Case Studies Exploring the Lived Experiences of Children and Young People with ADHD, and the Lived Experiences of their Parents

Paul Frederick Codling

Submitted in Part Requirement

for the

Doctorate in Educational Psychology (EdPsyD)

School of Education and Lifelong Learning

University of East Anglia

May 2022

Summary

This paper comprises three chapters: a literature review, an empirical paper and a critically reflective account. The literature review is in two sections: the first reviews some of the predominant debates that surround ADHD (Attention Deficit Hyperactivity Disorder), with the second section reviewing the literature pertaining to the lived experiences of CYPF (Children, Young People and Families). While the empirical chapter focuses on the experiences of CYPF living with ADHD, more than on the predominant debates, it is felt that an understanding of the latter is needed, in order to effectively contextualise the lived experiences of the participants in the empirical study.

This empirical chapter explores the lived experiences of children and young people (CYP) with a diagnosis of ADHD, and their parents, and has been constructed as a stand-alone paper. The discussion section focuses on four main areas: the lived experiences of CYPF living with ADHD; how participants attempt to make sense of ADHD; the lived experiences of assessment, diagnosis and medication; and finally, the lived experiences of systems, schools and support. Future areas of study are suggested and there is a section considering the implications for educational psychologists.

The reflective chapter explores some experiences of the research process, and the author’s development as a research-practitioner. This includes reflections around professional experiences and development; tensions around medication and diagnosis, and around professional boundaries. There are further reflections on the study’s epistemological and ontological positioning, on the dissemination of the research, and on the implications for future practice.

Access Condition and Agreement

Each deposit in UEA Digital Repository is protected by copyright and other intellectual property rights, and duplication or sale of all or part of any of the Data Collections is not permitted, except that material may be duplicated by you for your research use or for educational purposes in electronic or print form. You must obtain permission from the copyright holder, usually the author, for any other use. Exceptions only apply where a deposit may be explicitly provided under a stated licence, such as a Creative Commons licence or Open Government licence.

Electronic or print copies may not be offered, whether for sale or otherwise to anyone, unless explicitly stated under a Creative Commons or Open Government license. Unauthorised reproduction, editing or reformatting for resale purposes is explicitly prohibited (except where approved by the copyright holder themselves) and UEA reserves the right to take immediate ‘take down’ action on behalf of the copyright and/or rights holder if this Access condition of the UEA Digital Repository is breached. Any material in this database has been supplied on the understanding that it is copyright material and that no quotation from the material may be published without proper acknowledgement.

Acknowledgements

Firstly, I would like to thank my two amazing children, Elijah and Madeleine for giving me the time, support and encouragement that I have needed to complete the EdPsyD and this thesis. They have been incredibly understanding, and patient with their dad being exhausted, all-consumed and forever-busy. I have really enjoyed how curious they have been about my work, my studies and my thesis. Perhaps they are destined to become future psychologists, or educators themselves?

I must thank Carla for her support and care over this last year. It has been invaluable having you there to listen to me, and believe in me, when this thesis felt like a mountain, too big to climb.

I am forever grateful to my mum for nurturing my sense of academic curiosity, and to my dad for teaching me the importance of hard work, determination and self-discipline.

I need to thank my research supervisors, Dr Andrea Honess and Dr Kimberley Bartholomew. They have helped me to feel incredibly supported and contained, even during the more challenging times. I feel very grateful to have been able to draw upon their knowledge and expertise.

I must also thank my academic supervisors, Dr Miriam Craddock and Dr Imogen Gorman for your guidance and advice. Additionally, I would like to thank my fieldwork supervisors: Elaine Price, Claire Catchpole, Rita Adair, Sean O’Donoghue and Elaine Nickolls for your invaluable support, guidance and care. I would also like to thank Dr James Thatcher, Dr Helena Bunn and the fabulous EPS team for their ongoing support and guidance.

This study would not have been possible without the children, young people and parents who volunteered to participate. It was a genuine privilege to hear your incredibly personal stories. I was particularly inspired by your candour when describing your experiences of living with ADHD. I learnt so much from you, and will continue to tell your stories for many years to come.

Contents

List of Tables

List of Figures

Glossary of Terms

ADDiSS (ADHD Information Service)

ADHD (Attention Deficit Hyperactivity Disorder)

ASD (Autism Spectrum Disorder)

BPS (British Psychological Society)

CAMHS (Child and Adolescent Mental Health Service)

CQC (Care Quality Commission)

CUT (Callous Unemotional Traits)

CYP (Children and Young People)

CYPF (Children, Young People and Families)

DSM-V (Diagnostic and Statistics Manual of Mental Disorders, 5th Edition)

EdPsyD (Educational Psychology Doctorate)

EF (Executive Functions, or Functioning)

EHCP/s (Educational Health and Care Plan/s)

EP/EPs (Educational Psychologist/s)

EPS/s (Educational Psychology Service/s)

GP (General Practitioner)

ICD-11 (International Statistical Classification of Diseases & Related Health Problems, 11th Edition)

LA (Local Authority)

NDS (Neurodevelopmental Service)

NICE (National institute for Care Excellence)

NQT (Newly Qualified Teacher)

Ofsted (Office for Standards in Education)

PRU (Pupil Referral Unit)

RQ/s (Research Question/s)

SENDCo (Special Educational Needs and Disability Coordinator)

SEND (Special Educational Needs and Disability)

TA (Teaching Assistant)

TEP (Trainee Educational Psychologist)

ToM (Theory of Mind)

VIG (Video Interactive Guidance)

VERP (Video Enhanced Reflective Practice)

Chapter 1: Literature Review

Introduction

This literature review is divided into two sections: the first attempts to review the predominant debates and issues surrounding ADHD, including: aetiological theories of ADHD; prevalence; prognosis; services; assessment and diagnosis; treatment and medication. The second section aims to review the literature reporting on the lived experiences of CYP with ADHD, and on parents of CYP with ADHD.

In searching for literature pertaining to the section 1 (immediately below), a wide search was initially conducted across all of the university's electronic databases, using the word “ADHD”. This found over 235,000 results. Scanning sections of this indicated that the vast body of literature in this field focused on the predominant debates around ADHD, as described above. A recent review of the literature around ADHD in the last two decades confirms this (Cortese & Coghill, 2018). Given the vast number of search results, a systematic approach was adopted in keeping with NICE guidelines for conducting literature searches (NICE, 2014). Several individual searches were therefore conducted for peer reviewed articles, systematic reviews, and literature reviews, using keywords such as “ADHD” and “aetiology”, “prevalence”, “prognosis”, “assessment”, “diagnosis”, “treatment” and “medication”, across the following databases: CENTRAL, Embase, MEDLINE, APA PsycINFO, ERIC, EPIP, Child Development and Adolescent Studies and the British Educational Index. Date parameters of approximately 10 years were set, but, at times, some literature beyond this range was included, if it was reported, or was thought to be, a seminal study. Clearly much literature was excluded herein, however, it is felt that the literature reviewed offers a broad and balanced account of some of the major topics encapsulating ADHD. It is noteworthy that the section entitled ‘Services and Assessment’ foregrounds some of the difficulties in services, both nationally and locally. This is deemed important in providing a context for this study.

Section 1: The Predominant Debates on ADHD

See the naughty, restless child,
Growing still more rude and wild,
Till his chair falls over quite.
Philip screams with all his might,
Catches at the cloth, but then
That makes matters worse again.
Down upon the ground they fall,
Glasses, bread, knives forks and all.
How Mamma did fret and frown,
When she saw them tumbling down!
And Papa made such a face!
Philip is in sad disgrace.
(Heinrich Hoffmann, 1845).

This excerpt, from The Story of Fidgety Philip, serves to demonstrate how people have been trying to make sense of “naughty, restless” children for centuries (Schwartz, 2016). Over time, many labels have developed in a bid to classify, and make sense of children like Fidgety Phil, including “character impulse disorder; minimal brain dysfunction; organic driveness; cerebral dys-synchronisation syndrome; hyperkinesis; attentional deviation syndrome; hyperkinetic reaction of childhood, [and simply] disturbed children” (Schwartz, 2016, p.33). There is a long history of professionals, parents and others attempting to make sense of people with attentional and behavioural difficulties. Indeed there are records from 1775 of a German physician, Melchior Weikard, advising that, “the inattentive person is to be kept separated from the noise of any other objects; he is to be kept solitary, in the dark, when he is too active” (Schwartz, 2016, p.15). One might assume that, in the current age of rapid scientific advances, a consensus has been agreed. However, this literature review found that this is not the case: the topic of ADHD remains controversial and divisive, with even the most informed people still “disagreeing about ADHD diagnosis and treatment” (Parens & Johnston, 2009, p.1).

Diagnostic Criteria

ADHD is categorised as a neurodevelopmental disorder by the DSM-5 (2013). Globally, ADHD and ASD are the two most diagnosed neurodevelopmental disorders (WHO, 2011). The DSM-5 defines ADHD as:

> A persistent pattern of inattention and/or hyperactivity-impulsivity that interferes with functioning or development, as characterized by… six or more symptoms of both inattention and of hyperactivity-impulsivity. Symptoms must have persisted for at least six months to a degree that is inconsistent with the CYP's developmental level, and that negatively impacts directly on social and academic/occupational activities (DSM-5, 2013, pp.59-60).

There are three types of presentation: predominantly inattentive; predominantly hyperactive/impulsive and a combined presentation. The severity is also specified as mild, moderate, or severe (DSM-5, 2013, pp.59-61). It is noteworthy that while emotional dysregulation is not included as a core trait of ADHD, there is an ongoing nosological argument that it should be included as one, due to its reported high prevalence in people with ADHD, rather than being viewed as a comorbid trait (Barkley, 2015; Nigg et al. 2020; Shaw et al. 2014). Emotional dysregulation, as seen in people with ADHD, is defined as, “an impaired regulation of emotional states, excessive and inappropriate emotional expressions, high excitability and lability, temper outbursts, low tolerance to frustration, and slow return to baseline” (Masi, 2020, p.1). One existing hypothesis attempting to explain the high prevalence of emotional dysregulation in people with ADHD is that attentional deficits may make it harder for those with ADHD to recognise and apportion attention to emotional stimuli (Shaw et al. 2014).

Another trait that is associated with ADHD is callous-unemotional traits (CUT), that is described as reduced guilt, remorse, and empathy, a disregard for others, callousness and lacking prosocial skills and emotional affect (Masi et al. 2020). CUT is not exclusive to ADHD and is also reported in people with ASD (Leno et al. 2015).

The DSM-V (2013) and the ICD-11 (2022) are widely accepted as the principal diagnostic criteria for ADHD (Bruchmüller et al. 2012; Foreman & Ford, 2008) and the primary criteria used within psychiatry (BPS, 2013). It is noteworthy that the continual revisions to the DSM and ICD suggest that they remain works in progress (BPS, 2013). In the UK, the NICE guidelines are widely recognised as the legal entity and guidance for clinicians, including those in the NHS, educational and clinical psychology services and social care (NICE, n.d). The NICE guidelines define ADHD as “a heterogeneous disorder characterised by the core symptoms of hyperactivity, impulsivity and inattention, that are judged excessive for the person's age or level of overall development.” (NICE, 2019, para 1). The heterogeneous aspect of this is considered important in recognising that ADHD is not a homogenous disorder, as it is sometimes perceived to be (Thapar et al. 2013).

ADHD is frequently diagnosed co-morbidly with other conditions, including Rejection Sensitive Dysphoria, Oppositional Defiance Disorder, Intermittent Explosive Disorder, Mood Dysregulation Disorder, personality disorders and anxiety (Bedrossian, 2021; Gnanavel et al. 2019; Kadesjo & Gillberg, 2001; Pliszka, 2003). It is reported that as many as 75% of people with ASD have comorbid ADHD (Antshel et al. 2016).

The Aetiology of ADHD

Aetiology is defined as “the study, or cause of a disease” (CD, n.d. 2). The aetiology of ADHD is a highly contentious topic with an enormous amount of research conducted around it (Thapar et al. 2013). It warrants inclusion in this review as differing aetiological narratives shape socio-cultural views and perceptions of ADHD, and inform decisions around treatment plans and medication (Ringer et al. 2020). For example, it is reported that parents who are offered biological aetiological explanations for their child’s ADHD are more likely to seek medication as a first-line of intervention (Ringer et al. 2020).

ADHD has many perceived aetiologies causing widespread confusion, with public opinion reported to be shaped by the media’s reductionist portrayal of ADHD (NICE, 2018, 1.5.4). Cooper and Ideus (1996) conducted an extensive literature review on the pervasive cultural attitudes towards ADHD in the UK and USA, finding eight orientations that remain relevant today (see Appendix 1.0). Of these, the bio-medical aetiologies are perhaps the most pervasive. These put forward that ADHD is caused by abnormalities in the prefrontal cortex, the brain region associated with executive functioning, including self-regulation and inhibitory control, sustained behaviour control, working memory, attention, planning and organisation (Lambek et al. 2011; Mahone et al. 2002). The bio-medical model includes studies of neurotransmitters such as serotonin (Hou et al. 2018); dopamine and norepinephrine (Wegmann, 2015). These are commonly referred to as the dopaminergic and norepinephrine hypotheses respectively. These are founded upon brain-imaging studies that have reported neurotransmitter dysfunction, decreased regional cerebral blood flow and alterations in the prefrontal cortex, and other areas of the brain, of CYP with ADHD-like symptoms (Linnet et al. 2003). Despite the advances in recent years, the direction of causality remains unclear, i.e. do the alterations that are observed at a molecular level, cause ADHD-like symptoms, or are they, in fact, additional symptoms of it? It seems widely accepted that no known biological markers, nor ADHD-specific gene variations have been recorded in populations with ADHD at this time (DSM-5, 2013; Thapar et al. 2013). Given this, there are a growing number of voices, including the British Psychological Society, voicing “serious concerns … about the increasing medicalisation of distress and behaviour…the ‘functional’ diagnoses… of disorders such as ADHD… for which there is substantial evidence for psychosocial factors in its aetiology, and very limited support for the disease model…” (BPS, 2013, p.2).

Additional aetiological associations include the pervasive bad parenting hypothesis (Timimi, 2005), a view that has been perpetuated through popular media (Ahmed et al. 2017). This may have been compounded by the similarities in behavioural traits, observed between CYP with ADHD and those with attachment disorders, including increased emotional dysregulation across both populations (Franke et al. 2017; Waters et al. 2002). There are many other aetiological hypotheses that cannot be explored in this paper. Some are included in Appendix 2.0.

In short, there appear to be many complex aetiological factors at play, including genetic, epigenetic, heritable, neurological, perinatal, psychosocial, and environmental factors (Thapar et al. 2013). It is reported that the aetiology of ADHD is frequently presented, in the media, through a reductionist lens, and frequently as having one homogenous causal aetiology rather than being a complex web of associated aetiologies (NICE, 2018, 1.5.4; Thapar et al. 2013). Such polarising and/or reductionist aetiologies are said to misrepresent the current literature, and aetiologies may be better explained as “complementary rather than competing explanations” (Thapar et al. 2013, p.12).

The Prevalence of ADHD

Reviewing the extant literature found that the prevalence of ADHD is also a highly contentious topic (Schwartz, 2016) with ADHD reported as both over diagnosed (Bruchmüller et al. 2012) and underdiagnosed (Sayal et al. 2018). Its high prevalence in some regions has led to it being described as a socially and culturally constructed phenomenon (Schwartz, 2016; Willcutt, 2012), thus creating further doubt around the legitimacy of the disorder.

Credible prevalence figures range between 1.5% (PHE, 2016) to 9% (Roughan & Stafford, 2019). A meta-analysis reported a prevalence of ADHD in CYP between 5.9 – 7.1% worldwide, with a higher prevalence reported in CYP from lower socio-economic backgrounds, and a higher rate in boys than girls (Willcutt, 2012). There appears to be a consensus that ADHD is under-recognised, underdiagnosed, and therefore under-treated in girls (Biederman, 2005; NICE, 2019; Sayal et al. 2018).

The Prognosis of CYP with ADHD

The DMS-5 (2013) reports that ADHD is associated with traits such as laziness, irresponsibility and a failure to cooperate; reduced school performance and academic attainment; an increased likelihood of injury, and of being involved in traffic accidents and violations; an increased risk of obesity; negative family interactions, peer rejection and teasing; and reduced intellectual scores. In adulthood, there is an increased risk of poor vocational achievement and unemployability; increased risk of conduct disorder and anti-social personality disorder; substance use disorders and incarceration; a higher risk of suicide in early adulthood; low frustration tolerance; increased irritability, and mood lability (DSM-5, 2013, pp.62-63).

Services and Assessment

The assessment, diagnosis and treatment of ADHD has caused considerable controversy and disagreement, even among highly informed professionals, with little sign of abating (Hooft et al. 2016; Parens & Johnston, 2009). In the UK, one typical pathway for a child to be referred for an ADHD assessment is through their GP (NICE, 2019). As such, GPs are deemed a primary source of information. However, it is reported that not all GPs are given adequate training in this field, when compared to other specialists, with "less than half of GPs (46%) [in England] undertaking a training placement in a mental health setting" (Mind, 2016, para 1). This suggests that, not only, are GPs potentially ill-equipped to inform others about ADHD, its complex aetiology and various lines of treatment, but that they are potentially more likely to present a medicalised and pathologising position in keeping with their training. This suggests that they may be more likely to offer 'within-child' pharmaceutical approaches rather than considering 'with-out child', or systemic approaches. (Jutel, 2009, p.286).

The waiting times from referral to neurodevelopmental assessment can vary greatly depending on location within the UK, presenting a reported "post-code lottery" (Boseley, 2018). CAMHS are typically tasked with overseeing services for CYP in the UK, including the assessment, diagnosis, treatment and mental health (Brady, 2014). Although there are regional differences, nationally, CAMHS have been widely criticised for long waiting times, that reportedly vary from four weeks to over a year for an initial assessment with further delays of up to 18 weeks following assessment (Roughan, 2019).

Services - Local Context

For the sake of anonymity, the region/LA in which this study took place will not be named, or made identifiable. The area will therefore be referred to as region 'A', or LA 'A'. Identifiable references to region A were included and verified at the time of submission by the research supervisors, and later by an internal and external examiner in the viva examination process, prior to their removal.

Locally, waiting times for NHS assessments are reported to be between two to three years. Moreover, the NHS foundation trust that oversees CYP's mental health in this region, has been under significant scrutiny, receiving 'Inadequate' CQC ratings in 2022 and in years prior to this. Region 'A's 2020 CQC inspection reported that the local NHS trust must ensure that adequate staff resources are made available to reduce the patient waiting lists for triage, assessment and treatment in the CYP service and for ADHD patients. This should include ensuring that patients who remain on waiting lists are supported safely. This aligns with national reports that “nearly all parents of children with ADHD seek help, but only a minority receive evidence-based treatment or were able to access appropriate services” (PHE, 2016, p.16), with waiting lists up to 100 weeks from referral to treatment, with variable service quality (DoH/DoE, 2017, p.9). While there are some support services available in this region, the latest SEND inspection report stated that not enough families know about the existence of a range of other organisations that are available to help them. This inspection concluded that a written statement of action was required because of significant areas of weakness including poor access to services, long waiting times for assessment and for neurodevelopmental diagnosis, with not enough being done to seek out the views of those children with SEND who are deemed under-represented in giving their voice. In response to this, LA ‘A’ produced an area SEND strategy stating a number of key priorities for improvement (see Appendix 3.0). While LAs and other services are working at times of unprecedented financial cuts (Clifford, 2021, p.2051), they must adhere to their legal obligation to safeguard CYP as stated in the Working Together to Safeguard Children legislation (DfE, 2018). This places an emphasis on the importance of inter-agency working in effectively safeguarding and promoting the welfare of children. This is also in keeping with BPS Practice Guidelines stating that psychologists have a legal duty to “protect specific children who are suffering, or likely to suffer significant harm” (BPS, 2017b, p.39) and “prevent the impairment of mental health…ensuring that children … [have] effective care, by taking action to enable all children to have the best life chances” (BPS, 2017b, p.39).

Diagnosis of ADHD

Providing a diagnosis of ADHD is reported to offer some CYP, their parents and teachers some benefits, including a potential reduction in self-blame and parental-blame; a greater sense of understanding and credibility; and a recognised framework from which interventions, and collaborative approaches to improving challenging behaviour may be delivered (Wienen et al. 2019). In addition, by interpreting children’s behavioural difficulties through the lens of a disorder, parents have been found to “replace their feelings of anger and irritation, with feeling of empathy and compassion” (Ringer et al. 2020, p.385). Conversely, it is reported that giving a child a diagnostic label of ADHD can lessen their sense of personal responsibility (Honkasilta, 2016; McCubbin & Cohen, 1999) and that parents may seek a within-child diagnosis as a way of diminishing their perceived culpability, and sense of self-blame as bad parents (Timimi, 2005). Lauchlan et al. (2017) reported that when CYP receive a diagnosis, it can also reduce a teacher’s confidence in working with them, as they feel less able to effect change. There are also reported concerns that the pervasive practice of diagnosing CYP serves to uphold the legitimacy and authority of the medical paradigm, its power, and the financial benefits that accompany it through the mass sales of psychopharmacological medications (McCubbin & Cohen, 1999; Schwartz, 2016).

Schools can play a key role in initially identifying ADHD traits in CYP. Weinan et al. (2018) reported that it is often school staff that raise concerns around CYP’s behaviour, leading to the assessment and diagnosis of ADHD. Teaching staff can therefore be seen to offer parents helpful and considered support and advice around ADHD (Ahmed et al. 2017; Singh, 2012). However, Brady, (2014) suggests that schools can also serve to perpetuate the increased prevalence rates of diagnosis, and, in turn, serve to uphold the medicalisation of childhood behaviours. Teachers and school staff are also reported to be working in times of limited resources, and frequently encounter behavioural challenges and difficulties in the classroom (Kos et al. 2006). In addition, CYP with ADHD are associated with increased teacher stress (Greene et al. 2002), and subsequently there are reports that some schools can implicitly, or explicitly pressure parents and carers to seek diagnosis for ADHD, and to medicate their child (Timimi, 2005).

Treatment and Medication

The treatment of CYP with ADHD continues to be divisive, with reports that we are seeing a global psychiatrisation of childhood (Mills, in Williams et al. 2017). There is considerable backlash against the treatment of ADHD with psychopharmacological medications, due, in part, to there being “very limited support for a disease model… [of ADHD]" (BPS, 2013, p.2). There are a growing number of voices expressing that, despite the limited evidence supporting the bio-medical model of ADHD (Jutel, 2009), by continually treating ADHD with medication, further enforces the disorder as having an underlying biological basis (BPS, 2018b; Brady, 2014; Pickersgill, 2014; Schwartz, 2016).

Of course, there is evidence supporting the use of approved drugs to treat CYP with ADHD, namely, the psychostimulants methylphenidate, dextroamphetamine and the selective noradrenaline reuptake inhibitor atomoxetine (Wegmann, 2015). ADHD medication is reported to improve the core symptoms of ADHD and improve quality of life (Pickett, 2016). That said, Brady (2014) describes how most people, with or without a neurodevelopmental disorder, report improved concentration and 'feel better' taking psychostimulants, leading to some neurotypical CYP seeking ADHD medication just to improve their academic grades and to feel better (Schwartz, 2016; Wegmann, 2015).

NICE guidelines do not support medical treatment as the first line of intervention. Clinicians are advised to take a holistic approach; consider the severity of symptoms; consider diet and exercise in treatment, and discuss the "benefits and harms of non-pharmacological and pharmacological treatments…" (NICE, 2018, 1.5.2-4). NICE guidelines (2018) recommend involving CYPF in management plans as much as possible. Yet, there is evidence to suggest that "little is known about how well ADHD guidelines are implemented in routine clinical practice" (Sayal et al. 2018, p.181).

The literature reviewed herein suggests that, for the most part, it is parents who are the decision-makers around their child's medication (Ahmed et al. 2017; Brady, 2014; McElearney et al. 2014). NICE guidelines state that the decisions around medication choices should include the preferences of the CYP (NICE, 2018). There are increasing calls for CYP to have greater involvement in decisions around whether they take medication, and how much medication they take (Brady, 2014; McElearney et al. 2014; Singh, 2012). In particular, the BPS are among the voices arguing for greater consideration of the child's choice/voice in their treatment, summarised by the principle of “no decision about me without me” (BPS (2017, p.23).

A number of influential factors impacting upon parents’ choices for medicating are explored in the section below, but include attempting to improve their child’s school performance (Ahmed et al. 2017) and in managing challenging behaviours (Corcoran et al. 2017). The latter appears to be significantly influenced by the views of friends, family and school staff, and is, in turn, influenced by the role of media and other stigmatising factors. Stigma is considered a socio-culturally formed environmental stressor, potentially enabling self-stigmatisation, unfavourable perceptions, and a “degraded self-identity” (Mueller et al. 2012). Stigma can influence decision making around treatment as parents feel pressurised to rapidly adjust their child’s behaviours, in a bid to adhere to societal norms and diminish stigmatisation; conversely, the parental act of medicating a child can potentially be stigmatising in itself (Mueller et al. 2012).

While this literature review found a limited body of evidence pertaining to how much informed choice CYP have in taking medication for their ADHD, it found evidence reporting that the majority of CYP spoke positively about taking medication for their ADHD (Holbrook et al. 2017; McElearney et al. 2014). Nonetheless, one study found that 40% of its participants (n=40) were non-compliant, or refused to take their medication (McElearney et al. 2014), with another study reporting this to be as high as 59% of the 50 CYP interviewed who refused (ADDiSS, 2005). This review found a gap in literature considering the extent to which CYP are informed about what their medication does, its potential side-effects, and the potential implications of taking it longer term. Indeed, Brady (2014) reports that more research is needed to explore the factors that allow, or inhibit agency in choices around taking medication.

As mentioned above, schools appear to play a significant role in driving assessments for ADHD, and in decisions around medication (Weinan et al. 2018), with teachers reporting that CYP with ADHD are “significantly more stressful to teach than their classmates without ADHD (Greene et al. 2002, p.79). That said, teachers and TAs in one study, self-reported as receiving inadequate training on ADHD (Greenway & Rees-Edwards, 2020). This potentially means that teachers may be putting pressure on parents to medicate their child for their ADHD (Timimi, 2005) with little knowledge of ADHD medication, or its effects on CYP (Greenway et al. 2020). Moreover, studies report that boys are more likely to be treated medically for their ADHD than girls in primary-aged settings due their behavioural presentation, especially those younger boys born later in the academic year (Vuori et al. 2020). Accordingly, some authors have questioned whether it is ethical to medicate children in a bid to reduce teacher stress, and make CYP more classroom compliant (King et al. 2013; McCubbin & Cohen, 1999).

Beau-Lejdstrom et al. (2016) investigated the drug prescribing patterns for ADHD in the UK between 1992 and 2013, in children under the age of 13 years. They found that between these dates there has been a reported 34-fold increase in drug use as the primary treatment for ADHD, in the UK (Beau-Lejdstrom et al. 2016, p.1). Other data reports that there has been a “92-fold increase in the rate of psychostimulant medication being prescribed to children under the age of six between 1992 and 2001… painting a worrying picture” (Hill, 2017). Beau-Lejdstrom et al. (2016) also reported that 60% of CYP were still on medication after two years, with CYP in the UK, persisting with ADHD medication for longer than in other countries, despite growing concerns that the long-term use of such drugs has potentially serious health implications (Mills in Williams et al. 2005, p.142), including potentially adverse side-effects (Gov.UK, 2014; McCubbin & Cohen, 1999; Wegmann, 2015), and being highly addictive (Wang et al. 2017).

There have been long-standing arguments that the pervasive use of psychopharmaceutical medications to treat ADHD, is indicative of the inadequate support that is available for families in modern societies and symptomatic of educational systems that are increasingly “pushed to do more with less” (McCubbin & Cohen, 1999, p.81) with increased pressures placed upon teachers and larger class sizes (Schwartz, 2016). Such factors are becoming increasingly recognised within educational psychology with EPs becoming increasingly concerned about the application of medical intervention, without giving due consideration to wider systemic factors, such as living in adversity and the effect of existing in stressful environments (Hill, 2017). This view is echoed by the BPS Division of Clinical Psychology who published an open position paper calling for a “paradigm shift… towards a conceptual system that is no longer based on a ‘disease’ model” with “limited reliability and questionable validity” (BPS, 2013, p.1-2).

Section 2: The Lived Experiences of ADHD

Introduction

The following section reviews selected literature exploring the lived experiences of CYP with ADHD and their parents. For this, a separate round of searches was conducted using the following databases: CENTRAL, Embase, MEDLINE, APA PsycINFO, ERIC, EPIP, Child Development and Adolescent Studies and the British Educational Index, using the terms “ADHD” with “lived experience/s”, “child experience/s”, and “parent experiences”. Date parameters of 2012-2022 were set, in an attempt to draw upon literature that was deemed more relevant, with approximately 200 results found. The vast majority of studies were not deemed to be appropriate for review, mostly because they had adopted very specific lines of enquiry, including studies on gender, race and culture, co-occurring conditions, and the effectiveness of specific interventions. Eight appropriate studies were found and are reviewed in total. These studies were selected due to their predominant use of qualitative, or mixed methods approaches in eliciting the voices of experts by experience, i.e. those living with ADHD, rather than experts through non-lived experiences. Of these, three included CYP and parent voices, one of which is a meta-synthesis (Corcoran et al. 2017), and one an older study (ADDiSS, 2005). Three studies researched the parent’s views only, with only two appropriate studies found that focused on the voice of CYP. The literature search conducted for this review therefore revealed that there is limited qualitative literature exploring the experiences of CYPF living with ADHD. This aligns with reports that, despite such studies holding great value in helping to understand the nuanced and complex experiences of CYPF living with ADHD (Honkasilta, 2016), that such accounts have been largely overlooked (Brady 2014).

ADDiSS (ADHD Information Service) (2005)

ADDiSS (2005) conducted a study with 50 children and 90 parent participants, exploring the impact of ADHD on their education. It adopted a mixed-method approach utilising surveys and focus groups. It reported the UK media as partially culpable in perpetuating the myth that ADHD "does not exist" (ADDiSS, 2005, p.2) running headlines such as, "Why have we created a medical condition to excuse our spoilt brats?" (ADDiSS, 2005, p.2). This is in keeping with other studies reporting on the media's negative influence around the perception of ADHD (Ahmed et al. 2017; NICE, 2018). ADDiSS (2005) also reported that:

- 42% of CYP with ADHD were sent out of the classroom, at least once per week.
- 59% of CYP did not want to take medication for their ADHD.
- 77% described concentration difficulties as the hardest part of having ADHD.
- 69% had difficulties with teachers.
- 50% had difficulties in their friendships.
- 58% of parents were uncomfortable with their CYP taking medication for their ADHD (ADDiSS, 2005, pp.5-9).

The mixed methods approach adopted in this study is considered a strength, in quantifying the participants' qualitative reports. However, in critiquing this study, it does not offer the lack of qualitative depth and exploration provided in some of the studies below, that are accordingly, given greater weight. However, it serves its purpose in further corroborating the view that more is needed to hear and understand "the views of children themselves, currently going through the school system", (ADDiSS, 2005, p.1) an area that remains relatively unexplored.

Brady (2014)

Brady (2014) conducted a qualitative study with seven CYP participants, using interviews to elicit their views and understand more about how they sought "control within the constraints of diagnosis" (Brady, 2014, p.218). Although the data was collected over a decade prior to this, it warrants inclusion as it is one of the infrequent studies in this area exploring the views of CYP in relation to taking medication for ADHD. The author puts forward the view that ADHD is frequently reported in terms of financial burden and societal costs, and that the voices of CYP with ADHD are largely neglected as a consequence of them holding low socio-political standing in the UK. Moreover, the accounts of CYP are infrequently sought as they can serve to challenge the dominant, pathologising, and with-in child accounts that exist in the UK (Brady, 2014, pp.218/219). Brady argues that more needs to be done to move away from the authoritarian medical model of treatment that acts to maintain control over CYP's lives and their behaviours (Brady, 2014). Seen through this lens, Brady suggests that CYP's challenging behaviours may be interpreted as their own attempts to regain some control over their lives. This study concludes that, while the participants were able to see some of the advantages and disadvantages of taking medication, CYP are rarely provided with legitimate and meaningful opportunities to discuss their medication and the potentially significant side-effects. This, she argues, is representative of a decline in critical inquiry, and a lack of criticality of the systems around CYP that are perpetuating both the medicalised, and within-child narratives of ADHD (Brady, 2014).

Corcoran et al. (2017)

Corcoran et al. (2017) conducted a meta-synthesis and comprehensive review of 80 published and unpublished qualitative studies that focused on the views of parents raising CYP, aged 4-17 years, with a diagnosis of ADHD. Older studies were included i.e. those from the 1980s onwards. They reported that parents of CYP with ADHD were able to notice differences in their child's behavioural presentation from an early age. They also found a wide range of parental emotional burden including feelings of exhaustion, isolation, anxiety, irritation, desperation, frustration, anger, powerlessness, and helplessness across the body of research (Corcoran et al. 2017).

Parents reported struggling to make sense of their CYP's behaviour and found it difficult to come to terms with the diagnosis at different stages. Parents' understanding of the bio-medical reasons for ADHD were "sketchy" (Corcoran et al. 2017, p.343) and there was some reported resistance to the bio-medical model as an explanation for their CYP's behaviours. Moreover, parents "yearned for definitive information" (Corcoran et al. 2017, p.343) in a bid to understand what was happening to their CYP. They also reported that stigma around ADHD was a persistent factor, describing how parents frequently felt that others perceived the ADHD label as a 'cop-out' for bad behaviours. This review found that over time, parents felt more able to accept their CYP's diagnosis; parents also felt a sense of relief, and a general reduction in self-blame and frustration. Parents felt that the diagnosis helped them to reshape their perception of their CYP from feeling that "they won't control themselves", to, "they cannot control themselves" (Corcoran et al. 2017, p.347). In turn, they felt less ineffective as parents as they modified their expectations of their CYP in light of their diagnosis.

Across studies, Corcoran et al. (2017) found that parents' decisions around medication were reportedly influenced by the views of friends, family, school staff and health care professionals. Parents were reportedly ambivalent towards medicating their CYP and sought alternative treatments, perceiving psychopharmacological treatments as a "last resort" (Corcoran et al. 2017, pp.333-337). Other studies reported that parents medicated their CYP in a bid to improve social relationships, in keeping with Pickett (2016). A main reason for the discontinuation of medication was due to concerns around the side-effects.

