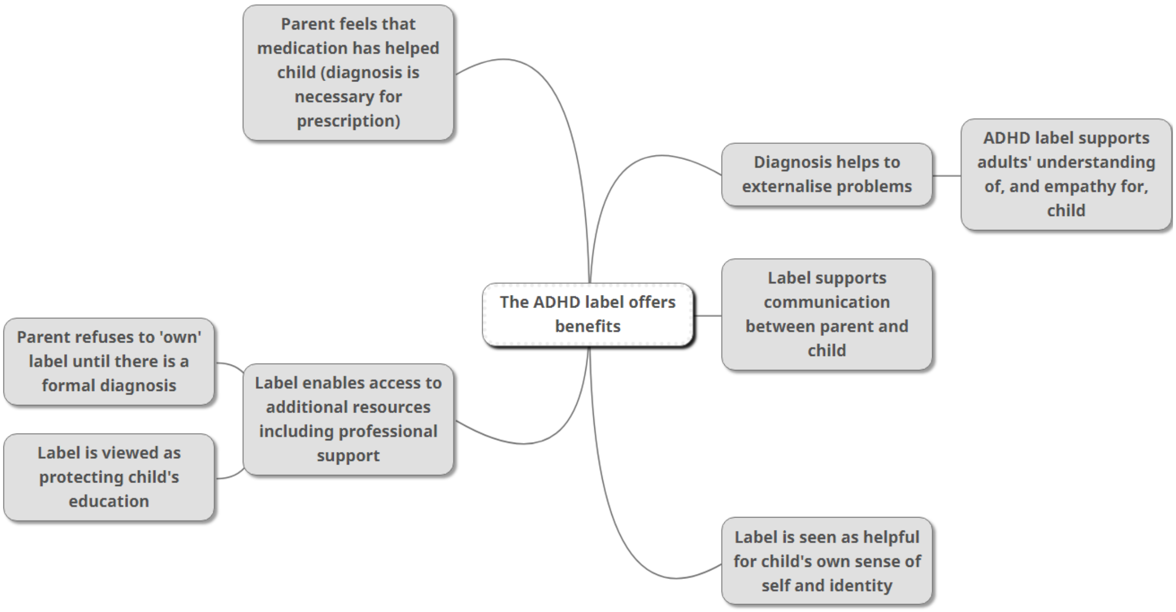


Fig. 9: Thematic Map: Theme 2

A second theme was created to capture what participants had described regarding the utility of the ADHD label (and, sometimes interchangeably, diagnosis) for the child and parent. It emphasises the multifaceted role of a label in providing validation through externalising problems, enhancing communication, and offering practical solutions through treatment and school accommodations.

For many participants, a formal diagnosis of ADHD plays an important role for the parent in facilitating communication with their child. P5 explained that,

> *“what was mostly helpful was us understanding that something was going on with her that wasn't her fault. So it's not out of a rebellious attitude that she*

> *wouldn't listen to us. It was that, you know, it wouldn't register in her brain because too much was going on and it wasn't an interesting thing that was going to grab her attention. So for us in terms of […] our compassion and understanding of her that was that made a great difference"*

In this description, and similar comments from other participants, the diagnosis is described as providing a shared vocabulary that can ease tensions and support emotional understanding, resulting in parents responding to their child more favourably and having a positive impact on their relationship. P10 also explained how she would talk about the "*sitting still doctor*" with her son, but emphasised that she would not use this as, "*a judgement call on him, but it was just like, oh, it's OK that you find this a little bit tricky*".

One parent, who is also a SENCo herself, reflected on how she felt a diagnosis (which she was currently seeking through private healthcare) would affirm her own evaluation of her daughter's difficulties:

> *"I don't want her to have these difficulties. But if she does, I want them to be acknowledged. However, if she doesn't have a diagnosis, I don't know where that leaves us. Does it still leave us in this case of limbo? […] So am I wrong? Professionally and as a mum? Like, have I misjudged this absolutely wildly? There's so much to it and so much validation from that label that I never saw before. Whether it's a validation of knowing your children, a validation of professionalism, I guess as well. Is there a validation for [daughter]? Yeah, I feel like to access those [SEND-specific extra-curricular] groups. And maybe there is an element of self-doubt. Maybe there is still an element of what if?*

> *Because there’s still maybe a niggling doubt that maybe [daughter] doesn't have these difficulties” (P12)*

The desire for a formal diagnosis is described here in terms of its function in affirming her professional judgment as a SENCo and her intuition as a mother. The label would both acknowledge the child's struggles and also the parent's credibility in understanding and addressing those struggles. This suggests that some parents may feel uncertain or insecure about their judgment without a formal diagnosis, and the label provides reassurance in their efforts to support their child. The process of seeking a diagnosis can be loaded with uncertainty, and parents like P12 struggle with the idea that they might be ‘wrong’ about their child’s difficulties. Furthermore, even when services do not require a formal diagnosis – such as the extra-curricular clubs mentioned here – there is a sense that it would be inappropriate to access them until such a diagnosis is obtained; as P12 said, “*I feel like it's, I don't know, fraudulent”.*

In this theme, parents also view the ADHD label as important to ensure that other adults outside of the family unit are able to understand their child. This suggests that the diagnosis acts as a bridge for parents to advocate for their child’s needs, especially in the school context. P13 explained that they have, “*persisted with the diagnosis not because it's an issue for him, but it's been an issue for the settings that he's been in to appreciate him and understand what's going on for him”.* Similarly, P4 explained that seeking a diagnosis was motivated by a desire “*to help [teachers] understand her and the way she ticks, so that then they can use more targeted strategies in helping her*”. Sometimes parents anticipated concrete accommodations such as extra time in exams (P1). Other parents shared examples of more generalised changes in approach, such as shifts in teachers’ perceptions of a child from one in which he is viewed as ‘naughty’ towards an understanding of him as having a special educational need that needs to be carefully managed; P9 explained,

> *“in school, all the time he was getting in trouble [but] now they're trying to find a strategy, so when he gets hyper and starts to call out and shout out the teacher, now she is like […] approaching him in a different way. So when he gets hyper, she sends him […] to the hall […to] jump outside in the corridor [until] you feel calmer”*

Another parent described a vicious circle in which professional involvement is needed before such support can be given: “*if you do not have professional reports, a child, who has enormous struggles, is being punished, told off, criticised, threatened to be excluded”* (P1).

An important facet of this theme is the practical utility of a formal diagnosis in enabling access to medication. Whilst not every parent was interested in their child taking prescription medication to help them manage their ADHD symptoms, others felt their child had benefitted and this was one important advantage of ‘*the actual piece of paper*’ (P1). Participants shared how much they relied on the psychiatrist’s biomedical explanations of their child’s difficulties when making decisions about treatment:

> *“I had a mental block against the medication because I think I just felt like […I had] absorbed all of the media stuff about, Americans over-medicating their children […] but when the psychiatrist explained it essentially like the chemical makeup in her brain is such that you're just sort of topping up something that*

> *she doesn't have that other people have already. Then it felt kind of a bit different. So we took the view that we would trial it" (P1)*

Initial reservations about medication (influenced by media portrayals) were mitigated after P1 was presented with a physiological explanation, and she transitioned from being sceptical to more accepting once the treatment was framed as addressing an underlying biological need. P2's psychiatrist also recommended medication, and she agreed because her son was *"really struggling in school […] I just felt that it was important for him to kind of have some sort of assistance to be able to, you know, navigate throughout society throughout school".* This mother explained how, after trialling three types of medication which did not work (and had very unpleasant side effects), her son was now on medication which was "*amazing*". Melatonin was also referenced as a medication prescribed in relation to the difficulties with sleep associated with a child's ADHD diagnosis. One participant, P10, noted that this was "*life changing*" for the whole family, including the child whose behaviour improved in the day because he was getting more sleep.

Finally, the ADHD label was described in ways which suggested it was helpful for the child's *own* sense of self and identity, given the awareness they have of being different to their peers. P1 felt that her daughter, *"felt a little bit like Peter Rabbit. Like, 'everyone finds it really easy to be good. Why don't I …?"* whereas after she had been diagnosed with ADHD, she felt "*part of a gang*". Another parent (P12) shared how her child had returned home from school after a 'neurodiversity awareness' assembly and was self-identifying with the descriptions of what it is like to have ADHD. Amongst participants, there was a sense of the importance of their child being able to use the label as a way of explaining their difficulties to themselves as well as others: As P4 noted, “*we felt as though it would help her to be a bit kinder to herself too*”.

This theme demonstrates how many parents spoke of the ADHD label from an assumption that it would be helpful for their child. The diagnosis was seen as a way of unlocking support for, and greater understanding of, their child and their needs.

4.3.3. Theme 3: Navigating complex systems is hard

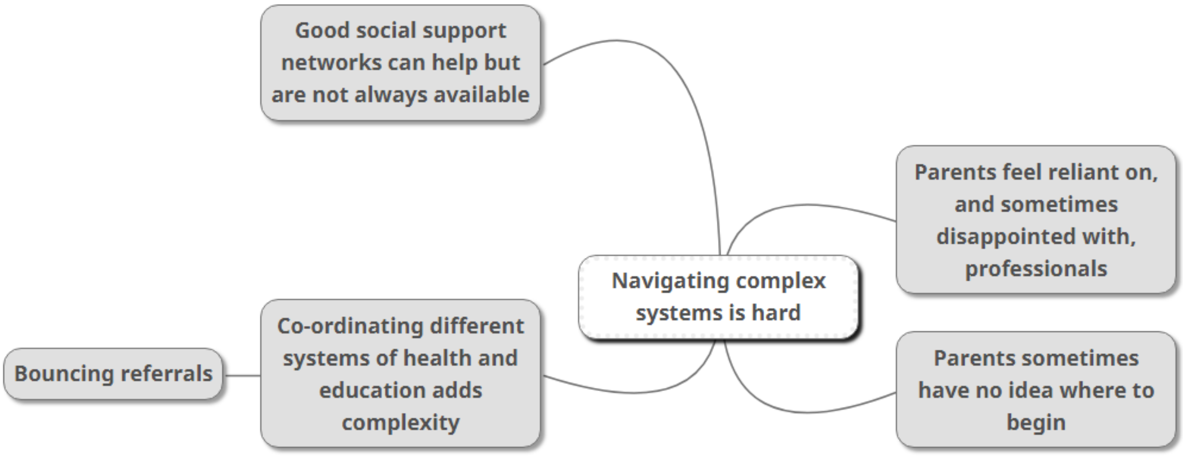


Fig. 10: Thematic Map: Theme 3

When explaining their processes of help-seeking, parents often spoke of how difficult it was to navigate the system. Parents explained how they had no idea where to even begin when they first started seeking help:

> *“I couldn't even work out how to go about getting a diagnosis through the NHS anyway […] I cannot figure out the entry point, like, I think I have to have an appointment with my GP but then people talk about being able to self-refer to*

> *CAMHS but I don't know where CAMHS is. It doesn't seem to be consistent… so I can't figure out what the entry point is" (P1)*

This parent summarised the whole process as a *"a bit of a magical mystery tour"* and said how useful it would be for parents to have access to a *"decision tree"* which has *"your first step where can you go to and then what are the options from that"*. Without that, current attempts to find information to help her understand the processes make her *"brain hurt"*.

Another parent shared that she was "embarrassed" to admit that she began by searching online:

> *"I guess that like in hindsight, I think maybe going to the GP should have been maybe my initial sort of stage, but that was the next step. But there was some traits and I typed it into Google and then it come up as ADHD. And then I then went to the GP and said, you know, we need a referral to see exactly what's going on." (P2)*

When I suggested that this is likely a very common approach amongst parents, and wondered with her about why she was embarrassed by it, she said she "*naïve*" and that it is more appropriate to seek help from "*somebody who has a professional background*" because otherwise "*you could just type anything in Google and anything could come up"*.

Like P1 and P2, P11 noted that at the beginning of the process*, "you don't know where to push. You don't know what data to gather"* and P3 noted that there was an element of chance to what information parents happen to access, in her case because she had happened across a radio programme: *"we only found out about this kind of website with loads of information on the back of that radio programme*

[…] despite having done research on this for two years trying to see what's out there".

Even when they have made the first step, it was clear that co-ordinating different systems of health and education adds complexity for parents, and this can involve bouncing referrals between services or even within them, leading to parents having to chase: P14: *"I have a meeting booked with GP to get all the documentation from the school. So for the referral […] It bounces between doctor and schools".* As P4 noted, *"Everything's separate. There's no central point. And it's incredibly frustrating because you just feel like you're trying to grab everything and get it all to come together when you don't know how things work. It's like trying to shoot in the dark"*.

In some LAs, there is also a separation within health services; P6 noted that, *"it's very confusing actually to get my head around it all, but CAMHS deal with the medication side treatment of it, whereas the [community paediatrics centre] deal with the diagnosis of it, I think".* For other parents, age cut-offs that fall within the waiting time can make things even more frustrating:

> *"there is an age cut off, so he's now post the age where he should be looked after by developmental paediatrics. […] They're sort of like, oh, he should be with CAMHS. Now this whole transition thing, whereas I don't really feel like we've explored, you know, I would prefer to have explored the medication conversation with them rather than joining another waiting list and you know getting to the point where, let's say it was really, he was really desperate for something like that and having to be in a queue again" (P10)*

Given the difficulties in navigating these systems, parents felt they were reliant on professionals to support them through the process and were sometimes disappointed. Human errors made at points within the process can have a significant impact when it has taken families so long to make progress. P5 shared that she *"wasn't super happy with the experience, like part of the report has another child's name in it, so you can tell it's been copy and pasted from another."* Sometimes it was school staff who gave parents cause for concern; P6 explained that, *"we didn't know that the school hadn't referred [Eldest daughter]. They thought they had, but there was an administration error."* Others were concerned that a lack of teacher training in this area would impact their child's outcomes; P12 recalled that, *"the class teacher told me that he'd learnt everything he knows from podcasts! Which is not what a parent really wants to hear".* This mother then explained how this impacted the assessment process:

> *"it came to the point of filling out forms and all sorts of referrals. And [the class teacher] was saying, well, how would you have filled it out? Which again is not the purpose of asking a class teacher to fill them out really. So we were quite cautious that we wouldn't get referred" (P12)*

Contrastingly, a pro-active SENCO is a vital part of the process for parents when navigating these complex systems. Often parents described how they had been unable to make progress in their help-seeking until a particular SENCo became involved:

> *"a new SENCo started and she took one look at our daughter and went, 'there's something going on. I'm putting her on the top of my list'. So we're like, 'thank God for you' […] She was like, 'let's just try everything'. And she did referrals*

> *here, there and everywhere and some weren't necessary and some were, and it was, it was great" (P3)*

Similarly, for P12, it was a meeting with a "*very on-board*" SENCo (who had just returned from maternity leave) which resulted in a referral being made within four days. For P14, it was the SENCo's "*personal understanding of neurodiversity*", which meant she "*felt so understood […] after some period of difficulties and disappointment and needs being neglected, [here was] someone showing once again that OK, it can be done*".

Along similar lines, the difficulties of navigating complex systems is eased for parents when they have good social support networks with others who have similar experiences. P11 noted that going through the process the first time "*is incredibly different to it being your second and third time because you [know] so much more, and more people, you've got more of a village. That first time is so lonely, so isolating*", which echoed how P10 referred to herself as a "*lone campaigner*". P14 shared how she, "*could no longer relate to people who do not have neurodiverse children. Because I really felt misunderstood. Judged*." This parent went on to explain that she has accessed support from other "*parents of neurodiverse children*" in the local community and on social media, and has found it "*an enormous support*" to be able to connect with others who can relate to her experiences. P5 explained more about why these networks were so helpful; "*you know, people are willing to talk about it and exchange and, between parents of neurodivergent children, there's no stigma at all. Like it's all very supportive and you know, understanding [whereas] I would say with the larger community there seems to be suspicion around diagnosis*".