The Corcoran et al. (2017) review is significant in identifying a number of key themes around the area of medicating CYP and how such decisions are complex and difficult one for parents. The study concludes that there is a need to retain a critical and ethical position when considering the use of medication, in keeping with Brady (2014). It also suggests that social workers can play an important role around the exploration of medication choices for CYPF living with ADHD. This suggestion was not reported in the other literature reviewed for this literature review. The findings of the Corcoran et al. (2017) study suggests that parents struggle to make sense of the aetiology of ADHD, due to varying aetiological theories and orientations, and felt resistance towards passively accepting the explanations given to them.

Ahmed et al. (2017)

Ahmed et al. (2017) conducted a qualitative study with 16 parents, utilising focus groups in Australia. This aimed at ascertaining greater knowledge about the complex processes that parents experience in considering the initiation, continuation, modification, and cessation of medication for their child, diagnosed with ADHD. The study demonstrated that parents were generally sceptical about ADHD and its diagnosis, in part due to the views of other parents, friends and sensationalised media influences, in keeping with the findings of NICE (2018). Parents also sought to exhaust other treatment possibilities, including natural remedies and behaviour management programmes, before using medication.

Crucially, the study found that decisions around the initiation of medication for CYP was significantly influenced by the CYP's school, with parents feeling pressurised to medicate their CYP due to poor behaviour and low academic attainment. Such pressures also acted as drivers for the continuation of medication (Ahmed et al. 2017). Parental reasons for the cessation, or modification of medication were attributed to concerns over the long-term side-effects, including diminished appetite, weight loss, affected sleep, and the continued stigmatisation of ADHD (Ahmed et al. 2017). The study also reported that parents were offered inconsistent information and advice from healthcare services. This study provides further insight into the "largely unheard" (Ahmed et al. 2017, p.97) voices and experiences of parents of CYP with ADHD. It is deemed significant as it reports upon the largely undocumented, parental pressures placed upon families to medicate CYP, thus identifying a need for further research in this field.

Ringer et al. (2020)

Ringer et al. (2020) conducted a qualitative study of twelve Swedish parents' lived experiences of living with a CYP with ADHD, between the ages of three and nineteen years. This utilised semi-structured interviews between 2016 and

2017. In keeping with Ahmed et al. (2017), parents reported feeling pressures from their CYP’s school to seek diagnosis, due to behavioural expectations in school (Ringer et al. 2020). It also reported that receiving a diagnosis of ADHD for their CYP, had significant bearing on parent’s perceptions of their CYP in a number of ways, including helping them to turn feelings of distress into feelings of being able to cope, for example. That said, all parents in the study expressed difficulties in understanding and managing their CYP’s behaviour and coping with them. Parents reported feeling angry and powerless when their CYP misbehaved, and feelings of shame and a lack of control when their CYP got into conflict with other CYP (Ringer et al. 2020, p.384). Parents also felt feelings of sorrow and guilt at not being able to implement their parental values as they would have liked to. The way that parents attempted to make sense of their CYP’s behaviour was closely associated, and informed by their understanding of ADHD. Additionally, their ‘meaning-making’ took place over continual cycles, and over time (Ringer et al. 2020, p.382).

Parents reported difficulties in implementing and maintaining everyday routines. In particular, they found it difficult to manage societal demands when outside of the family home, where their CYP were more likely to have been seen through the perceptions of others, and did not meet other’s expectations (Ringer et al. 2020). Subsequently, parents sought out “unproblematic situations” where their CYP were less likely to be seen as deviant and difficult (Ringer et al. 2020, p.387). This is deemed to be an important finding, suggesting that parents of CYP with ADHD are making quite profound adaptations to their lives in order to cope with societal pressures, around perceptions of their child’s behaviour (Ringer et al. 2020).

This study reported that parents sought “valid, stable and useful explanations” (Ringer et al. 2020, p.384) for their CYP’s behaviour. As in the Corcoran et al. (2017) study, parents struggled to make sense of the explanations that were offered to them. Moreover, when attempting to make sense of their children’s behaviour, parents reported adopting self-accusatory stances, and tended to take personal responsibility for their child’s behaviour. Part of this was a reflective process in which they reflected and ruminated on themselves, as children, in an effort to make sense of their own CYP's behaviour. Both pre- and post-diagnosis, parents were described as going on “a quest for knowledge” (Ringer et al. 2020, p 385) to understand how to better support their child, from a wide range of sources, including friends and family, schools and health care services, books, and the internet. In keeping with Corcoran et al. 2017, having a diagnosis for their CYP was deemed beneficial for parents, who subsequently reported a change in their own self-perception, and began to reposition themselves as parents of a child with a SEND (Ringer et al. 2020). This study also reported that those parents who were offered more bio-medical aetiological explanations for their child's ADHD were more likely to seek medication as a first-line of intervention (Ringer et al. 2020).

Once their CYP were diagnosed, parents in the study reported feeling retrospective guilt regarding their reactive responses to challenging behaviours, prior to diagnosis; having a diagnosis helped parents to manage previous feelings of shame and it acted in a way to validate their parenting and efforts. They also went through a process of adjusting their proactive behaviours, including greater focus on planning and preparation; they felt more able to regulate their feelings towards their CYP, with feelings of anger and irritation being replaced with those of compassion and empathy (Ringer et al. 2020).

Leitch et al. (2019)

Leitch et al. (2019) conducted a qualitative study exploring the experience of stress in parents of children with ADHD. They conducted two focus groups with 13 parents of children with ADHD, that was analysed using thematic analysis. Four predominant themes were identified: their “child's behaviour feels like a wrecking ball; coping with the war at home; a divided family: relationships don't survive; and craving support: it's goddamn hard work” (Leitch et al. 2019, p.1). Rather than relying on the parental voices alone, to demonstrate the levels of stress that parents of CYP with ADHD can encounter, this study reported that the stress level in five of the parents met the clinical threshold for professional support. This was not found to be reported in the other literature reviewed herein, suggesting that the quantification of parental stress, in this area, may represent a gap in the literature. However, the Leitch et al. (2019) study did not provide a great depth of analysis, hence its limited discussion in this review.

Singh (2012)

Singh (2012) utilised a qualitative approach, and interview method to elicit the voices of CYP. This was a cross-cultural study with 151 CYP between the ages of nine and fourteen years. Recruitment was undertaken through the NHS in the UK (Singh, 2012, p.9). Information was also gathered through support groups, educational staff and clinicians, parents and carers. The study is presented as both child and parent friendly, with animated characters, linked to online videos to help CYPF make sense of ADHD.

The author foregrounds the study with a number of provocative statements and questions around medication, including describing Ritalin as “enforcement and psychological policing…” and questions, “are children being drugged into obedience and conformity?” (Singh, 2012, p.2). It also reports how medication can help CYP to manage, function and concentrate in school, if monitored and managed effectively. This study positions the CYP’s voice as essential in considering both the assessment and treatment of ADHD.

Aetiologically, Singh positions ADHD as an interaction between ecological-biological-developmental (eco-bio-developmental) factors, rather than a solely biological disorder. This aligns with an increasing body of voices (Thapar et al. 2013). Drawing upon Bronfenbrenner’s ecological model (1979), Singh develops a eco-bio-developmental model of ADHD, described as the child’s ecology (Singh, 2012). This considers how the presentation of ADHD may be understood in terms of interactions between personal attributes (biological), in familial, everyday environments (school/home etc), and wider spheres of influence, such as school and national policy.

Singh (2012) reported two overarching ‘niches’: a conduct niche and a performance niche. When both niches were valued, this was referred to as a hybrid niche, in which importance was placed on both conduct and academic performance. Singh puts forward that the societal emphasis that is placed upon these niches, in turn, influences the manner in which ADHD is perceived and treated, having significant bearing on the CYP and their perception of self. Singh (2012) suggests that in the USA, a greater emphasis is placed on the performance niche, while in the UK, a greater emphasis is placed on the conduct niche. This suggests that societally, greater value is placed on academic performance in the USA, and on good conduct in the UK. Moreover, it reports that in the UK, there is potentially a greater focus on CYP taking medication to improve behaviour, to reduce aggressive and impulsive behaviours, to promote “self-control and better moral decision making” (Singh, 2012, pp.15-16).

Singh (2012) reports that children’s perception of ADHD, as an entity, affects their self-perception. Through the lens of the performance niche, CYP saw themselves as “thick and slow” (Singh, 2012, p.19), and wanted to keep their ADHD a secret from others. Those who perceived themselves through the conduct niche saw themselves as angry, aggressive, naughty, and as having “anger problems” and were purposefully “wound up” by other children (Singh, 2012, p.18). They were also more likely to be both victims and victimisers of bullying, and due to the high visibility of their conduct, CYP were more likely to tell others about their ADHD. CYP, under both niches, reported their ADHD symptoms as having significant bearing on their perception of self and self-esteem. Other CYP in the study did not know what the acronym ‘ADHD’ stood for, with many not even knowing that they had ADHD.

Adolescents in the study were more likely to tell others that they had a diagnosis. However, due to the stigma that is attached to having ADHD, most CYP attempted to keep their ADHD a secret, as it brought about feelings of shame and anxiety This, the author claims, is due to a pervasive silence around ADHD, that is not helping to tackle the stigma around the disorder (Singh, 2012). In keeping with Ringer et al. (2020), parents reported having a diagnosis as helpful in enabling a perceptual shift away from maternal blame towards one of “brain-blame” (Singh, 2012, p.29).

Some CYP in the study reported that they would not tell their teacher/s that they have a diagnosis of ADHD. Some CYP reported that teachers did not help them to manage their ADHD. Only a few reported discussing ways to manage the classroom with their teacher/s. There was also evidence suggesting that teachers lacked sufficient, in-depth training on ADHD, and that they were largely uninformed about it. This offered one potential explanation as to why CYP in the study reported having either neutral, or negative experiences in school (Singh, 2012).

Overall, CYP did not feel that their medication affected their own sense of self, but 40% of nine year olds interviewed felt like a different person. Likewise, parents too described their CYP as a different person when they took their medication (Singh, 2012). Only 8% of CYP on medication reported feeling any side-effects; studies reporting numerical evidence around the proportion of CYP who encounter side-effects for their ADHD medication were not found in this literature review, suggesting that this may be a potential gap in the literature. A significant aspect of Singh's (2012) study was in considering whether CYP felt that they had genuine opportunities to participate in decisions around their healthcare and treatment. The findings in this study indicate that CYP demonstrated the potential to discuss issues such as ethics and medication. However, it recognised that power imbalances did exist, creating potential barriers to the co-construction of management plans and meaningful collaboration (Singh, 2012). This is in keeping with Brady's (2014) view that CYP are perceived to be of low social and political status and are therefore overlooked in decisions around medication.

The Singh (2012) study also questions whether too much emphasis is placed on medication, over developing agency and self-development, and moral development (Singh, 2012). It provides evidence that others, including teachers, felt that CYP with ADHD could not control themselves, potentially diminishing the high expectations and personal responsibility placed on CYP with ADHD (Singh, 2012, p.29). This may, in turn, add to the stigma that CYP with ADHD cannot act as moral agents as there is something within them that is beyond their locus of control. However, CYP in the study, reported that they still felt a sense of moral agency and with the support of their medication, felt able to exhibit some control over their impulsive behaviours, and an increased ability to be able to “stop and think” (Singh, 2021, p.24).

CYP in the study reported feeling that it was helpful when teachers did help to support them with their concentration, restlessness, self-esteem and confidence. Noisy and chaotic classrooms were found to be overly stimulating and CYP with ADHD reported day-dreaming as a way of escaping the intensity of the classroom. However, doing so, was reported to reduce social and learning opportunities (Singh, 2012).

Honkasilta (2016)

Honkasilta’s (2016) study, Voices Behind and Beyond the Label, is a Finnish dissertation. This paper adopted a social constructionist approach, interviewing 13 adolescents between the ages of eleven and sixteen years, and their parents. The study aimed at challenging the ‘master narrative’ i.e. the pervasive psycho-medical model of ADHD, focusing on CYP with ADHD in the school context.

Honkasilta (2016) found that ADHD is a priori a stigmatising label due to it being situated within the psycho-biological model. This, in turn, affected how CYP constructed their self-identity in relation to their ADHD, with its varying, and sometimes contradictory socio-cultural interpretations. Honkasilta asserts that the master narrative is not only unproductive, but is oversimplified, uncritical and insufficient in truly understanding ADHD and its bearing on CYP with ADHD, and their families. It concludes that for education to be truly inclusive, the master narrative must be challenged, moving away from a culture of “deviance labelling” towards a more humanistic and progressive approach (Honkasilta, 2016, p.70). In order to achieve this, the voices of CYPF must be heard to reconstruct new progressive narratives (Honkasilta, 2016).

In keeping with Ahmed et al. (2017), Ringer et al. (2020) and Singh (2020), this study reported that parents, and particularly mothers, are put under pressure to seek assessment and diagnosis for their CYP, primarily as a response to continuous feedback from schools about their CYP’s behaviour and performance (Honkasilta, 2016). This is accompanied by feelings of maternal blame, that is then reframed, though diagnosis as the ‘pathologisation’ of their child’s behaviour/condition. Seen another way, the perception of CYP’s behaviour is repositioned from one of nurture, to one of nature. Crucially, it found that mothers frequently felt as though they had no choice in seeking diagnosis, with their attempts to seek more inclusive, humanistic and understanding approaches being disregarded (Honkasilta, 2016).

However, once parents had received a diagnosis for their child, mothers felt able to move from a position of self-blame to understanding, perceiving diagnosis as a powerful “label of forgiveness” (Honkasilta, 2016, p.69). This reflects the findings in the other studies cited above. It offers an example of the complex and often contradictory tensions that exist in this field, as parents feel both powerless and coerced into seeking a diagnosis, yet empowered and better understood following it. Parents felt that the stigma of diagnosis extended to them, but, at the same time, they also felt somehow less stigmatised and validated as a good parent, post-diagnosis. Furthermore, while feeling like they had pathologised their CYP in seeking assessment, the subsequent diagnosis allowed parents to feel more forgiving and hopeful that their CYP would be offered greater support, have increased access to resources and be provided with more compassionate, empathetic and inclusive educational experiences.

At the same time, mothers also reported feeling “powerless”, “submissive” and “worn out…due to unequal institutional power relations between home and school” (Honkasilta, 2016, p.63). Moreover, they felt victimised by schools, with negligible evidence that they felt like educational collaborators and partners (Honkasilta, 2016). The findings therefore suggest that confused and conflicting narratives exist: when viewing ADHD through a medical lens, ADHD was seen as “controllable, uncontrollable and controlled” at the same time (Honkasilta, 2016, p.70). This reflects the findings in Ringer et al. (2020), in which parents sought stable and valid explanations, while struggling to make sense of this incredibly complex and contradictory, highly emotive, heterogeneous disorder currently called ADHD.

CYP in the study also reported feeling stigmatised by the label and sought to distance themselves from it. CYP accepted that they had the diagnosis, but were not the diagnosis itself, in a bid to retain their own sense of identity and agency. Some CYP felt that their diagnosis exempted them from moral responsibility, development and questioning, in keeping with Singh’s (2012) findings. Yet, they also felt able to hold themselves to account, at times, suggesting that they felt somewhat able to act as rational, thoughtful and moral agents (Honkasilta, 2016).

Some of the richest findings in this study came from considering the CYP in the school context, in which the voice of the CYP remains lacking (Honkasilta, 2016). Honkasilta's (2016) study identified five narratives evaluating teacher behaviours, that are briefly explored here, namely: disproportionate, traumatising, neglectful, unfair, and understanding. CYP in this study reported feeling that teachers reactions to their behaviour/s was disproportionate and indicative of traumatising sanctions. This resulted in CYP feeling victimised, abandoned, or intimidated and subsequently either submissive, or resistant in response. In turn, this led to long-standing feelings of grief, shame, exclusion and stigma (Honkasilta, 2016, p.65). The author concludes that current educational systems focus on the imposition of institutional needs, over meeting children's human needs, as reported by Singh (2012), Timimi (2005). This may be interpreted as systems that perpetuate exclusion over inclusion, and shame, over personal growth. This suggests a need for greater teacher knowledge and understanding and a critical analysis of the school system, its "micro-cultures and child-teacher interactions" (Honkasilta, 2016, p.68). In addition, the study suggests that the act of labelling needs critiquing as the negative connotations that are associated with ADHD, can in itself establish a fundamental teacher-child relationships that carries negative connotations and expectations, that may well encourage a type of "self-fulfilling prophecy" (Honkasilta, 2016, p.71). Conversely, CYP reported that when teachers did approach them with compassion and support, they felt that it helped to bring about greater control.

Honkasilta (2016) also prompts us to consider schools' role and attitudes towards ADHD and presents an argument that schools can act, rightly or wrongly, as catalysts for the growth and increased prevalence of ADHD diagnoses. In doing so, they, perhaps unconsciously, perpetuate the dominant medical narrative and the diagnostic model, that is constructed upon an institutionalised interpretation of childhood behaviour (Honkasilta, 2016).

Honkasilta (2016) also looks to psychological theory as a way of better understanding CYP with ADHD. Firstly, the study references Glasser (1997) who posits that CYP will show increased self-control and willingness to learn, if “their basic needs for belonging, power, freedom, and fun are satisfied” (Honkasilta, 2016, p.77). This is in keeping with Maslow’s hierarchy of needs (1943) who writes, “In our society the thwarting of needs is the most commonly found core in cases of maladjustment and more severe psychopathology” (Maslow, 1943, p.381). This also aligns with Brady (2014) who suggests that CYP’s behaviours may be interpreted as a manifestation of their need for greater control. This begs consideration that, perhaps the needs of CYP with ADHD are different from CYP with a neurotypical profile and that, potentially, the typical classroom might not satiate their fundamental human needs, resulting in institutionally undesirable behaviours, such as the day-dreaming reported in Singh (2012).

Lastly, Honkasilta suggests that future research may focus on using videoing technology to study the interactions between CYP and teachers in their educational setting. This is a tool increasingly used by educational psychologists, who are well placed to utilise such approaches. (Murray et al. 2018). This is considered an area of high value as it may deepen the respective understandings of both teacher and CYP; it has the potential to increase empathy and develop teacher-pupil relationships, through becoming more conscious of each other’s needs (Honkasilta, 2016, p.82). It is thought that this may be an area that could be taught, supervised and navigated by educational psychologists who already employ VIG (Video Interactive Guidance) and VERP (Video Enhanced Reflective Practice) as a part of their work, studying the quality of the attuned interactions between CYP and key adults. There is a growing evidence base reporting the effectiveness of such practices (Murray & Leadbetter, 2018).

Honkasilta’s (2016) study is deemed to be significant in that it demonstrates that the predominant reliance on medical narratives, alone, are insufficient in helping us to understand the complex and contradictory lived experiences of CYPF with ADHD. The author concludes that the meaning of ADHD from a youth perspective is still not fully understood and interviewing and eliciting the views of CYP is crucial to re-define, and re-narrativise ADHD through a discursive social constructionist position (Honkasilta, 2016, p.63). This aligns with Singh's finding that some CYP simply do not know what their diagnosis of ADHD is, which in turn, makes it much harder to make sense of. Perhaps, Honkasilta's most pertinent finding, in keeping with all of the 'lived experience' studies reviewed herein, is that more needs to be done to listen to CYP with ADHD, and their parents. This coincides with existing guidance that urges us to follow the principle of "no decision about me without me" (BPS, 2017b, p.23).

Conclusion

This review began by drawing upon the early examples of Fidgety Phil (1845), and Melchior Weikard (1775) highlighting that, discernible difficulties, in keeping with ADHD traits, have been observed over centuries at the very least. Further, this paper attempted to highlight that the extant literature pertaining to ADHD is vast for a number of reasons: it is a heterogeneous disorder, and therefore covers a number of broad traits, or symptoms; the presentation of ADHD varies considerably from person to person, and as such, diagnoses include sub-types, with varying degrees of severity; ADHD has a high level of co-morbidity with other conditions/disorders and can be difficult to delineate; ADHD is classified as a medical disorder, but crosses different paradigms and disciplines.

This review found evidence supporting the notion that the use of psychopharmacological treatment has assisted in improving the lives of many people with ADHD (Wegmann, 2015). Modern science has found observable differences at a molecular level in those with ADHD, yet the direction of causality remains unclear and it is still widely accepted that no known biological markers, or ADHD-specific gene variations have been recorded in populations with ADHD (DSM-5, 2013; Thapar et al. 2013). Therefore, the treatment of ADHD with psychopharmacological treatment, based on the medical model remains highly controversial. While providing a brief account of some of the topical areas around this, it is conceded that this warrants much more nuanced attention. This review also explored some other controversial and divisive areas around ADHD, including the diagnostic criteria, assessment, aetiological factors and its prevalence. It is argued that while the DSM-5 and the ICD-11 now appear more congruent in their thinking, they remain works in progress (BPS, 2013). Evidence was also found reporting an argument to include emotional dysregulation as a fourth core trait in future incarnations of the diagnostic criteria (Nigg et al. 2020; Shaw et al. 2014).

A brief description of the current service-level situation was provided, in order to contextualise the systems in which CYPF living with ADHD currently find themselves situated within. A brief overview of the strategies for improvement was also provided.

This review has put forward an argument that the confusion, controversy and disagreement surrounding ADHD (Parens & Johnston, 2009) in the wider body of empirical literature, is in turn reflected in the reported accounts of CYPF living with ADHD. However, contemporary literature exploring the lived experiences of CYPF with ADHD remains limited, thus identifying a discernible gap in the body of literature. At the same time, when detailed qualitative studies are conducted that they can offer significant and profound insights, knowledge and understanding, warranting a greater depth of investigation in this field.

Some of the key conclusions from the literature on CYPF's lived experiences include finding that over half of CYP in one study did not want to take their ADHD medication (ADDiSS, 2005). Brady (2014) and Corcoran et al. (2017) suggest that such findings raise pertinent ethical questions, arguing that more needs to be done to listen to CYP with ADHD around medication, choice, control and decision-making, and that the behaviours of CYP with ADHD may be misinterpreted, especially in a school setting (Hartmann, 2019; Honkasilta, 2016; Maslow, 1943). This aligns with the growing voices seeking more critical analysis of the systems around the child (Ahmed et al. 2017; Hill, 2017). Corcoran et al. 2017 reported parents to exhibit a “sketchy” knowledge of ADHD and its aetiology, while Ringer et al. (2020) found parents were yearning to understand more about ADHD, and were caught in a cycle of parental self-blame. Ahmed et al. (2017) and Honkasilta (2016) explored the pressures placed on parents to assess and medicate their children, and found this to be compounded by media pressures. Singh (2012) and Honkasilta (2016) explored and reported upon the complex stigma that surrounds ADHD and the way in that this has bearing on CYPF. The latter reported quite unique findings in that CYP reported feeling that the school sanctions that they received felt traumatising, and victimising – a profound finding that clearly warrants much further investigation. Singh (2012) also brought to light some profound findings in terms of how ADHD affected CYP's self-perception. Leitch et al. (2019) shone a light on the familial and relational strain that ADHD can have. A number of the papers reported parents feeling powerless (Corcoran et al. 2017; Honkasilta, 2016; Ringer et al. 2020) suggesting much more needs to be done to support parents in feeling empowered to a greater extent.

The first section of this review aimed to provide a summary of the predominant debates around ADHD. The second section aimed to review some of the key considerations arising from studies reporting on the experiences of CYPF living with ADHD. Moreover, the second section attempted to illustrate the rich and profound findings that can arise from such studies, and to exemplify the discernible gap in the existing literature as noted by Brady (2014), Honkasilta, (2016) and others. As Brady (2014) and Singh (2012) suggest, the diminutive evidence base in this area, may be due to the low socio-political standing of CYP with ADHD, and because such research may serve to challenge the more pervasive with-in child, medicalised accounts (Brady, 2014). However, there are a number of voices discussing the importance of listening to CYPF with ADHD as experts by experience (ADDiSS, 2005; BPS, 2017b; Brady, 2014; Honkasilta, 2016). This is reported as being crucial in providing more humanistic perspectives in this area (Honkasilta, 2016), and in further challenging the prevalent, yet reductionist accounts of CYP with ADHD, as being simply "naughty" children, as portrayed in the poem of Fidgety Philip (Hoffmann, 1845).

Chapter 2: Empirical Paper

Abstract

This study explores the lived experiences of children and young people (CYP) with Attention Deficit Hyperactivity Disorder (ADHD) and their parents. A purposive sampling method was employed with CYP with ADHD identified though the local authority's children's services and local schools. Utilising a qualitative approach, semi-structured interviews were carried out with five CYP with ADHD, and their respective parents, forming five cases in total.

Interview data was analysed using IPA (Interpretative Phenomenological Analysis). CYP participants reported knowing little about ADHD, and attempted to make sense of it, primarily through their own lived experiences and their presentational difficulties, both in and out of school. CYP participants reported knowing little about the assessment process, their diagnosis, or their medication. All CYP participants felt misunderstood in school, and experienced significant difficulties in nurseries and in schools, leading to some participants being moved to new settings. Parents expressed significant emotional burden and struggled to make sense of their child's behaviours, and their emotional dysregulation. Parents reported on other factors, including: stigma, social exclusion, their self-perception as parents, relational strain, and complex tensions around medication. Parents widely reported feeling that they were fighting with services, and schools, and overwhelmingly felt let down by them.

This study concludes that more needs to be done to understand and support CYP and families living with ADHD, including involving CYP in the assessment process, in decisions around treatment and education. Moreover, there is a need for extensive in-school training around ADHD, with many schools needing to do more to make reasonable adjustments. There also needs to be significant changes at a systems level, including greater inter-service collaboration, and significant improvements to the support provided both pre- and post-diagnosis. The implications for educational psychologists are also discussed.

This study further concludes that much more needs to be done to listen to the lived experiences of both CYP and their parents in understanding ADHD from a humanistic perspective, over a predominantly medicalised one.

Introduction and Rationale

For the sake of anonymity, the region/LA in which this study took place will not be named, or made identifiable. The area will therefore be referred to as region ‘A’, or LA ‘A’. Identifiable references to region A were included and verified at the time of submission by the research supervisors, prior to their removal.

ADHD

A broad literature search was conducted across all available databases, using the term “ADHD”. This found over 235,000 results. After scanning sections of this it appeared that the majority of literature reporting on ADHD aligned with more positivist approaches, rather than along more humanistic lines of enquiry. Indeed, a recent empirical review of the body of literature studying ADHD across the last two decades confirmed that research on ADHD had predominantly focused on areas such as diagnosis and “diagnostic definitions, epidemiology, genetics and environmental causes, neuroimaging/cognition and treatment” (Cortese & Coghill, 2018, p.173). Following this, several individual searches were conducted for published, peer reviewed articles, systematic reviews, and literature reviews, using keywords such as “ADHD” and “aetiology”, “prevalence”, “prognosis”, “assessment”, “diagnosis”, “treatment” and “medication”, across the following databases: CENTRAL, Embase, MEDLINE, APA PsycINFO, ERIC, EPIP, Child Development and Adolescent Studies and the British Educational Index. The findings from these searches form the basis of the review below.

ADHD is defined as “a persistent pattern of inattention and/or hyperactivity-impulsivity that interferes with functioning or development… [with] symptoms [that are] inconsistent with the CYP’s developmental level, and that negatively impacts directly on social and academic/occupational activities” (DSM-5, 2013, pp.59-60). Credible prevalence rates of ADHD in CYP are between 5.9 – 7.1% worldwide. The higher prevalence rates of ADHD reported from lower socio-economic backgrounds, and in boys has perpetuated the myth of ADHD as a socio-culturally constructed phenomenon (Schwartz, 2016; Willcutt, 2012), delegitimising the validity of ADHD. ADHD is widely reported to be underdiagnosed in girls (Cortese & Coghill, 2018; Sayal et al. 2018) and over-diagnosed in boys (Willcutt, 2012). ADHD in childhood is associated with traits including reduced school performance and academic attainment; risk-taking behaviours and increased risk of injuries; and negative relational interactions. In adulthood, there is an increased risk of unemployability; risk of conduct disorder and anti-social personality disorder; substance-use disorders; incarceration, and suicide (DSM-5, 2013, pp.62-63).

Aetiologies of ADHD

The aetiology or “cause” (CD, n.d. 2) of ADHD is a highly contentious topic. ADHD has a wide-spread aetiological association with the bad parenting hypothesis (Timimi, 2005) associating poor parenting and low socio-economic status with ADHD. Such public opinions of ADHD are reported to be shaped by the media’s reductionist portrayal of the disorder (Ahmed et al. 2017; NICE, 2018). While there are many aetiological theories, and associations implicated in ADHD (see Appendices 1.0 and 2.0), the most widely accepted is reported to be the ‘bio-medical’ model putting forward that ADHD is caused by abnormalities in the prefrontal cortex, the brain region associated with executive functioning, including: self-regulation and inhibitory control, sustained behaviour control, working memory, attention, planning and organisation (Lambek et al. 2011; Mahone et al. 2002). In support of this model, studies have shown differences in neurotransmitters in the pre-frontal cortex, including in serotonin (Hou et al. 2018), in dopamine and norepinephrine (Wegmann, 2015). However, this remains a contentious topic as the direction of causality remains unclear. The bio-medical model is also supported by twin studies reporting that ADHD is a highly heritable disorder (Bélanger et al. 2018). However, there are a growing number of voices expressing “serious concerns … about the increasing medicalisation of distress and behaviour…[and] the ‘functional’ diagnoses… of disorders such as ADHD… for which there is substantial evidence for psychosocial factors in its aetiology, and very limited support for the disease model…” (BPS, 2013, p.2).

ADHD and Co-occurring Conditions

ADHD is frequently diagnosed co-morbidly with other conditions, including Rejection Sensitive Dysphoria, Oppositional Defiance Disorder, Intermittent

Explosive Disorder, Mood Dysregulation Disorder, personality disorders and anxiety (Bedrossian, 2021; Kadesjo & Gillberg, 2001; Gnanavel et al. 2019; Pliszka, 2003). It is reported that as many as 75% of people with ASD have comorbid ADHD (Antshel et al. 2016). While emotional dysregulation is not included as a core trait of ADHD, there are some calling for it to be recognised as one, rather than it being viewed as a comorbid trait (Nigg et al. 2020). Another trait that is associated with ADHD is callous-unemotional traits (CUT). This is described as reduced guilt, remorse, and empathy, a disregard for others, callousness and lacking prosocial skills and emotional affect (Masi et al. 2020).

The Lived Experiences of CYP with ADHD, and their Parents

In order to review the literature on the lived experiences of ADHD, further literature searches were conducted using the terms “ADHD” with “lived experience/s”, “child experience/s”, and “parent/carer experiences”, using the same databases described above. Again, date parameters between 2012-2022 were set. While approximately 200 results were found, the vast majority did not meet the inclusion criteria, mostly as they had adopted very specific lines of enquiry around topics including the effectiveness of specific interventions, for example. The lack of empirical literature in this area aligns with Ahmed et al. (2017) who argues that the voices of CYPF experiencing ADHD are largely unheard and largely undocumented, and by Brady (2014) who asserts that not enough is being done to elicit the voice of the child with ADHD. Both suggest that there is a significant need for further research in this field. Moreover, of the studies included in this review, only two included the voices of both CYP and parents together, suggesting a notable gap in research capturing the voices of both CYP with ADHD, and their parents.

The Lived Experiences of CYP with ADHD

Two studies specifically explored the lived experienced of CYP with ADHD. Singh (2012) utilised a qualitative approach, and interview method to elicit the voices of CYP between the ages of nine and fourteen years. In keeping with Bronfenbrenner’s ecological model (1979), Singh developed an eco-bio-developmental model of ADHD, described as the child’s ecology (Singh, 2012).

This describes how ADHD in CYP may be understood in terms of interactions between personal attributes (biological), in familial, everyday environments (school/home etc), and wider spheres of influence, such as school and national policy. Singh (2012) reported that the self-perception and self-esteem of CYP is significantly affected by the societal values, or niches, in which they find themselves. The author identifies a conduct niche, and a performance niche. Through the lens of the performance niche, CYP perceived themselves as “thick and slow” (Singh, 2012, p.19), and wanted to keep their ADHD a secret from others. Through the conduct niche, CYP perceived themselves as having “anger problems, being aggressive, naughty, and were purposefully wound up by other children” (Singh, 2012, p.18). They were also more likely to be both victims and victimisers of bullying. Some CYP attempted to keep their ADHD a secret as they felt that it brought about additional feelings of shame and anxiety, and feared that their diagnosis would further stigmatise them. Some CYP in the study did not know what the acronym ‘ADHD’ stood for, with many not even knowing that they had ADHD, making it harder for them to make sense of (Singh, 2012).

Honkasilta’s (2016) study, Voices Behind and Beyond the Label, is a Finnish dissertation, interviewing 13 adolescents between the ages of eleven and sixteen years, and their parents. Honkasilta (2016) reported ADHD as a stigmatising label due to it being situated within the psycho-biological model. This, in turn, affected how CYP constructed their self-identity in relation to their ADHD, with its varying, and sometimes contradictory socio-cultural interpretations. In turn, CYP’s own behaviours led to them having feelings of grief, shame, exclusion and stigma (Honkasilta, 2016, p.65). This meant that they perceived others to view them as naughty children, which in turn, affected their ability to form stable and positive self-identities. Thus child participants not only felt stigmatised by others, but were also caught in a cycle of self-stigmatising, perpetually shaped by their perceived perceptions of others’ views of them. The cyclical nature of this pattern reportedly creates a type of self-fulfilling prophecy (Honkasilta, 2016), in which CYP potentially act in a way that is in keeping with their self-perception i.e. as a naughty child. Therefore CYP in the study reported seeking to distance themselves from the label of ADHD.

Honkasilta (2016) reported that while CYP were accepting of their diagnosis, they did not view themselves as the diagnosis itself, in a bid to retain their own sense of identity and agency. Some CYP felt that their diagnosis exempted them from moral responsibility, development and questioning, in keeping with Singh's (2012) findings. The author concludes that the pervasive master narrative around ADHD must be challenged, moving away from a culture of "deviance labelling" towards a more humanistic and progressive approaches (Honkasilta, 2016, p.70). In order to achieve this, the author argues that the voices of CYPF must be heard, to reconstruct new and progressive narratives (Honkasilta, 2016).

The literature reviewed herein provides evidence that those living with ADHD struggle to make sense of their disorder, their behaviours, and their identity, and highlights that ADHD from a youth perspective is still not fully understood (Honkasilta, 2016). Moreover, CYP demonstrated a limited understanding of what ADHD is, and its aetiological basis (Corcoran et al. 2017); some CYP with ADHD did not know what ADHD stood for, with many not even knowing that they had ADHD (Singh, 2012). While the research findings above are considered informative, the evidence base is limited, identifying a significant gap in research. This suggests that there is much more to learn about the lived experiences of CYP with ADHD and how they attempt to make sense of ADHD themselves (Honkaslita, 2016).