To summarise, this theme captures how parents described their struggles with a complex and disjointed help-seeking process, facing unclear pathways, bureaucratic hurdles, and inconsistent professional support, but found relief through proactive SENCos and supportive peer communities.

4.3.4. Theme 4: Stuck in limbo whilst things get worse

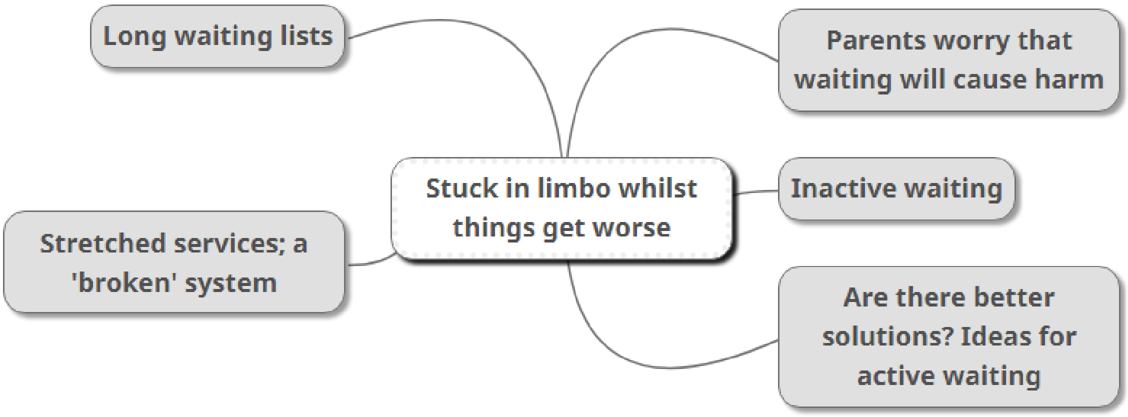


Fig. 11: Thematic Map: Theme 4

The fourth theme to be generated was labelled ‘Stuck in limbo whilst things get worse’ and was characterised by parents sharing their experiences of long waiting lists, and stretched services more broadly. In line with widespread media coverage, a picture of a broken system emerged, although some parents also shared hopeful ideas for how it could be improved.

Parents acknowledged that schools had limited resources. For example, P12, who works in a school and therefore has knowledge of interventions that might benefit her child, explained how she had, “r*eally pushed for an ELSA [Emotional Literacy Support Assistant] at the school, really pushed and said, I really felt like there's something you need [but] they've got massive budget restraints*.” Another parent felt that the school SENCo was,

> “*overwhelmed by the need and the lack of resources that they have to allocate really. So in the end, it becomes almost a confrontational relationship where all the parents feel like [their child has] all these needs [but the SENCo] has a limited amount of resources” (P5)*

Whilst P14 could understand the pressures on schools, and observed that “*it's almost not a surprise that they want to get rid of the problem*”, she also emphasised that the consequence is unacceptable; “*when you think a child is being objectified and being treated as a problem, that's really, really horrible*.”

P10, who works with young children, shared her growing sense that, “*every service is stretched, they're almost trying to look for, you know, where children tick off milestones even if they are at the lower end. It feels like things aren't flagged very early*.” Even “*getting an appointment with my GP is almost impossible*” for one participant (P1).

Unsurprisingly, long waiting lists to be seen by CAMHS for an ADHD assessment were frequently referred to, and parents’ mobilisation of resources in order to skip these will be explored further in Theme 5. Central to this theme, however, is the notion of waiting being *inactive*, with parents equating the waiting period with one in which harm may be caused to their child. P6 captured this sense of limbo:

> *“We were in the waiting system for about two years. No contact in that time to say where we were so [I was] constantly getting in contact, which was quite tricky because they're overwhelmed. …There's a real big disconnect from yes, you've been put on a waiting list either from the school or you've done a self-referral. There's no communication until your appointment […] so there's*

> *nothing, there's no support in the meantime. And I think there should be. It's almost like you've just been put out into space to float around for a bit, and the same is true for after you've got the diagnosis as well. There's no ongoing communication. I know it's hard. I know the NHS is really stretched."*

For one parent, P7, the worry about "*the impact [on] her self-esteem*" of not having a clear label for her behaviours meant that she sought a diagnosis privately (a concept explored further in Theme 5):

> *"I just didn't want [the school's negative response to her behaviours] to be something that she started to kind of internalise and so that's kind of how we got away from that […]I think it would have felt incredibly stressful if we had not taken that route because I would not have been clear about […] support that she might need"*

Others had concerns about the delay in being able to access medication which is seen as vital; for example, P12 explained, "*this period of time has felt like a long time, to wait another year. If [daughter] was worse and did need medication, you know, I've seen children far more prevalent than [daughter] who would need medication that would have been really vital for them*".

Such experiences clearly highlight the need for improvements in this stage of the help-seeking process. Whilst shorter waiting lists is one solution, one parent, P3, shared an example of how being actively engaged during the waiting period was helpful:

> *[Whilst] on the waiting list […] we get sent the SNAP questionnaire and the Strengths and Difficulties Questionnaire. I think it's like every three months for each of them and that's really helpful because on the site where it is, you can*

> *track the responses over time […] it's interesting as well, so even though she's not been seen yet, we can still see, OK, for her, defiance is less of an issue, but the hyperactivity is [*gestures it indicate it has become a larger concern*] and you can see that that's pretty constant, so that's really a useful thing, so I don't know if that's, I don't know if that's across everywhere or if it's just our like CAMHS trust, but that's really handy to see […] it has a little kind of graphs […] grouped into the various… I think one of them is pro-social. And one of them is regulation or something? I can't remember what they are, but it's really interesting to track because it gives you a bit of an insight into your child's, you know, progress or like how they are over time and what's constant and what's changed. So that's nice because you're giving the information to them, but you're still kind of getting to see it yourself. And I think particularly while you're waiting, that's quite nice because [although] you've not spoken to anybody yet, but you can see this data.*

Other parents shared a desire to increase their knowledge and understanding of their child's difficulties, although for most this was reliant on parents' own ability to develop this through accessing books and researching online, and therefore reliant on parents' levels of education and resources; P1, for example, "*went and bought a whole load of books for me and some stuff for [my daughter] as well, like 'Understanding my ADHD' and things like that… I just went on to Amazon and was just like, what looks good, basically*". It was suggested by one parent (P5) that it would be better if inclusion departments within schools could act as a conduit for this type of information, so that they could trust the source of information.

This theme conceptualises parents as 'stuck in limbo' due to long waiting lists and overstretched services, with limited school resources exacerbating delays, leading to frustration and concerns about their children's wellbeing. Hopeful suggestions for improvements include creating mechanisms for more proactive engagement during the waiting period and access to reliable information.

4.3.5. Theme 5: Mobilising resources works (sometimes)

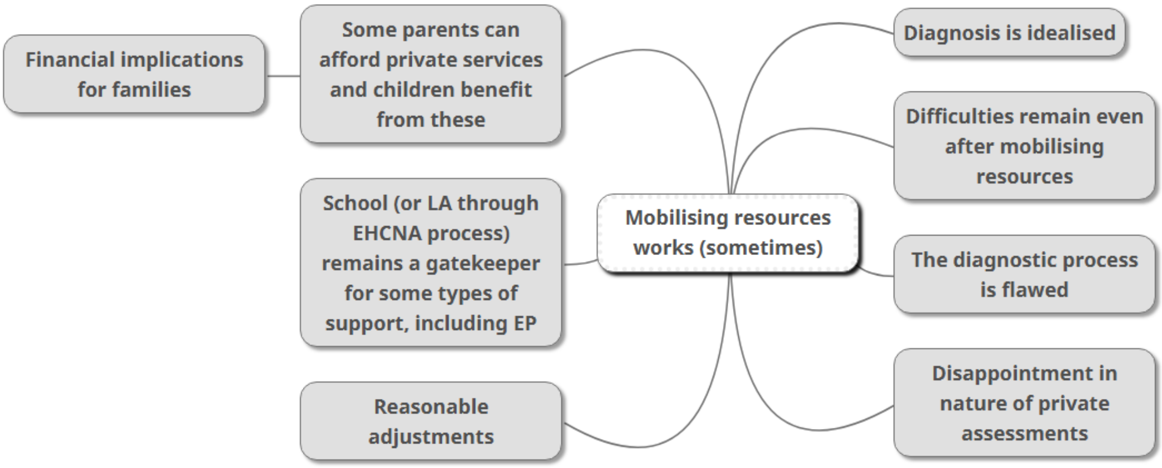


Fig. 12: Thematic Map: Theme 5

Theme 5 develops the idea of waiting that was established in the previous theme, and addresses circumstances shared in interviews whereby some parents can afford private services and children benefit from these. Rather than accepting their place on a waiting list as other less-wealthy families might have to, some parents are able to mobilise financial resources in order to access private services: P12 explained how they are, “*in a fortunate position […] that we can go private, but otherwise we would just be waiting in limbo*” and P1, similarly, “*circumnavigated the stress by throwing money at the problem*”. The financial implications were noted by participants; P1 wryly noted, “*it's not lost on me that we spent […] maybe one thousand pounds […] on a piece of paper that tells you something that you already* *know*". P5 had "*an allowance for a screening*" through private medical insurance, which they "*took advantage of*" and P4 chose a private assessment, "*knowing what the waiting lists were*" for NHS assessments. Others found different ways to "*wiggle the system around a little bit*" through knowledge of little-advertised loopholes in the system such as the 'Right to Choose' pathway (P13). However, for those who are not able to mobilise resources in these ways, it can feel like they are on the lower end of a two-tier system: P7 explained that she has observed,

> *"friends who can throw money at this are in a really, really strong position, I mean, we're talking thousands of pounds. And I have found that their understanding is incredible around their own children and what that means for them. I'm kind of hoping for the same miracle through state-funded support."*

Amongst parents such as P7 who were awaiting assessment for their child, diagnosis was at times idealised, for the reasons covered in Theme 2, including hopes that it would enable their child to access more resources – and reasonable adjustments - in school. Yet circumnavigating waiting lists by attaining a private diagnosis did not always lead to the hoped-for outcome, and difficulties remained for some even after mobilising resources. P1 explained that, "*one of the things that I hadn't really realised but now have realised, is that once you're in the private system, you're just in the private system*" which means having to pay expensive psychiatrist fees every six months in order to continue to receive prescriptions for the medication which her daughter finds helpful. P12 is prepared for this and, although her daughter was about to have an assessment privately, the family have been advised to also "*stay with the NHS*" so that she can access medication through GP-led care if needed. Others were disappointed in the nature of the private assessments; P5 noted, "*I wouldn't say it was very helpful actually*" but felt that they were "*stuck with* *that opinion [of the clinician]*” because “*you've gone through that process and your whole allocation from private healthcare is eaten up*”.

Schools (or the LA through the EHCNA process) remain gatekeepers for some types of support, particularly those related to seeing an EP. One parent had paid for a private EP to work with her child, which she found to be helpful, but was frustrated when this involvement was not taken into account by the LA during the EHCNA:

> *“they didn't want to agree to just go with the private report which was really challenging because I struggled to understand why that report [was rejected], which was so ‘about my child’, so professional, so impressive. And it wasn't, I don't know… So local authority rejected that idea. They sent their own educational psychologist. And that process was difficult for me” (P14).*

Whereas for other families, there had been “*no suggestion*” of having EP involvement (e.g., P12) or even if a child had been seen in school, the parent had not been involved (P11); P4 had been told explicitly that her child would not have access to EP involvement due to capacity: “*They had so many allotted visits for the academic year and we were told they'd used them all up by Easter, so it was basically, I mean, they're very kind about it and how they've raised it, but it was tough luck. So that was that*.”

4.3.6. Theme 6: Banging a drum but not always heard

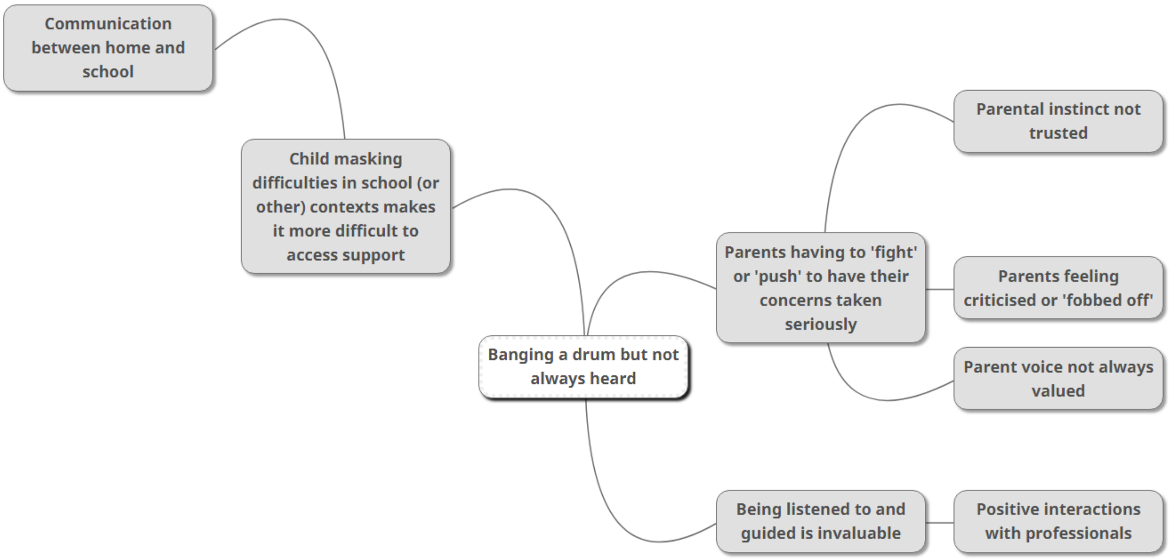


Fig. 13: Thematic Map: Theme 6

The final theme captures the frequent evocation of the adversarial nature of help-seeking for a child’s difficulties related to ADHD, with parents describing having to 'fight' or 'push' to have their concerns taken seriously. This theme develops the previous themes in that it demonstrates the additional emotional toll of help-seeking on parents when they feel they are not listened to, when they are doing their best to navigate complex systems on behalf of their child.

Advocating for a child is described as especially stressful when it is felt that professionals do not accept your concerns; P11 explained, “*when you are met with resistance, the very first thing that happens is your hackles go up*”. Parents described situations in which their concerns were dismissed: P3 said, “*there was a lot of like, oh, that's just a three-year old. That's just a four year old. Oh, that's just a five year old. Oh, that's just a six year old. And then it's like, oh, OK*” and P11 described a similar case of denial in which the school,

> *“kept saying ‘there were no problems. There were no problems. We have no issues.’ But he kept getting sent home. So I was saying there are clearly problems here because you're sending him home. [But the school said] ‘No, there are no problems. He doesn't have SEN, he's just naughty’.”*

Parents often shared that their instinct, whilst rejected at first, was often later shown to be correct when teachers began to share their view: P1 explained that when her child’s teacher eventually raised their concerns with her she “*was like, this is obviously not a surprise to me. I'd said a year before*”. However, another parent, P12, whose child had not yet been assessed, explained how the need to advocate was also leading to self-doubt:

> *“I always feel like it's me and my husband banging this drum repeatedly and pushing for professionals. And it's always that there's a massive self-doubt there. What if we're wrong? Like what if we're wrong? And we've pushed and pushed and pushed, so to speak. And then we're still wrong. And then where do we stand, you know?”*

Being listened to, and gaining access to appropriate support is especially complicated when children’s difficulties present differently at home and school; P6 explained that her daughter is, “*very good at masking her outbursts in front of people outside of the family*” and P3 explained how this creates a disconnect between her observations and other’s perceptions:

> *“The difficult thing is when you kind of feel like it's bit of a lonely battle because people don't necessarily see it because also there's the other thing of behaving like an angel somewhere else and then feeling safe at home and therefore*

> *letting it all out so other people don't even necessarily see the really challenging bits."*

Similarly, P8 shared her anger at her GP when he "*told [her] that, if [son] had an issue at home, but he's fine at school, then the issue must be with home*".

Sadly, some parents also felt their voice was not valued during involvement with an EP. P13 recounted a meeting in which, rather than being asked for his insights into his child's strengths, instead he had to listen to a "*very negative*" account of his son based on standardised assessments whilst, "*crying and looking at the SENCo saying, 'is there anything that he can do?' […] hearing all of that negativity from the professionals that I valued was hard*". Similarly, P14 recalled being excluded from the conversation with the EP; "*I started answering the question, but she literally put her hand like to do the stop sign and said […] I would like to hear the teachers view on that*."

Parents often had ideas or hopes for the type of personalised or holistic approaches that their child might benefit from, but were frustrated in their attempts to secure these. When P13 asked school to support his son's organisational skills by providing a visual timetable, he was disappointed: "*they did a very generic black and white one…and none of it related to what he actually had*." CAMHS too, were sometimes seen as providing only limited treatment options: P6 recalled that when she asked about talking therapies rather than medication, she was told, "*no, sorry. That's not what we do here…it's medication. […] the only route we were being funnelled down is medication, medication, medication*".

Some participants were conflicted in their approach, wanting to assert their rights but also feeling like they should take a more submissive line in order to get the help they sought:

> *"On certain things, I pushed back like law, and I would quote the law or stuff like that. But then I really focused on nearly begging for help. Yes, I went from that person who was like, 'You have no right doing this' to, 'Can you please help me? […] He really needs you. He really needs your help. We cannot do it on our own.'" (P14)*

On the other hand, when parents feel heard and supported, they expressed gratitude, and it was clear throughout interviews that effective communication with professionals significantly improves parents' experiences when seeking help for their child's difficulties. P14 described an experience with an EP who "*understood my child so well and I felt that I was listened to*." P2 was also very keen to emphasise how highly she regarded the CAMHS doctor, with whom she had "*built a very good rapport*", who "*gives you the time, especially in the crisis that we're in*."

To summarise, this theme captures how help-seeking processes were often experienced as adversarial, with parents feeling dismissed and having to fight to have their concerns taken seriously, leading to emotional strain and self-doubt. This was especially the case when children masked difficulties whilst at school. However, when professionals listened and communicated effectively, parents felt validated and supported.

4.4. Summary of Findings

These findings highlight the interplay of family, environmental, and systemic factors that shapes both a child's presenting difficulties and the challenges that parents face in seeking help for those difficulties. Parents described how they felt a formal ADHD diagnosis was helpful in fostering empathy and improved support in schools as well as providing a shared language for their own understanding of their child. A diagnosis was also noted as facilitating access to accommodations and treatments. However, the pathways to gaining a diagnosis were described as unclear, with parents confused about entry points, and lack of teacher expertise hindering progress. Effective SENCos were seen as crucial in making this process easier.

Long waiting lists for assessment were frequently referred to, and parents noted the lack of interim support during this time. Some bypassed waiting lists through mobilising financial resources and seeking assessments privately, whilst others remained reliant on stretched NHS services, highlighting inequalities in access. However, private assessments did not always result in meaningful additional support in schools, and sometimes left parents in a difficult ongoing position of having to pay for their child’s prescriptions.

Together with results of quantitative data analysis highlighting parents’ mixed satisfaction with their child's treatment and emphasising the overwhelming nature of knowing where to seek help, these results highlight the need for empathetic, flexible, and holistic systems to support children and their families effectively. Parents’ experiences emphasise the importance of being listened to by professionals, and having their insights as experts on their own child validated. A discussion of how findings support and extend the established literature on parental help-seeking, and implications for EP practice, will be presented in the following chapter.

5. Discussion

5.1. Introduction

The previous chapter detailed the help-seeking processes of participants in this study, who were a sample of parents who have a child experiencing difficulties related to ADHD. In this chapter, I discuss these findings in relation to previous literature on the topic, the progressive stages of help-seeking frameworks that were outlined in the introduction, and in response to the following research questions:

1. How do parents describe their experiences of help-seeking for a child who has difficulties with attention, concentration, impulsivity and/or hyperactivity?
2. How do parents describe their involvement and interactions with different professionals in relation to their child's difficulties?
3. How, according to parents, might educational psychologists best support children and their families who experience these difficulties?

In this section I also acknowledge the limitations of this study, as well as considering possible implications of the research for my own and others' professional practice. Finally, I suggest areas for future research.

5.2. RQ1: Parents' experiences of help-seeking

5.2.1. Initial stages of help-seeking: Behaviour defined as problematic

The findings of this study support and extend those of previous literature (e.g., Flack, 2018) on the heterogeneity of ADHD in children, linking to the lack of consensus on the aetiology of the condition (Nilsson Sjöberg, 2021). The first theme created from a thematic analysis of interview data, *Unique problems need unique solutions*, alludes to the interplay of a wide variety of family, environmental, and systemic factors that shape both a child's presenting difficulties and the challenges that parents face in seeking help for those difficulties, in line with Bronfenbrenner's (1977) theory.

Previous research has suggested that parents are more likely to seek help if they believe their child's difficulty is due to biological causes (Johnston et al., 2020): Unsurprisingly, given that participants must have already identified behaviours related to ADHD in their child in order to respond to the survey, descriptions of 'within-child' concerns were common, including symptoms outlined in the DSM-V (2013) related to hyperactivity and concentration. However, other concerns related to a diverse range of presentations such as sensory processing and anxiety, were also highlighted. This supports previous literature on the high degree of co-occurrence with other neurodevelopmental conditions, such as autism (Fibert & Relton, 2020) but also highlights the importance of holistic assessment and treatment (Hill & Turner, 2016) as appropriate interventions for hyperactivity, for example, may be very different to those for hyposensitivity. Sleep difficulties were also commonly cited (consistent with associations found in previous studies, e.g., Becker, 2020) again emphasising the importance of gaining a full and complete picture of a child's difficulties during assessment. Importantly, the presence of such co-occurring needs may have intensified parental stress, complicated service navigation, or influenced the types of support accessed, and this variability may limit the generalisability of my findings. Parents' experiences of help-seeking may have been shaped not only by the difficulties related to ADHD but also the complex interplay of needs, and therefore may not be representative of families whose children present with fewer co-occurring challenges.

In line with previous literature on the cumulative effect of adverse childhood experiences on ADHD diagnosis (Banerjee et al., 2007; Klein et al., 2015) some interview participants highlighted their child's experiences of developmental trauma. While participants themselves expressed an awareness that these experiences may have influenced their child's presentation, it was not suggested that they were actually considered during the diagnostic process. This is concerning given previous research indicating that children with a history of developmental trauma may be more at risk of developing negative self-beliefs as a result of receiving an ADHD diagnosis (Rostill & Myatt, 2005). Whilst two mothers in this study shared how they were personally ensuring their child had access to more therapeutic approaches – through counselling, or narrative approaches – they were providing this through privately-obtained services and these were not included as part of the state-funded diagnosis-treatment pathway, highlighting inequalities of access to intervention based on socioeconomic status. It should be acknowledged that parents who are resourced enough to take part in research may be more likely to make such provision, but if this is not centralised and free-to-access, other children may miss out. This extends earlier literature (e.g., Johnston & Burke, 2020) on possible structural and financial barriers to parental help-seeking in this area.

Drawing on biopsychosocial theoretical frameworks which emphasise the impact of environmental factors (e.g., Bronfenbrenner, 1977), this study explored factors in the wider ecosystems around a child which may impact on their presentation of ADHD-related behaviours. At the forefront of such environmental influences were those related to school. Building on prior research (e.g., Gwernan-Jones et al., 2016; Prosser, 2008), this study provides additional evidence that school and classroom expectations on children can be unrealistic and trigger ADHD-type symptoms. Three parents described the difficulties their children had when faced with rigid school policies, covering homework, uniform and behaviour. A father’s example of his seven-year-old receiving a detention for incompletion of a (developmentally inappropriate) homework task was a particularly pertinent illustration of unresponsive practice in some schools, with the resulting punishment leading to the removal of the very thing – movement at break time– that helped his child to regulate. The participant recognised that the school’s lack of adaptation to his son’s needs may have contributed to him being identified as requiring neurodevelopmental assessment. In doing so, he highlighted the role of sociocultural norms in shaping the way children are labelled. This is especially concerning given the subjectivity of such norms; as Graham stated in 2008, what is bothersome to one class teacher may not be bothersome to another.

Linking to Hargreaves (1976), the phenomenon of labelling in schools emerged in relation to children’s experiences of behaviour management systems when their behaviour was deemed non-compliant with school norms. Behaviourist approaches to manage children’s behaviour at school generally involve application of rewards for desired behaviours and escalating sanctions for undesired behaviours (Harold, 2017): In P1’s description of her daughter’s difficulties in lining up quietly, what could be labelled in some contexts as energetic was regarded as ‘naughty’ and responded to within behaviourist frameworks, with the child labelled ‘orange’ rather than ‘green’. Such approaches, in contrast to relational approaches which seek to understand and change unhelpful behaviours (Harold, 2017) may be stigmatising for children, in their constant reminder about who are the ‘bad’ and ‘good’ children (see Graham, 2008). For P1, the concern about the damage done to her child’s self-esteem by such practices was a motivating factor in seeking a diagnosis of ADHD and subsequently using medication to treat the condition.

5.2.2. Seeking diagnosis

Gaining a formal diagnosis was seen amongst interview participants in this study as having great utility, as captured in the theme, '*The ADHD label offers benefits'*. This builds on previous research which suggests parents place a high value on a diagnosis for a wide range of reasons, not only as an 'exonerating construct' (Graham, 2008) for parents who are met with societal criticism and accusations of poor parenting (e.g., Leitch et al., 2019) but rather as the result of an accumulation of difficulties and concerns which lead parents to seek help. Parents in this study spoke of an ADHD diagnosis as a protective mechanism for their child, supporting them to access additional resources in school, as well as medication. Interestingly, and in contrast to the view that children may take on an ADHD diagnosis as a deficit account of themselves (Billington, 2021), this study's participants also viewed the ADHD label as supportive of their child's sense of self by offering them a compassionate way to understand their thoughts, feelings and actions (see Pajares & Schunk, 2001) as well as offering the possibility of a social identity (see Tajfel & Turner, 1979) through membership of a group – '*part of a gang*' as P1 noted.

In a recently published article exploring TikTok-inspired self-diagnosis amongst adolescents, Foster and Ellis (2024) expand on the concept of 'biographical illumination' (Hallerod et al., 2015). This concept refers to the idea that individuals can find the process of diagnosis transformative as through it they are able to make sense of past experiences. The authors, noting that parents seek diagnostic certainty for a number of reasons that were also highlighted in this study's fundings (e.g., understanding of need; see also Ringer et al., 2020), also hypothesise that parents may be prompted to seek diagnosis for a child after encountering online content and finding that it resonates with their experiences. In a sense, these online encounters can help parents to feel heard and understood. In line with this hypothesis, this study's results also indicate both the use of social media platforms as a source of help for participants, and the strong sense of validation that a diagnosis offers. This will be considered later in section 5.4. when discussing the role of EPs.

5.2.3. Referral to services

In the quantitative phase of this study, almost three quarters of respondents cited 'not knowing where to find help' as a barrier to accessing support, with two thirds feeling that the steps to seek help were overwhelming, aligning with previous research in the UK by Sayal and colleagues (2015) which found parents did not know where to go for help for a child with difficulties related to ADHD. The theme, '*Navigating complex systems is hard'*, captures some of these difficulties and highlights how parents can struggle to co-ordinate the different systems of health and education. Across the qualitative dataset in this study, the pathways to gaining a diagnosis were described as unclear, with parents confused about entry points. Results from this study's survey suggest that, in the absence of knowing where to go, parents primarily seek help for their child's ADHD from schools, particularly school SENCos and their child's classroom teacher. This finding offers further insight into an earlier study by Sayal (2006) which found that only one third of children deemed as having ADHD had received evidence-based treatment from specialist health services, with the main barrier to care being a lack of presentation of problems to GPs by parents. With parents being reliant on education professionals to support their help-seeking, it is important to note that this is often not an area of expertise for teachers, and many have not received any formal training at all (Ward et al., 2021) – something that was highlighted by P12 when she noted that her child's teacher (who was required to fill in assessment forms which would influence whether or not her child received a diagnosis) was trying to learn about ADHD through podcasts. Contrastingly, where SENCos were proactive (sometimes as a result of their own lived experience) they were shown to make a meaningful difference to parents and children, suggesting that parents' ability to navigate these systems is partly down to luck regarding who they encounter on the way.

Quantitative results also demonstrated parents' additional reliance on informal sources like books and social media. However, interview participants expressed frustration regarding difficulties in accessing reliable information, linking to research which has found inaccurate content on social media platforms such as TikTok (Yeung et al., 2022). Some parents in this study, like those in Davidson and colleagues' (2022) research, expressed a preference for written information (such as a leaflet) as this was deemed to be more reliable. Participants in this study also felt it would be better if inclusion departments within schools could act as a conduit for this type of information, so that the sources of information could be trusted. A recent rapid review of signposting services for people with health and care needs (Cantrell et al., 2024) indicates that, for a small number of users who receive effective navigational signposting, this may even be sufficient to satisfy their needs without further intervention, although this would require further research with the target population of this study.

Further to widespread media coverage (e.g., Thake, 2024) and more investigative studies (e.g., Valentine et al., 2024) participants in this study frequently referred to long waiting lists for assessment and expressed disappointment about the lack of interim support during this time. The theme, '*Stuck in limbo whilst things get worse'*, captures these difficulties. Like the interview participants in Clarke's (2013) study, parents experienced being referred from service to service, such as P14 who described ‘bouncing’ between school and the GP. Limited school resources exacerbated delays, leading to frustration and concerns about their children's wellbeing. In response to these delays, some parents took matters into their own hands, and the fifth theme, ‘*Mobilising resources works (sometimes)*’ details how some parents were able to bypass waiting lists through mobilising financial resources and seeking assessments privately, whilst others remained reliant on stretched state-funded NHS services, highlighting social and financial inequalities in access. This finding of a ‘two-tier’ system extends previous research into financial barriers affecting outcomes for children in the US (Johnston & Burke, 2020) to a UK population and confirms my own previous research (Wall, 2023) in which EPs shared their experiences of working with parents who had turned to private healthcare providers, as well as echoing the findings of a recent independent task force (see Borrett, 2025). This is particularly concerning given that previous research has highlighted an increased likelihood of children from families of lower socioeconomic status (SES) experiencing difficulties related to ADHD (Russell et al., 2016), so the fact that so many of the participants in my own study have been forced into paying would suggest that these inequalities are being exacerbated.