The Lived Experiences of Parents

While the literature exploring the lived experiences of parents of CYP with ADHD is also limited, what is available suggests that parents do not feel well informed about ADHD and were still attempting to make sense of their child's ADHD symptoms (Corcoran et al. 2017). Moreover, parents of CYP with ADHD reported feeling emotional burden, exhaustion and isolation; they felt powerless and craved for greater support due to the incredible strain that they were under (Corcoran et al. 2017; Honkasilta, 2016; Ringer et al. 2020).

A meta-synthesis conducted by Corcoran et al. (2017) reviewed published and unpublished qualitative studies that focused on the views of parents raising CYP, aged 4-17 years, with a diagnosis of ADHD. They reported that parents noticed differences in their children from a young age. Post-diagnosis, they struggled to come to terms with their child's diagnosis, and to make sense of their CYP's behaviours. In a bid to make sense of their CYP's ADHD and behaviours, parents "yearned for definitive information" (Corcoran et al. 2017, p.343). This is in keeping with Ringer et al. (2020), reporting that parents sought "valid, stable and useful explanations" for their CYP's behaviour (Ringer et al. 2020, p.384). Moreover, parents' ability to make sense of their CYP's ADHD was not helped by parents' "sketchy" understanding of the aetiology of ADHD and of the bio-medical reasons offered to explain it (Corcoran et al. 2017). Some resistance to bio-medical aetiological explanations for their CYP's behaviours were reported.

Ringer et al. (2020) investigated the lived experiences of Swedish parents living with a CYP with ADHD, reporting that parents comprehensively expressed difficulties in understanding and managing their CYP's behaviour and coping with them. This included difficulties in implementing and maintaining everyday routines. The way that parents made sense of their CYP's behaviour was closely associated with, and informed by their understanding of ADHD. Additionally, their 'meaning-making' took place over continual cycles over time (Ringer et al. 2020, p.382). Parents reported significant levels of emotional strain, including feelings of anger and powerless when their CYP misbehaved, and feelings of shame and a lack of control when their CYP got into conflict with other CYP (Ringer et al. 2020). Parents also felt feelings of sorrow and guilt at not being able to implement their parental values as they would have liked to. Corcoran et al.'s 2017 review similarly reported that parents presented with a range of emotional burden including feelings of exhaustion, isolation, anxiety, irritation, desperation, frustration, anger, powerlessness, and helplessness. This is further supported by the findings of a qualitative study investigating the experience of stress in parents of children with ADHD. The authors identified four predominant themes: their "child's behaviour feels like a 'wrecking ball'; coping with the 'war at home'; a divided family: 'relationships don't survive'; and craving support: 'it's goddamn hard work'" (Leitch et al. 2019, p.1). This study reported stress levels in some parents, that met the clinical threshold for professional support (Leitch et al. 2019). This reflects the findings from Harpin's

(2005) study, reporting that living with a child with ADHD can have “adverse effects…on parents and siblings, causing disturbances to family and marital functioning” (Harpin, 2005, p.2).

Ringer et al. (2020) also reported that parents found it difficult to manage societal demands when outside of the family home, where their CYP were more likely to be seen through the perceptions of others, and did not meet other’s expectations. This led to them seeking out “unproblematic situations” where their CYP were less likely to be seen as deviant and difficult (Ringer et al. 2020, p.387). This may be partially attributed to parent’s concerns about being perceived as ineffective, or “bad parents” (Timimi, 2005), which is reported to be a pervasive stigma affecting parents. This was also found by Corcoran et al. (2017) reporting that stigma around ADHD was a persistent factor, with parents frequently feeling that others perceived ADHD as a ‘cop-out’ for bad behaviours. Indeed stigma, is reported as being a powerful socio-culturally formed environmental stressor, that can potentially bring about a “degraded self-identity” in CYP and parents living with ADHD (Mueller et al. 2012). The stigma around ADHD has been reported to be so significant that parents have been found to seek out dual-diagnoses of ASD/ADHD feeling that ASD is better understood, is less stigmatised socio-culturally, and is taken more seriously by schools, services and by others more generally (Mueller et al. 2012).

Assessment, Diagnosis and Treatment

The assessment, diagnosis and treatment of ADHD is an area of ongoing controversy and disagreement (Hooft et al. 2016; Parens & Johnston, 2009). Firstly, there are reports that parents feel pressurised from schools to have their CYP assessed for ADHD (Ahmed et al. 2017: Ringer et al. 2020; Timimi, 2005). There are also reports that schools seek to medicate CYP with ADHD in a bid to reduce teacher stress, and make CYP with behavioural difficulties more classroom compliant and school ready (King et al. 2013; McCubbin & Cohen, 1999). Secondly, it is reported that parents may seek a within-child diagnosis, or label, as a way of diminishing their perceived culpability, and their own sense of self-blame as bad parents (Timimi, 2005). There are also widespread concerns that the pervasive insistence on diagnosing CYP only serves to uphold the legitimacy and authority of the medical profession, its power, and the financial benefits that come with it through the mass sales of psychopharmacological medications (McCubbin & Cohen, 1999; Schwartz, 2016). Moreover, it is reported that giving a child a diagnosis can diminish their sense of personal responsibility (Honkasilta, 2016; McCubbin & Cohen, 1999).

In the UK, the typical pathway for a child to be referred for an ADHD assessment is through their GP (NICE, 2019). While GPs may therefore be deemed as primary sources of information, it is reported that GPs are not all given adequate training in this field (Mind, 2016, para 1). This has led to arguments suggesting that, not only, are GPs potentially ill-equipped to inform others about ADHD, its complex aetiology and various lines of treatment, but that they are potentially more likely to presuppose a with-in child, medicalised and pathologising position in keeping with their training, and more likely to offer pharmaceutical approaches rather than considering ‘with-out child’, or wider systemic approaches (Hill, 2017; Jutel, 2009).

There are also ongoing ethical debates investigating the level of involvement that CYP have in decisions around assessment and medication. Some guidelines for assessment of CYP posit that assessments should “aid the child and family in developing a clearer understanding of their own difficulties and give them an opportunity to reflect on the information they share” (Srinath et al. 2019, p.159). This is a complex area, that is currently addressed through ‘Gillick competency’, stating that psychologists working with CYP who are “deemed to be competent to make their own decisions [or are Gillick competent] can give consent to involvement with a psychologist” (BPS, 2017b, p.27). Therefore, while CYP should be provided with meaningful opportunities to be involved in their own management plans, as recommended in the NICE guidelines (2018), in reality, “little is known about how well ADHD guidelines are implemented in routine clinical practice” (Sayal et al. 2018, p.181), suggesting this is an area that is currently under-researched.

In the UK, CAMHS are tasked with overseeing services for CYP, including the assessment, diagnosis, treatment and mental health of CYP (Brady, 2014). However, waiting times from referral to assessment vary greatly depending on location, presenting a type of “post-code lottery” (Boseley, 2018), with reports of long waiting times for neurodevelopmental assessment, and poor access to services. At the time of writing, the NHS foundation trust that oversees CYP’s mental health in this region is categorised as ‘Inadequate’. This aligns with national reports that “nearly all parents of children with ADHD seek help, but only a minority receive evidence-based treatment, or were able to access appropriate services” (PHE, 2016, p.16), with waiting lists “up to 100 weeks from referral to treatment, with variable service quality” (DoH/DoE, 2017, p.9). Additionally, a recent CQC/Ofsted inspection report for SEND in this county stated that region ‘A’ is not doing enough to seek out the views of those under-represented in giving their voice, especially families who have children with SEND. This is pertinent given that the importance of early intervention is already widely reported and recognised (DoH/DoE, 2017). This raises concerns as to whether enough is being done to safeguard CYP and “protect specific children who are suffering or are likely to suffer significant harm” (BPS, 2017b, p.39) and “prevent impairment of mental health…ensuring that children … [have] effective care, by taking action to enable all children to have the best life chances” (BPS, 2017b, p.39).

Once assessed, parents have reported feeling that having a diagnosis for their CYP can offer them, and their teachers some benefits, including in reducing feelings of blame, and providing a recognised framework to build future collaborative approaches on (Wienen et al. 2019). Diagnosis is reported to offer parents a greater sense of understanding and credibility, leading to the implementation of more proactive approaches to challenging behaviour (Honkasilta, 2016; Wienen et al. 2019). Moreover, post-diagnosis, parents have reported feeling empowered to reconsider, and re-frame their self-stigmatising perspectives of being bad parents, in keeping with Honkasilta (2016) and diminish feelings of parental self-blame (Corcoran et al. 2017; Honkasilta, 2016; Timimi, 2005). In addition, by re-narrativising their CYP’s behaviours in terms of a disorder, or disability, parents reported feeling more able to “replace their feelings of anger and irritation with feeling of empathy and compassion” (Ringer et al. 2020, p.385). Post diagnosis, some parents reported feeling empowered to challenge others about their child’s behavioural traits, framing their child’s difficulties within the bio-medical model, as a “chemical imbalance”, validating them and their parenting abilities. In one study, it was reported that having a diagnosis of ADHD added to parents’ sense of stigma, as the ADHD diagnosis was perceived to be an a priori stigmatising label due to it being situated within the psycho-biological model (Honkasilta, 2016).

Medication

The medication of CYP with ADHD is another area of controversy (Hooft et al. 2016; Parens & Johnston, 2009). Singh (2012) reported that there is a societal emphasis on medicating CYP with ADHD, in order to improve behaviour, reduce aggressive and impulsive behaviours, to promote “self-control and better moral decision making” (Singh, 2012, pp.15-16). There are a number of studies reporting that parents feel pressure from their CYP’s school to medicate their child (Ahmed et al. 2017; Corcoran et al. 2017; Ringer et al. 2020; Timimi, 2005), leading to some reports that schools implicitly serve to perpetuate increases in ADHD prevalence rates, and, in turn, uphold the medicalisation of CYP behaviours (Brady, 2014; Honkaslita, 2016). Parents reported feeling significantly influenced in their decisions around medication by family, friends, and other professionals (Corcoran et al. 2017), but have reported receiving inconsistent advice around this (Ahmed et al. 2017).

ADHD medication is reported to improve the core symptoms of ADHD and improve quality of life (Pickett, 2016). This includes reducing levels of hyperactivity and impulsivity, improving emotional regulation, and concentration (Singh, 2012). That said, it is reported that most people, with, or without a neurodevelopmental disorder, report improved concentration and ‘feel better’ taking psychostimulants (Brady, 2014), leading to some neurotypical CYP seeking ADHD medication just to improve their grades (Schwartz, 2016; Wegmann, 2015). Others have criticised the use of ADHD medication, suggesting that it is taken in order to make CYP classroom ready (McCubbin & Cohen, 1999); in order to improve academic attainment (Wegmann, 2015); and in some cases, that it can diminish a child’s sense of personal responsibility (Singh, 2012). NICE guidelines (2018) state that ADHD medication should not be used as a first-line of treatment for ADHD. However, some parents reported that giving their CYP medication felt like it was the last resort available to them (Corcoran et al. 2017). Parents cited the fundamental reason for the cessation of medication was related to concerns around side-effects (Ahmed et al. 2017; Pickett, 2016).

There is a wide body of empirical research reporting on the efficacy of pharmaceutical treatments for ADHD, with the trend towards more positivist research, in this area, set to continue (Cortese & Coghill, 2018). While important, this should not over-shadow more humanistic enquiries, including a greater focus on ethical considerations such as choice and voice, control and decision-making around medication (Brady, 2014; Corcoran et al. 2017). This is currently an area that is under-represented and under-researched (Brady, 2014; NICE, 2018). Moreover, the ongoing focus on the efficacy and longevity of medication for ADHD potentially serves to further legitimise the pervasive narrative of ADHD as a within-person disorder, over other valid interpretations, conceptualisations and accounts (Brady, 2014; Hill, 2017; Johnstone 2017; Johnstone & Boyle, 2018), including investigations of the ecological systems influencing CYP, and their related behaviours/symptoms/traits, in keeping with Singh (2012) and Bronfenbrenner (1979).

Schools and Support

It is often school staff that raise concerns around CYP’s behaviour leading to the assessment of ADHD (Weinan et al. 2018). Teachers are working in times of limited resources, with well documented behavioural challenges in the classroom (Kos et al. 2006). Moreover, it is have reported that CYP with ADHD are “significantly more stressful to teach than their classmates without ADHD” (Greene et al. 2002, p.79). This has led to some questioning whether it is ethical to medicate children in a bid to reduce teacher stress, and make them classroom compliant (King et al. 2013; McCubbin & Cohen, 1999). Teaching staff are also reported to offer parents helpful and considered support and advice around ADHD (Ahmed et al. 2017; Singh, 2012). CYP participants in the Singh (2012) study reported that TAs were helpful in supporting them. Similarly, Honkasilta (2016) reported that when teachers did approach CYP with ADHD, with compassion and support, they felt that it helped to bring about a greater sense of control. However, despite their role in advising parents, and supporting CYPF with ADHD, it is reported that TAs and teachers receive inadequate training on ADHD (Greenway & Rees-Edwards, 2020; Singh. 2012), with teachers feeling even less confident in effecting change once CYP have been diagnosed (Lauchlan et al. 2017).

Research by Honkasilta (2016) found that parents of CYP with ADHD felt victimised by schools. Moreover, there were reported power imbalances between CYPF and schools, with parents reporting that they did not feel empowered to act as educational collaborators and partners (Honkasilta, 2016; Singh, 2012). The Honkasilta (2016) study also identified five narratives evaluating teacher behaviours, namely: disproportionate, traumatizing, neglectful, unfair, and understanding (Honkasilta, 2016). CYP in this study reported feeling that teachers reactions to their behaviour was disproportionate and indicative of traumatising sanctions, resulting in them feeling victimised, abandoned, or intimidated and subsequently either submissive, or resistant. In turn, this led to long-standing feelings of grief, shame, exclusion and stigma (Honkasilta, 2016, p.65). The author concludes that current education system focuses on the imposition of institutional needs, over meeting children’s human needs, in keeping with Brady (2014), Singh (2012) and Timimi (2005), meaning that the systems around CYP potentially perpetuate exclusion over inclusion, and shame, over personal growth, thus calling for a critical analysis of the school system, its “micro-cultures and child-teacher interactions” (Honkasilta, 2016, p.68).

Knowledge Gaps and Rationale

This literature review revealed gaps in the existing body of literature around the topic of ADHD. It found that the vast majority of literature has investigated the predominant debates around ADHD (Cortese & Coghill, 2018), and while incredibly important, there was a discernible gap investigating the lived experiences of both CYP with ADHD and their parents/carers. This meant that the voices of CYPF experiencing ADHD remain largely unheard, and undocumented, with not enough being done to elicit their voices (Ahmed et al.

2017; Brady, 2014). Moreover, it is put forward that to truly understand the lived experiences of CYP and their parents, a comprehensive approach must be adopted, seeking to understand how they attempt to make sense of ADHD; their experiences around assessment and diagnosis; medication and treatment; and their experiences of schools, services and the support that they have/have not received.

The extant literature, reviewed herein, exploring the lived experiences of CYPF demonstrates that when detailed qualitative studies are conducted, they can offer significant and profound insight, knowledge and understanding, warranting a greater depth of investigation in this field. Indeed, the drive to hear and listen to the voices of those with SEND and mental health difficulties has gathered significant momentum in recent years, supported by the introduction of the SEND Code of Practice (2015), the Children and Families Act (2014), and the Transforming CYP's Mental Health Provision green paper (DoH/DfE, 2017). However, despite this, the UK Secretary of State for Education, Nadhim Zahawi recently conceded that "too many parents and carers of CYP with SEND feel [that] they aren't heard" (Keer, 2022). At a time of unparalleled financial cuts to LAs, schools and services (Clifford, 2021), and with the recent SEND review green paper (DfE, 2022), reporting that CYP are still caught in a "vicious cycle of late intervention and inefficient resources" (DfE, 2022, p.6), there is clearly an argument for more to be done in considering how CYPF have been affected by existing in such times. This study's aims, therefore, align with regional aims to do more to seek out the views of those under-represented, especially families who have children with SEND. Furthermore, it is in keeping with the BPS' view that practitioner psychologists need to listen more to CYPF, and work more collaboratively with clients and Experts by Experience… (BPS, 2017b, p.23). This is aptly summarised by the principle of "no decision about me without me" (BPS, 2017, p.23).

This section aimed to provide a justification and rationale for conducting this study. Building on the gaps identified above, the research questions (RQs) and sub-RQs are detailed below.

Research Questions

RQ1: What are the lived experiences of children with ADHD?

RQ2: What are the lived experiences of parents with children who have ADHD?

In addition, there are four sub-RQs:

Sub-RQ1: How do participants make sense of ADHD?

Sub-RQ2: How do participants make sense of the assessment process and of diagnosis?

Sub-RQ3: How do participants make sense of the medication and treatment of ADHD?

Sub-RQ4: How do participants make sense of the support they have/have not received?

Ontology and Epistemology

Ontology is commonly described as the study of ‘being’ and is therefore concerned with what constitutes reality (Scotland, 2012). Ontological positions are often depicted on a linear scale, with realism at one end and relativism at the other.

Epistemology is concerned with the nature of knowledge and what it really means to know something, how knowledge is acquired, understood and communicated (Scotland, 2012).

This study aligns with a critical realist position. This sits within the ontological position of interpretivism (Scotland, 2012) and within the epistemological position of subjectivism, meaning that “knowledge is both socially constructed and influenced by power relations from within society” (Scotland, 2012, p.13). In turn, this recognises how power relations and societal positioning are constructed and mediated through language.

Assuming a critical realist position is deemed important in the context of this study, as it positions ADHD as a real phenomenon, but one that cannot be fully discovered without experiencing it, through the subjective experiences of those living with it, in keeping with IPA (Interpretative Phenomenological Analysis) (Smith et al. 2012). This aligns with Heidegger's Dasein, that may be understood as a conceptual representation of man/woman existing in the world, in which it is thrown into, thus representing 'Being-in-the-World', with its inter-relatedness with others, rather than Being-in-the-World, in isolation (Smith et al. 2012). Dasein, in this sense, finds itself adopting and making sense of language, relationships, culture, and objects to hand, in the environment in which it exists (Heidegger, 1962/1972). It is argued that philosophically, IPA, case studies and critical realism align as they sit within the interpretivist position, accepting that while there are stable and enduring features of reality that exist independently of human conceptualisation, that individuals attach different meanings to experiences, as they experience different parts of the same reality (Bhaskar, 1978).

Design, Methods and Methodology

A case study design was used to investigate the phenomena of ADHD. Case studies are frequently employed in qualitative studies as an essential method for data collection (Radley & Chamberlain, 2001) in providing an established method for "appropriately examining a contemporary phenomenon within its real-life context" (Yin, 2003, p.13). Moreover, case studies provide an effective method for understanding complex situations from multiple perspectives, providing rich data, with a focus on depth over breadth (Lauckner et al. 2012).

Five children, and five parents were interviewed, comprising five cases in total, each consisting of one child and their parent. This is reported to be an appropriate amount for a professional doctorate (Smith et al. 2012). Each case was analysed as a single entity, ensuring a detailed focus on its idiography, that is a central focus of IPA (Hefferon & Gil-Rodriguez, 2011; Smith et al. 2012), so not to lose the "idiosyncrasies of individual cases" (Stoecker, 1991, in Lauckner et al. 2012, p.6).

Research that is undertaken from interpretivist/subjectivist/critical positions is more likely to draw upon research methods including case studies, interviews and focus groups, and is most likely to generate qualitative data (Howitt & Cramer, 2007). It is acknowledged that this research will not be generalisable to the wider population as is common with much qualitative research (Cohen et al. 2011), however, there is also a recognition that qualitative research can serve to bring about changes in policy and service delivery (Finfgeld, 2003).

Data was collected through employing semi-structured interviews, that are provided in Appendix 4.0. The interviews were then transcribed and analysed using IPA. This has been described as an ideal methodology for case studies and for capturing rich and nuanced first-person accounts of participants' lived experiences (Oxley, 2016; Smith et al. 2012) as it focuses heavily on the subjective lived experience (Hefferon et al. 2011) and on the personal experiences of a particular phenomenon (Howitt & Cramer, 2008). Further, IPA takes an idiographic approach, meaning that it focuses on a small sample of "experts…with no attempt made to generalise…" (Oxley, 2016, p.57). While, IPA is a qualitative approach, the quality and validity of research can still be demonstrated, with a greater emphasis placed upon trustworthiness, credibility, and transferability, over the notions of reliability and validity, seen more commonly in quantitative research (Teddlie & Tashakkori, 2009).

Data Collection

Despite being given the choice to have another adult to support them during the interview, all parent participants interviewed alone. This created a space for a strong rapport to be developed (Smith et al. 2012) and allowed parents to speak with candour and openness. Similarly, child participants were offered the choice of being interviewed alone, or with peer/parental support; three were accompanied by their parents. No carers, or adopted parents were recruited in this study.

The use of semi-structured questionnaires prevented the interviews from becoming overly informal. The interview structure was led by the research aims and the RQs. Some additional questions were included, in case participants were less forthcoming (see Appendix 4.0). The broad areas of focus were:

- Aetiology
- Lived experiences
- Assessment and diagnosis

- Medication and treatment
- Support

Interviews began by exploring each participant's perceptions of the aetiology of ADHD, i.e. what they think ADHD is and its causes, or associations. The interview began with this epistemological questioning, as their understanding of this would, in turn, have bearing on their subjective ontological position/s i.e. their experiences of living, or 'being' in the world with ADHD. No other information was collected, apart from that gathered during the interviews. Interviews took between 60 and 120 minutes, with parent interviews typically taking longer.

Ethics

This study required careful ethical consideration and a comprehensive ethics application was submitted to the UEA's Ethics Committee. Evidence of this is in Appendix 5.0. As the researcher was on placement in a LA as a trainee EP; the LA required a separate ethics proposal before the study could commence. All stages of the research were conducted in accordance with BERA (2018), the HCPC Standards of Conduct, Performance and Ethics (2016); the HCPC Standards of Proficiency (2015) and the BPS Code of Conduct and Ethics (2018).

At the study planning stage, face-to-face visits were only allowed for 'essential visits' due to Covid-19. It was therefore agreed that all interviews would be conducted remotely, with no visual footage recorded. Prior to interviewing participants, the researcher sent his one-page profile, as is considered good practice in the LA's EPS. Recordings were stored on a password protected, encrypted laptop only and were destroyed after transcription. Only the researcher had access to the raw data.

Full anonymity began from the point of transcription and pseudonyms were employed to maintain absolute anonymity and confidentiality. This study was conducted in accordance with the General Data Protection Regulation (GDPR) and the Data Protection Act, 2018. It was agreed that the researcher would be bound by a duty of care for the child participants, meaning that any safeguarding issues would need to be shared with the school's DSL (Designated Safeguarding Lead), and with his research supervisor/s.

Particular ethical consideration was given to the fundamental principle of 'non-maleficence', or to 'do no harm' (Grieg et al. 2013). In practice this meant that careful consideration was given to how participant's mood and well-being might be affected, during and following their interview. To this end, the researcher conducted the interviews sensitively, and offered wellbeing checks during, and after the interviews. Following the interviews, child/parent support sheets were provided (see Appendices 6.0 and 7.0). This was aimed at ensuring that participants knew where and how they could seek professional advice in the unlikely event that they felt particularly affected.

Participant Recruitment

The researcher was on long-term placement in a LA educational psychology and specialist support team. Parents, schools and other services/agencies refer CYP to this service for support and assessment. CYP's SEND and associated diagnoses are stated on the incoming referrals, thus identifying CYP with ADHD. Permission was granted for parents/carers to be verbally asked if they would consider participation in the study at their first point of contact. EPs and Trainee EPs therefore acted as gatekeepers to the study. They were provided with a concise script to enable them to accurately explain the study to potential participants, including: the overall aims of the study; and their potential role in it. This is provided in Appendix 8.0. It was decided that the researcher would not work with any of the families in a professional capacity, so not to compromise professional/researcher roles.

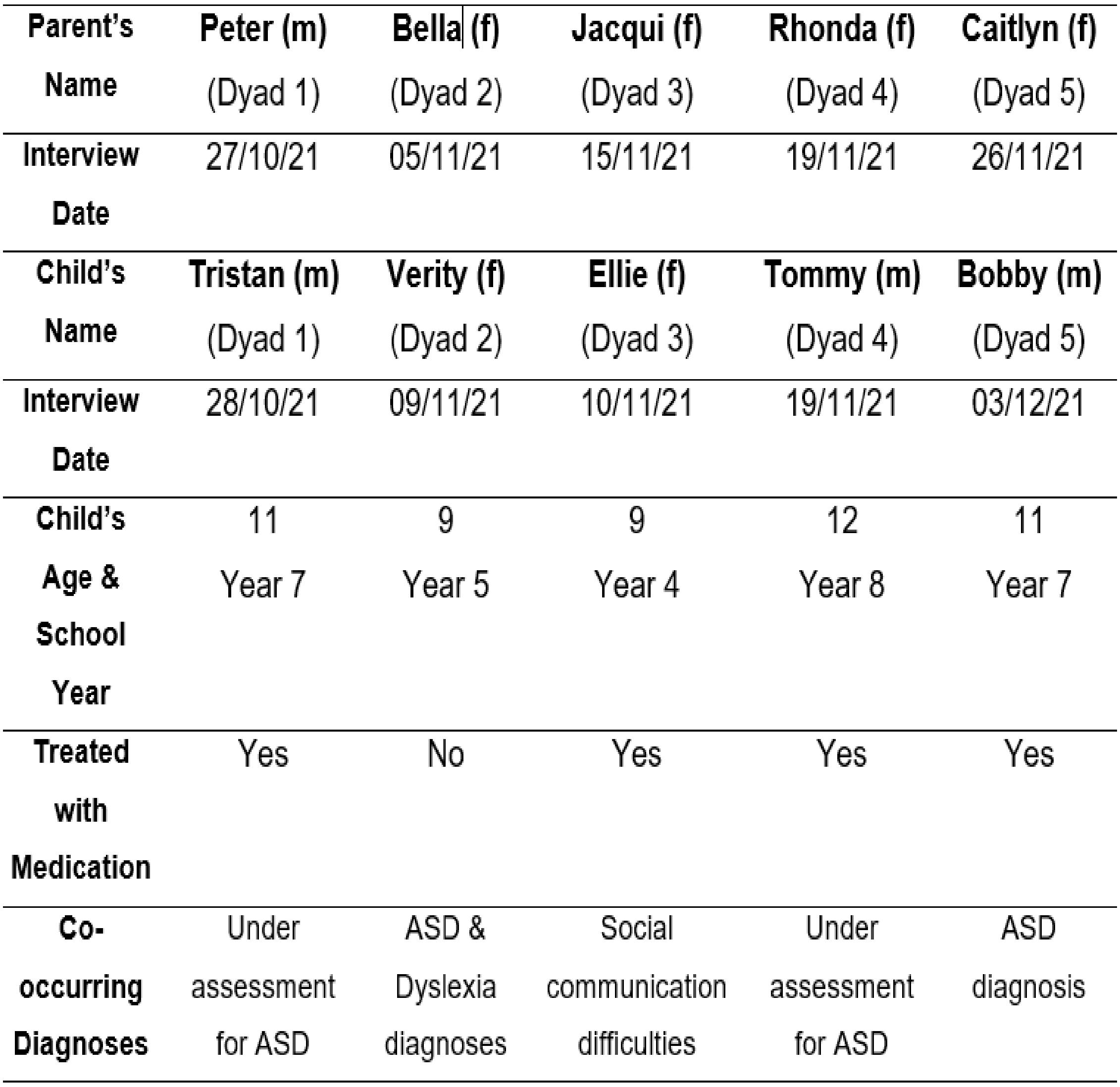
A later amendment to the ethics applications enabled schools to also act as gatekeepers. Schools working with the LA EPS were able to approach CYPF, using a similar approach to that above, using a slightly adapted script. The study was open to CYP between the ages of 8 and 18 years, in keeping with other similar studies (Corcoran et al. 2017). However, the child participants recruited were, in fact, aged between nine and twelve years of age.

Once verbal consent was voluntarily provided, parent and child information sheets were provided electronically. These are provided in Appendix 9.0 and 10.0). Consent was needed from both parent and child participants; this can be found at the bottom of the respective information sheets. Following this, dates for interviews were arranged. This process of recruitment aligns with a purposive sampling method, and is in keeping with similar models of recruitment observed in other studies (Ringer et al. 2020).

Table 1.0 below shows the pseudonymised names of the participants, with further relevant information.

Table 1.0

Participant Information



Parent's Name	**Peter (m)** (Dyad 1)	**Bella (f)** (Dyad 2)	**Jacqui (f)** (Dyad 3)	**Rhonda (f)** (Dyad 4)	**Caitlyn (f)** (Dyad 5)
Interview Date	27/10/21	05/11/21	15/11/21	19/11/21	26/11/21
Child's Name	**Tristan (m)** (Dyad 1)	**Verity (f)** (Dyad 2)	**Ellie (f)** (Dyad 3)	**Tommy (m)** (Dyad 4)	**Bobby (m)** (Dyad 5)
Interview Date	28/10/21	09/11/21	10/11/21	19/11/21	03/12/21
Child's Age & School Year	11 Year 7	9 Year 5	9 Year 4	12 Year 8	11 Year 7
Treated with Medication	Yes	No	Yes	Yes	Yes
Co-occurring Diagnoses	Under assessment for ASD	ASD & Dyslexia diagnoses	Social communication difficulties	Under assessment for ASD	ASD diagnosis

Table 1.0 shows the parents’ pseudonyms at the top of the table, with their respective child’s name beneath them, forming a single case, or dyad. Beneath this, is the child’s age and year group. The penultimate row indicates if the child participants take medication for their ADHD, with the last row showing their co-occurring diagnoses, or difficulties.

Data Analysis

This study largely followed the IPA six-stage process of data analysis as proposed by Smith et al. (2012). This is summarised in Appendix 11.0. The authors’ approach emphasises the exploration of the lived experiences of the participants, with particular attention paid to their meaning-making (Smith et al. 2019). In line with IPA, the analysis in this study moved through a deeper analytical process through utilising the hermeneutic circle, in which the researcher attempted to make sense of how the participants made sense of their experiences, eliciting meaning and understanding.

As described in section 2 of Appendix 11.0, the transcript was annotated in blue for descriptive comments, in green for linguistic comments, and in red for conceptual comments. Utilising an inductive approach, potential emerging themes were written, in pencil, in the left hand section of participant’s transcripts, as they arose, as seen in the example in Appendix 12.0. Given the long length of some of the parent interviews in particular, as many as 280 *potential* emergent themes were initially recorded in a single transcript. Once this was completed, these potential emergent themes were recorded in the left-side table column, in the order that they arose in the interview, as seen in Appendix 13.0. Then following a slow, iterative process, these were further reduced into emerging themes, as seen in the middle column of Appendix 13.0. This was repeated again, with themes being further consolidated, and merged, as seen in the right-hand column entitled Consolidated Themes (Appendix 13.0). Following this process, participants’ subordinate themes, and later, their superordinate themes emerged. These were collated into two master tables of subordinate themes, and a final table of superordinate themes. These can be found, following the findings below, in Figures 1.0 and 2.0, and in Table 2.0.

Findings

The findings are presented under each child participant, followed by their respective parent.

Tristan, Dyad 1 (Child 1)

Tristan is 11 years of age, and in year 7 of a mainstream secondary school. He lives with his parents and his younger sister. Tristan takes medicine for his ADHD. He is due to be assessed for ASD. He was interviewed alone.

In describing his ADHD, Tristan placed a heavy emphasis on the presentation of his anger, and behaviour, and the way it affects others:

> Tristan: Well, with the behaviour …usually, if someone is really, really trying to get on my nerves, if they were getting on a normal person's nerves… I would crack, and get really frustrated with them quite early on and before someone without it [ADHD] would (99 – 103).

Tristan's reference to other children as "normal", suggests that he potentially, perceives himself as abnormal. Furthermore, his account, suggests that he is much more likely to "crack" before others his age. This suggests a quick, sharp, aggressive reaction, one that is perhaps beyond his locus of control. The notion of control appeared at other times in his interview too. Here, he describes how hard it is to stop aggravating his sister:

> Tristan: it's the bit where they say stop winding me up, you don't really…
> Researcher: You find it difficult to stop?
> Tristan: Yeah, sometimes… basically, it is just that… you're in the flow of things and you are just trying to… you're already doing it, and it's really hard to just stop doing that thing, just stop, stand still, stop what you're doing, you're sort of in the full flow when you're angry and it's harder to stop (207 – 221).

Tristan later told how “winding her up”, can actually mean physically fighting with his younger sister. Tristan raises a profound point here, in that, once he has begun upsetting his sister, that there is a momentum, or a “flow” that appears to make it incredibly difficult for him to stop, again suggesting a very real perceived sense of a lack of control. Tristan was able to name this later in the interview:

> Tristan: It’s hard to… control yourself and sometimes you think about your actions after you’ve done it… (758-759).

This suggests that Tristan does have the capacity to reason and reflect upon his actions, however, he feels unable to do this while engaged in the “flow” of upsetting others. Additionally, he perceives it to be harder for him to stop than it would be for others without ADHD, or ‘neurotypicals’:

> Researcher: …like you said, it is very, very difficult to stop, and it may be more difficult [for you] than for other children to stop at that moment?
> Tristan: Yeah (212-215).

However, Tristan also describes feeling that he is not devoid of control at all times:

> Tristan: I usually wind somebody up to the point that they break and then they usually hit me first (199).

Tristan puts forward that he can provoke and instigate someone, or a situation to the point that they will “break”. This plausibly serves to create an impression of him as the victim, rather than the victimiser, once the other party has hit him first. In turn, this suggests that he has some element of control in some situations in which he is feeling heightened, as he purposefully appears to manipulate a situation to provoke the response he wants, while appearing less culpable himself.

Tristan does not appear to perceive his ADHD/behaviours to have much bearing on his relationship with his younger sister:

> Researcher: Do you think your relationship with your sister is more strained because of you having ADHD?
> Tristan: Not really… we used to be really fighty, but then when I, sort of, got a lot better, we got a bit more close (190-193).

In addition, while Tristan seems to be able to see that his behaviours are challenging: “you’ll just be running about like you’re actually really, really crazy…” (518), he does not seem to have contemplated the full impact that it has on his parents, as exemplified in the excerpt from his father’s interview:

> Peter: Tristan’s mother will just come down in tears…and sometimes I just have to leave the house because I just can’t…I can’t take … the disrespect…you know, lots of hurtful comments… it, is every week, every few days a week…every day there is something” (1003-1039).

Tristan was not the only child who appeared unable to fully comprehend, or express the impact that their behaviours were having on those around them. It is plausible to suggest that this is partially due to parents protecting their children from understanding the full extent of this. However, there was also evidence to suggest that, even when they were explicitly told about this, children still appeared unable to grasp, or comprehend the significant impact that they were having on others.

When asked about his other areas of difficulty, Tristan cited his concentration as being challenging for him:

> Tristan: So, if it is a subject, or something … that I’m quite interested in, I can sit and listen to that for a long time, but if it is not very good, and I’m getting quite bored by it, I will sort of lose concentration and start looking at someone else… or start to chat with my friends (285-291).

This suggests that Tristan is not fully in deficit of attention as might be suggested in the ADHD acronym, rather that he can focus when it is related to an area of particular interest. That said, Tristan placed much greater emphasis on his behavioural difficulties and anger, over his attentional difficulties.

Tristan recalled the assessment as being remote, due to Covid-19, long and “really draining” (431). On receiving his diagnosis, he felt worried about how others would treat him, and expressed a strong desire to keep his diagnosis from others, in a bid not to be treated differently, especially in his school. Tristan described himself as “happy” (271) about taking medication for his ADHD, as he feels it offers him greater control over himself and his actions:

> Tristan: Yeah, it helps me to think about my actions before just doing it… with my tablets… I’m already really calm, because I’m not going to do whatever I was going to do (264-268).

He suggests that when on his medication, he has a greater understanding of himself, is better able to gauge his interactions with others, and feels a greater sense of control. Therefore taking medication seems to be a stabilising factor and he feels much less likely to get angry. However, he also acknowledged that there is a point in which he may still become dysregulated and still “do it” (265) even when on his medication. Tristan also discussed his hyperactivity traits and how his medication affects this. However, initially he frames his high energy levels as a positive trait:

> Researcher: Does ADHD come with any benefits?
> Tristan: … one of them is that if you don’t take your tablets, you’re actually a little ball of energy (484-486).

This was the only time that Tristan really framed any ADHD traits in a positive light. That said, he did appear eager to play down the effect that ADHD had had on him and other’s lives, perhaps presenting an optimistic outlook. Here, Tristan puts forward the idea that being hyperactive, or a “little ball of energy” can be beneficial, especially when playing sports: “So, you can do a lot of physical sports… you can run quite a lot and other people will… be like, why does he have so much energy?” (488-490).

This begged the question whether Tristan might not take his medication purposefully when playing sports to aid his performance. However, he told how he still takes his medication, even if it reduces his energy levels:

> Researcher: …when you're playing football, would you not take medication?
> Tristan: I would probably 'cos… there are people who are bad sportsmen out there, and if I don't take it… they're going to annoy me and it gets to the point of, "Go away, go away…" (495-496).

Tristan seems to suggest that he feels compelled to take his medication during sporting events, as he needs to maintain his sense of control, if, and when, others annoy him. Further, he suggests that other's annoying him is not just a possibility, but an inevitability: "they're going to annoy me". This again, reflects the extent to which Tristan feels that he is more likely to become provoked and angered during everyday events than his peers, with potentially graver consequences for Tristan, given his difficulties in controlling his physical behaviours when emotionally dysregulated. While it might be presupposed that having elevated energy levels may be desirable, Tristan suggests the contrary:

> Researcher: Do you wish that you still had that energy?
> Tristan: Mmm, I don't really wish I always had that energy.
> Researcher: Is it too much?
> Tristan: Yeah, a bit too much and if I haven't worn myself out over a long period of time… I'm literally going to be bouncing off the walls, and no one really wants that (504-515).

Tristan indicates some awareness that others will not want him to be "bouncing off the walls". However, his high energy level (off medication) is not the only reason that he prefers to take his medication:

> Researcher: … so let's say it is a rainy day, you haven't had your medication… what is going to happen?
> Tristan: …you'll get really angry with things …you'll just be running about like you're actually really, really crazy… so if I don't

> take my tablet, I'll be literally running around really fast… I'll bang into things and I'll get frustrated (514-523).

This suggests that, not only, will Tristan potentially have too much energy, but, that it can be problematic for him in the home environment, and can lead to further emotional dysregulation, and feeling "a bit too much for him", or feeling uncontained. In this sense, his medication offers him a sense of greater control, concentration, reasoning ability, and increased psychological wellbeing.

Tristan described some the difficulties that he has had with some teachers. In particular, he struggles to cope with the amount of teacher talk:

> Tristan: History is really, really, really hard, because the teacher, he talks a lot about what the work is about, and all the things that we are doing that day, but then we never get to do the work… (302-306).

This appears to be a particular issue for Tristan as it has a bearing on the amount of homework that he has to do:

> Tristan: …because you want to get it done in the class, but the teacher is talking too much…so he sends it for homework, which… is really, really frustrating (305-314).

Tristan also discusses how he struggles with some inconsistencies with varying teacher approaches, with some being "reasonable" (426) and supportive, while others will, "give you detentions straight on the spot" for not doing the homework. In terms of support, he described wanting "to be treated the same as everyone else" (597) and feels "proud… for not taking advantage of it (ADHD)" (394-395):

> Tristan: [ADHD] doesn't affect how smart you are, or anything, or the way you understand things… you can still get to the answer and where you're going to, in the end, you just maybe take a longer time, or you're seeing the problem in a different angle… (603-609).

This seems to stem from an inner-sense of belief that he is a capable person, even with ADHD.

When asked about wider support he may have received from organisations such as the NHS, or from children's services, he reported feeling that he had not received any organisational support (701). He described his primarily support as coming from his "family and friends" (706). When asked about how children with ADHD might be better supported, he suggested that people are still uneducated around what ADHD is:

> Tristan: It would be a lot better if people knew what it was… I'm not entirely sure that many people know what it is… (710-711).

Clearly Tristan feels that others do not understand what ADHD is, and suggests that other disorders are better understood: "when…they say, they have autism, then they're like, OK, I understand. With ADHD, I'm not sure that people know what it means" (716-718). Tristan clearly feels that ADHD is not as well understood, or recognised in the same way that ASD is.

Peter, Dyad 1 (Parent 1)

Peter lives with his wife, his son Tristan and Tristan's younger sister. Peter works in the same school that Tristan attends.

Peter described ADHD as a "chemical imbalance, where they haven't got the function, the way the brain connects" (11-12). He described the symptoms of ADHD as including intolerance, impatience and emotional dysregulation:

> Peter: Whereas a normal person might, think, for instance, if something annoys them, they just think 'idiot', and it ends with that, whereas someone with ADHD hasn't got that connection…it angers them to a point that they can't not say anything, or do anything… he will get angry and cross, and I don't think there is that process in his head… (14-18).

Peter describes his experience of living with a son with ADHD, as missing neural connections meaning that Tristan becomes emotionally dysregulated, rather than having the ability to momentarily pause and consider an alternative, less provocative action. What's more, his experience of this is one of exaggerated emotions: "he can get very frustrated…he can't sit back and take a step back…it just becomes, "it's failed, I have failed – I'm useless, it's wrong, I hate this – I hate my life" (30-33). Peter uses repetition to express the full extent of Tristan's difficulties. Moreover, he describes them in binary terms, as in "failed", and "wrong", suggesting that he experiences Tristan's behaviours as extremes. He also describes those who don't behave in such a way as "normal", implicitly suggesting that Tristan's behaviours are 'abnormal'. Peter provides many other examples of Tristan's behaviours:

> Peter: He is screaming, shouting and chucking things around… kicking, throwing things, slamming doors repeatedly, and crash around for half an hour… yeah I think the reaction is greater and bigger" [in people with ADHD] (227-241).

Peter describes how homework can act as a particular trigger, as Tristan himself reported.

> Peter: We get it an awful lot at home, I mean any piece of homework…you almost dread having to do it with him, because you just know that there is going to be some sort of rupture and explosion… It can be, "Why don't you just clear off an leave me alone" or "I can't do this, I hate school…" name calling to us, and screwing the homework up…it can become quite physical… (111-123).

Again, to help us appreciate the extent of the difficulties, Peter draws upon linguistic extremes, such as, "rupture", "explosion" and "hate", clearly indicating the distressing nature of living with a child with ADHD. Peter clearly struggles to make sense of such behaviours, and how it might best be approached:

> Peter: Sometimes, if I try and step in and help, I just get met with anger or, "Do you think I'm stupid?" and I try not to be cross with

> him…I find it so confusing because there is never one right thing that will help and each situation is very different (41-46).

Peter's candid description elucidates how difficult it can be in his parental role, and indicates that such behaviours put a strain on him personally:

> Peter: Sometimes I just have to leave the house because I just can't, you just think, I can't… the disrespect… telling you "you're stupid… get out of my… I wish you were dead… I wish you hadn't given birth to me…" …lots of hurtful comments, and you know he's got ADHD, but the difficulty is… you are trying to help (1011-1018).

Peter describes how he is not only dealing with his dysregulated child, but feels bound as a parent to "help". However, doing so can further escalate the situation. Despite this, Peter feels compelled to reason, support and educate Tristan as his father, as people will "not tolerate it" (956) as he gets older. He also feels a heightened sense of urgency to correct Tristan's behaviours, because of his ADHD (963).

When asked if having a child with ADHD puts a strain on his family, he responded: "Oh definitely! Yeah, definitely, I think definitely…" (1005), and cites his wife often, "being in tears" (1009). There is also clearly a lot of sibling conflict that can culminate in Tristan's sister screaming and imploring Tristan to "stop it, stop it" (974). Additionally, he feels that there are quite heavy social implications:

> Peter: If Tristan went to places, or if you had friends of his around… sometimes it can turn into fisticuffs… and sometimes you worry when you go to meet some of your friends… you feel embarrassed and end up leaving (387-394). You don't know whether behind closed doors people are saying… "Oh God, let's not invite him…" you worry about that. (708-712).

Peter evidently feels that Tristan’s behaviours not only affect Tristan’s relationships, but he fears how others may be judging them as a family and socially excluding Tristan as a result.

Peter emotionally described an incident in which Tristan struggled to makes sense of ADHD:

> Peter: He was so confused and frustrated and to have your nine year old son just sobbing in your lap, trying to work out, “what is wrong with me, what is wrong with me? Why am I like this?” was, kind of powerful, and I was hurt as a parent as my son shouldn’t be going through this, he shouldn’t be experiencing this at nine, he should be out there jumping in puddles, or riding his bike, or doing whatever he wants to do, you know? (596- 604).

This provides a very poignant insight into the world of a parent and child, collectively trying to make sense of “what is wrong” with Tristan. Peter postulated “whether Tristan feels that he is failing him, and therefore “is useless” (38-40), further compounding Tristan’s feelings of not being good enough.

While it is impossible to establish exactly what they were internalising, there is a sense of their lived experiences feeling unjust, unfair, confusing and deeply upsetting for both father and son. Peter described how Tristan “feels slightly lost in the world”. However, the overarching and lasting impression, was of a family who feel somewhat lost in the world together (643).

Peter referred Tristan for assessment after, “getting calls from school saying he’s been in trouble (438)… being disruptive… getting angry and frustrated” (461-462); and as they were “getting a lot of grief at home” (437-439). Additionally, he described some societal pressures to seek assessment:

> Peter: …because you feel judged as parents, by these parents who don’t have children with ADHD, or other conditions…(495).

Peter suggests that parents of CYP with “other conditions” are less likely to be judgmental. This is explored more below.

In terms of support, Peter not only describes getting very little service support from any organisations, but also feeling that he was, “fighting a system… to try and get some acknowledgement” (890-891), with not “an awful amount out there for you” (889). However, Peter expressed how Tristan’s school were particularly proactive in attempting to expedite Tristan’s NDS (Neurodevelopmental Service) referral:

> Peter: The school has got a very good SEND team…they were aware and pretty brilliant in offering us advice… when they came to do the assessment in school, they made sure that he was doing lessons that he didn’t like, so that they could see a reaction, because they said, “if they come into a lesson and he is doing something that he likes, they probably won’t see anything…” (498-505).

Peter was keen to acknowledge that the school were not necessarily pushing for an assessment themselves, but that they “knew the processes…wanted the best for him…” and were “helping us to get further along the process as they could see that we needed the help” (514-523) and knew how long it took to get a child assessed. Peter told how the assessment process took “about five years…” (533). He attributes the long assessment period to the pervasive societal stigma and lack of understanding around ADHD:

> Peter: I think there should be greater resources for it, I think it is still surrounded by stigma, by those who still don’t experience it, or don’t understand it, or don’t wish to understand it… I mean effectively it is a mental health problem (546-550).

Peter draws a comparison with dyslexia in how this was perceived “years ago” as “kids who were lazy, and couldn’t be bothered to read”, suggesting that societally we are still playing catch-up with ADHD, and that it is families like theirs that are subsequently suffering (570). His challenging experiences with services have led him to question the perception and knowledge even amongst professionals working in this area:

> Peter: … I mean do they [professionals] really understand, on the ground when people live with it, day in, and day out…?

Peter suggests that the lack of knowledge around ADHD is not confined to that of the general public, or society at large, and questions whether it is truly possible to understand ADHD, without having experienced it first-hand.

After a long assessment process with the NHS, Peter describes Tristan getting his diagnosis:

> Peter: …we felt relieved that we were right… when they said, “He’s got it [ADHD]”, we were just like, OK, good, that explains a lot…
> Researcher: It sounds like it offered you some validation that it wasn’t you as parents?
> Peter: Yeah, and all these years of people hadn’t believed us… my wife’s parents were very sceptical about it all until we went on holiday with them one time… and they actually experienced it first-hand and they were like, “OK, right, we see what you mean” (181-196).

This demonstrates that the scepticism that they experienced was not only at a societal level, but was felt even from their closest relatives. In turn, they felt further validation when their family members experienced ADHD for themselves, first-hand, as they were then able to understand it better through experience. Perhaps surprisingly, Peter felt a greater sense of stigma after Tristan was diagnosed with ADHD:

> Peter: I think some people might have a bit more of a stigma when you have it [ADHD], when there is something wrong with them… I don’t think a lot of people actually understand what it is” (737-746).

On further exploration, Peter describes the stigma they felt as:

> Peter: …people have said, well they're just naughty kids aren't they? … there is still a whole kind of stigma to it… you know ADHD, is it just council estate kids who get it because their parents don't care about them and that is still prevalent nowadays (171-177).

Peter puts forward that his lived experience of stigma, is one closely associated with judgements around poor parenting, leading to the development of 'unboundaried' and "naughty kids". He also perceived there to be an unkind, and unhelpful association between ADHD and lower socio-economic status (175).

For Peter, decisions around medication were taken "very seriously", considering "how it is going to affect Tristan's life…" (683-685). They sought advice from their GP and felt, "pretty reassured… that the medication is much more refined, and… much better" (762-765). Moreover, he described how Tristan, "can have a choice [in his medication], but… we can notice when he doesn't have it" (762). While his parents can, "see it helping him" and his grades have increased incredibly" (782-784), they also expressed some mixed emotions as, "the school get all the benefits" (782), while they "get" a Tristan who is unmedicated, and more likely to present with the challenging, and often upsetting behaviours described above.

Verity, Dyad 2 (Child 2)

Verity is 9 years of age, and in year 5 of a mainstream primary school. She lives with her parents and two younger siblings. In addition to her diagnosis of ADHD, she has diagnoses of ASD and dyslexia. Verity is the only child in the study not taking medication for her ADHD. Her mother supported her during the interview.

Verity frequently spoke about her ADHD in terms of her anger:

> Verity: Sometimes, I get angry and hurt people (92)… I feel angry with myself…I'm not OK in front of them sometimes (213).

This was quite unusual for Verity, as she demonstrated quite a lack of awareness of her difficulties and of their consequences during the interview. Verity's presentation appeared more complex than Tristan's, and her mother frequently helped her to respond to the questions, as Verity struggled with them. As with Tristan, Verity described her perceived lack of control: "…sometimes I do things, it's weird but I don't really mean to…It's weird, but then I get told off straight away sometimes" (78-81). Verity is able to perceive that some of her behaviours are "weird", but cannot, in this instance, seem able to understand the immediate consequences of getting "told off". In keeping with Tristan, she describes how her behavioural arousal can be rapid, going from "0 to 100 angry straight away" (337-341). On exploring how Verity's behaviours manifest when she perceived herself to have been bullied, she seemed to be quite unaware of them, or unwilling to express them, until prompted by her mother:

> Researcher: …Is there anything else you do that might wind them [the bullies] up?
> Verity: I don't know.
> Bella: What do you do when they try to wind you up though?
> Verity: Kill them.
> Researcher: What do you mean you kill them?
> Verity: I try and fight them.
> Researcher: Ah, do you literally try and fight them with fists?
> Verity: Yeah (190-194).

This serves to demonstrate the severity of some of her thinking. Her described actions point towards the impulsive aspect of ADHD, suggesting that this is an area that Verity struggles to make sense of. Prior to her describing how she attacks others herself, Verity had put forward an argument that she herself, was the victim of bullying. While this may be the case, her mother prompted her to acknowledge that Verity can exhibit highly aggressive behaviours to other children as well. Such occurrences have led to Verity seeing school, with some of its pupils, as an unsafe, volatile and upsetting place:

> Verity: Me don’t want to go to school anymore…I don’t like school cos they’re mean to me and it makes me upset (665-666).

Verity perceives herself to be misunderstood, and sees the manifestation of her ADHD as “bad”. This in turn has led to her being removed from her class, her learning and her peers:

> Verity: …it was the corridor, and they used to make me stay out there for a very long time (286-287).

Due to her behaviours, Verity was required to spend considerable time out of the classroom, away from her peers and learning, with the Head Teacher. Verity seemed to struggle to make sense of why she was treated this way: “Well the Headteacher used to get quite angry with me and then that would make me scared and sad…”. Verity’s understanding of the consequences is clearly limited and rather than understanding how her challenging behaviours may have brought about unwanted responses (such as being sent out), she appeared to only see that the Head teacher got angry, and how that in turn makes her feel “scared and sad”. This suggests that Verity is struggling, not only to make sense of her own behaviours, but of the responses of those working with her, and subsequently her own feelings and emotions.

Verity’s isolation was not confined to lesson times. Here she describes how she was required to spend her break times with the younger children and away from her peers:

> Verity: I don’t want [to go to school], cos at school, at the moment they make me play with year 1s.
> Researcher: How does that make you feel?
> Verity: Upset (834-837).

Both Verity and later her mother report that Verity was isolated from her peers and made to spend her breaks with year 1 children, despite being in year 5 herself. This was an upsetting experience for her. The following statement left a lasting impression of Verity: “I just think… they think that I was bad… I don’t think they kind of understand me, cos I'm not bad" (400-404). Verity struggled to make sense of her lived experiences in school. She not only found school to be an upsetting experience, but she was also left feeling misunderstood, and perceived herself to be a "bad" child in this environment.

Below, her mother interjected to talk about how ADHD has affected Verity's friendships:

> Bella: …you've said before that you weren't getting invited to things…
> Verity: Yeah, all my friends get invited to do stuff but I never do.
> Researcher: …why do you think they're not inviting you…?
> Verity: Well maybe because, they don't like me, or…
> Researcher: Do you think they don't like you or…any behaviours they don't like?
> Verity: Maybe behaviours.
> Researcher: Do you think it's that you get angry?
> Verity: Yeah maybe, sometimes I get… I hurt them.
> Researcher: Oh do you?
> Verity: And then I feel really sad, cos I didn't mean to… (820-832).

It appeared that Verity understood that her behaviours were having some impact on her friendships, resulting in her feeling some social exclusion. By explaining how she "feel[s] really sad" and "didn't mean to", suggests that she is struggling to make sense of her own behaviours, just as others are trying to make sense of them as well.

When describing the support that she receives, Verity told how it was mostly her mother that supported her and, "makes me feel safe" (714). She told how, "I feel, really not supported in school" (797), which is reflected in the passages above. She did comment that a TA "helps me sometimes" (758), but that she would like further support at school (819). This is unsurprising given that she reported finding school to be an upsetting and isolating experience (666).

Verity had a very limited recollection, or knowledge of her ADHD assessment, her diagnosis, or around decisions related to medication/treatment:

> Researcher: Do you take medicine?
> Verity: No.
> Researcher: No… why did you decide not to? Or was it mum’s decision not to?
> Verity: I don’t know.
> Bella: It was mine (577-582).

Bella’s thinking around this is explored below.

Bella, Dyad 2 (Parent 2)

Bella and her partner, live with Verity and her two younger sisters.

On discussing ADHD and its aetiology, Bella described herself as having limited knowledge. However, the understanding that she provided suggests that she is quite the ‘expert by experience’. For example, based on her lived experiences, she postulated that:

> Bella: even ADHD is a spectrum, the same as autism, and some days people [with ADHD] will behave, or present differently… sometimes she will have good days, where you might not notice that she has ADHD… sitting still, and concentrating, and then she might have one day where she cannot sit still and she cannot concentrate and that is when they think that it [ADHD] is a choice (746-755).

This offers insight into the world of ADHD, challenging some existing preconceptions that ADHD is fixed, rather, Bella postulates that ADHD is fluid and changeable.

Bella tells of ADHD-type traits in her family, and how, “these things are in the family” (148), “in their genetic make-up” (178) and are affected by “the way your brain is wired” (61). She offers an example of Verity “struggling to remember” things that, “I literally just told you” (65). At the same time, she suggests that there is an element of “random selection” from each parent” (180). Additionally, she shows awareness of some of difficulties in the assessment of ADHD as, having a “chaotic upbringing” can “mimic ADHD” and “you can’t just do a test for it” (166-170). Subsequently, Bella was eager to describe what ADHD is not, and how her own perception of ADHD has developed through her experiences with Verity. She acknowledged that she had previously perceived ADHD to be due to “bad parenting”. This meant that initially, she felt sad as she felt that she had “done something awful” and that it was her “fault” (25).

Bella described feeling, “convinced that Verity was going to be a criminal as she gets older” (27). On reflection, she considered that her initial preconceptions around ADHD and its aetiology were informed by the media, and by the pervasive societal perception and association with “that Jeremy Kyle thing that people talk about” (775). While Bella initially felt that Verity’s outlook was likely a bleak one, it was the voices of others who shifted her opinions around the prognosis for people with ADHD.

> Bella: … I met other people, especially girls, that had ADHD and adults who were women who were successful and have ADHD… obviously they have to live slightly different to accommodate their ADHD (28-32).

Bella suggests that there were some more informed voices counter-balancing other, more negative stereotypes and stigma, with it now becoming, “more popular for mainstream media to talk about it” (163).

Bella spoke most frequently about Verity’s behavioural presentation, noticing differences from a young age:

> Bella: I started noticing stuff…it was probably when she was about 18 months and it was going to play-groups and activities and she just wasn’t able to engage like some of the other children… she never concentrated for very long, it was always flitting around… she was just a bit dangerous, she was climbing everything…would run away all the time, she had no sense of danger (236-243).

Bella offers examples that are in keeping with the attention deficit, hyperactivity, and impulsivity traits of ADHD. Her concerns seem to be more apparent in comparison to, “some of the other children” (239). However, Verity’s behaviours were complex, later leading to diagnoses of ADHD/ASD and dyslexia. Bella endeavored to make greater sense of this by attempting to demarcate Verity’s behaviours into their respective disorders:

> Bella: I think if we just concentrate on the ADHD, the ADHD bit is that she hasn’t ever been able to sit with us and watch a film, or she doesn’t stick to an activity – it is very rare that she will finish something, she is quite messy, she’s just disorganised… (260-263).

Bella also describes some of the ways Verity’s behaviour affect the family dynamic:

> Bella: She will just be jumping up and down next to you…She interrupts play quite a lot…the girls will be settled and…she’ll come in and say “I want to play, I want to play, I want to play”… and then two minutes later she be like “I’m not playing anymore”, and it’s kind of chaos as Verity sort of erupts…” (275-286).

Bella makes clear the intensity of Verity’s requests through exemplifying the repetition of “I want to play”, and in turn the extent of the ensuing fall-out alluding to an “eruption” to demonstrate the abrupt and intense nature of Verity’s interactions. In terms of the affect this has on her personally, she described how:

> Bella: I get really stressed out because it is impossible sometimes. I just want to get something done… and there is someone who is defiant and arguing and not being what you’ve asked (469-472).

Recounting the extent of her difficulties as “impossible” serves to illustrate the severity of her lived experiences. In turn, she describes the emotional strain this has placed on her as being “broken” (111), “incredibly stressful” (579) “horrid” (1132), “sad” and feeling “guilty for not having all the answers” (1160).

Bella describes how Verity’s influence and difficulties are not confined to the family home:

> Researcher: Do you worry about Verity’s influence on the younger girls…
> Bella: Yeah, definitely, I’ve noticed … it’s been really difficult actually and that’s been one of the things we’ve struggled with the most, is that there’s been lots of copied behaviours… so we actually moved the younger two to a different school… (295-313).

Bella was so concerned about Verity’s influence on her younger children in their educational setting, that she took the difficult decision to move them to a different school:

> Bella: We were having quite a lot of difficulties with Verity going into school, which was then impacting ‘J’ (younger sister) going into school…
> Researcher: That is a massive decision…
> Bella: Yeah, ‘J’ and ‘K’ (other sister) have now moved to a different school (310-327).

Bella clearly felt that it was in the best interests of her youngest two daughters to move them, meaning that Verity would not have the same social interaction with her siblings in school. However, the decision was not solely due to Verity’s influence but also due to the school’s impact:

> Bella: … because at lunch time, Verity fights…the problem is that the boys know that if they wind Verity up, she will react…so [the school] have decided to move Verity to the front playground, which is where the year 1s are and, basically, Verity was with ‘J’ every lunch time and I didn’t think that is right (327-336).

This not only heavily influenced Bella's decision to move Verity's siblings, but also socially isolated Verity from her peers. Bella suggests that her social isolation is not confined to school: "I think she is lonely and that is really hard…she wants that friendship, but she doesn't have a way-in that works…(641-643).

Bella describes the ongoing challenges that she has had with schools, systems and support: "I've never gone to school and felt happy and relaxed to drop my child off… I worry about it every single day" (1056-1060). This is not a new feeling for Bella, previously culminating in her decision to move Verity to a different primary school due to ongoing concerns from the school, about Verity's behaviour:

> Bella: they kept pulling me in about inappropriate behaviour, but it was stuff like kicking her legs in the air and showing her knickers and hugging people, like hugging male staff… They were saying that it was making the staff feel uncomfortable, which annoyed me because she was four, or five [years old] (510-519).

Moreover, Bella's concerns are currently ongoing to the point that she believes that Verity will need to move to a specialist provision:

> Bella: you can't get what she needs in mainstream [school] and that seems like a bigger fight, which… I can't fathom how having a TA, which is X amount of money compares to a place in a special school, which costs way more (947-951).

She also felt that there were variations in the knowledge and competency of different teachers. In particular, she felt that there was one newly qualified teacher who seemed unable to cope with Verity's behaviours. On reflection, Bella considered that her lack of experience was exacerbating Verity's difficulties in school. In addition, Bella described her experiences of support as only coming "when you are in a crisis point" (1094):

> Bella: …they [CYP with ADHD] have got mental health issues… that is what worried me the most…if you spent your whole life feeling not quite right in a setting… or in society… and they're trying to change you, and tell you that you are bad, or wrong, it takes so long to diagnosed, and that is how I feel with Verity, she is a smart little girl and has noticed that she is different. We should celebrate that more than trying to make her just blend in, you know, you can be different and that's fine (100-1109).

Bella puts forward a powerful notion that those with differences should be celebrated, not told that they are, "bad, or wrong". Indeed she feels that she has observed services spending "more time fighting people" (961) than helping them, due to the issues around financing and the political systems at play: "it's just about money, and I get that 100%, but also, it's political" (959-960).

Bella summarises her experience of services in that: "You're just chasing people…it's just impossible…you have got to be the person who complains and makes a fuss" (1002-1006).

In terms of assessment, Bella felt that she was the driver for this, unlike some of the other cases in this study. She felt that she knew that Verity's behaviour "was not normal" and that her previous school, and her teacher were uninformed around ADHD (535). However, she juxtaposes this with her positive experiences in her current school in which they initially listened to her, and sought the opinion of an educational psychologist "within the first week", suggesting that school differences, and knowledge differences can make a significant difference.

Bella described frustrations with the length of the assessment process (1105) and wished that, "someone had signposted" her to support services while they were waiting, rather than doing "endless parenting courses" (716). In hindsight, she expressed how she would have liked someone to tell them to "just act as if she has been diagnosed" (718) and recalled how she "used to cry everyday" due to it being, "incredibly difficult, and really, really stressful" (586).

On receiving Verity’s dual diagnosis of ADHD and ASD, Bella recalled feeling both, “shocked and sad”, and expressed regret, and guilt, at how she had been, “trying to change her…trying to fix her” to be “normal”. This again, inherently suggests a perceived sense that Verity was somehow abnormal, which in hindsight left Bella “feeling guilty” at how she had attempted to change her daughter, now knowing that, for the larger part, it was beyond her locus of control.

Bella told how she felt incredibly let down by the system of “diagnose and discharge” (909-910). Despite the diagnosis, Bella finds herself explaining what ADHD is to others, as she feels they still perceive it to be, “that Jeremy Kyle thing” (775). This suggests that she feels ADHD is still shrouded in misconceptions around bad parenting, socio-economic status and class.

Bella’s chose not to medicate Verity, despite feeling pressure from a teacher who was, “really pushing for me to medicate her” (813), and “kept going on and on about it” to try and “make her [own] life easier” (861). This decision was heavily influenced by complications around Verity’s sleep, and other side-effects. Moreover, she described a fundamental tension between knowing that medication could be helpful, and being, “scared of giving something so powerful to her young brain”:

> Bella: …it’s difficult because there sometimes has been pressure to [medicate], just for her attention span, but I feel that she should be accommodated and be able to learn in a way that is suitable for her… and not be medicated as it might make life easier for a teacher… (29-37).

In many ways, this encapsulates Bella’s overarching message: she feels strongly that there is a pervasive societal misunderstanding around ADHD, that perpetuates the notion that CYP with ADHD should be medicated for the benefit of the school system, when really, more needs to be done to accommodate their needs without the necessity of medical intervention.

Ellie, Dyad 3 (Child 3)

Ellie is 9 years of age, and in year 4 of a mainstream school. She lives with her mother, god-father and her younger sister. In addition to her ADHD, her mother, reports that she presents with social communication difficulties/ASD traits. Ellie wears a hearing aid and was supported by her mother during the interview.

Ellie appears to have conceptualised her understanding of ADHD through her own lived experiences. She likens ADHD to a lack of emotional control, anger, and not being able to learn “properly”. Ellie did not know what ADHD stood for:

> Researcher: Do you know what ADHD stands for?
> Ellie: No.
> Researcher: It stands for Attention Deficit, which means that people can’t hold their attention so well, that’s the ‘AD’, the ‘H’ is hyperactivity and the ‘D’ means disorder…
> Ellie: Yes, but sometimes I can’t control my emotions (81-97).

Ellie seemed perplexed as the traits that she has learnt to associate with ADHD were not present in its label. She also recognised these traits in others: “I can tell if someone has ADHD if they are in a mood…I can tell that he has ADHD as he loses control sometimes” (253). Ellie appears to have conceptualised, and partially made sense of ADHD, through foregrounding these specific traits (loss of control, anger, moodiness), which she sees in herself and in others, presupposing that they too must have ADHD.

As a young child in nursery, Ellie told how she felt, “angry all of the time, and sad”, and remembers, “throwing keys down the toilet”. Ellie was “dis-cluded” (or excluded) from her first primary school:

> Researcher: You moved primary schools?
> Ellie: Yes.
> Researcher: Oh, that is massive… and you said it was because one of the teachers was being mean to you?
> Ellie: Yep, she accused me of pushing my friend into the road… I think I might have accidentally done it, but I didn’t though, and I

> was dis-cluded and everything, so like I didn't get to go outside, I didn't even get to sit with my friends… then mum called the teacher and shouted at her and I was home schooled for a bit.
> Researcher … Do you think … you did push your friend?
> Ellie: Yes.
> Researcher: OK, and were you angry with your friend at that time?
> Ellie: No, she's my best friend.
> Jacqui: She didn't actually push her, sorry… (741-760).

Ellie seems confused about her role in this incident and equivocates around her recollection of events. This was a difficult episode for Ellie to make sense of, with a final narrative yet to be fully reconciled. What she does seem to be clear about is her mother shouting at the teacher, and her being excluded. The idea of the teacher "being mean" appears to be a euphemism that her mother offered Ellie to make sense of this episode and is described more comprehensively in Jacqui's account below. Being home-schooled and later moving to another school also affected Ellie socially: "I feel sad that I have lost my best friend" (784).

Ellie later described how she made sense of the decision to move schools:

> Ellie: I don't think it was because of my ADHD, it was just because the teacher was being mean to me.
> Researcher: …do you think that your teacher was being mean to you because of your ADHD?
> Ellie: No, I've never thought of it that way (791-799).

Interestingly, Ellie did not make sense of this episode, or attribute any of it to her ADHD, rather she appears to have conceptualised it as the teacher just "being mean" to her. It is noteworthy that Ellie recognised that this event had significant bearing on her mother and family:

> Ellie: I don’t want to be home-schooled, because… we were like poor… it’s like we didn’t really pay the rent so I had to go to school, and mum had to go to work… (792-795).

This seems like quite a profound awareness of the way her family were affected, and is not typical of the awareness exhibited by other child participants. Ellie also exhibited some awareness of the affect that her behaviours have had on her mother:

> Researcher: when might you run away?
> Ellie: When I’m mad.
> Researcher: and how often do you get mad.
> Ellie: Erm, quite a lot.
> Researcher: Even on the medication?
> Ellie: Mmm-hmm [affirmation].
> Researcher: Who do you get mad with?
> Ellie: Unfortunately [inaudible] everyone.
> Researcher: Everyone?
> Ellie: Especially mum
> Researcher: Mum gets it worst?
> Ellie: Yes (823-834).

While her mum “gets it worst”, her challenging behaviours are, in many ways indiscriminate, and “unfortunately… everyone” may feel the impact of Ellie being “mad”. This passage also suggests that Ellie has few effective coping mechanisms that she can employ to re-regulate her emotions and control her behaviours. While Ellie’s lack of control and her emotional dysregulation are highly challenging factors for her, her concentration difficulties and hyperactive traits are also significant:

> Researcher: Were you worried about sitting still because of ADHD?
> Ellie: I have never sat still, like that before for, like, 10 or 5 [minutes] (452).

This demonstrates the extent of her restlessness, in that she can only sit still for a very short period of time. This serves to illustrate how difficult she finds it to sit still for whole lessons in an educational setting.

Ellie spoke candidly about not wanting to take medication for her ADHD:

> Ellie: Even though I have my tablets, I feel like I don't want them (205-206)…I wouldn't be worried [not taking medication] as I am happy that I don't have my medication, and I could finally be myself (591-593).