Whilst circumnavigating waiting lists by getting private assessments can result in quicker treatment, it does not necessarily remove all barriers for parents and their children. In line with previous reports within the mainstream media about the potentially inaccurate and even slapdash judgements made by private clinics (e.g., Khan, 2023) parents expressed concerns about the nature of the assessment process. Furthermore, private assessments did not always result in meaningful additional support in schools, and sometimes left parents in a difficult ongoing position of having to continue to pay for their child’s prescriptions, creating financial strain on the family. The overall impression parents gave is that they would prefer there to be a single, streamlined process of assessment that their child could access in a timely fashion.

5.2.4. Later stages of help-seeking: Treatment and management

Thematic analysis demonstrated that an important aspect of seeking a diagnosis was the access to treatments it facilitated, especially medication. Whilst not all children with an ADHD diagnosis referred to in the study were taking medication, two participants described how stimulant medication had helped their child by supporting their ability to focus on tasks in school, in line with previous research into the short-term effectiveness of commonly-prescribed stimulants (Cortese et al., 2018). Participants did voice concerns about possible negative side effects, and one explained that she took steps to limit these through stopping medication over weekends and holidays (also demonstrated in Ahmed et al., 2017). Significantly, thematic analysis indicated that participants relied on their child’s psychiatrist’s biomedical explanations of their child’s difficulties when making decisions about treatment (see Graham, 2008). Amongst those participants whose children were not yet taking medication, there was a sense that this was a future possibility, and they may move to medication if difficulties become too much to manage, in line with Cormier (2012) and Clarke (2013).

Quantitative data from this study’s survey indicate fewer children than might be expected are receiving psychological interventions such as behavioural therapy or counselling. Previous literature proposes possible reasons for this; Power and colleagues (2005) note that the social validity of a service influences its selection and use by a parent, with medical models of ADHD dominating. In Dreyer and colleagues' study (2010), parents were least likely to engage in recommendations for psychological services such as therapeutic support for the child or training for themselves, with the authors proposing a lack of time or discomfort with psychological services as possible barriers. Indeed, results from this study indicate that psychological interventions remain underused: Of the children referred to by parents in response to the survey, fewer than might be expected have received interventions such as counselling even though almost half of those children who have a diagnosis of ADHD are taking medication. However, this low-uptake of psychological interventions is not necessarily due to parents not choosing these services; further exploration of the topic during interviews revealed that one parents' attempts at securing talking therapy for her child was rebuffed by the treatment team at CAMHS, who insisted that medication was all they could offer. This is in contravention of NICE guidelines (2019) that state non-pharmacological approaches should be the first line of treatment (Hill & Turner, 2016), and links to previous research that has noted non-pharmacological and psychosocial treatments may be more acceptable to parents (Brinkman & Epstein, 2011; Town et al., 2016). Indeed, whilst these guidelines emphasise the importance of a holistic treatment plan that takes into account both parent and child preferences (1.5), only half of parents who responded to this study's survey said they were either 'somewhat' or 'extremely' satisfied with their child's treatment. This finding highlights the need for better decision-making support, as well as access to unbiased treatment information. It also indicates an area in which social inequalities are being exacerbated, with little on offer by way of therapeutic interventions (which are more costly to the NHS than medication) free at the point of need.

Of the non-pharmacological management options, parent training was commonly cited amongst participants in this quantitative phase of this study. Previous studies have suggested that caregivers who agreed with their child's diagnosis, and who had more knowledge, were more likely to seek parent training (Tamm et al., 2023) although in the UK context, participants in this study explained that attendance at a parent training course was a compulsory step in the diagnostic pathway. Interestingly, whilst Daley and Colleagues' (2021) small scale trial suggests that an online self-help parenting programme could provide an accessible way for parents to increase their parenting efficacy whilst sidestepping barriers posed by in-person parenting programmes (such as perceived stigma), one participant in the current study indicated that in-person workshops can be an important meeting space for parents; she is still regularly in contact with parents who she met through a workshop and receives social support through this channel. This is especially important given this study's quantitative results suggesting that social networks – particularly those in the wider community outside immediate family – are relied on less than might be expected by parents. This participant proposed that parenting workshops would be better conceived and delivered as support groups, as often the delivered workshop content is not as helpful as the relationships that are established during the sessions.

In summary, much of what was found in this study regarding parents' experiences of seeking help for a child with ADHD-related difficulties aligns with previous research, with some notable additions and areas that have important implications for EPs, which will be explored further in section 5.4 below.

5.3. RQ2: Parents' involvement and interactions with professionals

This study indicated that parents' involvement and interaction with different professionals at the mesosystemic level had a significant impact on the ease with which they moved through the help-seeking process. Some of the findings provide further insight into previous observations of parents feeling like professionals did not listen when they asked for help (Sayal et al., 2015). To examine this, I will firstly discuss the different ways that parents approach professionals from a position of advocacy and explain how these were illustrated in this study's findings, and will then consider participants' experiences of different professionals including SENCos, teachers and EPs.

5.3.1. Parent advocacy

This study was predicated on the notion that parents tend to be the voice of their child in advocating for them in matters pertaining to their health or education (Boshoff et al., 2016). All four types of parent advocate proposed by Trainor (2010) – intuitive, disability expert, strategists and agents of systemic change – were represented in the participant sample although the 'disability expert' (better described here as a the 'ADHD expert') was the role most frequently evoked, with parents referring to their prior knowledge either from previous family experience of neurodivergence or professional roles such as SENCo or teacher. In fact, five of the fourteen interview participants were familiar with SEND processes as a result of their professional role, with the participant sample including two SENCos, an EP, and two SEND teachers. This is important given previous studies indicating that parental knowledge and attributions of ADHD can predict where and how parents choose to seek help (Bazier et al., 2024), with accurate labelling leading to help-seeking (Jackson et al., 2023) and parents who have more knowledge or work in the field being more likely to advocate for their child (Burke et al, 2018). Given the significant difficulties in navigating the system that were described even by these well-informed participants, it would not be inappropriate to assume that parents who do not have this knowledge may experience even greater difficulty. Sayal and colleagues (2002) noted the 'responsive' nature of GP services, explaining how parents who asked for a referral to specialist ADHD assessment clinics received one, whereas those who were unaware of their child's difficulty (which the researchers had established separately as being above the threshold for referral) were not referred. Given that those parents who are in a position to advocate are more likely to receive the support they are looking for (putting aside aforementioned concerns about overmedicalisation of problematic behaviours) this highlights the unevenness of parental help-seeking experiences within a social context in which resources are not equally distributed, and indicates how, from a social justice perspective, parents who are less equipped to advocate for their children in this way will require additional proactive support from professionals.

In this study, parents spoke of the process of help-seeking being, at times, adversarial, with parents' descriptions of feeling dismissed. This adds to similar findings of previous studies (e.g., Sayal et al., 2015) and echoes the concerns highlighted by SEND charities and the AEP (2024) that parents are being branded as 'pushy' when they are simply trying to advocate for their child within a broken system. The final theme of this study's thematic analysis, '*Banging a drum but not always heard'* highlights a pattern of parents' voices not always being valued; of them having to fight to have their concerns taken seriously, and the emotional toll of help-seeking. The SEND code of practice (Department for Education, 2015) emphasises the importance of parents' right to active involvement in decision-making for their child's educational provision and the right to contribute to discussions around their child's needs and provisions. Whilst this is not always convenient for schools or LAs (as it can have implications for the allocation of limited resources), parents do have a legal right under the Children and Families Act 2014 to be listened to. In line with Trainor's (2010) 'strategist' advocate, parents such as P14 found themselves referring to their legal rights in order to be heard, although this led to discomfort for the participant and a desire to appeal to professionals in a more relational way. Further difficulties were expressed by participants who felt they weren't believed by school staff due to their daughter 'masking' ADHD-type behaviours whilst at school, highlighting a possible flaw in assessment protocols using the DSM-V (2013), which states symptoms need to occur across two settings, usually home and school. This finding contributes to previous literature which has suggested possible gender biases at assessment stage (Bussing et al., 2003) and the decreased likelihood of girls being diagnosed with ADHD (Martin, 2024).

Contrastingly to the more negative experiences discussed above, it is important to note that this study's thematic analysis also demonstrated that professionals who listened to parents, and took the time to understand their child and their difficulties, were cherished by participants. The following sections considers findings – both positive and negative - that relate specifically to school staff, and then EPs.

5.3.2. Parents' interactions with school staff

As noted in section 5.2.3., quantitative results in this study indicate the central role of the school SENCo – and class teacher - both in parents' initial stages of help-seeking and afterwards, with effective SENCos perceived to be crucial in supporting and signposting parents to help them navigate complex processes and arrange appropriate support in school. One participant spoke especially fondly of a school

SENCo that was able to relate through personal lived experience, linking to previous research indicating that SENCo's individual attitudes can have a greater impact on their work with parents than legislative frameworks (Maher, 2016). In two descriptions of multi-professional meetings, SENCos were portrayed as being the more supportive of the professionals around the table.

However, this study suggests that, although all participants hoped for collaborative and constructure partnerships with their child's teachers and school SENCo, this was not always the case, linking to previous literature indicating that parents may feel they have to advocate more where there is not a strong positive relationship with the child's school (Burke et al, 2018). Participants sometimes found themselves in 'confrontational' situations of fighting for their child, which they acknowledged was partly due to SENCos themselves working with limited resources, suggesting a breakdown at the mesosytemic level which can impact child outcomes according to Bronfenbrenner's ecological systems theory (1977). Further systemic concerns were highlighted in this study, regarding teachers not feeling well-equipped or knowledgeable (Ward et al., 2021) and having to update their own knowledge through self-directed learning with podcasts, highlighting the importance of good-quality training for school staff. This is particularly vital given teachers' roles in completing referral forms, as well as providing ongoing learning support for the child.

5.3.3. Parents' interactions with EPs

This study provided some evidence of EPs capturing children's needs in a holistic way where the current dominance of a medical model might oversimplify children's needs. This finding aligns with previous research suggesting that EPs tend to hold more inclusive attitudes regarding ADHD, and greater knowledge of the condition than other education professionals (Flack, 2018; Toye et al., 2019; Wiener, 2020), and highlights the necessary role of EPs in supporting children and families where difficulties related to ADHD have been identified (see Hill & Turner, 2016). Almost half of survey respondents in this study had sought help from an EP at some point in their help-seeking which is perhaps higher than might be expected, and not reflected in the interview sample where LA EP involvement was mainly reserved for those children who were going through statutory assessment for an EHC plan. Interview data in this study suggest that schools remain the gatekeepers for EP services; if parents themselves want to access an EP, they must find one who practises privately, as schools use up their capacity of LA visits quickly. This links to Flack's (2018) finding that, "the only issue raised [by parents] was not seeing [the EP] enough" (p.105).

One participant in this study shared her positive experience of working with an EP, corresponding with Atfield and colleagues' (2023) DfE workforce review in which families described how EPs had listened to and empowered them where they had been previously let down by other services. Unfortunately, two participants recalled more negative experiences of feeling devalued or excluded during interactions, with P14 feeling rudely dismissed in a home-school consultation, and P13 sharing the distress of hearing a negative 'within-child' account of his son during a feedback meeting. This finding underscores the importance of EPs working within their own frameworks for practice (such as the HCPC competences, 2016) and being held to high standards of competence through supervision (see Dunsmuir & Leadbetter, 2010; MacKay et al., 2016).

Some of the more innovative and evidence-based activities that EPs are able to engage in, such as Video Interactive Guidance (VIG) which celebrates and reinforces positive examples of parenting (and is referred to in Atfield et al.'s 2023 workforce review), were not mentioned during interviews. This illustrates how often the most impactful aspects of EP work only represent a small fraction of what we do in terms of workload. Further suggestions for ways that EPs may offer support to the group of families implicated in this study are considered in the following section.

5.4. RQ3: Ideas for how EPs can best support this group

The third research question asks how, given the findings of this study, might EPs best support children and their families in their help-seeking for difficulties related to ADHD. The following suggestions have been drawn from the experiences and perspectives of participants in this study, and are discussed in relation to previous literature. Links to my own anecdotal experiences as a trainee EP on placement in an inner city London LA EPS will be considered later, in section 5.6. Here, drawing on Bronfenbrenner's (1977) ecological systems theory, I consider the EP role at different levels of a child's ecosystem; involvement with the child themselves; support for parents; support for schools; and wider macrosystemic involvement.

5.4.1. Support for the child

The heterogeneity of ADHD and related difficulties as established through the literature and this study's findings indicates that EP support must be holistic and tailor-made; whilst one child's attentional difficulties may be impacted by their adverse childhood experiences and will therefore need trauma-informed approaches to education, another child's difficulties may be related to unmet sensory needs, and require a different approach. In their focus on 'what works' (see Burnham, 2013), EPs have a key role in both applying evidence-based interventions for ADHD-related difficulties such as that outlined in DECP guidance (2022a), as well as providing more individualised support which may draw on a wider range of bespoke strategies (Atfield et al., 2023; Hill & Turner, 2016).

EPs can also directly support children to understand the situational context in which their difficulties occur (see Graham, 2008), supporting them to separate out symptoms from their core sense of self, perhaps through narrative strategies (see Wall, 2023) or by finding exceptions through Solution Orientated Approaches (Molnar & De Shazer, 1987). In this study, results from the thematic analysis indicated how the ADHD label was perceived as supporting children's identity development (see section 5.2.2); in order to locate other ways of achieving this objective, EPs are able to draw on psychological frameworks of selfhood and identity (e.g., Borba, 1989) and design direct interventions that support children in developing selfhood more holistically through fostering recognition of individual strengths and traits, as well as difficulties, rather than applying a label that may, in time, become restrictive.

5.4.2. Support for parents

Parents' experiences emphasise the importance of being listened to by professionals, and having their insights as experts on their own child validated. Previous research has established that the experience of parenting a neurodivergent child - and the processes of obtaining help for that child - can be linked to higher levels of stress (e.g., Boshoff et al., 2016), feelings of isolation and helplessness, and challenges that overspill into parents' own wellbeing, relationships and jobs (Corcoran et al., 2017). Given this, EPs can provide much-needed emotional support to parents through empathetic listening during consultations. Parents in this study also talked about how difficult the EHCNA assessment processes had been, and the sometimes-dehumanising effect it had on their child, with its relentless focus on providing evidence of difficulty and need; EPs can work to combat this through more person-centred and hopeful approaches (e.g., ‘Planning Alternative Tomorrows with Hope’; Pearpoint et al.,1997) as well as encouraging peer support through facilitating in-person parent groups, which were deemed to be helpful for this study’s participants.

The desire for clearer signposting and information came through strongly in this study’s thematic analysis. Parents spoke of having to rely on internet searches which they did not always trust, and being overwhelmed by information, in line with previous research (Bloomfield & Kendall, 2012). For this study’s participants, there was also an element of chance as to what information parents happened to access, for example, if they caught a radio programme which mentioned certain websites. Given the statutory obligations that Local Authorities are under, via the SEND code of practice (Department for Education, 2015) which insists that parents be provided with accessible information regarding services that can support their child, EPs working within LA children’s services are well-placed to support the creation and distribution of more reliable, streamlined sources of information. By working in collaboration with parents, and using research skills which are developed during EP training, EPs could even support the development of user-informed websites such as that initiated in Scholze and colleagues’ (2023) study (see Appendix 2.3). This study found that co-ordinating different systems of health and education adds complexity for parents, as they are not sure where to enter the system. Such difficulties in navigating these systems could be mitigated, as one participant suggested, if there was access to a clear tool such as a decision tree; again, EPs working in LAs are well-placed to gather information across different services in order to produce such decision-making aids that are, crucially, context-specific. Training providers can facilitate the development of such resources by introducing different ways of assessing trainees' progress, incorporating practical LA project work into the assessed curriculum in addition to formal written essays (as is the case in Year 2 of my own training course at the Institute of Education).