Ellie asserts that she would be happier not taking her ADHD medication and could 'be herself' when off it. This is a profound statement, suggesting she does not feel like herself when taking her daily medication and that the primary reason for taking it is because "my teachers would be worried [if she didn't take medication]" (591). This suggests that Ellie is taking her medication, not so much for her own benefit, rather for the benefit of the school, so that they can manage her.

Ellie spoke extensively about her emotions, her behaviour and her anger. She recalls feeling both "really angry all the time, and sad" concurrently (307-308). Ellie described her ADHD as "really bad" (185) and suggests that this is another primary reason why she "has to have medication, [while] some people don't have to…" (185-189). Ellie had clearly conceptualised her ADHD as a "problem" (24). This became more evident when speaking about what she feels ADHD is:

> Researcher: What do you think ADHD is?
> Ellie: I think it is just because you can't control your anger, and emotions… I can't control my emotions and I can't learn properly, so that is why I have to have controlled drugs (86-87).

On further investigation, it seems that medication also offers Ellie a sense of control that she does not otherwise feel:

> Researcher: …how do you feel when it [medication] starts to wear off?
> Ellie: I feel a little out of control… [compared to] when I don't have it (565-568).

While she acknowledged that taking medication can be beneficial in this sense, she also described attempting to make sense of some complex and contradictory tensions, in feeling "calm", but also "sometimes crazy", while sometimes feeling "normal" (574-579) when on medication. This presents insight from the perspective of a child with ADHD: for Ellie, taking medication is not simply a stabilising factor, but much more variable and complex than this. From Ellie's perspective she would prefer to feel a little crazy, and be herself, rather than taking her medication and feeling "normal".

Ellie did not recall why her mother felt the need for the assessment, as she was, "just really little then" (360).

Ellie spoke of one TA who, helps her "when I run away" and helps her "to relax" (880). Her TA supports her throughout her day, but Ellie did not think this was due to her having ADHD (891). Other support included her family and friends. She perceived that her school "sometimes" (971) offers support, but that she doesn't want it when she is feeling "normal". If we take "normal" as being when she is on her medication, as described above, this suggests that she prefers, and needs less in-school support, when she is on her medication.

Jacqui, Dyad 3 (Parent 3)

Jacqui lives with Ellie, Ellie's younger sibling, and her god-father. Jacqui works with children with SEN.

Jacqui described ADHD through her life experiences of having Ellie: "Ellie is very impulsive [and] she doesn't always focus and understand things…" (113-114); also she is "very hyperactive… like a Duracell bunny, she's just everywhere… bouncing about" (168). Jacqui's description suggests that Ellie is ever-present, with boundless energy. This, Jacqui explains, "drove her insane", (174), especially being "hyperactive until she went to bed" (178).

In keeping with other parents, Jacqui described ADHD as a “chemical imbalance in her brain”. However, she described it as “not [being] hereditary,” (116), and “pot-luck” (185), suggesting that there is an arbitrariness around who gets ADHD. Prior to her lived experiences of ADHD, Jacqui described being “a bit sceptical” of it and worried about Ellie being diagnosed as “she did not want the judgement…” (127-128) or to be challenged by people with stigmatised perceptions of ADHD, including that it “doesn’t exist [or] is just naughty children…” (135-136). This is in keeping with Peter’s and Bella’s views. Jacqui also retrospectively reflected on her own scepticism of ADHD, and how she didn’t know any better at that time.

Jacqui noticed differences in Ellie’s behavioural presentation around the age of two years:

> Jacqui: I really struggled with her as she was lashing out at kids [at nursery], she had scratched their face…then started being really quite nasty to her little sister…I had to go and pick her up all of the time because they couldn’t handle her (286).

Jacqui describes traits that are in keeping with impulsivity in particular, aligning with her perception that Ellie “has always had issues with her self-regulation”.

Such difficulties in nursery and home, saw Jacqui receiving support from her health visitor, and later from a paediatrician. Jacqui made the decision to change nurseries, to one that was like a “forest school” (381). This meant that Ellie could “be outside all of the time” and “be around lots of animals” (382/1094). Jacqui reported this as an incredibly positive experience for Ellie, and subsequently for Jacqui. Ellie then had a delayed entry to school, as Jacqui didn’t think she “would cope” with this.

School began relatively well for Ellie as she “got a lot of support from her teachers” (480). However, Jacqui reported a dramatic change when Ellie got a new teacher, getting “phone call, after phone call” with Ellie “coming home crying because she was not being listened to; she was being told off for things that weren’t her…”, and described how her teacher, “could not handle” her (525-527). This culminated in Jacqui witnessing the teacher “screaming at

Ellie… and saying how naughty she was" (521). In turn, Ellie was screaming at the teacher and "hyperventilating" (519). Jacqui later "confronted the teacher, and… decided to take her out [of the school] as it "wasn't healthy" (528).

This was clearly an incredibly challenging period for both Ellie and Jacqui. Both felt a sense of injustice that Ellie had been conceptualised as "the naughty child" (540-541). Unlike Bella (Parent 2), Jacqui expressed how, it was "the older generation of teachers" who are "not re-educated" about ADHD, with the "newer teachers" being "more aware of it" as "it's in their training" (571/2).

It feels important to consider the bearing that Ellie's educational experiences and related behaviours were having on Jacqui. She described her feelings and emotions in the following ways:

- "I was in tears" (290)
- "I was struggling at home" (292)
- "It was embarrassing" (292)
- "It was really frustrating" (579)
- "It was ridiculous" (483)
- "It was just horrible" (522)
- "It was horrendous" (516)
- "It was horrible dropping her off" (584)
- It was really, really stressful" (292)

This shines a light on the extent of distress that Jacqui felt, which had significant bearing on her mental health:

> Jacqui: [My mental health was effected] massively, absolutely massively. Before… I was a very sociable and confident person, and then having her I didn't take her to places, or I'd leave early from places. I got so much anxiety from other people judging me as a parent, so yeah, massively and it has completely changed my personality having her…obviously I love her to pieces…but …my personality and my characteristics, that's completely changed… (420-427).

Jacqui’s incredibly personal description illustrates the extent to which her own mental health was affected. Jacqui clearly felt conflicted in expressing such feelings about her own beloved child. This illustrates the profound, and widely unreported personal affect, on a particular parent, experiencing ADHD through her child, while attempting to navigate her safely through a variable, and unpredictable education system.

Jacqui also spoke of how she even questioned her ability to parent:

> Jacqui: Yeah, you question it obviously… my friend’s partner… would be able to stop her behaviours really easily and I always used to think, well if he was her parent, would she need this diagnosis? …It does make you question it a lot (816-822).

Jacqui had frequently questioned whether Ellie’s ADHD-traits were causally associated with her own parenting ability, which was further compounded when she drew comparisons to another parent. This reflects a type of self-stigmatising thinking that brought about parental self-blame and guilt.

Jacqui further reflected on her old pre-child parenting expectations, and how they differed from her perceived reality.

> Jacqui: … I thought I was going to be this parent – I had this image in my head of what parent I was going to be, and then having Ellie, I was nothing like it at all… I thought I would be this really calm, lovely mum and I’m just really stressed all the time (826-830).

In this sense, Jacqui expressed a felt-sense of cognitive dissonance in which she felt unable to meet her own pre-existing notions of parenthood, as a “really calm, lovely mum”, further adding to her own distress.

Ellie is on medication for her ADHD symptoms. Jacqui is the only parent to discuss medication more frequently than any other theme. Jacqui reported the decision to medicate Ellie as a “big” one, and while Ellie was involved in the decision making, “she wasn’t really that bothered” about whether she took it

(989). Jacqui cited the potential side-effects as being a significant concern in the decision-making process.

Jacqui reports that when Ellie is taking her medication, she is less hyperactive and displays “a little bit of attention” (167). This suggests that while effectively reducing her hyperactive symptoms, it appears less efficacious in improving her concentration. However, Jacqui explained that when Ellie’s medication wears off, she “instantly forgets” and “goes off on a really random tangent” (19-20), and “she can go absolutely scatty and eat everything in the house” (1020).

Jacqui was able to discuss decisions around medication with her family, but felt pressure from other parents not to medicate her: “Oh no, you shouldn’t do that, you shouldn’t give children medication like that” (920-921). She also felt some influence from a school TA who said:

> Jacqui: [The TA said] I obviously can’t tell you to give her medication, but the children that we have seen, that are on medication, have progressed so much more at school. (927-929).

Jacqui reported not feeling any explicit pressure to medicate, but that the TA’s voice was a “big factor” and influential in the decision” (946). Fundamentally her decision to medicate was predicated on the belief that it would “definitely [help] her education” (939):

> Jacqui: Ellie was so behind because her concentration just wasn’t there, I think that was a big factor in it. I thought, if this is going to help her with her schooling and is going to help her concentrate and make her school day a lot easier and her not be so behind, then it’s got to be a good thing.

Jacqui expressed feeling justified in her decision in that, “it is a hell of a lot easier… now that her medications have gone up” (55-56). Similarly to Peter and Bella, she feels that the benefits of medication are felt by the school, with there being, “no changes at all, at home”, aside from some perceived improvements in her social skills. The overarching impression was that Jacqui felt that the choice to medicate was a positive one, and even on the “smallest dose", there were some perceptible improvements "in her concentration", with Ellie appearing "more grounded" (1006), and finding "her school life so much easier" (971).

Jacqui spoke, at length about the variable support from school and other services, suggesting it was of importance to her. She felt that Ellie's school "did try" before just "giving up" – although she cited having a "really good TA", who was nice to talk with (1107-1112). She also received support from a parent liaison officer, from Ellie's school who, "gave me a little bit of support…and so much advice". Jacqui reported that Ellie was receiving some therapeutic support from a local organisation, to help develop her self-regulation…" (1171).

Ellie was assessed through the NHS CAMHS team; Jacqui described this as such a "long process", with Ellie being diagnosed when she was six" (213-216). Jacqui felt that the diagnosis would "help me to get some support" (129-130), and "needed the support to know I wasn't going mad" (811), indicating the extent to which she needed support and advice in supporting Ellie.

Jacqui went to her doctors seeking support for her own mental health, but reported the following:

> Researcher: And did they [the GP] provide you with extra help?
> Jacqui: No, they literally just said, you need to find some extra help, don't you, because, obviously, it is too much for you (418-419).

While thinking that Ellie's diagnosis, would "open doors" to support services, she did not feel she received this: "I think they [the NHS] just presumed that I knew, and then they gave me a few leaflets" (216). She described how she was offered a parent ADHD workshop as a way of support, but, "…never managed to get there, just because… they don't think that parents… have jobs, because it is always during the day" (149-152).

Jacqui also wondered if Ellie's allocated ADHD nurse might be able to offer them some support, but:

> Jacqui: The ADHD nurses… when I've needed them, like, in a crisis, I've called them up and gone, "I haven't heard from you in months and I'm really struggling". I don't get a lot of help back from them…. [unless] I have needed to up her meds (1152).

In turn, she described the paediatrican (and the ADHD nurse) as providing information that "wasn't brilliant…" (206-208), and while an educational psychologist, "came in and has given her report…I don't know what happens after that?" (1154-1156). Finally, Jacqui spoke about her prior experiences with children's services:

> Jacqui: …I haven't really got a very good relationship with them, because when I was struggling with Ellie… I thought I was getting loads of support [from them], I thought I had a really good relationship with this woman… and it all just got chucked in my face… (1184-1192).

Jacqui described how she felt that her trust with children's services had been broken as you, "just can't really be that open with them because things will get twisted". She suggested that "a lot of people just think that children's services have an ulterior motive" … and "children's services would overwhelm me, with the whole idea of them … picking apart my parenting style…" (1198-1209).

On balance, it appears that Jacqui and Ellie have had input from quite a range of various professionals, yet it still felt that she was not receiving the level of support that she was hoping for. When questioned around what this might look like, she described: "it doesn't necessarily need to be expert help", hence why she felt supported by the school's TA, who was not, potentially, as knowledgeable, or well-trained around ADHD, as other professionals, but she "listened to me and…knew what I was talking about…" (1130-1131). This suggests that Jacqui was not necessarily seeking the highest level of expertise, rather she would value having access to an empathetic person, who she can develop a trusting relationship with. In this instance, the school was the closest in providing this for her.

Tommy, Dyad 4 (Child 4)

Tommy is 12 years of age, and is in year 8 of a mainstream secondary school. He lives with his mother, and three year old brother. As well as ADHD, he is under assessment for ASD/communication difficulties. Tommy takes medication for his ADHD. He was interviewed alone.

Tommy told how he was making sense of his ADHD through his own lived experiences:

> Tommy: I think I'm teaching myself most of it, because I've got it, so it is easier to teach myself, when you know something, or when you've got it. …so, I taught myself [about being] hyper because I'm hyper when I don't have my tablets… (77-82).

Tommy had arguably used his experience of taking his medication and feeling less "hyper", and had compared it to his feeling hyper when not on the medication, giving him a point of comparison. When asked what he thought ADHD is, Tommy suggested that hyperactivity was its primary trait:

> Tommy: Well, if you say you have ADHD… you can't really sit still properly, or it is hard for you to sit still, and you have such energy…I've got that too…and can be really hyper (17-22).

Being "hyper" was presented as a predominantly challenging trait, especially in the school context. However, Tommy went on to discuss how this can be both positive and negative:

> Tommy: Some days it can be bad and some days it can be good
> Researcher: How…?
> Tommy: So, when it is good, I can be at a tournament and I can have loads of energy, but when it I bad, I can be in an exam and I have lots of energy and keep getting up and down… (101-106).

This is an interesting reflection, putting forward that being hyperactive in itself is not necessarily a bad trait. However, it is clearly challenging for Tommy if he is feeling hyperactive, while being required to attend sedentary learning tasks. This reflects Tristan’s perspective described above.

When asked how he thinks others view ADHD, he described:

> Tommy: …maybe they think it is something that makes life extremely tough and they don’t want to live with it, because everything would be extremely, extremely hard because of it” (898-900).

For most of the interview, Tommy appeared to minimise his symptoms, and difficulties in school, and did not use superlatives such as “extremely” during his interview. Therefore, his use of, and repetition of the words “extremely, extremely hard” perhaps represent a moment in which he felt able to openly express the true extent of his difficulties.

Tommy spoke, at length, about his difficulties with some teachers and his school’s perceived inflexible consequence system. He reported finding school “stressful” (243) as some teachers do not offer him the support he needs:

> Tommy: I can’t remember because I have got a really bad memory…I think it is because of the stress of school right now.
> Researcher: Is school stressful?
> Tommy: Yes, sometimes because some teachers can’t help as much…
> Researcher: Do you feel that there are some teachers who understand ADHD, and you, and there are others that don’t?
> Tommy: Yeah, I guess so. Yeah (239-251).

Tommy suggests that the stress caused by school is affecting his memory. He cites stress related to learning repeatedly in his interview. Coupled with his inattentive traits, and finding it difficult to concentrate, this leaves Tommy feeling considerably disadvantaged in the classroom. This appears to be compounded by a lack of understanding by “some teachers”. Tommy describes how the stress, caused by school affects him in other ways:

> Tommy: …I just think… that I am not hungry at school
> Researcher: …because of the medication?
> Tommy: Erm, no I just think it is out of stress really.
> Researcher: Gosh, you've mentioned stress a couple of times…
> Tommy: Yes, the stress is quite hard to deal with.. [I] have less time to… some people write down stuff down really quickly, and then we'll have to move onto the next slide, but then I might not have finished writing, and that is stressful (471-483).

Tommy seems quite able to acknowledge his difficulties in a number of areas. While not being particularly critical of teachers and the school system, he clearly puts forward strong indications that he feels that some of his teachers are not doing enough for him:

> Tommy: I might not be able to sit down, so I might get a detention, or an A1… it is also for talking…
> Researcher: But isn't that hard though, if you've got ADHD? Isn't that one of the main features of it?
> Tommy: Yeah, but I always get some warnings before it…
> Researcher: Do you ever feel like saying, "But hold on, I can't sit still today – I've got too much energy?"
> Tommy: Yeah – they might let me stand outside for a little while (497-507).

Tommy described how his school operate a consequence system in that pupil's get one warning (an A1) and then a detention, for a second infraction. Tommy describes his inability to sit down akin to an involuntary action: i.e. "not being able" to do otherwise. While he reports being given informal warnings prior to this, and how they might let him, "stand outside for a little while", Tommy goes on to say that he gets two weekly detentions (the maximum amount), despite his best efforts. Furthermore,

> Tommy: When they give me an A1 straight away … it makes me feel like I haven't had enough time to calm down.

> Researcher: And …is it more likely to set you off, like… how am I going to get through this lesson?”
> Tommy: Yeah.
> Researcher: So, actually giving you that A1 really early on isn’t a great idea?
> Tommy: Mmm [affirmation] (530-537).

Tommy not only finds the school environment stressful, the perceived inflexibility of some teachers, within the school’s behavioural system seems to make it feel that he is less likely to succeed in certain lessons, and is more likely to get detentions as well. This is in addition to Tommy not feeling that teachers understand his ADHD, nor his symptoms:

> Tommy: So, say a teacher told me off for being hyperactive, I’d say, “can you just give me a minute or something outside, because I have got ADHD” and if they said no, because you don’t really need it, I would be like, but “like I’m hyper and all that” and I’d have a full-on argument with them sometimes…Some of the teachers do [get it], and some of the teachers might not get it as much… 264-279).

Tommy’s lived experience is that he feels misunderstood, disclosing how he might attempt to justify his behavioural presentation, or his ADHD symptoms, by explaining his disorder to them. However, he describes how this is not always successful, potentially leading to conflict with the teacher, in turn affecting his relationship with them:

> Tommy: Some of them don’t really get me as much, but then if I tell them, if they still don’t learn, that is when I… don’t really get on with them.
> Researcher: Yeah, and is that because you want them to understand what ADHD is and what you’re going through?
> Tommy: Yeah
> Researcher: Does is it surprise you that teachers are supposed to be really highly trained…?

> Tommy: No, because they might not have done much on ADHD, they might do more on autism… because autism is a bigger thing than ADHD (263-287).

Tommy describes how he feels that it is his role to inform the teachers about his presentation, and how ADHD manifests in the classroom. Moreover, he feels additional stress when teachers “still don’t learn” from him. Subsequently, this has bearing on his perception of his teacher/s and their relationship. Additionally, Tommy is not surprised that teachers don’t know more about ADHD, suggesting that they, “might not have done much on ADHD”, and are more likely to be better informed around ASD, as he feels it is a “bigger thing…”.

Tommy had little recollection of the assessment process, or when he received his diagnosis of ADHD.

Tommy does take medication for his ADHD and has made sense of this as something that is mostly positive and helpful for him: “when I don’t take my tablets I’m hyper and when I do take my tablets, I’m good for most of the day” (86-88). He did not seem to want to discuss the potential side-effects of taking his medication, choosing to focus on its benefits:

> Tommy: No, there’s not really any side-effects to having ADHD
> Researcher: No? Has it changed your appetite?
> Tommy: Erm, the tablets kind of stunted my growth.
> Researcher: Oh do they?
> Tommy: Yeah, not by much, but a little bit (460-464).

As described above, while citing having little appetite, he attributes this to school-related stress, over an association with medication. However, Tommy demonstrated that he had reflected on his medication, and its efficacy:

> Tommy: …so it kind of helps me to concentrate a little bit more…
> Researcher: Do you know how it does that… ?

> Tommy: No… it might just be a normal tablet, and mum is saying that it makes me calm, so that makes me calm … the actual tablet might not work, I don't know…

Tommy exhibits an understanding that his medication may help his concentration, and, at times, allay his hyperactivity, allowing him to sit still for longer. He also questions whether his medication is, in fact, anything more than a placebo, and seems curious around this. It is therefore plausible to suggest that Tommy is not overly informed about the medication that he is taking.

Rhonda, Dyad 4 (Parent 4)

Rhonda lives with Tommy and his younger brother. She is a single parent, who "has always worked in childcare" (181).

When asked about the aetiology of ADHD, Rhonda described how no information was provided to her when Tommy was diagnosed with ADHD, rather she described it as "he has ADHD, do you want him medicated?" (103-105). She told how no other forms of treatment were offered. In terms of understanding ADHD, she cites a hereditary association and a neural basis for ADHD:

> Rhonda: I read a little bit about how it can be hereditary, and that they are born with it… like their brain is wired differently, I don't really know how to explain it… (99-100).

Rhonda gives the impression that her quest to make sense of what ADHD has been a rather solitary one, especially as, "none of my family really know, or really understand anything about it". (118-119). Therefore, like other participants, Rhonda appears to understand ADHD through her own lived experiences:

> Rhonda: …my understanding of ADHD is not being able to concentrate, having that impulsive behaviour… the hyperactivity… one minute really hyper, and the next minute really calm… that inability to listen…listening to more than one instruction at a time

> – he particularly finds difficult… his mind is elsewhere… he doesn't always take in the information… (40-52).

It is noteworthy that Rhonda spoke more frequently about her child's behaviours than any other parent. She also described Tommy's "meltdowns" as being highly difficult:

> Rhonda: I've gone through two TVs and five phones because he gets really aggressive and really, really frustrated… he can get quite violent at times.

Rhonda described numerous incidents with Tommy including, physically restraining him in public during a "massive meltdown", that was "just really, really embarrassing" (1231-1236); breaking his arm twice (205); the police coming as Tommy "screamed, and screamed and screamed...was hitting and kicking me" (250-251). Such events seem in keeping with the core trait of impulsivity. In addition it reflects significant emotional dysregulation:

> Rhonda: It is that impulsiveness… particularly in those times, he finds it difficult to kind of think about things, he just thinks it and does it, it's just that impulsiveness…
> Researcher: Almost like there is no space between the desire to do it and doing it?
> Rhonda: Yeah (1197-1206).

Rhonda suggests that the bigger incidents, described above, are less frequent now, and "as he is getting older, it is more… that impulsivity; it's more of that defiance [and] he still whinges like he is a toddler" (284-287). This suggests that Tommy's presentation, and ADHD, is not static, or unchanging, rather that it is changeable over time.

Rhonda frequently described the emotional strain placed upon her as feeling, "upset, embarrassed, and angry" (246). She told how she felt that ADHD had "very impacted" her because "everything revolves around Tommy" (561). When asked how, or if she coped, she described feeling:

> Rhonda: extremely tired… it is exhausting constantly trying to entertain your small child as it is, let alone when they have extra needs… and I felt really sad… you know he was screaming…he would scream at me…
> Researcher: That sounds exhausting.
> Rhonda: It was… (403-416).

In addition, to her emotional burden, Rhonda expressed experiencing social isolation due to Tommy's behaviours: "you know, when he was younger I wouldn't take him places as I was worried that he would have a meltdown" (562-563). This had the effect of her feeling that she was dealing with Tommy on her own, and was unable to attend social events… unless she had additional adult support to manage Tommy "if he had a meltdown" (581-585).

Furthermore, Tommy's friendships were also "definitely" affected in terms of "the quality and the number of friends" he has, as friends "find it difficult to manage those… explosive moments… and that is why he has ended up fighting…" (888-893).

Rhonda reported, not only, dealing with Tommy's extreme behaviours, but also with the stigmatising perception of his behaviours, that she describes as being quite unique to ADHD:

> Rhonda: I think there's a lot of stigma around it… it's almost seen as, "Oh, that child has just not been brought up properly" and that's definitely not the case with Tommy… I think it would have been different if he had a heart condition, or diabetes, or something because you don't have to justify that so much, you don't have to give a reason as to why he has that diagnosis, whereas with ADHD, I really feel like you do (148-156).

Stigma around Tommy's behaviours and his ADHD left Rhonda feeling "really embarrassed" and "uncomfortable to talk about it…" because she "felt like people were judging me…" (133-135). Rhonda described feeling that other's perception of ADHD is just, a "naughty boy syndrome" (169). She described this being exacerbated with the additional perceived stigmatisation of her being a single parent. This further compounded the stigmatising perception of ADHD as simply being “bad parenting” (1211). Therefore, for Rhonda, receiving Tommy’s diagnosis was validating, as she felt that it helped others to understand that Tommy’s behaviours were not solely attributable to her parenting style.

In summary, Rhonda described being the single parent, of a child with highly challenging behaviours, who was, for the most part, working it out alone, while feeling stigmatised, judged, and in many ways feeling unequipped to manage with her daily reality. In turn, the challenging behaviours led to Rhonda declining wider social activities, and support, as she felt that it would go wrong and would perpetuate her sense of being judged, further affecting her emotional state.

Leading up to assessment, Rhonda noticed quite different individual differences in staff knowledge and approaches: the nursery teacher, “definitely had some kind of background knowledge of what ADHD was” (501), while the Reception teacher was “dismissive” and did not have “any idea of what ADHD was, or how it affects children” (503-504).

Similarly to Bella, she felt that this lack of knowledge and understanding was indicative of her being, “very new to teaching” (505-507). However, by year 1, the school appeared to be recognising that Tommy’s traits were in keeping with ADHD, despite Rhonda referring to it as “a fight” to get the school to understand what ADHD is and how it presents (732-734). While the school then recommended taking Tommy to the doctors, Rhonda did not feel under any external pressure to do so. Rather:

> Rhonda: I was definitely putting pressure on myself to get Tommy assessed, or diagnosed, as I just wanted what was best for him…(519-521).

Rhonda’s self-confessed pressure to have Tommy assessed, was due to his highly challenging behaviours: “I mean, those times were difficult – he wasn’t easy – he was having meltdowns, he was hitting and kicking and screaming and shouting…" (535-537). It is inferred that Rhonda felt it necessary for the researcher to understand just how hard it was for her, and just how much she needed the support, and validation that she was doing her best as a parent.

Tommy was assessed by an NHS CAMHS team; Rhonda described the assessment process as being not "too bad" and "was only a year" – the shortest time described by any parent in the study. That said, she was eager to point out that she had been "fighting for a long time before that" (700-701). On receiving the diagnosis, she reported feeling that she had to "justify why he had ADHD, and the diagnosis to others: "to start off with it just felt a bit embarrassing… even with family and friends" (130-131). In addition, Rhonda felt a pressure to "justify that decision" (139) to medicate Tommy as well.

Rhonda felt she that she "knew straight away" that she wanted to medicate Tommy for his ADHD (921-922), but had some reservations:

> Rhonda: you hear of children going on to ADHD medication and being zombies… I would rather put up with his ADHD than see his personality stripped, so I did think about it, but I also wanted what was best for him and if that meant trialing the medication then that meant trialing the medication (930-934).

Rhonda had concerns around the side-effects, and around being judged for putting her son on medication. In particular, she felt that her father's side of the family judged her and said that "he didn't need to go on medication" (940-945). That said, she felt the positives of being on medication were apparent:

> Rhonda: He was like a different child. He was able sit for longer. You know, he's got ADHD, so he's never going to be able to sit for a massive amount of time, but he was able to sit and watch a programme for half an hour or something… he just felt calmer on the medication…(958-964).

Rhonda felt that this was a validating experience for her. She also felt further justification in her decision to medicate Tommy after receiving more positive school reports:

> Rhonda: …for me to hear that he was definitely calmer at school… is able to sit for longer, and able to follow instructions, simple instructions, but instructions, it definitely gave me peace of mind that …was the best thing… (968-972).

In keeping with the views of Peter and Jacqui, Rhonda felt that the medication benefitted her child, mostly in the school environment, with Tommy also appearing “calmer and easier to talk to” on medication (479). Also, in keeping with Peter and Jacqui, Rhonda felt that the school benefitted from getting the medicated Tommy, with Rhonda getting “the unmedicated Tommy” (987). She described this as:

> Rhonda: Yeah, it sucks. It is frustrating, but I would rather him get an education, than worry what he is going to be like, in the evening…when he is off his medication… in the evenings, he eats and eats and eats and eats and eats, and he gets frustrated really easily and he still has that impulsivity… (991-998).

Here, Rhonda reports an emerging parental pattern, that the “school gets all the benefits” of medication. Similarly as with Peter, Rhonda also cites homework as being a particularly difficult endeavour:

> Rhonda: It is difficult because… and there’s an expectation… but trying to get him to sit down and concentrate and do that homework is very… difficult in the evenings… because he hasn’t got that ability to sit and concentrate for long and he gets frustrated and he tears up the work (991-1007).

The interview provided an opportunity to see the extent to which Tommy struggled with his inattention in the evenings, and offered a small window into how challenging it likely is, as a parent, to ensure that a child, with ADHD completes their set homework tasks.

As mentioned above, Rhonda described how the only support that they got post-diagnosis, was the offer of medication with “no information given when he was diagnosed…" (103). Consequently, this left her feeling as though she was "hitting my head against a brick wall" and "felt let down by the lack of services" available (1332). On asking her what sort of service she may have benefited from, she told how she "just wanted to be listened to and supported" (1442) and to "get it off your chest a little bit" (1446). She also expressed her frustration that services did not appear to be able to offer any support for single working parents, who are either working, or with their children (1255).

Rhonda spoke at length about her "fight" with Tommy's school:

> Rhonda: It has been a fight, even now, with his diagnosis, it is a fight… He doesn't get the support he needs at school, and it is a constant fight, having to shout about what Tommy needs (731-734).

Rhonda expressed strong concerns that Tommy was being punished for his ADHD traits, culminating in twice weekly detentions, with Tommy consistently attending both (1372). Rhonda described how one staff member appears to recognise Tommy's behaviours as his ADHD, but:

> Rhonda: that is just one person, and you need everybody on board, and definitely some teachers within the school, don't understand… much about ADHD – you know… Tommy is constantly being sent out for his ADHD traits (1366-1372).

The variability of teacher/TA knowledge and understanding of ADHD, was expressed by all five parent participants in the study. Rhonda's experience of Tommy's school is that there is just one sole member of staff championing Tommy, who appears to have a greater understanding of his presentation and how his ADHD traits manifest behaviourally.

Understandably, this left Rhonda feeling "frustrated" and embattled with the school, especially as she strongly felt that, "there are other ways that they could probably avoid it (sanctions)" (1084). She expressed that part of the difficulty with ADHD is that it is a "hidden disability" and because … teacher[s] can't physically see it, that not enough is being done for him" (1404). Rhonda held a view in keeping with other parents in this study: that her child would be better supported, in school, had he received a diagnosis of ASD, rather than ADHD. She reported being told, by educational staff, that “there will be more support that we can give him if he is diagnosed with autism” (1442).

Bobby, Dyad 5 (Child 5)

Bobby is 11 years old, and in year 7 of a mainstream secondary school. He lives with his mother, father, and his three younger siblings. In addition to ADHD, he has a diagnosis of ASD. His father also has ADHD. Bobby takes medication for his ADHD. He was supported by his mother during the interview.

As was the case with all five child participants, the most frequent theme that arose was around Bobby’s difficulties, or symptoms. When asked about what ADHD is, Bobby explained:

> Bobby: I actually don’t know. I’ve known I’ve had it for a couple of years now, but I’ve never actually gotten a clear explanation… I know what it does to me, but don’t know what it stands for (15-17).

In keeping with most child participants, Bobby knew little about what ADHD is or even what the acronym stands for. Bobby initially told how, “I didn’t have much difficulties in school” (84). This is an interesting contrast to his mother’s perspective, explored below. Bobby went on to describe his difficulties in his learning: “…understanding what is going on is something I don’t get” (93). On further exploration, he told how his, “mind decides to make it a… bit more complicated and complex” (97). This coincided with Bobby losing his concentration during the interview:

> Researcher: Is there a lot of writing in school?
> *No response*
> Caitlyn: Sorry, he’s zoning out.
> Bobby: I’m back in, I’m back in, back in.
> Researcher: You’re back in?
> Bobby: Mm hmm (affirmation) (110-117).

By describing how he was “back in”, suggests that he was “out” i.e. his mind was elsewhere for a period of time. He then told how he thinks others can see when his “mind is all over the place” (125), as there are physical symptoms that accompany this:

> Researcher: … when it [your mind] goes all over the place… do others notice?
> Bobby: …others do notice, because I’m getting unsettled, and I’m getting a bit shaky…not shaky, not shaky, but I’m getting a bit, I don’t know like…
> Caitlyn: He can’t see you – his camera is off. He is acting how he is – he is fidgeting.
> Bobby: It’s fidgety and unsettled…
> Researcher: Oh, he’s moving a lot?
> Caitlyn: He’s struggling…He has already slid across the floor a couple of times...

This provided an opportunity to better understand how Bobby’s attentional difficulties present as his medication “wears off” after school (924). This led to his mother suggesting that it would have been better to interview Bobby “with medication” (925). Of all the participants, Bobby appeared to struggle the most during the interview:

> Caitlyn: Bobby, you need to concentrate!
> Bobby I’m trying to….
> Caitlyn: He is really struggling to stay still….he doesn’t want to stay in one place… He is all over the shop….
> Bobby: I’m back in it now. I’ll remember that I am in this phone call and I am doing what I’m meant to be doing… (267-280).

In a bid to maintain focus for some time longer, Bobby engaged in self-talk, reminding himself to, “remember that I am in this phone call…” (279). When discussing how he felt about having ADHD, Bobby said he felt, both happy, “because I was different to others” and, “sad, because this is going to affect my learning, my understanding of things, probably for the rest of my life, so this is something quite hard to get to grips with” (429-431). It was clear that for Bobby, attempting to make sense of ADHD was confusing and complex:

> Researcher: Do you ever worry about ADHD as a young adult, do you think it might affect your life then?
> Bobby: Maybe, but if I am concentrated on something that helps me concentrate…it will make me well by the time I’m there.
> Researcher: So you think if you concentrate really hard, you can make ADHD go away?
> Bobby: Yes (436-443).

For Bobby, concentration difficulties appear as his primary symptom, so much so, that it affects his learning, and his ability to maintain conversational focus over a period of time. In turn, he had placed such importance on this, that he believed that if he “concentrates really hard [he] can make ADHD go away” (442). Bobby also cited organisation as being a difficult and confusing area for him:

> Bobby: Oh yeah, I find organising, not difficult, just very confusing…so, I’m organising myself very, very neatly with my pencils and stuff, and my, everything is neat, neat and in a line, but, but sometimes that line becomes, damn…and I forget about how clean I am, like neat I am and I just…I don’t know, I don’t know, just get muddy, or something…(206-213).

Bobby relates his sense of feeling organised to one of being neat, orderly and clean, and that when his mind becomes disorganised, it feels as though he is “muddy”, or sullied. He then extended this analogy to describe his impulsivity:

> Bobby: So, I have a new PE kit, playing football, I don’t really want to get wet, then someone comes with the ball, I slide tackle them because I completely forgot my PE kit is brand new…(213-216).

He goes on to describe how his impulsivity often manifests as thoughtless verbal expressions:

> Bobby: …with like something I shouldn't have said – I just do it very, very quickly, because I want to get out of the situation, despite making the situation longer and worse (shouting) (225-228).