The findings of this study in relation to parents' depictions of stretched services and limited resources in both educational and healthcare contexts indicate a further possible role for EPs in this area; creating mechanisms for more proactive engagement during the waiting period. Reflecting on definitions that were shared in the introduction to this thesis, one of which classified help-seeking "the active search for resources that are relevant for the resolution of [a] problem" (Zartaloudi & Madianos, 2010, p. 662) it is enlightening that, in many ways, it was the inactivity of this period that brought about so much discomfort for parents. By not being able to take action (because they were waiting for their child's assessment) participants described concerns about the 'damage' that was being done to their child. An interesting and unexpected finding of the thematic analysis relates to the concept of active – rather than inactive - waiting; one parent suggested 'remote monitoring' as a novel approach to monitoring and intervention that capitalises on widespread patient access to smartphone technologies, which can collect self-report data (as well as objectively-recorded data such as sleep and physical activity patterns, through wearable technologies) and support self-management of conditions (see Dogan et al., 2017, for a systematic review). The use of self-monitoring mental health apps for mood disorders have been shown to reduce symptoms (Kauer et al., 2012), and it may be that continuous monitoring approaches may help people to feel more in-control. Undoubtedly, further research would need to be undertaken to investigate how this could be implemented for this population, and it would be especially important to carefully consider potential adverse effects of continuous monitoring, such as parents feeling overwhelmed by additional responsibilities of logging their child’s difficulties, or even perceiving it to be a constant reminder of ‘illness’ in their child, making it more likely that a medical model is applied.

Even for richer families, circumnavigating waiting lists by attaining a private diagnosis did not always lead to the hoped-for outcome, and difficulties remained, such as having to pay expensive fees to renew prescriptions, or being dissatisfied by the nature of the diagnosis. Whilst I have undertaken this study from a critical realist and pragmatic position, and maintained a biopsychosocial understanding of ADHD (in order to resist judgement about whether or not parents are ‘right’ to pursue a medical diagnosis of ADHD for their child), in thinking about how EPs work with parents, it is worthwhile considering the utility of ADHD label. If we removed the label, how could we ‘fill the void’ (Graham, 2008)?

To do this, EPs must consider what diagnosis offers parents so that they can attempt to intervene in ways that may reduce the need for a formal diagnosis or, at the least, make the waiting period easier to endure. Previous research has indicated that a diagnosis is “a kind of mediating factor” (p. 382) whereby parents are given a “clear threshold to a new way of interpreting their child’s behaviours and needs” (Ringer et al., 2020, p. 384). Similarly, in this study, the diagnosis has been described as providing a shared vocabulary that can ease tensions and support understanding, resulting in parents responding to their child more favourably and having a positive impact on their relationship. The diagnosis has also been depicted as acting as a bridge for parents to advocate for their child’s needs, especially in the school context, shifting teachers’ understanding so the child is viewed as needing additional support rather than being ‘naughty’. As EPs, we can consider what other approaches can serve these functions, such as solutions-focussed consultations, narrative approaches, and newer approaches such as ‘VIG’. Further research investigating how these interventions can support parents at this point in their help-seeking would provide more evidence to their relative merits.

5.4.3. Support for schools and beyond

Linking to the previous section, it is also through consultation that EPs can have a key role in supporting teachers to resist the classification of a child’s difficulties as purely biological (and therefore outside of their control) and help them to consider aspects of their own pedagogical practice that can influence the child’s ability to focus. Sharing strategies and teaching approaches is a key part of the EP role (Atfield et al., 2023) and, in particular, the DECP (2022a) has published specific guidance on non-pharmacological interventions and classroom adaptations that teachers may not be aware of. Given that participants in this study indicated that they would like schools to be a conduit for information that may be helpful to them and their child, supplying schools with information in an accessible and usable format is an important aspect of the role. Finally, EPs are well-placed given their understanding of school cultures to provide the sort of staff-training that this study suggests teachers need on all aspects of ADHD or related difficulties, as well as feeding into discussions about how children’s difficulties in this area can be addressed on a national level.

5.4.4. Summary of EP Support

This study has provided evidence for how EPs can work with children, families and schools to address children’s needs related to ADHD and to improve parents’ experiences of help-seeking for their child. An overview of possible areas of EP work within the two central aspects of a child’s microsystem - schools and families -

suggested by this research is given in Figure 14, presented across three stages of help-seeking.

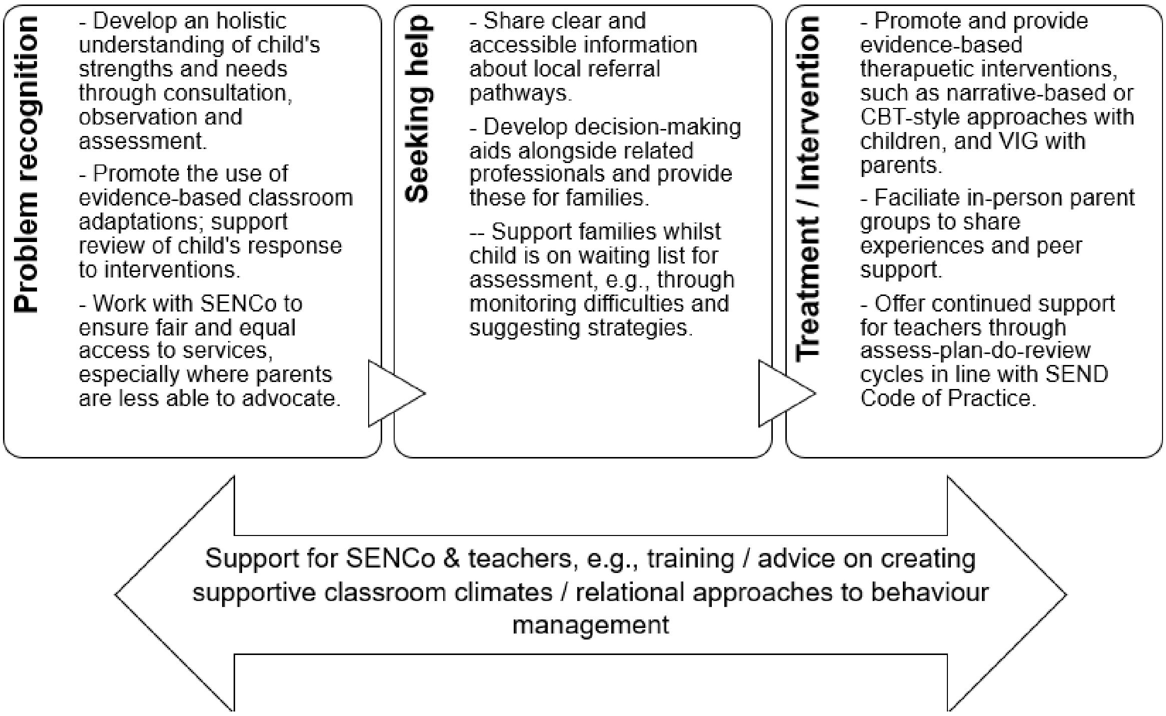


Fig. 14: Possible areas of EP work across the stages of help-seeking

In summary, EPs can respond to the varied nature of ADHD through holistic assessment, and by designing tailored and evidence-based interventions that support children to understand their strengths and needs. Importantly, EPs can ensure that parents are heard and validated, and that they are regarded as experts on their own children. Furthermore, EPs can provide support for parents during the stressful assessment process, as well as creating and providing the reliable, streamlined and accessible resources that parents so desperately want. This research has also highlighted the importance of understanding the function of a diagnosis in order to consider alternative or additional ways of meeting these needs. In this study, I have emphasised the importance of EPs working across the different systems that a child develops within. As such, there is a particularly vital role for EPs in training and guiding teachers, given their centrality both as a source of information for families, and as a dominant environmental influence on children's lives. However, it must also be noted that, amidst a crisis in SEND provision and a national shortage of EPs, as well as inconsistencies in patterns of EP service delivery across the country, EPs are not always able to provide these important services, and therefore must also take action at a national – macrosystemic - level.

5.5. Limitations

Whilst the current study adds valuable perspectives to the existing body of literature around parents' help-seeking for a child with difficulties related to ADHD, it has several limitations which I will now consider.

5.5.1. Self-selecting sample

Firstly, limitations related to the study's sampling strategy should be acknowledged. Participants had to confirm that they had a child who they felt met the criteria of having either a diagnosis of ADHD or related difficulties; given previous estimates that almost half of parents who have a child with mental health difficulties do not recognise symptoms (Sayal, 2006) the self-selecting nature of the sample necessarily limits the findings of this study to a sub-group of parents who *do* recognise their child's difficulties as being related to ADHD, which, as established in this study's literature review, may have implications for the way in which parents have advocated for their children. Furthermore, as participants self-selected, their experiences may represent those of a particular sub-group of parents who have unusually strong feelings about the topic, for example, because they have had difficult help-seeking experiences and are therefore more motivated to talk about them.

5.5.2. Recruitment strategy

Participants for this study were recruited using a non-probability snowball strategy which limits the sample's heterogeneity and the range of experiences represented in the data. Fathers were underrepresented, as were parents from low-income backgrounds, and the majority of respondents identified as White. Given that previous research covered in Chapter 2 Literature Review has identified differences in help-seeking related to demographic characteristics, this is an important limitation to the current study. Previous studies have noted that parents of lower socioeconomic status can be limited in their help-seeking by factors such as a lack of financial resources or more inflexible work arrangements (Lalvani, 2012); it may be that these factors also limit parents' availability for contributing to research such as the present study, particularly where the benefit of doing so is unclear. Given that the need for culturally-competent practitioners has been highlighted in previous research (Kappi & Martel, 2022) it can be assumed that groups that have been historically marginalised and discriminated against may experience even more barriers in their help-seeking experiences than the participants of this study.

Whilst the sample of 14 participants for the qualitative phase was broadly in line with other similar studies (e.g., Cormier, 2012), the sample for the first phase of the study – the survey – was smaller than hoped. Due to this, and other issues related to sampling already stated, the findings from this study cannot be assumed to be generalisable to the whole population (or even experiences of services in different parts of the country), although information related to the participant sample has been included in Chapter 3 Methodology to support the reader in evaluating the 'theoretical' transferability of findings to their own context. (Smith et al., 2009).

Despite the limitations of this study, there are some important findings that advance our understanding of parental help-seeking and can suggest directions for future research as well as professional practice.

5.6. Implications for future research and professional practice

By design, this study explored the help-seeking experiences of parents and, as such, the voice of the child is notably absent. To add this crucial perspective, further research with children could take a similar approach to exploring their experiences and perspectives across the help-seeking trajectory from when difficulties were first being recognised (by the adults around them) as being related to ADHD, through diagnosis and treatment.

Data on the geographical location of participants for analytical purposes was not collected in this study. In order to get an accurate understanding of facilitators and barriers to parents' help-seeking in a particular area where there is only one referral route (perhaps in order to make changes to service provision in that area) future research could follow processes set out by Sayal and colleagues (2002) to choose one single setting (e.g., a single London borough). Furthermore, data on the type of school – state-funded or private – attended by the participant's child was not obtained in this study. This would be an interesting area to explore, as the type of educational provision could have a significant impact on the resources that are available to meet the child's needs, both preventatively and in response to a diagnosed condition.

My own experiences as a trainee EP working within an inner London LA EPS support many of the key findings of this study. Reduced capacity in the EPS has meant fewer visits in schools, and, amidst a 'SEND crisis', this has often resulted in my work being restricted to individual casework designed to feed into applications for EHC needs assessments, rather than offer the types of early intervention described in section 5.4. Direct offerings to parents – such as the self-referral 'parent consultation' service - have also been reduced. That said, there has also been increased demand for training in schools on ADHD, and parents are also reaching out to EPs to enquire about the processes for assessment and management of their child's difficulties. There is clearly a need for the type of work that has been described above, and this research will support me to understand how I can best help local authorities to design, commission and deliver more effective services, including training and the production of appropriate resources, for children and families.

5.7. Conclusions

This thesis has illustrated how the adversarial nature of parents' help-seeking for a child with difficulties related to ADHD reflects broader systemic issues in which parents often feel dismissed, excluded, or undervalued in their efforts to advocate for their child. More positive experiences with professionals, who listen and collaborate, highlight the importance of effective communication and personalised support in improving outcomes and reducing the emotional toll on families.

This study has contributed to a body of literature examining parental help-seeking and extended it in a number of ways: it has explored parents' experiences of education services in England specifically in relation to the role of the EP. Through its qualitative focus, this study has also built on earlier work by offering detailed stories of parents' help-seeking experiences against the backdrop of a 'SEND crisis', whilst contextualising these stories through a wider sample of survey participants.

In addition to serving as a requirement for my doctoral qualification and subsequent registration as a practising psychologist, this thesis acts as a reminder that, whilst we may need to be tentative in discussions about the causes of ADHD, we should always be resolute in this: When parents seek support for their child's difficulties, we, as EPs, should listen and support them.

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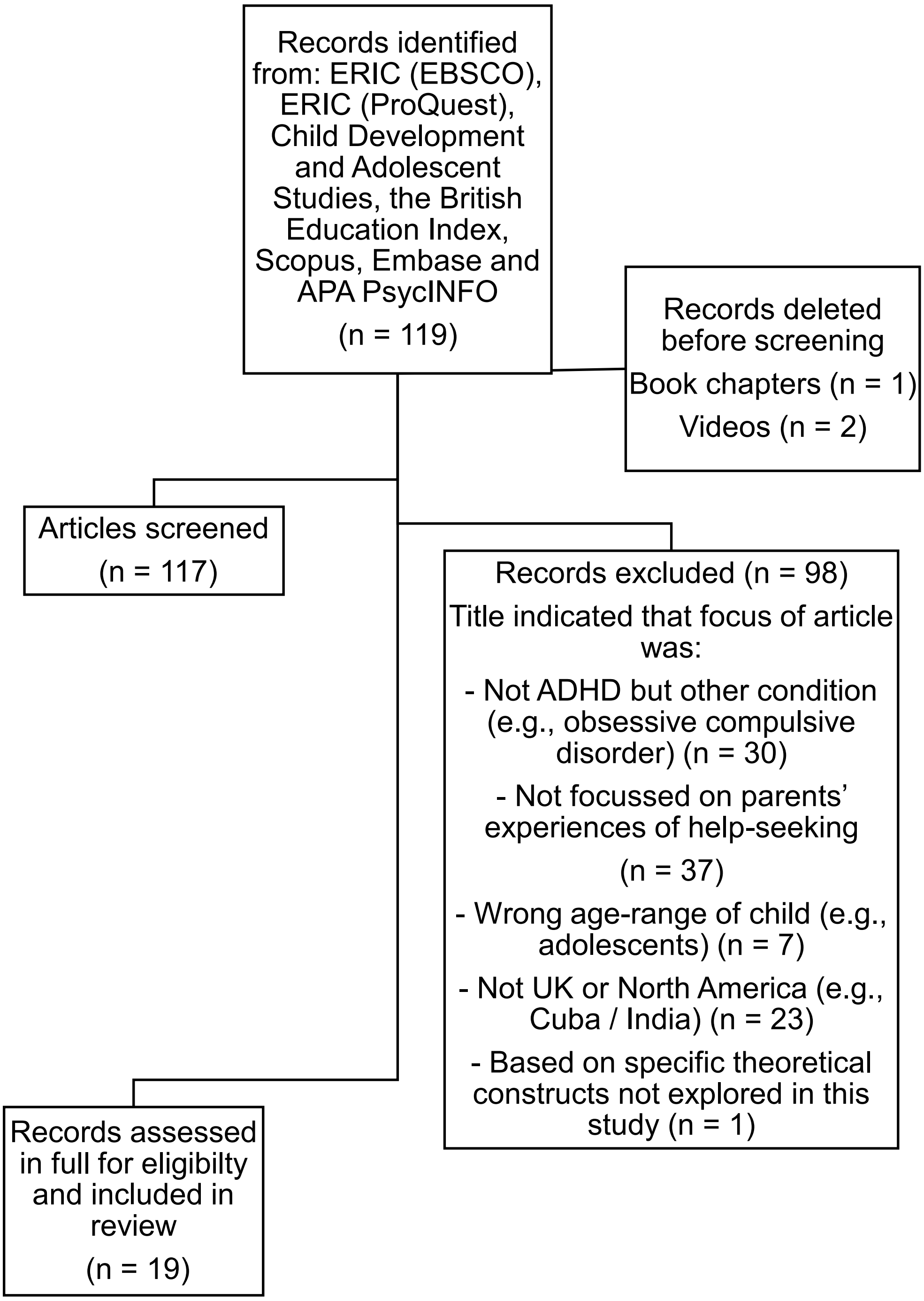
Appendices

Appendix 1.1: Screenshot of TikTok Trend

Screenshot obtained 28/11/2023

[image redacted for copyright reasons]

Appendix 2.1: PRISMA flowchart illustrating selection process for literature review



Appendix 2.2: Overview of papers for systematic search

Authors	Year	Methodology	Key findings	Country
Bazier, O'Laughlin Feinstein	2024	Quant.	Parental knowledge of ADHD was found to be a strong predictor of interest in help seeking. Regarding attributions, stability attributions were found to predict interest in informal services and attributions of higher child control predicted interest in medication.	USA
Bussing, Zima, Gary, Garvan	2003	Quant.	Girls and African American children were less likely to be assessed for ADHD even when a similar level of difficulty as their peers had been experienced, raising possibilities of gender and race bias.	USA
Bussing Koro-Ljungberg, Gary, Mason, Garvan	2005	Mixed Grounded Theory / Quant.	Children's difficulties may be perceived differently across race and gender e.g., misbehaving (African American girls) v 'indisposed child' who needs to be taken to the doctor (Caucasian boys). African-American parents found to be more likely to consult with their family networks and less likely to be engaged with medical treatment systems.	USA
Clarke	2013	Qual. Interviews TA	Mothers initially try to normalise behaviours privately before seeking help with professionals. Steps to help are characterised by the perseverance needed to withstand waiting and being referred from service to service.	Canada
Cormier	2012	Qual. Grounded Theory	Parents respond to struggles at home by 'doing what helps most'. Whilst many of the interviewees resisted medication at first, a lack of guidance from professionals and a feeling that other non-pharmacological approaches had not worked, led to the decision to move their child onto medication.	USA
Daley, Tarver, Sayal	2021	Quant. RCT	A self-help parenting programme can provide a more accessible way for parents of children with ADHD to increase their parenting efficacy and improve their child's social performance at school. Parents in the treatment arm made fewer negative comments to their children after the intervention than those in the control group.	UK
Davidson, Reynolds, Theule, Feldgaier	2022	Quant. Vignettes	Several factors were associated with stronger mental health literacy skills; being a mother, having mental health experience and higher levels of parental self-efficacy. When seeking help from professionals, parents expressed a preference for written information (such as a leaflet) which the authors propose may be indicative of a need for more reliable, streamlined sources of information for parents, online or otherwise.	Canada

Dreyer, O'Laughlin, Moore, Milam	2010	Quant.	Parents were likely to follow through on over 80% of clinical recommendations following their child's evaluation at an ADHD clinic, but least likely to engage in recommendations for psychological services such as therapeutic support for the child or training for themselves.	USA
Fibert & Relton	2020	Quant.	Current treatment-use in 175 families in the UK; nearly two-thirds of the children were taking a mainstream ADHD medication; a third of families had received behaviour-focussed therapy and almost three quarters of parents had received parenting classes. 45% had used non-mainstream treatments, mainly related to homeopathy and nutrition	UK
Graves	2017	Qual. Grounded Theory	A help-seeking theory explains 'filters of influence' on the process of seeking help for African American children living in poverty. Mothers reported receiving calls from school staff observing a child's externalising symptoms which was instrumental in initiating help-seeking process. Support from informal systems included those in church networks.	USA
Jackson et al.	2023	Quant. Vignettes	Parents' use of accurate diagnostic labels to describe children's behaviours, as well as their level of stress and the severity of the child's difficulties, predict help-seeking behaviours.	USA
Johnston et al.	2020	Review	Problem recognition includes: *problem appraisal*, including beliefs about the aetiology and stability of the problem (parents are more likely to seek help if their believe the problem is due to biological causes, and less likely to seek help if they think the problem will go away on its own); and "*perceptual, structural and financial barriers*" including those related to parents' previous experiences with professionals and their understanding of available services. Parental readiness to seek help was associated with the severity of child ADHD symptoms, greater problem perception and greater perceived parental burden.	USA
Kappi & Martel	2022	Systematic Review	The authors conclude that psychoeducational interventions are necessary to improve parents' help-seeking behaviour. Studies have considered barriers at the individual level (such as parental knowledge, as noted above) or at the community level (such as cultural beliefs) but not at the interpersonal level, where there is less evidence about how parents use social supports or networks in their help-seeking.	Mainly USA
Sayal	2002	Quant.	GP recognition of difficulty was associated with parent request for referral (i.e., when parents asked directly for their child to be referred for assessment, GPs agreed to do this) emphasising the significant role that parents	UK

			have in ensuring their child accesses professional support even when using a free-at-the-point-of-need service. The conclusions of this study indicate that if a parent is unaware of their child's difficulty, then it may also go unattended by professionals.	
Sayal, Goodman, Ford	2006	Quant.	Parents often contacted education professionals rather than health; parents do not tend to consult GPs. Only one third deemed as having ADHD has received evidence-based treatment from specialist services. Authors conclude that main barrier to care is a lack of presentation of problems to GPs by parents.	UK
Sayal	2015	Quant. Longitudinal	Child symptom severity and parental mental health problems were independently associated with health service use. The most common barrier was parents not having adequate information about who could help or feeling like professionals did not listen when they asked for help	UK
Scholze Gosdin Perez Schweitzer	2023	Qual.	Sharing their views on what would improve web-based information, participants indicated a preference for destigmatizing content (such as real-life stories of overcoming the challenges associated with ADHD) and clear (video-supported) guides on recognising problematic behaviours, alongside evidence-based strategies, and authors used the findings to inform the creation of a website	USA
Tamm et al.	2023	Quant.	Caregivers of children with greater externalising symptoms were more likely to seek classroom behaviour management while greater difficulty with attention was associated with seeking pharmacological treatment. Caregivers who agreed with their child's ADHD diagnosis, and who had more knowledge about ADHD, were more likely to seek behavioural parent training	USA
Thurston Hardin, Decker, Arnold, Howell, Phares	2018	Quant. Vignettes	Recognizing the problem was linked to a greater intention to seek help from most formal and informal sources, except friends and family. Black parents showed a higher tendency to seek help from religious leaders, while White parents were more inclined to use self-help resources.	USA

Appendix 2.3: User-informed website design

[Source: Scholze et al., 2023)

[image redacted for copyright reasons]

Appendix 3.1: Survey Questions

Section 1: Demographic Information

Age of Child:

6-7 years

8-9 years

10-12 years

Gender of Child:

Male

Female

Non-binary

Prefer not to say

Relationship to Child:

Mother

Father

Stepmother

Stepfather

Grandparent

Other (please specify)

Section 2: Initial Concerns and Diagnosis

Nearly all children are overactive or lose concentration at times, but I would like to know how your child compares with other young people of his/her own age. I am interested in how he/she is usually, over the last 6 months - not on the occasional 'off day'. Allowing for his/her age, do you think that your child definitely has some problems with overactivity or poor concentration? [Source: Goodman et al., 2000]

Yes / No

Which of the following best describes your current situation:

1. My child has a diagnosis of ADHD
2. My child does not have a diagnosis of ADHD but has been referred for assessment
3. My child does not have a diagnosis of ADHD but I think he/she has difficulties with inattention / hyperactivity / impulsiveness.
4. My child does not have a diagnosis of ADHD but others think he/she has difficulties with inattention / hyperactivity / impulsiveness.

At what age did you first notice symptoms of ADHD in your child?

Under 3 years

3-5 years

6-8 years

9-12 years

Which of the following best captures your child's difficulties?

1. Daydreaming / getting distracted easily / difficulty focussing on a task
2. Fidgety / restless / always talking
3. Both
4. Neither

What were the <u>first</u> symptoms that concerned you? (open)

How long after noticing symptoms did you seek professional help?

Immediately

Within a few months

Within a year

More than a year

I have not yet sought professional help.

Section 3: Information and Services

Information seeking: Some parents seek information from education or health or social care professionals.

When you first noticed difficulties, where did you go?

Since then, have you sought any information or support from any further sources?

	Went to first	**Been to since**
GP (General Practitioner) Teacher School SENCo Teaching assistant or other SEN staff in school Another adult in school Educational psychologist Family member Friend Books / Social Media / Online Chat rooms or other Online sources Self-help group Someone from social services (such as a social worker or family support worker) Other (please specify)		

Which of these services / sources of information did you find most useful?

Did you have to pay for any of these services?

Section 4: Support and Treatment

What types of treatment has your child received? (Select all that apply)

Medication

Behavioural therapy

Counselling

Special education services

Diet and lifestyle changes

Alternative therapies (e.g., acupuncture, homeopathy)

Other (please specify)

How satisfied are you with the treatment your child has received?

Very satisfied

Satisfied

Neutral

Dissatisfied

Very dissatisfied

What challenges have you faced in accessing treatment for your child? (Select all that apply)

Cost

Availability of specialists

Long waiting times

NHS coverage

Stigma or lack of understanding

Other (please specify)

Has your child's school been supportive in managing their ADHD?

Yes, very supportive

Somewhat supportive

Neutral

Not very supportive

Not at all supportive

What types of school-based support has your child received? (Select all that apply)

Education, Health and Care Plan (EHCP)

Classroom accommodations (e.g., extra time on tests, seating arrangements)

Additional adult support such as a Teaching Assistant in the classroom, or small group support

Counselling services

Behavioural interventions

Other (please specify)

Section 5: Impact on Family

How has your child's ADHD diagnosis / difficulties with… affected your family's day-to-day life?

Very positively

Somewhat positively

Neutral

Somewhat negatively

Very negatively

What types of support have you, as a parent / carer, received? (Select all that apply)

Parent training programmes

Support groups

Counselling

Educational resources

Online communities

Other (please specify)

Section 6: Barriers to support

Which of the following barriers to support, if any, have your experienced? [Source: Douma, Dekker & Koot, 2006];

	1 – Not at All	**2 – Somewhat**	**3 – A Lot**
Negative experiences with professional help Not knowing where to find help Distance to get help Having difficulty describing the problem Steps to seek help were overwhelming Considered problem temporary No trust in professional help Fear of being a burden Wanted to handle the problem themselves Believed the problem was not serious Fears of labels/stigma Busy/Other Priorities Other			

Is there anything else you would like to share about your experience?

Section 7: Demographic Information

What is your ethnic group?

Asian

Black / African / Caribbean

Mixed / multiple ethnic groups

Other

White

What is your annual household income?

Less than £20,000

£20,000 - £39,999

£40,000 - £59,999

£60,000 - £99,999

£100,000 or above

I would prefer not to say

Would you be willing to take part in a short online interview to describe your experiences in more detail? If so, please leave your email address here and I will contact you to share more information.

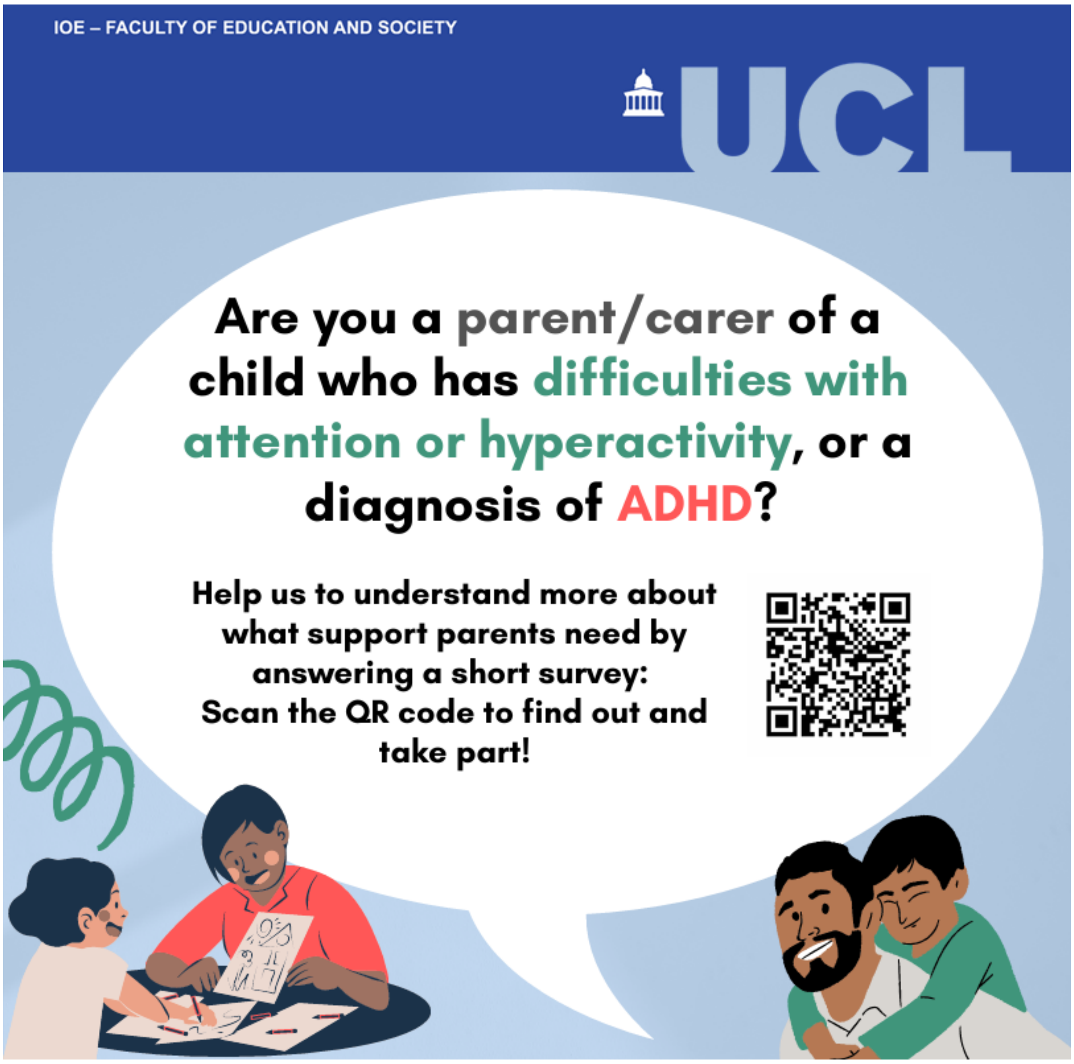
Appendix 3.2: Semi-structured interview schedule

Participant number:	05
Information from survey to consider when adapting schedule:	➢ ➢ ➢ ➢
Explain the following:	✓ Purpose of the research; to better understand parent experiences of seeking support for child with ADHD / associated difficulties to improve services ✓ Confidentiality; no names or identifying features will be used / interviews stored securely ✓ Opt-out at any stage; right to not answer any questions; after end of video the transcript will be integrated into analysis. ✓ Recording; video or not?