Despite knowing that saying things mindlessly and impulsively will usually make situations worse, he describes how it happens so rapidly that he appears to have little control over this. While, exhibiting some candour in his responses, Bobby did not appear completely willing to discuss his difficulties when questioned by his mother:

> Caitlyn: … so impulsive can also mean things like when you set fire to the paper, for no apparent reason, and things like that.
> Bobby: Oh, don't bring that up!
> Caitlyn: Oh, you're not in trouble, but that's what impulsive is (247-253).

Bobby clearly did not want his mother to raise this incident during the interview, suggesting that he was not ready to discuss some of his more challenging, and perhaps personal, behaviours.

When questioned around the assessment process, Bobby recalled:

> Bobby: …I didn't really know that it was an assessment… they never mentioned the assessment, but…I was a bit, just confused by what was happening… I didn't know if others did this assessment, so I didn't know if I was different or not.
> Researcher: Did you feel different? Looking at others in your class… or not?
> Bobby: Yeah, when I… [was] like moving about all about the classroom and they would just [be] sitting down… (368-373).

Bobby clearly did not realise that he was being assessed for ADHD, and was confused by the process. This potentially raises significant ethical concerns. Moreover, while Bobby had begun to notice some differences between himself and others in his class, he remained unsure if he alone was doing the assessment, or whether other children were doing it too. This must have been a perplexing experience for Bobby, and he suggests that he is still attempting to make sense of the assessment and his ADHD, with the support of his parents.

Bobby did feel as though there was some benefit in receiving his diagnosis of ADHD:

> Researcher: … do you think that before you had the diagnosis … they thought you were just a naughty boy?
> Bobby: I think they did. I think they just thought that I was a bit on the naughty scale and just a bit mad… It has helped me a bit more to have a diagnosis because teachers know what I want now…(328-332).

While Bobby was confused about the assessment process, it seems that he had begun to make sense of ADHD through his own life experiences. Receiving his diagnosis offered him some personal validation, in that others began to see him less as "a bit mad", and "naughty", and potentially began reframing his behaviours as symptoms of his ADHD. This view is shared by his mother who suggested that, "…certain teachers just thought he was a pain in the arse" (772-773).

In terms of taking medication for his ADHD, Bobby felt that, "if I get on medication more…the ADHD will wear off, and I won't have it as often" (434). It appears that Bobby may have conceptualized ADHD a disorder that can be worn away, with medical intervention. This is in line with his view that he can make ADHD "go away" if he "concentrates really hard" (441-442). Bobby had just started taking medication for ADHD, and told how he felt it should benefit him:

> Bobby: It's something to help me focus because I'm a bit… very, very everywhere, so… it helps me concentrate. But it's not been working, but we've doubled the thing and it's now starting to work and starting to become good (448-451).

Again, Bobby emphasises the extent of his difficulties, using the repetition of “very, very everywhere”. While Bobby seems to want to take his medication and is motivated to do well in school, he eloquently describes some of the complexities around this:

> Researcher: How do you feel when you take your medication…?
> Bobby: I feel better, but worse at the same time…I feel better because I’m more concentrated, I’m more focused, but I’m not very good because…the side of me that is happy… and talkative is fading away and I want that more than I want to concentrate (457-460).

Bobby describes the dilemma, and tension that he is attempting to make sense of: on the one hand, he feels the medication is improving his concentration and is therefore making him happier; on the other hand, the, “happy and talkative” part of Bobby is “fading” and he suggests that he would prefer to be himself more than, the medicated and better-focused Bobby:

> Researcher: So, am I understanding you right – you can concentrate more, but you don’t feel so chatty and happy?
> Bobby: Yeah.
> Researcher: How does that make you feel?
> Bobby: It makes me feel…I don’t know how I feel about it. It just makes me feel…
> Caitlyn: Don’t break my laptop
> Bobby: I don’t know… I don’t know how I feel.
> Researcher: …are you happy you’re taking medication, or would you prefer not to?
> Bobby: I’d prefer not, but it helps me, and I want to concentrate in school, and I just want to get better… (461-472).

Bobby is able to verbalise the extent of his predicament: to take medication and do better in school, or cease taking it and continue to feel like himself. While heavily distracted during the interview, Bobby succinctly summarises the crux of his dilemma: “I just want to get better”.

Bobby did not choose to talk about his school and teachers in great length. However, he clearly did not think that he has received enough support in his secondary school:

> Researcher: …Do you feel like there is enough support in school… (for those with) with ADHD?
> Bobby: Not really.
> Researcher: No? Were you expecting more support coming up from primary school?
> Bobby: Yeah (736-741).

Bobby concurred that “some teachers understand ADHD, and some don’t”, and that what makes some teachers “better” is their knowledge of ADHD. On reflection, Bobby described feeling, “a bit let down and ignored in some ways” (723).

In terms of support that Bobby would like, he described how he could see the benefit of having access to “an online service, in case you’re really struggling or something, like a website” (790).

Caitlyn, Dyad 5 (Parent 5)

Caitlyn works in children’s services. In addition to Bobby, she has three younger children.

Caitlyn has worked in schools, has been involved in NDS meetings, and currently works in social care. She told how she has a “good understanding of autism and ADHD” (88). In addition to her professional knowledge, Caitlyn makes sense of ADHD through her experiences of living with her husband, also with ADHD, drawing out comparisons between his and Bobby’s traits: “The ADHD brain doesn’t stop…can’t sleep, he can’t sit still; he can’t keep focussed” (509). As with other parents she referred to ADHD as a “chemical imbalance” (342). Caitlyn offered a knowledgeable account of ADHD:

> Caitlyn: …I just see it as about the way the brain processes information… it's everything from kind of, working memory, especially for Bobby; his impulse control… it's really hard because

> obviously he’s got the dual diagnosis; his perception; his ability to regulate… (240-245).

Caitlyn’s description of ADHD reflects both her professional and personal knowledge and experience. As with other parents in this study, she describes how it helps her to try and categorise Bobby’s behaviours into their respective disorders (ASD and ADHD), but finds this confusing, especially given the potential overlap between neurodevelopmental disorders. Caitlyn concluded that, “predominantly, it is the ADHD that makes it really difficult for him”.

As with other parents, Caitlyn used linguistic devices to express her experiences. For example:

> Caitlyn: … when they’re heightened…it's basically like a plug being pulled, and he can't access that part of his brain that he needs to: the bit that can reason, the bit that can think through the next consequences; the bit that can kind of get the information he needs. It's like a complete disconnect and it's like living with a toddler… (245-251).

Caitlyn’s language evokes powerful imagery of Bobby’s reasoning ability swirling down the plug-hole, and how, once gone, he is devoid of the reasoning skills necessary to think through his actions, in turn behaving like a “toddler”.

In terms of Bobby’s behavioural presentation, Caitlyn describes them as “those primitive responses and having “a really unnatural level of energy” (254/583). While she reported that Bobby used to have “full on meltdowns…It's got much better, as he can regulate himself much better, and notices it quicker in himself.” This again, suggests that ADHD is not fixed and that positive changes in presentation can occur over time.

Caitlyn feels as though there is a positive association with ADHD and intelligence:

> Caitlyn: The way his brain works is amazing… it [his brain] cuts through the bullshit sometimes…goes straight to the point… yeah,

> I definitely think there is some kind of link [between ADHD and intelligence], but…with how schools are set up…that’s what’s going to hinder him” (1150-1159).

Caitlyn frames Bobby’s intelligence as a within-child strength, and, in turn sees the predominant difficulties as being situated, not within-child, but within the school system itself, serving to his “hinder” and confine his natural ability. Moreover, Caitlyn expressed feeling that, “…certain teachers just thought he's just more pain in the arse” (772-773). In addition, she feels that teachers wrongly place too much focus on Bobby’s diagnosis of ASD: “every single one of them said… we know that Bobby has autism! The ADHD wasn't even mentioned, but it's actually the ADHD that makes school difficult for him” (820-822). Caitlyn proposes that Bobby’s school are wrong to foreground Bobby’s ASD as his primary diagnosis, suggesting that they do not understand, nor fully appreciate, the extent of difficulties associated with ADHD.

Caitlyn spoke in some depth about the “massive stigma” surrounding ADHD, including its perception as bad parenting. She described how, “there's a lot, especially old school teachers, saying “Oh no, it's just parenting…” (798-801). She therefore described how stigma exists in both the professional and non-professional domains, and how this can have the effect of making “you doubt yourself. I think is it me? Is it our parenting style?” (1368-1370). This, she feels, has had some bearing on her parenting, and on her self-perception as a parent:

> Caitlyn: …because the ADHD diagnosis… I don't ever want for it to be seen as a parenting thing…. I think because there's so much doubt in it already. I feel like I overcompensate on everything, [I’m] organised and sorted and homework and everything else, because, I don't ever want there to be any doubt…that it's his diagnosis. Does that make sense? … my kids have never been late for school… I'm really on it and it really stresses me out (905-916).

In Caitlyn’s experience, the stigma she has experienced adds additional pressure to “overcompensate” in order for her son’s ADHD/symptoms not to be wrongly judged as poor parenting.

Caitlyn felt strongly about challenging the pervasive stigmatised “association between ADHD, deprivation and parenting” (841-842). That said, while looking to eschew this stigma, her experiences of her husband being assessed and diagnosed with ADHD had also led her to consider whether there may be any truth underpinning this:

> Caitlyn: …that's why… the chances are that maybe their kids do all have ADHD because there's a really strong genetic link… maybe the reason mum is not getting them up and to school, or their electricity keeps going off is because…she's also struggling… I think it's because there's a genetic link (848-858).

Caitlyn describes a tension between the existing and pervasive stigma associating ADHD with parenting, while at the same time, considering the potential for many parents, of neurodiverse children to struggle with parenting due to their own neurodiversity. This, she suggests, may, mistakenly, perpetuate the stigma between bad parenting, socio-economic status and ADHD.

Caitlyn described how it was initially Bobby’s behaviours that were raised as concerns. Bobby moved nursery three times as the first two settings were “too chaotic for him” (62). The family’s health visitor noticed some developmental differences initially, followed by school staff raising some concerns when Bobby was in Reception year. His Reception year teacher was an NQT, which Caitlyn suggests was an advantage as she was “more interested and curious [when compared to] “somebody who had been teaching for 20 years” (224). This fits with Jacqui’s views. Caitlyn felt that Bobby was “lucky” in having a couple of really good teachers” (226), suggesting that teacher quality and knowledge in this area may be variable.

Despite the initial behavioural concerns, Caitlyn’s apprehensions developed more around Bobby not meeting his academic potential in school:

> Caitlyn: because he's just naturally quite academic… but every year he kind of dropped down a little bit more… so when I was trying to say Bobby needs some support, they were like well he's only working just below where he should be… (117-123).

Caitlyn did not, therefore, experience pressure from Bobby's school to assess him for ADHD, rather, the opposite, in that they did not feel it necessary as Bobby's ADHD traits were not so overt, or behavioural. Caitlyn describes how she was not "willing to… stand by and watch him struggle more and more… just because he started in a better position than other children" (152-154). This prompted Caitlyn to request that the school to seek EP involvement. She reports that this was resisted by the school as there were "lots of children who were a lot lower than him [academically]" (129). Caitlyn felt "riled" by this, emailed the school, and the school governors, reporting that they "got the EP booked in the next day…" (133). Caitlyn acknowledges using her professional positioning and knowledge to her advantage:

> Caitlyn: If I didn't already know that, I would have just stopped at that first hurdle. And I think that 99% of parents wouldn't know that, and they would have just said, OK, fair enough… I've been able to push it, when I know that actually that's what should be happening and that's their duty of care. (140-145).

Caitlyn describes how, from her professional perspective, she was able to "push" the system more than other parents, not in her position, would have been able to. She was acutely aware that her position and influence was advantageous:

> Caitlyn: So we went straight into NDS waiting list just with a letter from school…Truthfully, I think, if I didn't do the job … If I wasn't as articulate as I can be, I don't think it would have been that easy… We didn't have to argue it…I think if I was in a different position, I don't think that would have happened… that was my job role. We never got asked about parenting and stuff…

> whereas, I know that's a massive thing… It was definitely accepted what I was saying was the truth (53-970).

Caitlyn provides an insightful perspective into her experiences of seeking assessment, recognising that she was able to use her privilege, in a system that, she feels, often lays particular focus on developing parenting skills: “not once have I ever been told to do a parenting course” (978). This, of course, sits in contrast with other parents who, felt that they were doing “endless parenting courses” (Bella, 716), or “had to push” (Jacqui, 258) to get their child assessed. Despite this, she still reported the processes involved in seeking an assessment as incredibly challenging.

On getting Bobby’s diagnosis, Caitlyn told how, “I cried, which is ridiculous because I knew it was coming… it literally made me sob” (945). Even with her professional standing, she too felt validated by his diagnosis, and felt it would enable others to understand that “it [ADHD] is a thing”… (1349). Bobby was also diagnosed with ASD, which Caitlyn described as feeling:

> Caitlyn: really pleased with the dual diagnosis because I feel like that it gets taken more seriously…in high school with the autism/ADHD diagnosis, than with … the ADHD diagnosis [alone] (811-816).

This view is echoed by other participants in the study. Caitlyn described the decision around medication as being, “pretty simple…” as “I’ve seen the difference that medication makes for children with ADHD [and]… anything that I can do to make his life that little bit easier for him isn’t a bad thing” (1068-1069). However, she expressed some concerns around the potential side-effects, including weight loss and reduced growth/height. Given this, Bobby does not take his medication at the weekends, or over holidays.

While Caitlyn described feeling relatively comfortable with her decision to medicate Bobby, she also expressed some underlying tensions: “it does feel a little bit wrong to be playing about with… your child’s health really… more his emotional wellbeing…” (1106-1110), but “…you don’t want to see your kids struggle… why watch him struggle more than he needs to?” (945/1062). On balance, Caitlyn felt that Bobby needs the medication, in a bid to “level the playing field…for him”. She attempted to justify her decision, reporting that “schools aren’t geared up for children with ADHD” (950) and subsequently, Bobby will “probably [be on medication for his ADHD] throughout his school life…” (1111).

Despite her professional knowledge, Caitlyn described navigating the ADHD pathways, services and educational provisions as “a massive battlefield” (85). She discussed this more frequently than any other theme, and more than any other parent participants, suggesting its importance to her. Her difficulties with educational settings had persisted from nursery, through primary school, and into secondary school. Caitlyn expressed how Bobby’s differences were, perhaps, less noticeable in Reception Year as it “is just all about play” (686), becoming increasingly noticeable over years 1 and 2: as “his peers got older and stiller, Bobby never did”. This suggests that Bobby’s difficulties became “more and more noticeable as they got bigger” (688-692). For example,

> Caitlyn: He's good at math, but he'll randomly…get up and wander around the classroom. He'll be tapping… constantly being told to stop doing something, like stop tapping, stop moving, stop fidgeting, stop leaning over…and school felt like quite a negative place…he really didn't want to go…he’s started to get really disillusioned with school because, you're constantly… it's quite a negative experience… (712-735).

Caitlyn describes Bobby’s behaviours, not as “purposefully disruptive” (723), but rather as symptoms of his ADHD, many of which seem to be beyond his control: “he doesn't really know what he's doing….he's not doing it on purpose and then he does it again, and gets sent out” (733). In turn, this has bearing on Bobby’s perception of school, and of himself:

> Caitlyn: Bobby really hated school… and now… because he was noticing that he was really different, he was quite embarrassed by it… it's not how school systems are set up, is it? …Children aren't

> supposed to be moving and rolling around and stuff, and it's a shame because he is listening…that's how he listens... he needs to be moving…and they don't seem to have…really got that (719-751).

Caitlyn posits that while there are some good teachers, that seem to understand Bobby, the school system does not cater for Bobby's needs. While Bobby is reportedly academically able, Caitlyn feels that the school system is "constantly kind of shoving him into a hole that he doesn't really quite fit" (951).

Like other parents, Caitlyn cites homework as a "huge issue, massive issue… the only time… we have massive meltdowns to the point that he's breaking things or hysterical or lashing out, is over homework" (889-902).

In terms of support, Caitlyn expressed how "there hasn't been any support" (1184). To this end, "we paid privately, for… a clinical psychologist…she's done some kind of CBT-like regulation stuff… but we had to pay for that privately" (1238-1242).

Caitlyn spoke, at length, about a highly challenging consultation that she had with an experienced professional within children's services, because she felt that the practitioner was particularly judgemental of her parenting:

> Caitlyn: I found that meeting really, really difficult and that was me knowing that I'm doing my best and actually, I'm a good mum… as much as we can all be… and I know that, and I still came out of that meeting feeling like absolute shit (391-497).

On further investigation, Caitlyn described how she felt that the professional judged her as she did not understand the complexities of being a parent of a child with SEN. She described the affect this had on her:

> Caitlyn: It's really, really difficult… I don't think maybe they understand… you know they don't need to beat you up about it… we do enough of that for ourselves. You know, there's not a day goes by where I think should I have done that a little bit

> differently?... there's enough parental guilt, I think that's basically what being a parent is: you basically feel guilty for something pretty much all the time (407-413).

It seems that Caitlyn went into this meeting seeking support and understanding, yet felt hurt to encounter professional stigma and judgement, adding to her existing feelings of parental guilt. In addition, she felt that the professional’s report demonstrated a lack of understanding of the challenges involved in parenting a child with ADHD, and questioned if they would have perceived her parenting more positively, had she been a parent herself:

> Caitlyn: I felt really judged in that meeting… I don't think sometimes you realise how… it is constant. It's constant, constant, constant all the time... and I don't think that was understood, where I think… if someone was a parent… you know I had loads opinions about parenting before I had children and they quickly turned all those on their head – the lot of them... (431-438).

Following this, Caitlyn successfully requested that the professional’s report was amended, removing comments about her parenting being “laissez-faire” – a comment that “really upset [her] and [made her] really angry” (364).

In terms of improving support services, Caitlyn suggested that it would be useful for “parents and potentially for children…to be able to “pick up the phone and speak to someone who's knowledgeable, understanding…” (1224-1225). She feels that support could be in the form of peer support, as, “unless you're living it, day in day out, it's really hard to understand…” (1229-1230). Caitlyn suggests that other parents may act as helpful support, and even though they may be less knowledgeable from a professional perspective, it would be useful to speak with “other parents… going through similar things” (1233).

Creation of Subordinate and Superordinate Themes

Following on from the process of the individual participant's transcript analysis, above, the potential emergent themes that arose from this process were reduced, and consolidated a number of times, (see Appendix 13.0). This led to the creation of each participant's subordinate themes. The participants' subordinate themes were then collated in two master tables of subordinate themes with one for child participants and one for parent participants, as seen in Figures 1.0 and 2.0 below.

The participant's subordinate themes that arose most frequently in the interviews, are at the top of the table, with those that arose least frequently sitting at the bottom of the table. The total frequency that subordinate themes arose during participant's interviews is also included in brackets.

The subordinate themes were then finally categorised, and colour-coded under three superordinate themes, with each one relating to a RQ, and/or a sub-RQ. The colour-coded superordinate themes are in Table 2.0 below. Participants' subordinate themes were then colour-coded, to indicate the superordinate theme that they pertain to, as seen in Table 2.0 (below). For example, in Figure 1.0, Tristan's column shows the subordinate theme 'My ADHD, behaviour and my anger' at the top in green. The green indicates that this subordinate theme is classified under superordinate theme 1 (My ADHD, my symptoms, and its impact). This in turn pertains to RQ1 (What are the lived experiences of CYP with ADHD?) and sub-RQ1 (How do participants make sense of ADHD?). Moreover, its position at the top of the table indicates that he spoke most frequently about this particular subordinate theme. The frequencies in that participants discussed topics, is therefore represented by their position in their table, with those topics, or subordinate themes, discussed least frequently appearing at the bottom of the table.

It should be noted that situating the subordinate themes under the relevant superordinate theme was not uncomplicated, with some subordinate themes falling under two superordinate themes, hence appearing as two colours (as seen in Figures 1.0 and 2.0). This was done when it was felt that a participant's subordinate theme fell relatively equally under two of the superordinate themes.

For example, Peter’s subordinate theme of ‘The school’s influence’ (in Figure 2.0) falls under both the blue and red superordinate themes, as it was felt that this relates to ‘Systems, school and support’ (superordinate theme 3, colour-coded in red); but also relates to ‘Assessment, diagnosis and medication’ (superordinate theme 2, colour-coded in blue) as the school had influenced Peter’s decision to assess and medicate his child. Some further reflections around the process of data analysis are in Appendix 15.0, with further reflections on the process of creating the subordinate themes in Appendix 16.0.

Figure 1.0

Master Table of Subordinate Themes among Child Participants – Colour-coded to Represent the Superordinate Themes that they Fall Under

Tristan	Verity	Ellie	Tommy	Bobby
• My ADHD, behaviour & my anger (28) • Medication pros and cons (9) • Difficulties with teachers & homework (8) • Use of pronouns to create distance (6+) • Control yourself (6) • The support of my family, friends & school (5) • Treat me as you treat others (5) • Sibling conflict (4) • Stigma & how the perception of others worries me (4) • Hope for the future (3)	• My anger, my emotions, my difficulties & consequences (32) • Difficulties with peers & friends (9) • My world is confusing (ADHD/ ASD) (8) • My perception of self & others (7) • Social exclusion/ isolation (7) • I don't like school; I find it upsetting (6) • My support, & the lack of it (5) • Making it better (4) • Lack of awareness of difficulties & their consequences (2) • Mum's support makes me feel safe (2)	• My ADHD is bad: my struggle with emotions, concentration, behaviour & lack of control (45) • The support I get & what I'd like more of (24) • When things go well: coping, concentration & future hope (18) • Ambivalence around medication & not wanting to take it (14) • Medication & its benefits, including how it helps me concentrate & learn (11) • The side effects & decisions around medication (11) • School conflict (10) • Friendships & social exclusion (9) • Family conflict (7)	• My difficulties, including concentration, hyperactivity, impulsivity, anger, stress & sleep (34) • Some teachers don't understand ADHD, or do enough for me (34) • ADHD (& ASD): my struggle to understand (22) • Taking medication: it's pros & cons (17) • The school system doesn't help me (8) • My friends & family (7) • My future with ADHD (7) • People know about my ADHD (7) • The positives of having ADHD (7) • My feelings & mental health (6) • The support I do/have received (5)	• My difficulties, including concentration, organisation, hyperactivity, impulsivity, writing, communication & sleep (47) • How I make sense of ADHD: If I concentrate, I can be well (23) • Losing focus in interview/ fidgeting & lots of movement (16) • Assessment & diagnosis: confusion & mixed emotions (13) • Medication dilemma: it helps but I don't want to take it (13) • ASD, Anxiety & my intrusive thoughts (7) • My support has been variable (5) • Siblings: my fraught relationship with them (5) • People thought I was a naughty boy & a bit mad (3)

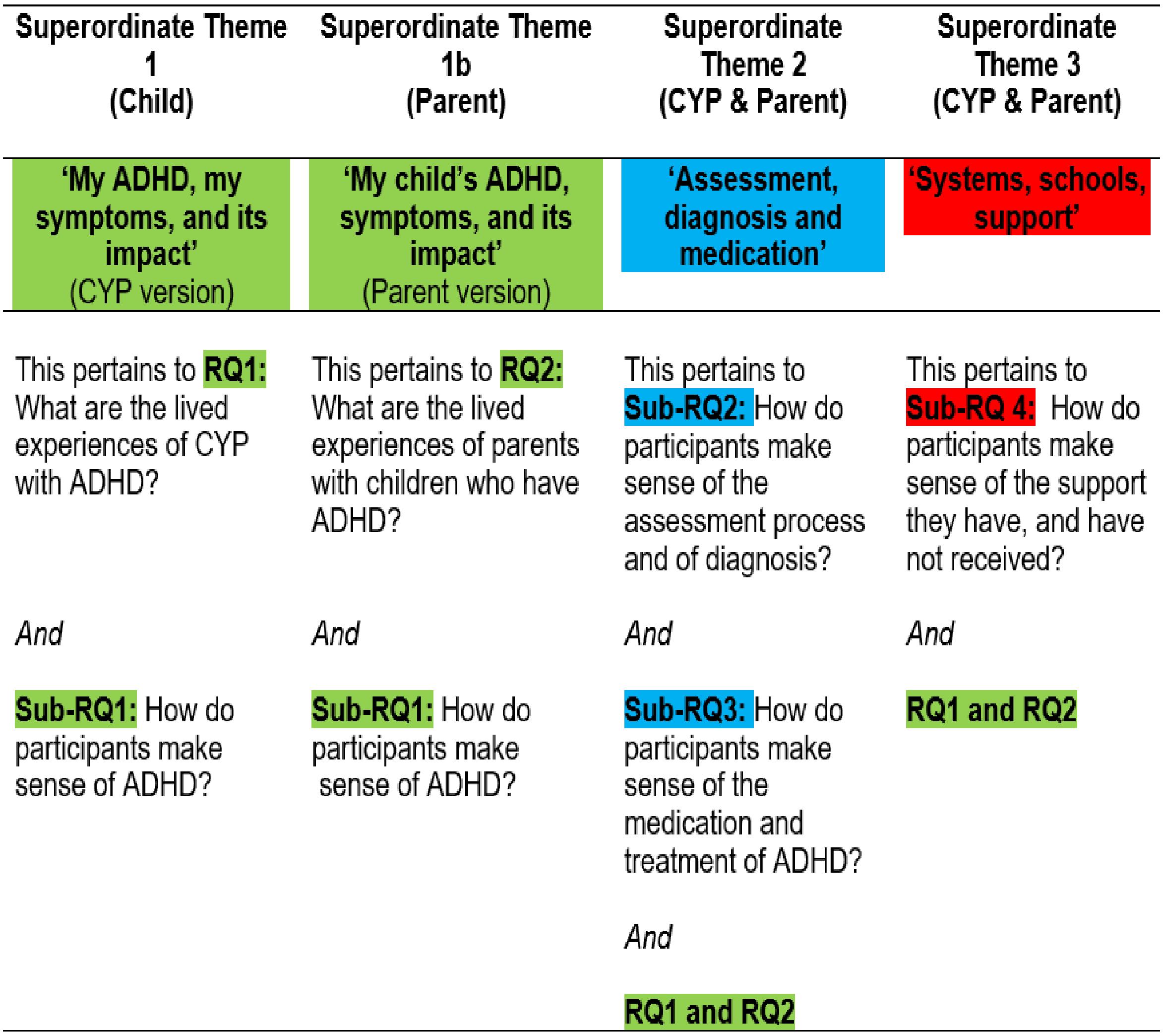
Figure 2.0

Master Table of Subordinate Themes among Parent Participants – Colour-coded to Represent the Superordinate Themes that they Fall Under

Peter	Bella	Jacqui	Rhonda	Caitlyn
• Making sense of ADHD & our child & their behaviours (33) • The parental role, family relationships, conflict & strain (12) • We get the worst of it: intolerance, impatience, & emotional dysregulation (11) • The assessment/ diagnosis process (9) • Stigma & the expectations of others (8) • Friendship difficulties & social impact (7) • The school's influence (6) • Child strengths & their future (4) • Medication in supporting child & the school? (3) • The role of support services (3)	• Behavioural symptoms & presentation (25) • Stigma, critical voices & societal pressures (19) • "Broken": The Parental role & emotional burden (self-blame, anxiety, stress (17) • The school is letting us down (16) • Fighting with the systems (12) • Exclusion/ isolation (8) • Lack of support (8) • Aetiology, co-occurrence & trying to make sense of ADHD (7) • The effect on her siblings (7) • Pressure to assess/ medicate (school/ teacher/ parent) (6) • Our dilemma around medication (3)	• Medication: benefits; external influence & justifying its use (32) • Absence of support & quality advice (plus some positive support) (30) • School & teacher differences in understanding & approach (24) • My child's behavioural presentation & impact (23) • The parental role; parental emotions, mental health & family issues (22) • Difficulties with assessment & the benefits of diagnosis (16) • Stigma & judgement (15) • My understanding of ADHD (11) • Social isolation/ exclusion (10) • Some positives & future hope (6)	• My child's behavioural symptoms & presentation (94) • My continual fight with school/ nursery (50) • Stigma, misunderstanding & the judgement of others (33) • Tears & struggle: How C's ADHD has affected me personally (24) • The support & advice I received (20) • Lack of service support: "off you go" (19) • Friendships issues & social exclusion & (13) • Medication: benefits, decisions & concerns (18) • My parental role: as researcher & hands-on support (6) • Aetiology: Nature vs nurture (4) • Signs of maturation, & hope (4)	• Difficulties with nursery/school system & teachers (57) • Support: our fight with services & lack of support (46) • My child's behaviours & presentation (43) • My understanding of ADHD (38) • My professional & personal advantage & those without it (37) • Stigma – bad parenting & judgement (36) • The difficulties of parenting guilt, (34) • Medication, decision making & how it's helping (21) • Progress, his positives & hopeful future (19) • Issues with siblings (7) • Assessment & diagnosis: upsetting, validating & helpful (4)

Table 2.0

The Three Colour-coded Superordinate Themes with their Respective RQs and Sub-RQs



Superordinate Theme 1 (Child)	**Superordinate Theme 1b (Parent)**	**Superordinate Theme 2 (CYP & Parent)**	**Superordinate Theme 3 (CYP & Parent)**
'My ADHD, my symptoms, and its impact' (CYP version)	**'My child's ADHD, symptoms, and its impact'** (Parent version)	**'Assessment, diagnosis and medication'**	**'Systems, schools, support'**
This pertains to **RQ1:** What are the lived experiences of CYP with ADHD? *And* **Sub-RQ1:** How do participants make sense of ADHD?	This pertains to **RQ2:** What are the lived experiences of parents with children who have ADHD? *And* **Sub-RQ1:** How do participants make sense of ADHD?	This pertains to **Sub-RQ2:** How do participants make sense of the assessment process and of diagnosis? *And* **Sub-RQ3:** How do participants make sense of the medication and treatment of ADHD? *And* **RQ1 and RQ2**	This pertains to **Sub-RQ 4:** How do participants make sense of the support they have, and have not received? *And* **RQ1 and RQ2**

Discussion

This section aims to discuss the findings under each of the superordinate themes, therefore, answering the RQs and drawing out conclusions from the study. Subsequent to this, the implications for educational psychologists will be discussed, followed by the conclusion, the limitations of this study, and proposed areas of future research.

Superordinate Theme 1: My ADHD, My Symptoms and its Impact (Pertaining to RQ1 and Sub-RQ1)

CYP in this study predominantly attempted to make sense of ADHD through their self-perceived difficulties, including their anger and emotional dysregulation, lack of control, hyperactivity, and impulsivity. For the most part, this aligns with Singh’s behaviour niche, in which participants saw themselves as “angry, aggressive and naughty” (Singh, 2012, p.18). This is also in keeping with Hemming’s (2017) study, exploring the experiences of students diagnosed with ADHD, and their teachers’ experiences. This found that CYP draw upon their personal experiences to help them to make sense of complex phenomena such as ADHD. Participants also attempted to make sense of their symptoms and difficulties in relation to school and their learning experiences, in keeping with Singh’s performance niche (Singh, 2012). These were expressed as difficulties in concentration and focus, and difficulties in planning, organisation, and keeping up with the pace of the learning. However, unlike the Singh study, this study reports less of a clear demarcation between the two niches, as the child participants’ behavioural symptoms appeared enmeshed with their learning, and in turn, had significant bearing on their relationships with teaching staff, effecting their perception as learners, and their self-perception more widely.

All child participants in this study reported struggling to make sense of their own behaviours – something not explicitly encountered in the literature reviewed. In particular, all child participants described a marked lack of control over their emotions and their behaviours, and, in turn, how difficult this was for them to reconcile with their, more positive notions of self. What became ostensible in this study was the immediacy of their emotions, and their actions, coupled with their difficulties in inhibitory control (Mahone, 2002). This meant that they often felt that their emotional dysregulation, and behaviours were a force, beyond their locus of control. Honkasilta (2016) presented the concept of control as a complex and contradictory phenomenon (Honkasilta, 2016); Brady explored control, putting forward a credible argument that the behaviour of CYP with ADHD may be interpreted as control-seeking acts, presumably manifesting at an unconscious level. Future research may explore the extent to which offering CYP with ADHD a greater sense of perceived control, may have bearing on their behavioural presentation, and in turn, on their self-perception.

CYP participants in this study reported great difficulty in making sense of their own impulsive behaviours, and high levels of emotional dysregulation, akin to a complex and perplexing Jekyll and Hyde-type personae. What’s more, when they were able to come out of their arousal cycles, they reported being faced with the aftermath of their uncontrollable actions. This included damaged relationships, social and educational exclusion, and often punitive sanctions. In keeping with Honkasilta (2016), the subsequent sanctions imposed on them were reported as feeling disproportionate and unfair, and indicative of exclusionary, over inclusive practices. Such impulsive behaviours support the bio-medical model of ADHD, associating the prefrontal cortex with executive functioning, including: self-regulation, inhibitory control, and sustained behaviour control, attentional control and task-switching/cognitive flexibility.

Most children in the study recognised that they had been physical with others, at times of emotional dysregulation, and, in keeping with (Singh, 2012) they described complex tensions between themselves as perceived victims, and victimisers. The behavioural traits of some child participants led to feelings of guilt, self-blame, sadness and feeling scared, in keeping with Honkasilta (2016) who posits that children with ADHD can feel intimidated, and subsequently submissive, or resistant as a response reaction. In keeping with Honkasilta (2016), child participants in this study perceived that others viewed them as naughty children, which in turn, had significant bearing on their ability to form stable and positive self-identities. Thus child participants not only felt stigmatised by others, but were also caught in a cycle of self-stigmatising, perpetually shaped by their perceptions of others’ views of them. It is argued that the cyclical nature of this pattern created a type of self-fulfilling prophecy (Honkasilta, 2016), in which the children potentially acted in a way that was in keeping with their self-perception i.e. as naughty. It is argued that such negative perpetuating cycles potentially make it more challenging, for others, to move away from a position of deviance labelling, towards more humanistic approaches in keeping with Honkasilta (2016).

That some of the child participants exhibited some self-blame, remorse and guilt foregrounds a tension in the notion of callous-unemotional traits (CUT) and its association with people with ADHD. Some child participants appeared to demonstrate some awareness of how their behaviours affected others, and their relationships with others, while others appeared to be significantly blind-sided by this. This did not become fully apparent until comparisons were made between the child participants and their respective parent's narratives. This inherently presents an argument that neither child, nor parent studies alone have the capability to capture the wider perspectives found within a combined parent and child analysis.