Area	Main questions	Further prompts
1. Onset / recognition of problem *How is the problem conceptualised?*	What were your first concerns about X? How were the problems impacting on the family? Who was it that first mentioned the possibility of ADHD?	How would you define ADHD? Do you see it as a life-long condition? Did anyone else express a concern about X? Who? What? Were there any other life events that were important influences for your family at this time? How much were X's difficulties upsetting or distressing him/her?
2. Decision to seek help *Problem threshold;* *Parental self-efficacy;* *Social / economic capital* *Attitudes and communication of professionals (both in the context of educational and health services)*	How have you tried to cope with these challenges? Why did you choose this strategy? Has this been helpful? OR [Have you tried to seek help?] What was it that made you seek help? Where did you go for help? why? 'Why did you choose this strategy? Has this been helpful?'	Resources? Paid for services? Formal / informal support? Education? Health? Were there ever any practical issues such as cost and convenience of getting to appointments? Did you ever have any other anxieties or concerns e.g., what other people would think?

	How easy was it to find information about where to seek help?	
3. Service selection / referrals / diagnosis *Adherence to recommendations*	What has happened since your child received the diagnosis? What support have you received? Have you received recommendations for what to do? What advice have you followed? What have you not followed?	Can you tell me about what happened when you went to see / spoke to the doctor (or whoever)? Can you tell me about your reactions when your child had received the diagnosis. What was it like? What did you think and feel? Attitudes towards medication? Are there types of support you feel more or less comfortable with? Did your child share their views about what was recommended?
4. Treatment / intervention *Barriers / facilitators*	What do think helps when it comes to support for your child's difficulties? What do you think is less helpful? Is there any support you would like to be offered that has not been? What would you like to see change that would help make this experience easier for you and for parents of other children with similar needs?	[Following diagnosis…] Has school put in any additional support? Have you tried anything else that we have not covered?
Anything else	**Seeing an EP:** **Did you see one at any stage? What support did they offer?** **When? Was the EP's input helpful / unhelpful?** **If not; explain how an EP works; ask if any of this would have been helpful? When?** In my work with people and families, I am interested in how different aspects of their life influence their well-being and help them to overcome the problems they are facing, for example, their cultural belongings, their religious or spiritual beliefs, the job they do, the class they come from and belong to … how about you?	

Appendix 3.3: Flyer shared on social media to attract participants



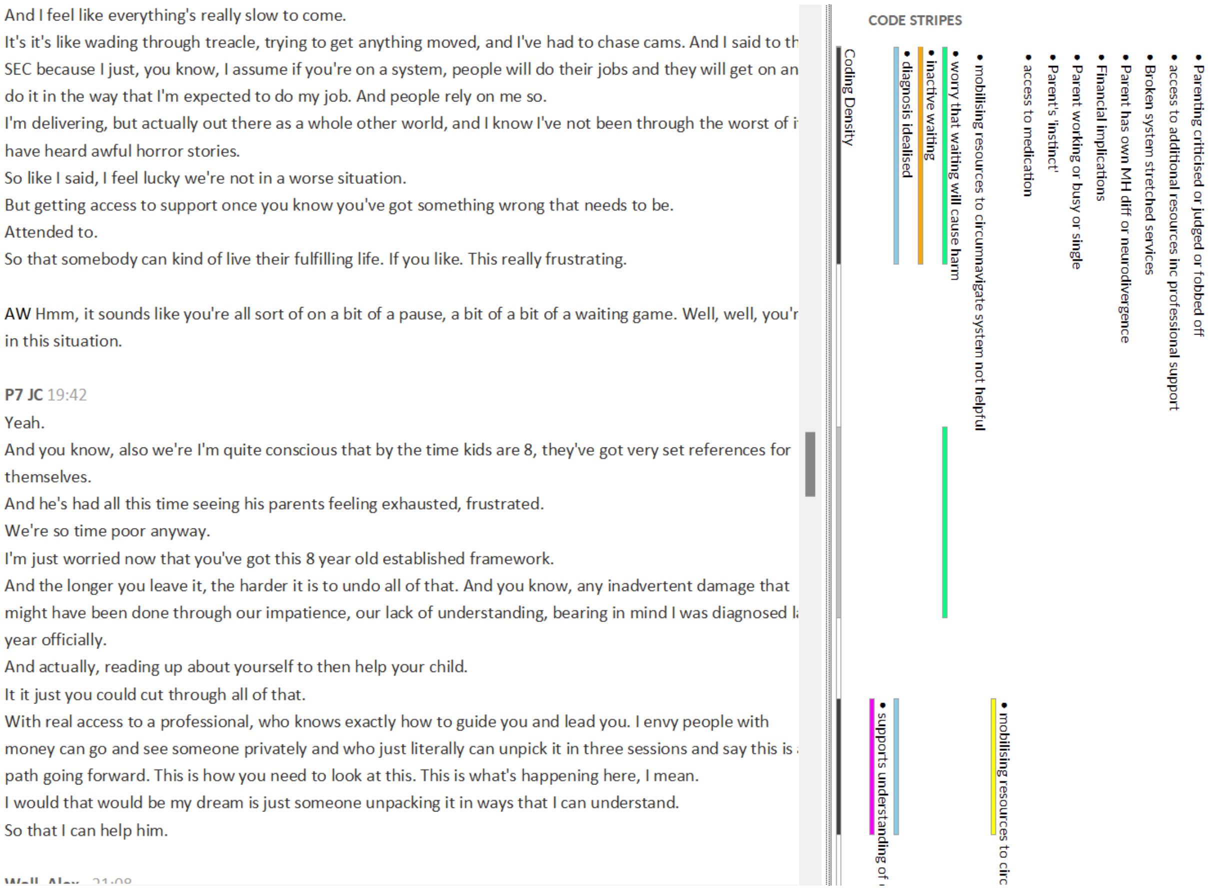
IOE – FACULTY OF EDUCATION AND SOCIETY

UCL

Are you a parent/carer of a child who has difficulties with attention or hyperactivity, or a diagnosis of ADHD?

Help us to understand more about what support parents need by answering a short survey:
Scan the QR code to find out and take part!

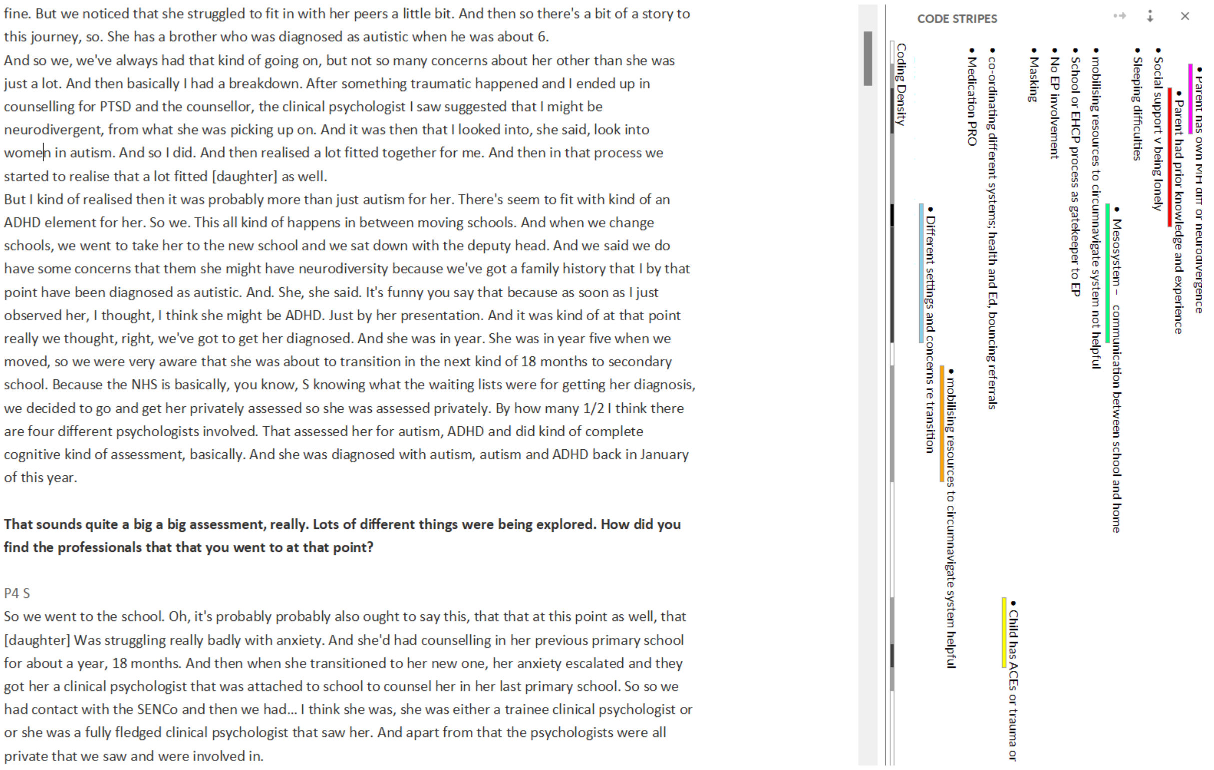
Appendix 3.4: Examples of coded transcript from NVivo



And I feel like everything's really slow to come.
It's it's like wading through treacle, trying to get anything moved, and I've had to chase cams. And I said to th
SEC because I just, you know, I assume if you're on a system, people will do their jobs and they will get on an
do it in the way that I'm expected to do my job. And people rely on me so.
I'm delivering, but actually out there as a whole other world, and I know I've not been through the worst of i
have heard awful horror stories.
So like I said, I feel lucky we're not in a worse situation.
But getting access to support once you know you've got something wrong that needs to be.
Attended to.
So that somebody can kind of live their fulfilling life. If you like. This really frustrating.

AW Hmm, it sounds like you're all sort of on a bit of a pause, a bit of a bit of a waiting game. Well, well, you'r
in this situation.

P7 JC 19:42
Yeah.
And you know, also we're I'm quite conscious that by the time kids are 8, they've got very set references for
themselves.
And he's had all this time seeing his parents feeling exhausted, frustrated.
We're so time poor anyway.
I'm just worried now that you've got this 8 year old established framework.
And the longer you leave it, the harder it is to undo all of that. And you know, any inadvertent damage that
might have been done through our impatience, our lack of understanding, bearing in mind I was diagnosed l
year officially.
And actually, reading up about yourself to then help your child.
It it just you could cut through all of that.
With real access to a professional, who knows exactly how to guide you and lead you. I envy people with
money can go and see someone privately and who just literally can unpick it in three sessions and say this is
path going forward. This is how you need to look at this. This is what's happening here, I mean.
I would that would be my dream is just someone unpacking it in ways that I can understand.
So that I can help him.

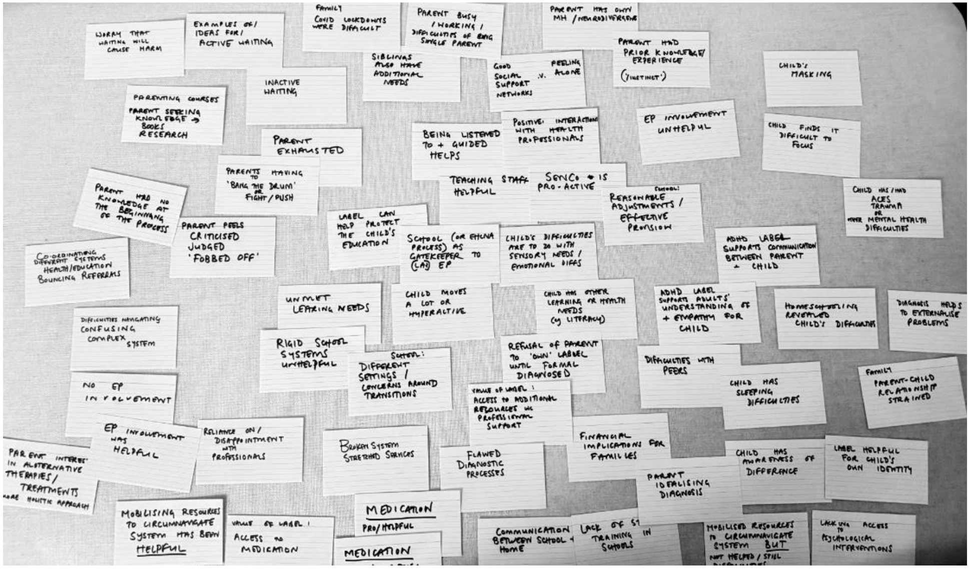


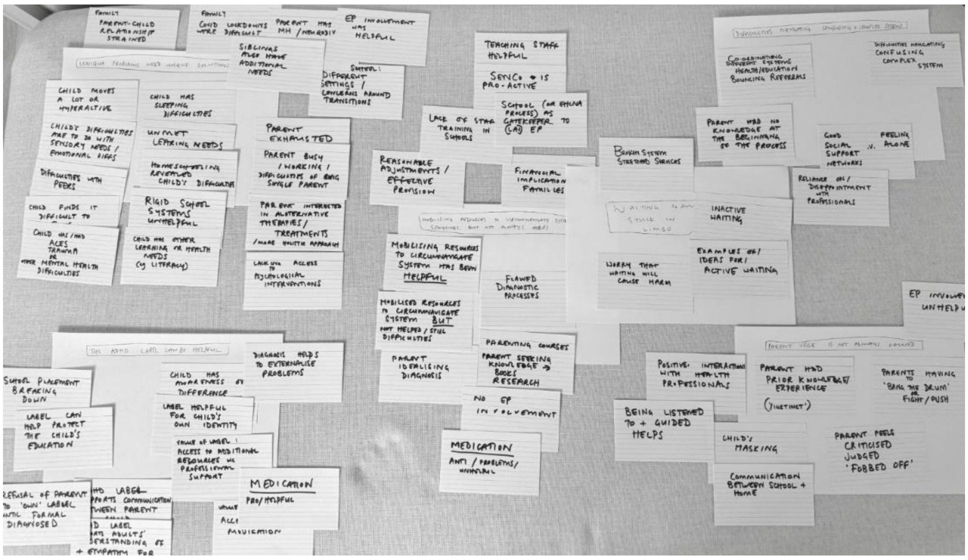
fine. But we noticed that she struggled to fit in with her peers a little bit. And then so there's a bit of a story to this journey, so. She has a brother who was diagnosed as autistic when he was about 6.
And so we, we've always had that kind of going on, but not so many concerns about her other than she was just a lot. And then basically I had a breakdown. After something traumatic happened and I ended up in counselling for PTSD and the counsellor, the clinical psychologist I saw suggested that I might be neurodivergent, from what she was picking up on. And it was then that I looked into, she said, look into women in autism. And so I did. And then realised a lot fitted together for me. And then in that process we started to realise that a lot fitted [daughter] as well.
But I kind of realised then it was probably more than just autism for her. There's seem to fit with kind of an ADHD element for her. So we. This all kind of happens in between moving schools. And when we change schools, we went to take her to the new school and we sat down with the deputy head. And we said we do have some concerns that them she might have neurodiversity because we've got a family history that I by that point have been diagnosed as autistic. And. She, she said. It's funny you say that because as soon as I just observed her, I thought, I think she might be ADHD. Just by her presentation. And it was kind of at that point really we thought, right, we've got to get her diagnosed. And she was in year. She was in year five when we moved, so we were very aware that she was about to transition in the next kind of 18 months to secondary school. Because the NHS is basically, you know, S knowing what the waiting lists were for getting her diagnosis, we decided to go and get her privately assessed so she was assessed privately. By how many 1/2 I think there are four different psychologists involved. That assessed her for autism, ADHD and did kind of complete cognitive kind of assessment, basically. And she was diagnosed with autism, autism and ADHD back in January of this year.

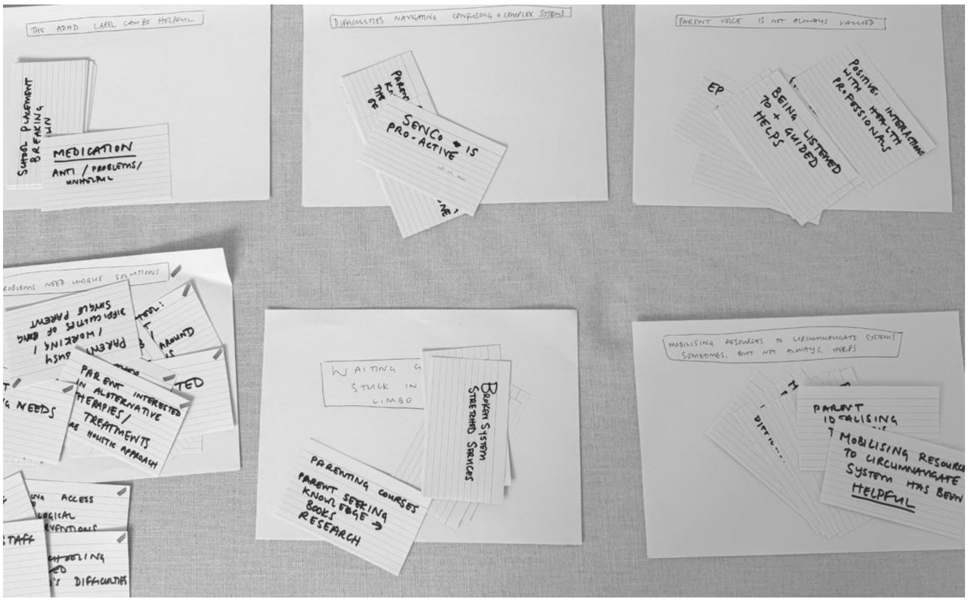
That sounds quite a big a big assessment, really. Lots of different things were being explored. How did you find the professionals that that you went to at that point?

P4 S
So we went to the school. Oh, it's probably probably also ought to say this, that that at this point as well, that [daughter] Was struggling really badly with anxiety. And she'd had counselling in her previous primary school for about a year, 18 months. And then when she transitioned to her new one, her anxiety escalated and they got her a clinical psychologist that was attached to school to counsel her in her last primary school. So so we had contact with the SENCo and then we had… I think she was, she was either a trainee clinical psychologist or or she was a fully fledged clinical psychologist that saw her. And apart from that the psychologists were all private that we saw and were involved in.

Appendix 3.5: Photographs of manual creation of themes



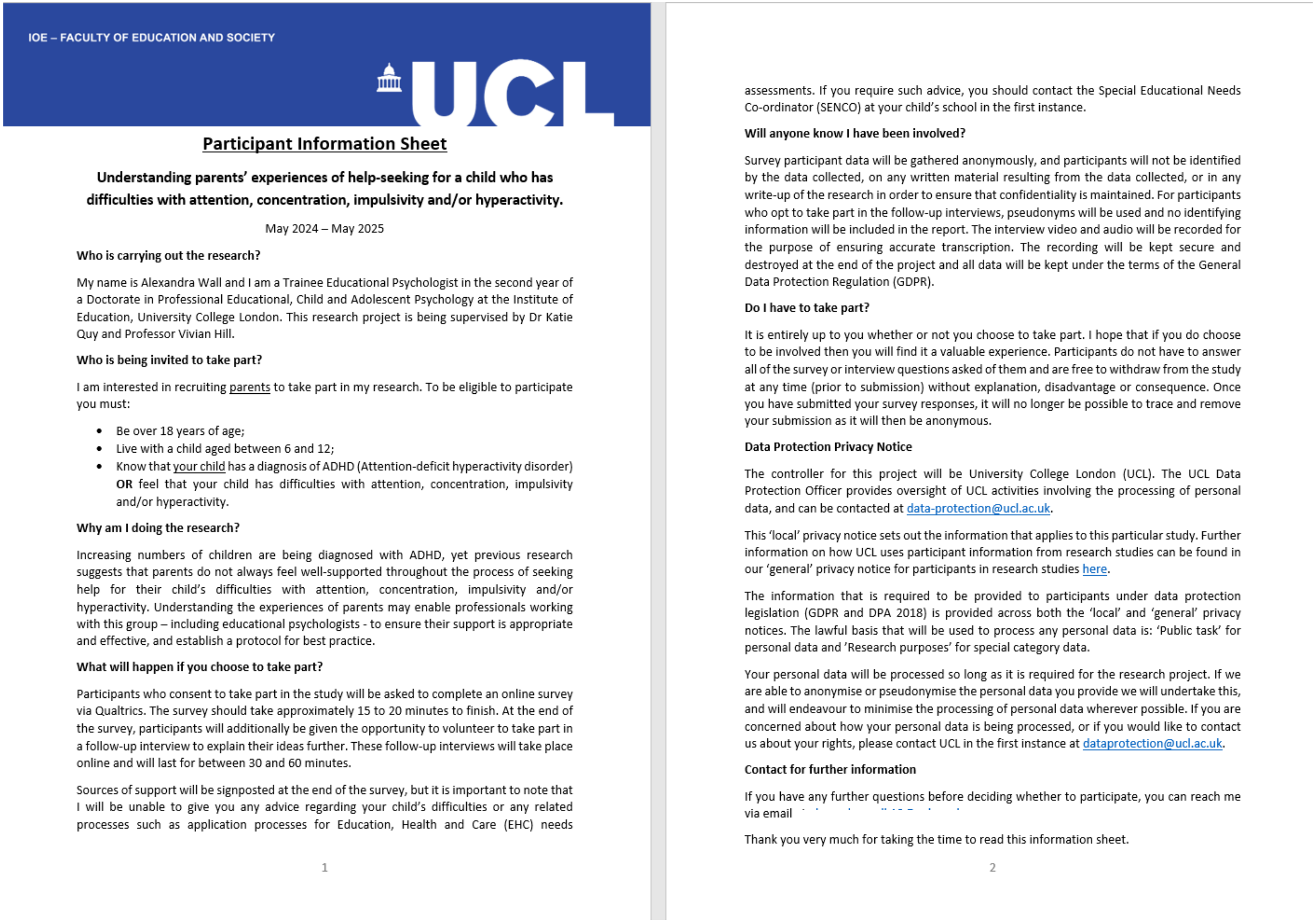




Appendix 3.6: Second coding run – new code labels

1. Child's difficulties – finds it harder than other children to focus or forgetful
2. Child's difficulties – moves a lot
3. Child's difficulties – emotional dysregulation
4. Child has other physical health concerns
5. Child has other MH
6. Child has experienced ACEs or trauma
7. Child has other learning needs (literacy)
8. Child has other learning needs (other)
9. Child's strengths
10. Child risk factor - pregnancy
11. Sleeping difficulties
12. Masking
13. Child viewed as strange or different by parent
14. Child viewed as strange or different by school
15. Child viewed as strange or different by community
16. Child views themselves as strange or different
17. Child identifies with diagnosis
18. Broken system stretched services
19. Difficulties navigating confusing complex system
20. co-ordinating different systems; health + Ed,
21. parent legal process
22. Having to bang the drum
23. cry for help – any help
24. parent exhausted
25. Feeling lonely or unsupported
26. Parent not listened to
27. Parent not kept informed
28. Parent had prior knowledge
29. Had no knowledge
30. Parent Instinct
31. Resources: bought books
32. Resources: parent has used internet
33. Parent has explored alternative therapies
34. Resources: parenting course
35. mobilising resources to circumnavigate system – helps
36. mobilising resources to circumnavigate system - does not help
37. Social support
38. Parent advised to seek diagnosis
39. value of a label: shorthand
40. value of a label: reasonable adjustments
41. reasonable adjustments without label
42. value of a label: protection of child's education
43. value of a label: access to additional resources
44. value of a label: supports communication between parent and child
45. value of a label: helps parent view child more empathetically
46. value of label: externalises problem
47. value of a label: supports school understanding of child
48. value of a label: access to medication
49. value of a label: for child's own identity
50. diagnosis permits child to act differently
51. Diagnosis should not be an excuse
52. Frustration that a label is needed
53. Refusal to 'own' label until formally diagnosed
54. Not accessing resources because no diagnosis
55. Negative perception of other parents seeking diagnosis
56. Parenting criticised or feeling judged
57. Parent viewed as difficult
58. active waiting
59. inactive waiting
60. worry that waiting will cause harm
61. Pharmacological intervention problem
62. Pharmacological intervention benefit
63. Parent wants medication
64. Parent does not want medication
65. Psychological intervention – access to talking therapy
66. No access to psychological interventions
67. Things that help child
68. Things that help parent
69. Financial impact
70. Family risk factor – income
71. Family risk– parent MH
72. Family risk– family size
73. Family risk– single parent
74. Child-parent relationship and attachment
75. Parent working or busy
76. Physical home environment
77. Screen technologies
78. School risk factor – bullied
79. School risk factor – unmet learning needs
80. Extra-curricular activities
81. SENCo is pro-active
82. Child presents differently in different settings
83. School placement breaking down
84. Teaching staff helpful
85. Lack of training in schools
86. Rigid school systems
87. Mesosystem – transitions and connections between school and home
88. Exosystem: Parents' work / community / neighbours
89. Macrosystem: Cultural trends and societal attitudes
90. Chronosystem: individual's personal history
91. Covid lockdowns difficult
92. Homeschooling revealed problems
93. Diagnostic process not robust
94. Reliant on professionals who are not always competent
95. No EP involvement
96. EP involvement helpful
97. EP involvement not helpful
98. Disappointment with professionals
99. Seeking diagnosis has been harmful

Appendix 3.7: Participant Information Sheet



IOE – FACULTY OF EDUCATION AND SOCIETY

Participant Information Sheet

Understanding parents' experiences of help-seeking for a child who has difficulties with attention, concentration, impulsivity and/or hyperactivity.

May 2024 – May 2025

Who is carrying out the research?

My name is Alexandra Wall and I am a Trainee Educational Psychologist in the second year of a Doctorate in Professional Educational, Child and Adolescent Psychology at the Institute of Education, University College London. This research project is being supervised by Dr Katie Quy and Professor Vivian Hill.

Who is being invited to take part?

I am interested in recruiting parents to take part in my research. To be eligible to participate you must:

- Be over 18 years of age;
- Live with a child aged between 6 and 12;
- Know that your child has a diagnosis of ADHD (Attention-deficit hyperactivity disorder) **OR** feel that your child has difficulties with attention, concentration, impulsivity and/or hyperactivity.

Why am I doing the research?

Increasing numbers of children are being diagnosed with ADHD, yet previous research suggests that parents do not always feel well-supported throughout the process of seeking help for their child's difficulties with attention, concentration, impulsivity and/or hyperactivity. Understanding the experiences of parents may enable professionals working with this group – including educational psychologists - to ensure their support is appropriate and effective, and establish a protocol for best practice.

What will happen if you choose to take part?

Participants who consent to take part in the study will be asked to complete an online survey via Qualtrics. The survey should take approximately 15 to 20 minutes to finish. At the end of the survey, participants will additionally be given the opportunity to volunteer to take part in a follow-up interview to explain their ideas further. These follow-up interviews will take place online and will last for between 30 and 60 minutes.

Sources of support will be signposted at the end of the survey, but it is important to note that I will be unable to give you any advice regarding your child's difficulties or any related processes such as application processes for Education, Health and Care (EHC) needs assessments. If you require such advice, you should contact the Special Educational Needs Co-ordinator (SENCO) at your child's school in the first instance.

Will anyone know I have been involved?

Survey participant data will be gathered anonymously, and participants will not be identified by the data collected, on any written material resulting from the data collected, or in any write-up of the research in order to ensure that confidentiality is maintained. For participants who opt to take part in the follow-up interviews, pseudonyms will be used and no identifying information will be included in the report. The interview video and audio will be recorded for the purpose of ensuring accurate transcription. The recording will be kept secure and destroyed at the end of the project and all data will be kept under the terms of the General Data Protection Regulation (GDPR).

Do I have to take part?

It is entirely up to you whether or not you choose to take part. I hope that if you do choose to be involved then you will find it a valuable experience. Participants do not have to answer all of the survey or interview questions asked of them and are free to withdraw from the study at any time (prior to submission) without explanation, disadvantage or consequence. Once you have submitted your survey responses, it will no longer be possible to trace and remove your submission as it will then be anonymous.

Data Protection Privacy Notice

The controller for this project will be University College London (UCL). The UCL Data Protection Officer provides oversight of UCL activities involving the processing of personal data, and can be contacted at data-protection@ucl.ac.uk.

This 'local' privacy notice sets out the information that applies to this particular study. Further information on how UCL uses participant information from research studies can be found in our 'general' privacy notice for participants in research studies here.

The information that is required to be provided to participants under data protection legislation (GDPR and DPA 2018) is provided across both the 'local' and 'general' privacy notices. The lawful basis that will be used to process any personal data is: 'Public task' for personal data and 'Research purposes' for special category data.

Your personal data will be processed so long as it is required for the research project. If we are able to anonymise or pseudonymise the personal data you provide we will undertake this, and will endeavour to minimise the processing of personal data wherever possible. If you are concerned about how your personal data is being processed, or if you would like to contact us about your rights, please contact UCL in the first instance at dataprotection@ucl.ac.uk.

Contact for further information

If you have any further questions before deciding whether to participate, you can reach me via email

Thank you very much for taking the time to read this information sheet.

Appendix 3.8: Interview Participant Consent Sheet

IOE – FACULTY OF EDUCATION AND SOCIETY

UCL

Understanding parents' experiences of help-seeking for a child who has difficulties with attention, concentration, impulsivity and/or hyperactivity.

Participant Consent Form: Interviews

If you are happy to participate in this study, please complete this consent form by ticking each item, as appropriate, and return to the researcher via the contact details below:

1) I confirm that I have previously read and understood the information sheet for this study, have completed the online survey, and have voluntarily shared my contact details in order to take part in a follow-up interview. ☐

2) I understand that my participation in the interview is voluntary and that I am free to withdraw at any time until submission, without giving any reason. ☐

3) I know that I can refuse to answer any or all of the interview questions. ☐

4) I agree for the interview to be recorded, and that recordings will be kept secure and destroyed at the end of the project. I know that all data will be kept under the terms of the General Data Protection Regulation (GDPR). ☐

5) I agree that small, direct, anonymised quotes from my interview may be used in reports. ☐

6) In understand that in exceptional circumstances anonymity and confidentiality would have to be broken, for example, if it was felt that practice was putting children at risk, or there were concerns regarding professional misconduct. In these circumstances advice would be sought from a senior manager from another local authority who will advise us as to the appropriate course of action and as to whether we need to inform the authority of what you have told us. ☐

Name:………

Signature: ……………………………………………………………………………… Date: ……………………………………………

Name of researcher: Alexandra Wall