On the other hand, the CYP participants' actions were, in many ways, in keeping with CUT in that their behaviours, at the time of emotional dysregulation, appeared to lack empathy, and prosocial skills, exhibited a disregard for others, and, at times, a perceived 'callousness' with lacking affect (Masi et al. 2020). Furthermore, all five child participants exhibited a lack of awareness about the extent that their behaviours were impacting upon the lives of others, in keeping with Nijmeijer et al. (2008). This further supports the notion of co-occurring CUTs to a greater extent, and whilst there was only a small sample in this study, interestingly, this exceeds the reported co-occurring ADHD/CUT prevalence rate of between 24-50% as reported in Masi et al. (2020).

There may, of course, be other plausible explanations for this observed phenomena. One would be in considering the notion of 'theory of mind' (ToM). This is described as the ability to make basic assumptions, or hypotheses about what is likely occurring in another person's mind (Smith et al. 2007), and is said to develop around the age of five years (Frith & Frith, 2005). Studies have reported a correlative relationship between CYP with ADHD and difficulties with the development of ToM, when compared to their neurotypical peers (Mary et al. 2016). This may go some way in considering why child participants, in this study, did not appear to understand the extent in which their behaviours were affecting those around them.

Difficulties with developing ToM, is associated with difficulties in executive functioning (EF), or ‘executive dysfunction’. A plausible EF explanation may be that CYP with ADHD have a reported low frustration tolerance, that is perhaps encapsulated in the DSM-5’s label of ‘Rejection Sensitive Dysphoria’, that is reported as co-occurring with people with ADHD (Bedrossian, 2021). Those with ADHD are also likely to present with emotional impulsivity and ‘deficient emotional self-regulation’ (DESR) (Barkley, 2015), to the extent that professional voices are calling for emotional dysregulation to be included as a fourth core trait of ADHD (Barkley, 2015; Nigg et al. 2020; Shaw et al. 2014). This may also explain why ADHD is reported to co-occur with Intermittent Explosive Disorder (DSM-5, 2013)[1]. Additionally, people with ADHD are more likely to present with difficulties in inhibitory control, self-regulation and sustained behaviour control (Lambek et al. 2011; Mahone et al. 2002) meaning that CYP with ADHD may well find it significantly more difficult to control their behaviours, as seen with the children in this study. Another potential factor may be that populations with ADHD report higher levels of hyperfocus (Grotewiel et al. 2022), that is described as experiences of “enhanced attentional focus and diminished awareness of time and the environment” (Groen et al. 2020) and difficulties in context/task switching/switching actions, or cognitive flexibility (Mary et al. 2016) as reported by, child participant, Tristan who spoke of being in a ‘flow state’ when engaged in upsetting his sister, that he found incredibly difficult to disengage from. Cumulatively, this may make it particularly difficult for CYP with ADHD to stop engaging in their dysregulated behaviours once engaged in them, thus appearing as ‘callous’, or unemotional in such moments.

---

[1] The DSM-5 (2013) places Intermittent Explosive Disorder under ‘Differential Diagnosis’, but states that it occurs in adults at rates above population levels (DSM-5, 2013, p.65).

Further, CYP with ADHD may well take longer to return to a state of emotional regulation than their neurotypical peers (Barkley, 2015) meaning that they may appear as unemotional, or uncaring, at times, as others may presume them to be in a re-regulated state of being, and may therefore mistakenly, believe that they are in a position to reason more effectively than they actually can at that time. This may partially explain why CYP with ADHD appear as defiant, and oppositional, and is in keeping with the high co-occurrence of ADHD and other disorders including Oppositional Defiance Disorder (Bedrossian, 2021; Gnanavel et al. 2019; Kadesjo & Gillberg, 2001; Pliszka, 2003).

Finally, attentional deficits may make it harder for those with ADHD to recognise and apportion attention to their own, and others' emotional states, both in times of emotional dysregulation, and in regulated states of being. Moreover, attentional difficulties are likely to have significant bearing on their ability to reflect upon their actions, and its bearing on others, at a deeper level, due to the attention and focus that is required to embark on such higher-order cognitive endeavours (Shaw et al. 2014). It is therefore put forward that by considering the children in this study through the lens of executive functioning difficulties potentially affords us a better understanding of the mechanisms underpinning their perceived 'callous' and 'unemotional traits' as put forward by CUT theory. This is an area that warrants further consideration and research.

In keeping with the findings in Ringer et al. (2020), while participants in this study sought out stable and valid explanations of ADHD, they frequently encountered incredibly complex and contradictory ones. This aligns with Flack's (2018) study, that qualitatively explored boys' experiences of ADHD. This reported that people with ADHD are likely to experience ADHD quite differently, due to its heterogeneity of symptoms. Most CYP participants in this study demonstrated that they knew very little about the condition, even what the acronym ADHD stood for, as reported in Singh (2012). Moreover, some significant misunderstandings around ADHD were reported, with one child describing how they could make ADHD go away if they concentrated hard enough. All of the child participants expressed how they were still attempting to make sense of what ADHD is and, in turn, to make sense of themselves. To date, there are limited studies reporting this (Singh, 2012). The child participants unanimously discussed their experiences of living with attentional difficulties, especially in a school environment aligning with Singh (2012) and ADDiSS (2005), with the latter reporting that nearly 80% of people with ADHD found this to be “the hardest bit” (ADDiSS, 2005, p.6). This aligns with it being “a persistent pattern of inattention” as defined in the DSM-5 (2013, p.59). Interviewing the CYP provided an opportunity to observe their attentional difficulties, first hand, with three of the five participants exhibiting significant difficulties in concentration over the course of the interview.

Four of the five CYP participants demonstrated little understanding of where ADHD might ‘come from’, or its aetiology. This may be partially explained by the relatively young age of the participants (between 9 and 12 years). However, it may also suggest that they were not provided with coherent, child-friendly, and memorable explanations of ADHD, that may have helped them to understand more about it and their symptoms, and ways of effectively managing them. While Singh (2012) similarly found that CYP lacked knowledge around ADHD, Honkasilta (2016) reported that CYP were, at least, aware of their diagnosis and what ADHD is.

Some other studies, most notably, Singh (2012) and Honkasilta (2016) have gone some way in exploring how CYP attempt to make sense of their ADHD, with the latter acknowledging that the meaning of ADHD from a youth perspective is still not fully understood (Honkasilta, 2016). However, almost comprehensively, child participants in this study relied on attempting to make sense of ADHD, through their own lived experiences. This was reported as being a complex process as they described their traits to be variable, rather than fixed, giving the impression, to others, that they may have more control than they actually have.

While the child participants in this study didn’t use the language of stigma, some clearly experienced feeling stigmatised. This was exhibited through most participants choosing not to tell others, even their teachers, in keeping with Singh’s (2012) study, as they did not want to appear different, for the most part. However, this created further tensions as they concurrently sought greater understanding and support from teaching staff. This appears to reflect the complex, confusing and contradictory nature of living with ADHD.

Superordinate Theme 1b: My Child's ADHD, Symptoms and its Impact (RQ1 and Sub-RQ1)

All of the parent participants predominantly attempted to make sense of ADHD through their experiences of living with a child with ADHD, and particularly through their child's behavioural traits. Parents appeared able to offer much richer, detailed accounts than their CYP, reporting the substantial impact that ADHD had on their lives, on their family members, friendships and education. Their accounts support the findings of Leitch et al. (2019), who reported significant familial and relational strain (Leitch et al. 2019). As described above, there were significant differences between child and parents accounts in this study. This may be partially explained by the CUT theory (Masi et al. 2020), or by considering theory of mind and executive functioning difficulties, for example. However, such discrepancies between parent and child accounts were not reported so conclusively in the literature reviewed, suggesting that this is a relatively novel perspective on this, and an important finding. It is also plausible that parents were able to offer particular candour in their interviews as they were not reflecting upon their own behaviours, rather they were reporting their child's difficulties, thus offering them an emotional buffer from the complex process of self-critiquing one's own behaviours. This is in keeping with reports that some CYP may be embarrassed to discuss the true extent of their difficulties, especially if it shows them in a bad light (Srinath et al. 2019). This study found that parents were predominantly attempting to make sense of their children, who were, in turn, attempting to make sense of their day-to-day lived experiences, their changeable perceptions of self, and of ADHD itself. Therefore, while IPA typically utilises the use of a double hermeneutic in which the researcher attempts to make sense of the participant's experiences (Smith et al. 2012), in this instance, the researcher was attempting to make sense of the parent, who was attempting to make sense of their child, who was attempting to make sense of their own self, thus creating a type of complex triple hermeneutic.

In keeping with Corcoran et al. (2017), all parents noticed differences in their child from a young age i.e. before the school entry age. All described their child's behavioural difficulties vividly and in depth, drawing upon different linguistic devices to ensure that the extent of their child's difficulties was heard. While many of the CYP's reported behaviours may well have been explained by the three core symptoms of hyperactivity, impulsivity and inattention, that are "judged to be excessive for the person's age…" (NICE, 2019, para 1), this did not satisfactorily encompass the significant behavioural difficulties reported in this research. This study therefore supports the notion of emotional regulation becoming a fourth core trait of ADHD rather than a co-occurring one; it is recognised that the sample size for this study is small and that while generalisations cannot be made from this alone, that further exploration around this topic is warranted.

An interesting finding arising from this study, and not obviously reported in the literature reviewed, was that the symptoms and traits commonly associated with ADHD are not fixed, or consistent, rather they were reported as being fluid, appearing variable on different days, and in different contexts. It is suggested that this warrants further investigation, especially considering whether there are patterns to the variability of symptoms, and what potential there is to reduce symptoms for longer periods of time.

While parent participants predominantly attempted to make sense of ADHD through the lens of their child, and their own difficulties, they mostly exhibited a better understanding of the aetiology of ADHD. This may be unsurprising given that they were the adults, and were taking overall responsibility for their child's development and wellbeing. However, the level of knowledge around ADHD was not consistent, and while all parents demonstrated some knowledge of there being either a "chemical imbalance" in the brain, or a hereditary association, understandings did not go much beyond this, with little exception. For example, parents did not refer to dopaminergic hypotheses, or to neurotransmitters, as widely reported (Hou et al. 2018; Wegmann, 2015). This is therefore, mostly in keeping with the finding that parents exhibited a “sketchy understanding” of the bio-medical model as an explanation for their child’s behaviours (Corcoran et al. 2017, p.343). One plausible explanation for this is that there are no known biological markers for ADHD that exist at this time (DSM-5, 2013). This, perhaps, offers a tentative explanation as to why parents relied on reductionist aetiological accounts, and knew little about the underlying function of their child’s medication: fundamentally due to a lack of hard evidence in this field. This is also in keeping with the media’s reductionist portrayal of ADHD (Ahmed et al. 2017) and its propensity to unquestioningly draw upon the pervasive bio-medical model (Mahone et al. 2002). It is argued herein that this is potentially one reason why parents of children with ADHD “yearn for definitive information” (Corcoran et al. 2017, p.343), yet find little to definitively come to terms with. This is significant and it is argued that many parents and beneficiaries of medicine would benefit from more detailed, nuanced accounts of the purported role, function and mechanisms of ADHD medication. Hemming (2017) put forward that providing a bio-psycho-social explanation of ADHD may be particularly beneficial in providing a greater sense of personal autonomy, and a sense of control and optimism to CYP with ADHD.

All parent participants described their child’s emotional dysregulation in terms of anger, hyperactivity, and being explosive. They also frequently spoke about the profound impact of their child’s behaviours. This study found that their child’s behaviours and attempting to manage them, had a “massive” effect on parental mental health, well-being and relationships, reporting feelings of sadness, emotional burden, upset, guilt, stress and in one case of feeling “broken”. This is in keeping with other studies reporting similar findings (Corcoran et al. 2017; Leitch et al. 2019). All parents reported such feelings were further compounded by stigma in various guises. This had significant bearing on parents’ self-perception as effective parents and on them socially, with parents making considerable adjustments in their lives, due to their acute awareness of the judgmental views of others. In many senses, parents appeared to unconsciously adopt self-stigmatising perceptions of their self, and an unfavorable degraded parental identity in keeping with Mueller (2012), despite some attempts to counter this.

In keeping with Corcoran et al. (2017), the stigma surrounding ADHD impacted upon parent's perception as effective parents, and saw them questioning their own parenting skills, thus effectively adopting the pervasive stigmatised portrayal of ADHD as "bad parenting" (Timimi, 2005). For some parents in this study, this had the additional effect of further compounding their own feelings of parental guilt, and self-blame. Parents also felt a sense of guilt as they felt unable to parent in the way that they wanted to, or previously thought that they were capable of, aligning with Ringer et al. (2020). In keeping with Corcoran et al. (2017) some parent participants reported that parental decisions were affected by family, friends, school staff and healthcare professionals. It was noteworthy that one parent described a tension that existed between feeling that he had to educate, discipline and correct his child's behaviours, while attempting to avoid further adding to his child's negative self-perception, and avoid triggering further emotional dysregulation.

It was telling that stigma was not confined to a wider societal level, as is commonly reported. Rather parents described how harmful and stigmatic views were pervasive, even within their own friends and families. This added additional complexities in feeling that they needed to find ways to justify their child's behaviours, and justify their decisions around seeking assessment and diagnosis, and in justifying the use of medical intervention to their inner-most circles.

All parents in this study attempted to make sense of their child through an ASD, or suspected ASD lens. They did this through attempting to decompartmentalise their child's symptoms, to their respective disorders. This was not previously identified in the literature review. The comorbidity of suspected, or diagnosed ASD, with ADHD in this study, was therefore 100%, exceeding the existing prevalence figures on this (Antshel et al. 2016). While there is some literature exploring the importance of early identification of comorbid ASD/ADHD (Manohar et al. 2018), less is known regarding the lived experiences of CYPF trying to make sense of co-occurring ASD/ADHD.

Nearly all parent participants reported that their child's behavioural traits had a significant bearing on both the child's social experiences and that of their parents. In keeping with Ringer et al. (2020), parents sought unproblematic situations in which their child’s behavioural difficulties would not manifest unfavourably, or be witnessed by others, therefore reducing the potential for further judgement. This had the effect of exacerbating their experiences as some felt that they could not attend social activities, that would otherwise have acted as protective factors for them. In many cases, parents were not only feeling the pressure that their child’s ADHD symptoms were having on their social lives, and potential support networks, but were also witnessing their child’s social exclusion, both at school, and within their diminishing friendship groups. This resulted in parents feeling that they were fighting for their child’s inclusion in school, and were left feeling resentful and angry towards those practices socially isolating their children. It is suggested that this finding justifies the critical epistemological position adopted in this study, as it explored issues relating to inequality, inclusion, and marginalisation, and further aligns with the emancipatory position embedded within the critical epistemological ideology (Scotland, 2012).

Studies have shown that living with a child with ADHD can have “adverse effects…on parents and siblings, causing disturbances to family and marital functioning” (Harpin, 2005, p.2). Parents in this study spoke at length about the effect that their child’s ADHD/behaviour was having on siblings, and to a lesser extent on their own marital/partner relationships. It is proposed that further research should investigate the impact that having a child with ADHD can have on both siblings and marital/partner relationships.

A somewhat unexpected finding of this study was around the impact that set homework was having on children with ADHD and their parents. Three of the five parents reported homework to be an incredibly challenging endeavour, and all said that it acted as a trigger to undesirable behaviours and emotional dysregulation in their child. One of the benefits of conducting the study from a bottom-up approach was that it enabled this to arise quite unexpectedly. A retrospective search found that there is some literature in this area, already reporting difficulties around homework in children with ADHD, especially those with inattentive symptoms, and for those with co-occurring conditions (Langberg et al. 2010).

Superordinate Themes 2 and 3: (Pertaining to Sub-RQs 2, 3 and 4)

Child Participants

Guidelines for assessment of CYP posit that assessments should “aid the child and family in developing a clearer understanding of their own difficulties and give them an opportunity to reflect on the information they share” (Srinath et al. 2019, p.159). However, the child participants herein expressed feeling largely unaware that they were being assessed, with little recollection of it. This is considered to be a unique and somewhat disconcerting finding. This added to their sense of confusion and potentially hindered them in making sense of the assessment, their diagnosis of ADHD and of their self-identity. Those CYP participants who were accompanied by their parent in their interview, took the opportunity to ask them more about the assessment process, in a bid to make sense of it, demonstrating a desire to learn more about this. For all CYP participants there was a perceived sense of their parents having full control over assessment decisions, which may be attributed to the children’s respective ages at the time. This is a complex area, that is currently addressed through Gillick competency, stating that psychologists working with CYP who are “deemed to be competent to make their own decisions can give consent to involvement with a psychologist” (BPS, 2017b, p.27). This study did not ascertain whether the CYP participants were Gillick competent, or not. However, given that none of the CYP participants were seemingly unaware that they were being assessed, suggests that outstanding questions remain as to whether CYP are offered adequate opportunities to make sense of, and understand the assessment process, in line with the BPS Practice Guidelines (2017).

Similarly, the child participants had little recollection of being diagnosed, or labelled with ADHD, and appeared to know little about ADHD in general, prompting us to question whether enough is being done in respect of this, and how much information was made clear to them post-assessment. As has been previously reported (Flack, 2018), this study found some pros and cons to CYP receiving a diagnostic label, for both the child and parent participants. While one child felt diagnosis would help others to understand their behaviours, the majority of child participants worried about what others would think of them, choosing to keep their diagnosis to themselves, rather than sharing this with others, in keeping with the findings from Singh (2012). It is therefore suggested that more could be done in considering how to empower CYP to better understand ADHD, and make sense of it, rather than being passive recipients of their diagnosis, as put forward by Hemming (2017). This may encourage CYP to feel more confident in sharing their diagnosis with others, without fear of further judgement, or fear of being treated differently.

Four children (80%) in this study were taking medication for their ADHD. Collectively they knew little about what they were taking. This suggests that the CYP participants were most likely, not meaningfully involved in their own management plans, as recommended in the NICE guidelines (2018). This supports the notion that “little is known about how well ADHD guidelines are implemented in routine clinical practice” (Sayal et al. 2017, p.181). Two children were positive about taking medication, reporting benefits in their concentration, and further describing it as a stabilising factor for them in reducing their hyperactive traits and providing a greater sense of inhibitory control over their emotions and actions. This is in line with the Singh’s (2012) study in which participants reported feeling some additional control over their impulsive behaviours, and an increased ability to be able to stop and think when on medication.

The other two children described a tension in taking medication: both felt some benefits, but at the same time, they expressed a desire to stop taking them. One suggested that while taking medication, he lost himself, with the other expressing a sense that he was medicating himself for the school’s benefit, and not his own. This potentially supports the notion that children can be mere passive recipients of medication, imposed upon them in a bid to make them classroom ready (McCubbin & Cohen, 1999).

This also prompts consideration as to whether too much emphasis is placed on medication, over supporting children’s holistic self-development and their sense of improved agency. It is put forward that, despite some reported benefits, there is still potentially an over-reliance on taking medication as the predominant intervention, over personal self-development and systemic adjustments, particularly in schools. This supports the notion that medication can “pose a threat to child development, potentially in diminishing a child’s high expectations and personal responsibility” (Singh, 2012, p.29). This study identified limited existing literature exploring CYP’s choice, and views, around taking medication for ADHD (Brady, 2014; McElearney et al. 2014; Singh, 2012). In line with these authors, it is argued that more enquiry is needed in investigating the extent to which the preferences of the CYP are included in medication choices, in line with the current NICE guidelines (2018).

In terms of superordinate theme 3, none of the child participants felt that they had received any service level support, pre- or post-diagnosis. This is in keeping with LA ‘A’s CQC and CQC/Ofsted reports, stating that more needs to be done to support CYPF in this region, and reflects similar findings in other LAs (Flack, 2018).

All child participants reported having significant difficulties in educational settings, with some referring to school as “stressful” and “scary”. A theme emerged of children feeling misunderstood and unheard, supporting evidence that many teachers lack knowledge and understanding around ADHD (Singh, 2012). The child participants in this study found themselves in conflict with particular teaching staff, and consistently found themselves being told off, or punished, leaving them feeling frustrated, angry and upset. This study therefore supports Honkasilta’s (2016) call for more to be done in examining and understanding school systems, their micro-cultures, and teacher-child micro interactions. Additionally, it is argued that much more needs to be done to ensure that CYP with ADHD are provided with reasonable adjustments in accordance with the Equality Act (2010) and the SEND Code of Practice (2014). It is put forward that schools, and educational staff who are inadequately trained as reported in Greenway et al. (2020) and do not operate in accordance with the Equality Act, are likely perpetuating exclusionary practices, rather than inclusionary ones aiming to increase participation for all children (Booth & Ainscow, 2011, p.9).

Most child participants described feeling persecuted, punished and socially isolated from their peers, in what they perceived as inflexible and punitive systems. This is in keeping with reports that the current education system focuses on the imposition of institutional needs, over meeting children’s human needs (Singh, 2012; Timimi, 2005). Moreover, they expressed being disproportionately punished for their ADHD traits, in keeping with Singh (2012) making it harder for them to come to terms with their condition, as those around them appeared to punish them for their symptoms. This led the two child participants who were due to be assessed for ASD to believe that they would be treated better once they had additional diagnoses of ASD, feeling that staff are better informed about this disorder. One child spoke of school as being a relatively positive experience; two said that they sometimes get support from the class TAs to help them with their concentration, which they reported as being helpful in keeping with Singh (2012). Three children felt that they did not get the level of support they needed in school, with one child reporting that teaching staff were so uninformed about ADHD, that it was his role to attempt to educate them about it. Children tended to see their family, and friends, as their primary support networks.

Superordinate Themes 2 and 3: (Pertaining to Sub-RQs 2, 3 and 4)

Parent participants

All parents cited challenging behaviours as a primary reason for seeking assessment for their child. While these were present and often highly challenging in the home environment, it was how the children’s behaviours manifested in pre-school, and school that served as key factors in seeking assessment. It is reported that some parents feel pressure, particularly from schools, to get their children assessed (Ahmed et al. 2017; Ringer et al. 2020; Timimi, 2005). However, the parent participants in this study did not express this, and for the most part, they reported seeking support from their child’s school to expedite the assessment process. Parent participants looked to their child’s school/nursery for advice around ADHD, and were met with quite variable responses. With some exceptions, parents in this study suggested that the quality of advice provided by schools was not always well informed, and was often provided through TAs, over teachers, or other professionals such as SENDCos. A retrospective search found limited research on TA’s knowledge of ADHD. However, in a recent study, TAs were actually found to have better knowledge of this than teachers, but still self-reported as feeling “inadequately trained” around ADHD (Greenway & Rees-Edwards, 2020). This suggests that if TAs and teachers are to continue to offer advice to parents, that they require more specialised training and knowledge in this field.

In keeping with the national and local reports on waiting times, nearly all parent participants spoke about their difficulties with long waiting times for assessment and diagnosis, with one parent going privately to circumnavigate this. This aligns with the regional service inspection reports citing long waiting times for neurodevelopmental diagnosis. It is put forward that this contravenes the county’s legal duty to “protect specific children who are suffering or likely to suffer significant harm” (BPS, 2017b, p.39) and “prevent the impairment of mental health…ensuring that children … [have] effective care… [and] the best life chances” (BPS, 2017b, p.39). This seems especially pertinent given that the importance of early intervention is already widely recognised (DoH/DoE, 2017).

In terms of their child receiving their diagnosis of ADHD, parent participants mostly described it as a validating experience. Diagnosis appeared to offer them some credibility and empowered them to reconsider, and re-frame their self-stigmatising perspectives as bad parents, in keeping with Honkasilta (2016). This also empowered them to challenge others about their child’s behavioural traits, framing their child’s difficulties within the bio-medical model, as a “chemical imbalance” and as something beyond their, and their child’s control, and importantly beyond the effects of their parenting style. To some extent, this served to diminish feelings of parental self-blame in keeping with Timimi (2005). However, in some cases, diagnosis left parents feeling further guilt that they had been trying to change their child pre-diagnosis. Some parent participants felt incredibly emotional, and sad about their child’s diagnosis and found it difficult to comes to terms with their child being labelled as ‘disordered’, and what that means for them, their child and their child’s future. In some senses, this appeared to open up more questions than they were able to answer. Their individual responses to diagnosis were therefore highly emotive, and parents clearly struggled to make sense of this.

Some parent participants felt that the diagnosis added to their pre-existing perceptions of stigma. In attempting to make sense of this, parents perceived there to be a socio-cultural misunderstanding around ADHD, that underpins and perpetuates it, in keeping with Mueller et al. (2012). Many parents also sought a dual-diagnosis of ASD/ADHD feeling that ASD is better understood, is less stigmatised socio-culturally, and is taken more seriously by schools, services and by others more generally. Moreover, they expressed feeling that having a dual diagnosis brings with it, greater value and capital, that can in turn, provide them with greater access to services, including health-care, and more inclusive educational practices. Many parents felt that ADHD is currently misunderstood, similarly to how dyslexia was perceived as a myth, decades ago, and struggled to make sense of why this was still the case. A brief library search of the words “ADHD” and “stigma” or “myth”, in the last 10 years, found approximately 100 results. However, little was found regarding the perceptions of ASD as being socio-culturally valued more than ADHD suggesting that this represents a potentially significant gap in the research literature.

All bar one of the parents made the decision to medicate their child. For some, this was a heavy decision, for most it seemed like it was their only choice and that they needed to trial it, in order for their child to stand a chance in school. All parent participants medicating their child, reported doing so for the school’s benefit, and struggled to make sense of why the school “got all the benefits” of medication, while they got none in the evenings. Parents generally felt that medication helped their child in having greater control over their emotional regulation, and that it offered them greater concentration, while diminishing their hyperactive traits to some extent, in keeping with Pickett (2016). At the same time, they struggled with the idea of medicating their child, and clearly worried about this. They also expressed quite grave concerns about the side-effects, namely: a loss of appetite; reduced body weight and height; disrupted sleeping patterns; and the re-emergence of traits as the medication wore off. In keeping with Pickett (2016) and Ahmed et al. (2017), parents cited that elevated side effects would be the most likely reason for the cessation of medication, as well as being influenced in their decisions by others, in keeping with Corcoran et al. (2017).

Existing studies have reported that parents feel external pressure to medicate their child for their ADHD (Ringer et al. 2020). While only one parent reported feeling an explicit pressure to medicate their child, the others described implicit pressures to medicate as no other valid choices were known to them. One extant study reported that parents medicated their children, as a “last resort” (Corcoran et al. 2017 p.333), with another reporting that their LA offers medication for CYP with ADHD as their main method of treatment (Flack, 2018). However, this study found that parents saw medication as the ‘only resort’, with no other tangible approaches being available for them. This was summed up by one parent, stating: “schools just aren’t geared up for children with ADHD”. Such findings appear to contravene the NICE guidelines that medical treatment should not be the first line of intervention (NICE, 2018). This raises serious concerns that parents are left feeling that they need to medicate their child due to a combination of factors, namely: a prolific lack of understanding around ADHD in schools; a lack of consistent (school) staff training on ADHD; and inflexible, and exclusionary behavioural systems. Of course, many schools will provide excellent provision to CYP with neurodiverse profiles, and this finding may be indicative of schools’ felt pressures to “do more with less” (McCubbin & Cohen, 1999, p.81). Such findings raise significant safeguarding concerns, suggesting that parents may be medicating children with powerful psychostimulants, to alleviate the pressures placed on schools to raise pupil attainment, and manage behaviour effectively, in keeping with King et al. (2013); McCubbin & Cohen, (1999), and Schwartz (2016). This in turn, may implicitly serve to uphold the rather inflexible and punitive practices reported in some schools in this study, rather than seeking organisational and systemic change. This was the view expressed by one parent participant who chose not to medicate her child for this very reason.

This study reported that one of the biggest battles that parents faced, was in getting schools to see their child’s behavioural presentation, not in terms of bad behaviour, but in terms of symptoms, or traits, of their disorder. In this sense, parents were not only attempting to make sense of their child’s ADHD, they were also attempting to make sense of why they needed fight the very systems that should be serving to protect, nurture and educate their children. It is put forward that the level of conflict and challenge that parents of CYP with ADHD, reported to have with schools and nurseries, was not previously fully understood, and that this was a significant finding of this study. Parents in this study reported feeling that they were having to fight to have their CYP's needs met in nurseries and schools, and reported that schools were operating, exclusionary, inflexible and punitive systems that did not take their child's disorder into account, as they felt they should have. Nearly all parents reported encountering conflict, and frequently uncomfortable conversations with teaching staff, and there were consistent reports that the level of knowledge, understanding, attitudes and approaches towards ADHD were inconsistent and highly variable. At times, this had serious implications, including parents removing their children from their educational provisions. There were also reports from parents in this study of feeling distrustful, and judged by some of the services and professionals that they had encountered. Parents described how they felt that there should be greater allowances in school systems before expecting parents to medicate their children. There are increasing professional calls in line with this view (BPS, 2013; BPS, 2022b; Johnstone, 2017; McCubbin & Cohen, 1999; Mills in Williams et al. 2005). While parents reported being persistent in their attempts to bring about reasonable adjustments in schools, they were left, for the most part, feeling powerless to effect positive change, and subsequently left feeling frustrated and angry in their pursuits to do so. This aligns with the findings of Honkasilta (2016) reporting that parents felt victimised by schools and were not empowered to act as educational collaborators and partners.

All parent participants in this study described their concerns and frustrations around long waiting times, scant services, and how they felt that they were left fighting the systems around the child. In short, they reported feeling that the systems were failing them. For the most part, this included the wider systems and services including children's services, NHS services, nurseries and schools. This is consistent with the county's inspection reports and with Flack (2018). Parents were therefore left, not only attempting to make sense of their child's ADHD, but were also attempting to make sense of why they were fighting with the very systems that they sought support from. This puts forward a strong argument that significant adjustments are needed to improve the services available for CYPF living with ADHD.

Implications for Educational Psychologists

It is suggested that there are a number of ways that EPs can offer support to CYPF with ADHD. Seen in terms of Bronfenbrenner's ecological model (1979), it is put forward that EPs can bring about positive changes at every level. In keeping with Singh (2012), this suggests that positive change can be effected at an eco-bio-developmental level, encompassing a child's wider ecology. Firstly, at an individual level, child participants expressed how they would appreciate being able to communicate with a professional to help them manage their feelings, emotions and actions. Of course, there are services, such as Kooth (n.d.) currently available. However, it may be prudent for CYPF to be able to access knowledgeable professionals who are trained specifically around ADHD, and the manifestation of its traits. Such a service may differ from existing mental health services in offering highly personalised and specific support strategies around difficulties including executive functioning. This could therefore help CYP in improving their concentration and focus; planning and writing homework; maintaining relationships and in effective emotional regulatory strategies. In addition, EPs and children's services might be able to do more to signpost CYPF to the existing support services available in this region, that are not widely known to many families.

The findings of this study suggest that some of the most pragmatic and influential change that EPs can bring about is at the micro-system level, working directly with parents and schools. Parents in this study spoke of how such a service would be of great value to them to, pre- and post-diagnosis. In particular, they expressed needing help with managing their child's triggers and emotional dysregulation. This service could potentially extend to siblings struggling to cope with the child's behaviours. At this level, EPSs might also be able to provide information to friends and family to educate them about ADHD, reduce stigma, and to offer ways in that they might better support CYPF living with ADHD. This would help to tackle the stark finding that while “nearly all parents of children with ADHD seek professional help, only a minority receive evidence-based treatment (PHE, 2016, p.16). When working with CYPF, it is deemed important that parents do not feel further judged, or criticised by professionals, who should endeavour to develop strong, containing and trusting relationships in keeping with the evidence base supporting the therapeutic working alliance (Bucci et al. 2016).

In terms of schools, educational staff are reported to need considerably more training around ADHD (Greenway et al. 2020) with EPs being particularly well placed to address this. As a core aspect of their work, EPs also provide consultations that are aimed at bringing about school-wide, systemic change (Fox, 2009). EPs routinely work in schools and build up strong relationships with staff. They are also highly trained and committed to promoting “equality, diversity and inclusion and in challenging prejudice and discrimination” (BPS, 2017a). EPs are therefore ideally situated to deliver such training and work in a consultative capacity to bring about evidence-informed, system-wide change. The benefits of this would include more inclusive support at a child level and potentially greater teacher tolerance (Greenway et al. 2020). EPs may serve to investigate school systems, their micro-cultures, and teacher-child micro interactions as suggested by Honkasilta (2016). This may potentially have the effect of parents feeling that their child is better understood and supported and potentially reduce parent-staff tensions. Moreover, staff themselves would likely feel better informed in talking to parents who come to them seeking advice relating to ADHD and other matters, as seen in this study. This may also have the effect of improving upon some negative child-teacher relationships (Honkasilta, 2016) and may encourage children to speak more openly to their teachers, and peers, about their ADHD and their difficulties in the classroom. This may potentially diminish their feelings of shame and anxiety, and enable them to positively re-shape their self-identity. Greater EP-teacher collaboration and training around ADHD in schools may help to tackle the under-recognition of ADHD in girls as is widely reported (Biederman, 2005; NICE, 2019; Sayal et al. 2018), as staff become better informed around this.

EPs are well placed to work with educators around specific cases that may be proving particularly challenging. In certain circumstances, it may also be that EPs draw upon their training to utilise VIG and VERP to support teacher and child relationships, to potentially increase empathy and mutual understanding through becoming more conscious of each other's needs (Honkasilta, 2016; Murray & Leadbetter, 2018).

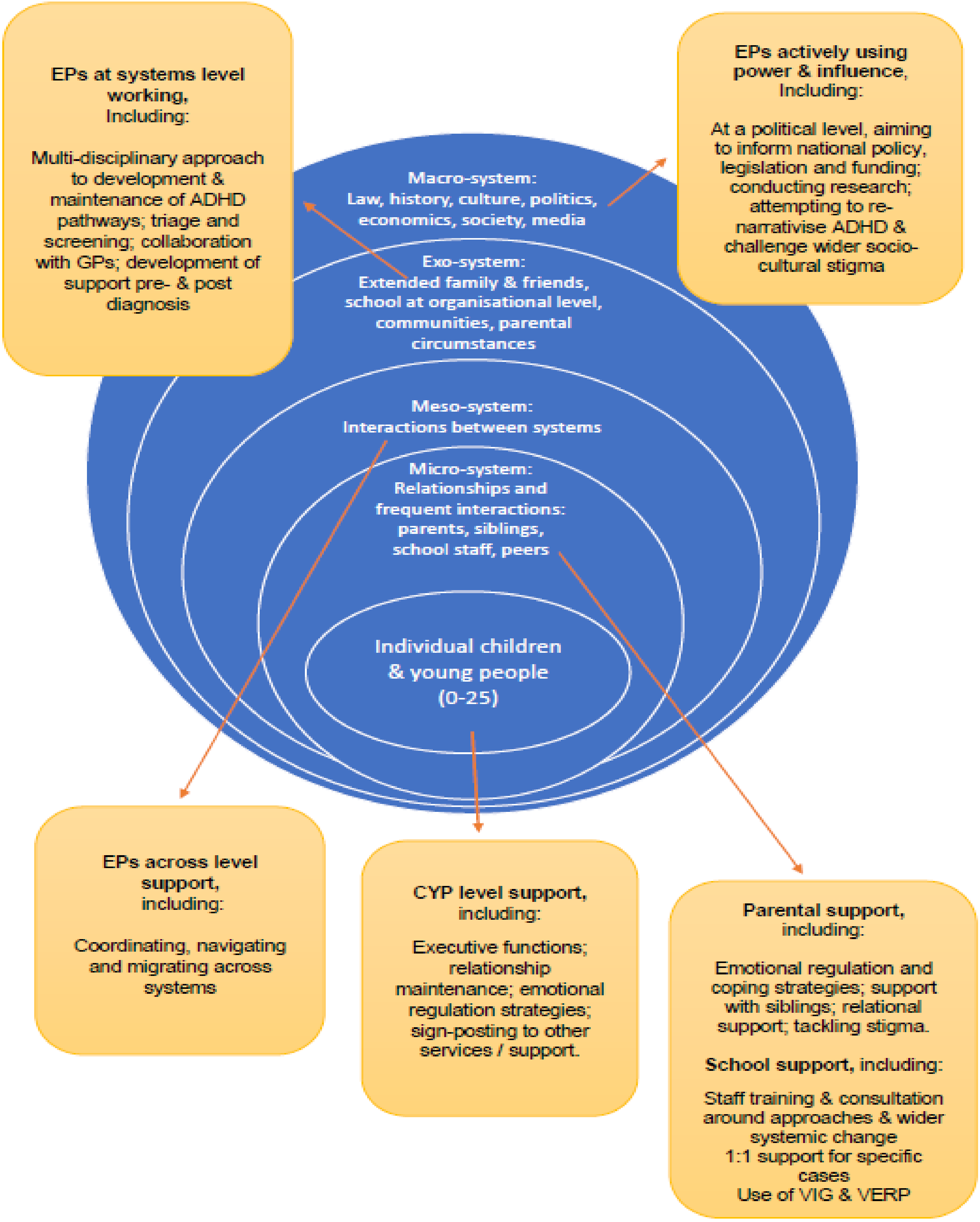
EPs could also offer more support at the exo-system level, through conducting their own screenings to support the NDS prior to assessment. This would likely include investigating a child's developmental history, and considering the complex presentational similarities that exist between ADHD traits, attachment difficulties and developmental trauma, for example. By doing so, EPs would be able to triage CYP, meaning that potentially fewer referrals are made directly to the NDS, thus potentially reducing the long waiting times reported in the region's CQC/Ofsted reports. They may also offer support to families while CYP are on the waiting list for assessment, with a view to protecting specific children who are "suffering or likely to suffer significant harm" (BPS, 2017b, p.39) and "preventing [further] impairment of mental health…" (BPS, 2017b, p.39). It is suggested that in order to support the diagnostic services, much closer inter-service collaboration would be needed. This aligns with the LA's strategy to provide timely and easy access to services and improve the effectiveness of inter-agency working, while effectively safeguarding and promoting the welfare of children. EPs may also aim to develop their inter-agency support, services and pathways through working collaboratively with clients and experts by experience in keeping with BPS guidance (2017). Additionally, they may consider working more closely with GPs, as they are frequently deemed as primary sources of information, yet are, reportedly, inadequately trained around mental health (Mind, 2016).

It is proposed that EPs have a moral duty to use their power and influence at a macro-system level in keeping with other reports (Boyle et al. in Kelly et al. 2017; BPS, 2022). This may include conducting research in this area, and informing decision makers at the wider systems level of influence, and shaping public policy. In turn, this may attempt to re-shape and re-narrativise assumptions about ADHD, and challenge the pervasive socio-cultural and economic stigmas associated with it. This aligns with this study's critical epistemological position, considering how economics, politics, and power structures shape and influence our knowledge and understanding (Guba & Lincoln, 1994; Scotland, 2012).

Finally, at a meso-system level, EPs are well-placed to migrate across systems in a bid to bring about systemic cohesion, across all levels. Of course, such additional service-level support has financial implications. While this would take much consideration, it is argued that, with this additional support, and early intervention from EPs, and other services, we could see some financial reduction in the £670 million in healthcare costs, reduced earnings and education that is currently reported to be spent on people with ADHD (PHE, 2016). What's more, the DfE has just published its SEND review green paper (2022), reporting evidence aligning with this study that CYP are caught in a "vicious cycle of late intervention and inefficient resources "(DfE, 2022, p.6). This review aims to provide targeted support to CYP when required, and develop co-produced inclusion-plans that provide CYP with excellent mainstream provision. It cites allocating 2.6 billion pounds to existing (and new) educational provisions (DfE, 2022). It is suggested that the financial resources are potentially available to fund such a project as the one suggested herein. Moreover, this presents with a timely opportunity for CYPF living with ADHD to get the additional support and understanding that they are desperate to receive. Table 3.0 summarises the potential wider role that EPs can undertake in supporting CYPF with ADHD.

Figure 3.0

The Potential Role of Educational Psychologists in Supporting CYPF with ADHD, applying Bronfenbrenner's Ecological Model (1979)



Conclusion

Children and Young People

This study reported many findings, some of which add to the existing body of evidence, with some more original contributions. This study found that, for the most part, children held simplistic views of what ADHD is, and attempted to make sense of it predominantly through their lived experiences of their difficulties, in school, and beyond. The extent to which child participants struggled with such complexities, and how this shaped their developing self-perceptions, adds to the existing evidence on this. Child participants reported that their difficulties lead to damaged relationships and social exclusion. In keeping with the existing literature, all children reported feeling a lack of control over their behaviours, at times. An argument was put forward that such issues are likely attributable to a complex interplay of executive functioning difficulties and a propensity towards emotional dysregulation. However, less was previously reported on how children with ADHD struggle to make sense of their own actions, during periods of later reflection. Far from having made sense of their ADHD, and associated traits, there was an overarching sense that all child participants were, at times, phenomenologically lost in the very worlds in which they exist.

Child participants' difficulties in attempting to make sense of their disorder, their behaviours and their worlds were compounded by being situated in school systems that frequently made them feel misunderstood, overlooked and undervalued. For the most part, participants felt strongly that they were not getting the school support that they need. Child participants found themselves in frequent conflict with teaching staff, and consistently found themselves being told off, or punished, leaving them feeling frustrated, angry, upset, and confused. Many perceived their educational settings as inflexible and punitive, leaving them feeling persecuted, and socially isolated from their peers. That said, they also reported pockets of positivity in school, and some educational staff that were supportive and understanding, although this was presented as highly inconsistent. These are considered to be significant findings.

Child participants had little recollection of the assessment process, and mostly did not know that they were being assessed at all. This is considered an original finding. They also knew little about their diagnosis, what ADHD is, or what the acronym ADHD means, making it harder for them make sense of it. Child participants mostly chose not to tell others about their diagnosis, in keeping with the findings of Singh (2012). None of the child participants felt they received any service-level support, and saw their primary sources of support in family, and some friends. Child participants felt that they would benefit from being able to access services to support them.

Four child participants reported taking medication for their ADHD, purporting some positive effects. Decisions around medication were mostly made by parents, although most said that they were open to greater child involvement, as they got older. Feelings around taking medication were mixed, with some focusing on the positive effects it was having on them in school, while others feeling ambivalent about it, describing a tension between wanting the benefits of medication, while not wanting to take them. This adds to the existing literature calling for CYP to have a greater role in decision-making around treatment and medication.

Parents

This study found that parent participants also struggled to make sense of ADHD, and had attempted to do so predominantly through their own experiences of living with their child, with ADHD. Parents offered rich, nuanced accounts, unanimously reporting how their child’s presentation had a profound effect on their interpersonal relationships, and on their own well-being, and mental health. While this was already reported in the wider extant literature, the extent to which parents, of children with ADHD, were struggling in this region, was not explicitly captured, or documented.

This study found that through a complex triple hermeneutic process, the researcher attempted to make sense of parents who were, in turn, trying to make sense of their children, who were similarly attempting to make sense of themselves and their own behaviours and difficulties. Discrepancies between parent and child accounts were discerned, suggesting that child participants were either unable, or unwilling or describe the impact that their behavioural traits were having on those around them. All children in this study had co-occurring ASD, ASD traits, or were under assessment for ASD, further complicating parents' sense-making. An interesting finding arising from this study was that parents and some child participants reported that schools, services and society more widely, perceive ASD to be of 'greater value' and validity than ADHD, with the latter perceived as being widely misunderstood, undervalued and underappreciated. This was not widely reported in the extant literature and is considered to be a significant finding, and an important area of future study.

In keeping with existing research, parents mostly understood ADHD through the bio-medical aetiological model. All parents reported struggling with the stigma around their child's difficulties and ADHD both pre- and post-diagnosis. Stigma was frequently reported, by parents, as having significant bearing on their, and their child's social lives and experiences, reducing opportunities for social interaction, and increasing social isolation. This often led parents to feeling that they were attempting to cope with limited support. This perpetuated a cycle of self-stigmatising, in that parents questioned their ability to parent effectively, increasing their self-doubt, and self-perception as bad parents. In turn, this led to parents feeling a greater sense of parental blame and guilt. An interesting finding was that parents were also affected by the stigmatising views of their own family and friends.

All parents sought assessment due to their child's challenging behaviours, and their educational difficulties. All were acutely aware of the long waiting times for assessment, and sought to take any advantage that they could to expedite the process in a bid to get their child assessed. This was not previously reported and warrants further investigation. In addition to this, parents reported feeling that they were caught in complex and tense battles, fighting services and schools and feeling failed by systems around their child. Parents reported feeling that there is a significant gap in available and accessible support services, pre- and post-diagnosis. The effect of this this, from the perspective of parents of children with ADHD themselves is not thought to be widely reported.

Parents reported feeling that many schools and nurseries operated inflexible and exclusionary practices, and they did not feel listened to in their attempts to address this. This often left parents feeling upset, angry and resentful, with some parents taking the difficult decision to move their child to different educational provisions. This, and the effect it has on CYPF, is thought to be largely unreported, especially in this region, and raises concerns as to whether educational provisions are doing enough in making reasonable adjustments for CYP with ADHD, in line with the Equality Act (2010). While parents reported pockets of support within educational settings, mostly from TAs and some teachers, they described how the quality and understanding of ADHD varied greatly. This aligns with self-reports of educational staff feeling inadequately trained around ADHD (Greenway et al. 2020), and warrants further investigation.

In keeping with existing evidence, parents reported that receiving a diagnosis for their child offered them some feelings of credibility and that it empowered them to reconsider their self-stigmatising perspectives as bad parents. It also enabled them to perceive their child with greater empathy and compassion. However, post-diagnosis, parents also reported experiencing feelings of guilt at how they had parented prior to receiving the diagnosis. Indeed, a complex picture emerged as some parent participants in this study felt that the diagnosis added to their existing perception of stigma. All parent participants reported struggling to make sense of the pervasive socio-cultural misunderstandings surrounding ADHD.

Four of the five parents chose to medicate their child for their ADHD, despite little understanding of the bio-mechanics of the medicine that was administered. Parents generally felt that medication helped their child in having greater control over their emotions and emotional regulation; offered greater concentration and diminished their hyperactive traits to some extent. At the same time, they struggled with the idea of medicating their child, and had ongoing concerns around the impact of side-effects. A notable finding was that parents reported feeling that they needed to justify their decision to medicate their child, to friends and family. All of the parents in this study, who chose to medicate their child, reported feeling that they were medicating them to make them ‘school ready’ in keeping with (McCubbin & Cohen, 1999), in some form, with all feeling that it was the only option available to them, as they perceived schools, to be inflexible and “not geared up for children with ADHD”, for the most part. They also reported feeling that the schools got all the benefits of the medication, while they got none. While there is some existing evidence supporting this, it is considered to be significantly under-reported, warranting further investigation.

This study places emphasis on the role of the EP and proposes that EPs are highly trained (BPS, 2017a) and particularly well placed to support CYPF, schools and services in a number of ways around ADHD. This could include offering greater advice, training, and support to both CYPF and to educational provisions. Furthermore, EPs are well placed to support the NDS in reducing the long waiting times for assessment. This study acknowledges that this endeavour would not be uncomplicated. However, it is put forward that this is achievable, and would align with the regional and national targets for improvement, and is well timed given the imminent proposals put forward in the SEND review green paper (DfE, 2022). It is also proposed that EPs are well placed to use their power to influence and inform the decision makers at a wider systems level.

Study Limitations

IPA was a useful tool in eliciting detailed and nuanced accounts of the participants’ lived experiences, focusing on depth, over breadth. However, while a strength of this study, it could also be considered a limitation as wider generalisations cannot be drawn from this research. Future studies may wish to draw from a much broader pool of participants, employing a mixed-methods approach, including data collection methods such as structured questionnaires and scaling. This may offer findings that are more generalisable, and that are potentially more widely accepted at an organisational level.

Due to the Covid-19 situation at the time of writing the ethics proposal, there were significant concerns amount meeting CYPF face-to-face. Subsequently, the interviews in this study were conducted remotely, with the cameras turned off. However, this meant that the researcher was unable to observe the child’s presentation, and learn from their non-verbal communication. During the interviews, some parents reported that their child had considerable difficulties in sitting still, and in focusing for the duration of the interview. Given that the research was conducted with CYP with ADHD, this was pre-empted, but the study had to be conducted in accordance with the ethics application. This is considered a limitation of the study and working face-to-face would have allowed the researcher to be more creative and responsive to CYP, in considering ways that they might be re-engaged. In turn, this may have led to child participants offering richer accounts. Future research with CYP with ADHD should endeavour to work face-to-face with participants wherever possible.

While this study effectively sought the voices of both child and parent, there was little direct parent and child dyadic analysis, exploring their shared experiences. Future research could also give greater weight to how meaning-making was co-produced, and negotiated, between parent/s and child.

While this study explored the participants' perception of services and schools, it did not seek the views of professionals working in these areas. Future research should take their views into account for a more comprehensive account.

Areas of Future Research

This study identified the following as future potential areas of study:

Lived Experiences

It is considered important that future research encapsulates the views of both CYP and parents. More research is generally needed to understand the lived experiences of CYPF living with ADHD, including its impact on families, marital/partner relationships and on siblings. More is needed investigating stigma, myth and the socio-cultural perspectives that exist around ADHD, and how a perceived socio-cultural lack of understanding around ADHD may impact how CYPF are able to make sense of ADHD. Further investigations around callous-unemotional traits, and around the notion of control are also considered important.

Assessment, Diagnosis and Medication

This study identified that more research is needed considering how CYP attempt to make sense of the ADHD assessment process and how they can feel better informed around this. Further investigations into how influential the voices of friends and family are in decision-making around assessment and treatment is considered prudent. More research is needed in considering the views, and role of CYP in relation to taking medication for ADHD.

More research is needed considering the potential inclusion of emotional dysregulation as a fourth core trait of ADHD. Lastly, this study found that CYPF struggled to make sense of co-occurring disorders, namely ADHD/ASD. Therefore, further research into this and how this differs from a lone diagnosis is warranted.

Systems, Schools and Support

It is put forward that further research is needed exploring the extent of teacher's and TA's knowledge, training and experiences around ADHD. Future research should also investigate the pressures that may be placed on parents of CYP with ADHD to assess and medicate their child. Studies should aim to explore participant's reported perception that ASD is valued more than ADHD, in schools and more widely. More is needed to consider if schools are doing enough to meet the needs of CYP with ADHD, and in considering if schools are providing reasonable adjustments for CYP with ADHD in line with legislation. More research is needed to investigate the extent to which parents of CYP with ADHD, feel listened to, and involved in their child's educational provision. Lastly, the impact of homework on CYP with ADHD, and on their parents is a suggested area of future research.

Chapter 3: Research-Practitioner: A Critically Reflexive Account

Reflection on the Research Process and Development as a Researcher.

Teaching Experiences

What follows is a critically reflective account, exploring my developing skills as a research-practitioner. This includes discussion around how my professional and personal experiences have shaped my thinking around ADHD and this research. I reflect upon some particular tensions that I have wrestled within my research, namely: around treatment and medication, professional boundaries, and challenges in the research process. I offer my reflections on my epistemological and ontological positioning, and in conclusion, I consider how the research findings might be effectively disseminated.

Although I taught many CYP with ADHD as an English teacher in a large, secondary mainstream school, on reflection, my knowledge of ADHD, and other neurodevelopmental disorders was limited. I made genuine attempts to differentiate my learning resources, and approaches to meet different pupil’s needs. However, at times, I was required to teach as many as 200 pupils in one day. On reflection, it was no wonder that I felt unable to truly meet the needs of the pupils with SEND. More often than not, it was the class TAs who worked closest with CYP with ADHD. I feel that my experiences as a mainstream teacher enabled me to hold in mind, the realities and pressures that are placed upon teaching staff, and moreover, helped me in not losing sight of the care, skills and knowledge that so many teachers provide to CYP.

My interest in ADHD developed further when teaching in a PRU. I recall one year 8 pupil who I, and other members of staff, found particularly challenging. Staff spent a lot of time literally chasing him around the school, trying to get him back into the classroom. He had a recent diagnosis of ADHD and soon began trialing medication. The contrast was night and day, appearing almost as a different child, warm, endearing and hard working. His medication clearly had some effect, at a superficial level, at least. This left me feeling curious about what the medication was at a bio-molecular level, and how it affected such drastic changes in a child’s presentation.

Professional and Personal Development

There were then a number of occurrences that came about within a similar timeframe: I worked with a number of children with diagnoses of ADHD (among other diagnoses) in a tier three CAMHS setting. A close adult relative was then diagnosed with ADHD. Then, and perhaps most significantly, it became increasingly evident that my son, most likely, had a neurodevelopmental disorder. He was subsequently referred to the NHS NDS for assessment. However, three years on, and we are still, quite astonishingly, waiting for his assessment to be conducted. Over the years of waiting, I have found myself reading widely on ADHD in a bid to understand my son and support him better. Fundamentally, my personal enquiries shaped my professional perspectives, and academic curiosity: in many ways, there was an inevitability about me conducting my research in this area.

Now that I know ADHD through my personal experiences as a parent, I am able to appreciate and reflect upon my lack of understanding as a teacher, and even as a professional in CAMHS. I have also personally felt the effects of attempting to navigate the very services that I work in, and around, professionally. Therefore, while I continue to feel an acute sense of injustice in how long it has taken to get my son assessed, I have tried to retain a sense of balance, and wider perspective in not allowing my personal experiences to taint my research, by presenting an overly subjective account. This was made easier as I previously worked as an assistant clinical psychologist in an understaffed NHS adult learning disabilities team, with long waiting lists. I therefore understand the feelings of desperation, and exacerbation of working in a service that is vastly under-resourced. In addition to this, I have now worked in children's services as a TEP for almost two years. Given these experiences, I feel that I have gained a unique and wide perspective on this topic, allowing me to feel justified in conducting my research in this area, and a confidence in talking about it personally and professionally. However, as I proceeded with this, I was acutely aware that in exploring people's personal experiences, and by shining a light on the 'Inadequate' services locally, I felt as though I was publicly critiquing my friends and colleagues working in this area. This was not my aim, and I hope to have found the right balance. However, I also felt assured that the wider goal of helping other CYPF should transcended such worries. However, in truth, this has left me continually thinking about how hard to push this line. To help me in this, I have been well supported by other educational psychologists who have continued to provide their insight, and balance, and through my research supervisors, who have been confident in asking me to reflect upon areas of my writing. More often than not, they have asked me to reflect upon the tone and nuances of my writing, mostly particular word choices that were perhaps implicitly, rather than explicitly demonstrative of my personal and professional frustrations. Research supervision has therefore offered me an incredibly reflective space in which I have felt able to explore such tensions openly and honestly.

Tensions around Medication and Diagnosis

In my own quest to learn more about ADHD, I was recommended many books. On reflection, these held quite anti-psychiatry and anti-pharmaceutical perspectives, that were perhaps indicative of my health colleagues' perspectives, values and philosophies. These clearly shaped my early views, and I can see how my preliminary research proposals represented quite a biased perspective with regard to ADHD medication. Indeed, this was reflected in the feedback I received in response to my first literature review draft, that I sought to reflect upon and address as this research developed.

I therefore aimed to read more to offer me different perspectives on ADHD, disorders, and mental health. However, rather than challenging my presuppositions, the more I read, the more that my earlier perspectives were re-enforced. For example, a CAMHS Arts Psychotherapist colleague recommended that I read R.D. Laing's The Divided Self (1965). While Laing speaks specifically around schizophrenia, I detected a discernible transferability to other mental health conditions and to ADHD. Laing postulated that people's seemingly aberrant, or atypical behaviours, and disorders, should not be solely situated, and labelled, as within-person difficulties. Rather they may be better understood as unconscious physical manifestations, or symptoms, in response to living in stressful and impeding environments, and systems. In my earlier clinical roles, I also received training on the Power, Threat, Meaning

Framework (PTMF) (Johnstone & Boyle, 2018). This assumes a humanistic and alternative approach to the use of psychiatric diagnosis, that is now finding its way into educational psychology practice. This too, places emphasis on systemic change over within-person difficulties and is gaining support through the BPS (2018b). I feel that having knowledge of such thinking gave me greater permission, in interviews, to dig a little deeper around the topic of systemic support, and encouraged me to apply greater criticality towards various systems in my writing.

My reading around ADHD led me to a compelling, and pervasive argument that there has been an exponential rise of CYP diagnosed with ADHD driven by big pharmaceutical companies, such as Shire (producers of Adderall and Vyvanse) and Janssen (producers of Concerta), “targeting the UK” as “areas of financial growth” (Schwartz, 2016, p.112). I attempted to find peer-reviewed empirical articles to provide some counter-balance to this. However, this was further complicated when finding that some of the more prolific writers, purporting the benefits of ADHD medication, were reportedly funded by large pharmaceuticals themselves (Schwartz, 2016), making many of the more frequently cited papers appear less credible. I felt frustrated by this and therefore sought empirical evidence reporting scientific explanations of the biological mechanisms underpinning ADHD medication in a bid to draw my own impartial conclusions. While I found some evidence reporting differences in neurotransmitter bio-availability in people with ADHD (Hou et al. 2018), to my knowledge, there is still no conclusive evidence of biological markers of ADHD (DSM, 2013; Férat et al. 2021; Parens et al. 2009), meaning that its diagnosis, and medical treatment is still determined by a person’s behavioural presentation (Férat et al. 2021).

This presented an ethical tension that I carried throughout my research. As a relatively informed practitioner, I found myself wanting to advise others about what I had discerned: that it was unsurprising that ADHD medication sees improvements in CYP’s presentation as the most common labels are either amphetamine-based, or methylphenidate. Thus meaning that most people would likely feel better taking them, and have better concentration, as all five variants of ADHD medication (NHS, 2021) are psychostimulants, increasing the levels of norepinephrine and dopamine levels in the pre-frontal cortex (Wegmann, 2015). I also carried concerns about the addictive nature of them, supported by empirical evidence (Wang et al. 2017).

Listening to the voices of parents whose children were taking medication for their ADHD marked a change for me, as they presented me with some more positive perspectives on medication. I was pleased to hear that the participant's children were generally doing somewhat better, in school, since beginning medication, and that there were some improvements around their core traits of ADHD. However, reflexively, I recognised a tension within myself when they discussed their medication choices, as I did not get the impression that they were well informed on this matter. However, I acknowledge that I am not medically trained, and felt acutely aware of my duty to work within the limits of my knowledge, training, and competence as stipulated in the BPS and HCPC practice guidelines (BPS, 2017b, p.5; HCPC, 2016, p.1). This felt challenging at times, and I felt some pull as a parent and a professional, to offer some guidance around this, or even to highlight some of the potential issues around addiction to psychostimulants in later life, that parent participants seemed quite unaware of. I therefore needed to remain reflexive during the interviews and remind myself that I was speaking to them, not in consultation, but as an interviewer/researcher, and that these roles are very different. This was made easier as my research supervisor had earlier recognised the potential for parents to seek medical advice from me, and subsequently we agreed to state that I could not offer medical advice, on the parent and CYP information sheets. This was also added to the ethics proposal.

As mentioned above, I am curious about the use of diagnostic labels, and hold some concerns around situating disorders as 'within-child'. It was, therefore, quite surprising to me, that my research offered me an influential counter-perspective around diagnostic labelling. In particular, this was due to parent participants' reports of feeling validated when their CYP received their diagnoses, encouraging an understanding that it was not their bad parenting at fault. While I had read this in prior research, it was profound to hear it first-hand, and it enabled me to understand how much it had helped parents to re-narrativise their CYP's behaviours, to reduce their sense of stigma, and in turn, diminish their self-stigmatising feelings. It had also, quite profoundly helped parents to engage with their children more compassionately, and had encouraged them to adapt their parenting methods. That said, I remain ambivalent around within-child labelling as I feel it potentially diminishes the expectation for schools, and systems to change, further entrenching the perception that it is the CYP who is disordered, rather than the environment in which the CYP is situated. Moreover, providing a child with a diagnosis can reportedly have the effect of diminishing their sense of personal agency, responsibility, moral and personal development as they perceive their difficulties to be beyond their locus of control as reported in Singh (2021). This was the case with one child participant who appeared to use her diagnosis as a way of diminishing responsibility for her self-development and learning. This tension therefore remains unresolved, and I feel that I will continue to attempt to make sense of this for many years ahead.

Professional Boundaries

As a developing researcher, I attempted to remain reflexive, open-minded and curious in exploring topics such as service provision during the interviews. In truth, this was often challenging and I could feel definite tensions between me as a researcher, me as a protective and empathetic parent of a child with SEND, and me as a relatively informed professional, identifying poor practice and wanting to act in the best interests of the child. I became quite aware of this tension when transcribing Peter’s interview, which was my first transcription. This was an incredibly slow process, allowing me time to reflect and to hear my own lines of enquiry from more of a detached position, or meta-perspective. On reflection, I felt that I had allowed my parental-self to become too empathetic with his position, and sought to validate his struggles, through offering examples of my own parental challenges. I felt some concern that I may have led his thinking through my own affirmations, and responses. I therefore took this to my primary research supervisor, who felt that I had not done so to a greater extent, reminding me that this is one of the intricacies of conducting interviews, and was a valuable part of the learning process. That said, I made immediate adjustments to my interviewing style, attempting to remain more impartial, while retaining my sense of empathy. This was helpful and allowed me to feel much more boundaried from here on in. However, this was not to say that this issue was fixed, and I felt it re-appeared at times. For example, Bella (Case 2) expressed a strong criticism of the assessment services and long waiting times. In response to this, I found myself saying:

> Researcher: …one of my concerns is that it is those parents like yourself who are going to speak up and are going to battle and are going to have the wherewithal to do that, and are probably going to get more for their children…but it is those children of the parents who don't have the voice, and don't have the capacity to do that…I just wonder where they're left [behind] and what their outlook is like? (1034-1040).

While actively summarising Bella's views, I concede that I allowed my own personal views and biases to creep in. This is perhaps indicative of my relative inexperience in research, but also of my years of therapeutic training, in which I frequently draw upon the strategy of therapeutic self-disclosure (Ruddle & Dilks, 2015). This strategy involves providing boundaried, personal accounts, in the moment as a method to develop the therapeutic, or working alliance (Bucci et al. 2016). At times, it was clearly challenging for me to separate out my professional and personal identities, and myself as a developing researcher. I have since reflected that it is quite expected for these roles to overlap, to an extent, especially given that I was attempting to elicit participant's views while working in an empathetic and containing manner, in keeping with my therapeutic training. What I have learned from this is that my interviewing style sometimes pushed the boundaries as a researcher – something I must be mindful of in future research. Moreover, interviewing participants, using a semi-structured approach requires continual reflexivity, reflection and micro-adjustments, that I hope will develop with greater experience, over time.

Research Processes

I found conducting the literature review to be a considerable challenge. As demonstrated above, ADHD is fraught with complexities, controversies and disagreements (Parens & Johnston, 2009). Moreover, ADHD is not a homogenous disorder (NICE, 2019), and given its heterogeneity, it covers a vast ground, situated across many paradigms and disciplines. Indeed, one study reported that the heterogeneity of symptoms makes it harder for those living with ADHD to make sense of it (Flack, 2018). At the same time, in order to understand people's lived experiences of ADHD, for me, meant understanding both its breadth and depth. Additionally, I felt I needed to adopt a broad approach in preparation for what participants might raise in their interviews. Considering what to exclude took a huge amount of energy, and I was quite anxious about leaving out literature that might be deemed essential to other readers. Additionally, at some level, I felt that I was still seeking out literature that implicitly, or explicitly supported my own narratives and biases. Perhaps unsurprisingly, this was noted in my first literature review feedback.

There were three factors that helped me in addressing this: Firstly, I took time to meet with many professionals in this field, including clinicians working for the NDS itself; private ADHD professionals; clinical psychologists; educational psychologists; specialist teachers, and a local SEND support service. This offered me a much more balanced perspective than my reading had allowed. Secondly, there was a significant period of time for me to reflect on this before returning to my literature review, allowing me some needed distance from my own writing, allowing me to see it with a renewed criticality. Lastly, as mentioned above, the participant's interviews offered me renewed insights, and I subsequently returned to the literature review many times over, during the course of the interview period. This highlighted the distinct advantage of working from an inductive position, allowing new perspectives to arise, that informed my thinking quite profoundly, and in turn informed my current and future professional practice. Consequently, I feel that my final literature review/s, offered a much more balanced and critical account of the extant literature.

My literature review identified significant gaps in the body of research exploring the lived experiences of children with ADHD and their parents, both nationally and locally. This made the decision to conduct a qualitative study a relatively easy one. Decisions around how to operationalise it were teased out through research supervision. This was invaluable in exploring a number of considerations, including: whether to draw upon thematic analysis, or IPA, and whether to include focus-groups and seek additional information. I had built up trusting relationships with my two research supervisors, and had felt confident to tell them that one of my self-identified weaknesses is that I can attempt to do too much, and collect too much information, in a bid to be comprehensive. I recognised this in myself during my master's degree research and was adamant that I would not make the same mistake again. I felt great comfort when my research supervisors suggested that they provide me with firm parameters, strongly discouraging me from collecting further data and broadening out my study. This felt incredibly containing, and it subsequently gave me permission to focus on drilling down into the nuances of people's accounts, rather than focusing on collecting a breadth of information. I feel that this was also a factor in choosing IPA over thematic analysis, as IPA aligns with my propensity to focus on the minutiae of expression, in keeping with IPA's emphasis on ideography (Smith et al. 2012). That said, at times, I received feedback that I was attempting to provide too much close analysis of language, akin to discourse analysis. I feel that this may have been the case, at times, and sought to be mindful of this. On reflection, I feel that this was likely brought about due to my background in English language and literature.

I also struggled with the notion of the study being bottom-up, or inductive, rather than a top-down, deductive one. Typically IPA aligns with a bottom-up approach as it works from a pre-supposition of not knowing, or not anticipating how participants have phenomenologically interpreted their experiences (Smith et al. 2012). In my mind, this pre-supposes not imposing too many a priori theoretical constructs of the phenomena under scrutiny. While I therefore knew that this was the approach I ought to adopt, it left me feeling somewhat disingenuous, as I had already formed many theoretical constructs, and opinions around ADHD, based on my experiences and reading. I wrestled with this for some time. Through supervision, we concluded that an inductive approach was predominately the 'best fit', as researchers must have some knowledge in their areas of research, in order to identify the existing gaps in the wider research in the first place. Moreover, I attempted to be reflexive, and open-minded in my analysis of data, to allow for new themes and ideas to develop, rather than seeking ones that fitted with my pre-existing expectations. This aligns with IPA's heavy emphasis placed upon trustworthiness as put forward by Teddlie et al. (2009). What's more, I was keen to have my interpretations checked by my research supervisor to ensure that my findings were not overly influenced by the extant literature. I found this to be a validating experience, but would have appreciated more of it. Given this, I think that I would take solace conducting future research with others. I had also thought about member-checking some of my findings, but in truth, did not have time to revisit the ethics proposal, in order to do so. I would ideally ensure I did this in future research in order to develop the credibility of the study as purported by Teddlie et al. (2009).

Finally, I struggled with the idea of going into interviews with only a few over-arching questions, under each RQ as advised by my research supervisors. Therefore, I initially devised longer and more prescriptive interview schedules, as seen in Appendix 17.0. On reflection, I think I did this in an attempt to be comprehensive in answering all of my RQs and sub-RQs, and to reduce the risk of any biases creeping in. Once again, the supervision process was crucial in discussing this, and in giving me permission to reduce my questions to their simplest form, thus encouraging greater room for participants to explore their lived experiences with more freedom. I feel that this encouraged a more authentic bottom-up approach.

Reflections on Epistemological and Ontological Positions

In terms of my epistemological and ontological positioning, I felt that my decision to adopt a critical realist position was the best fit. Clearly my research did not sit at the more positivist/quantitative end of the spectrum as I had identified that this is where the vast body of literature already exists. Additionally, I felt confident that critical realism aligned with my values of seeking an emancipatory approach aiming to provoke enquiry around issues including social justice, inequalities, inclusion, and marginalisation (Scotland, 2012). What's more, a critical realist position critically considers how historical, economic, political, societal influences, power structures, and systems, shape our current knowledge and understanding of phenomena in the world (Guba &

Lincoln, 1994; Scotland, 2012). I felt as though my research was capable of achieving this, but I had concerns about critiquing the services and systems that I am working in, as described above. I also felt concerned that I would be critiquing some of the schools that I am working in as a TEP, and future EP, as some participants were recruited from those schools. At times, I found this balance incredibly challenging. However, in keeping with the critical realist position, I concluded that, in order to effect change, we must be able to critique the systems in which we, and our participants exist. I feel that this would not have been possible, had I attempted to adopt more of a realist/positivist position.

As mentioned in the empirical paper, the process of creating meaningful, trustworthy and accurate themes was not uncomplicated, hence why some subordinate themes are coloured in two colours. While there is not space to discuss further examples here, I have included some specific reflections around this in Appendices 15.0 and 16.0.

Dissemination and Implications for Practice

As expressed in the empirical paper, there are many potential implications for EPs and other services arising from this study. The larger consideration is how the findings of this research is disseminated and how the potential for greater multi-agency collaboration may be brought about. Firstly, I am presenting the findings and my recommendations to the wider psychology and SEND support service at an event later in 2022. Additionally, I aim to develop and disseminate a one-page summary of the study to leaders in children's services as a way of opening dialogue around ADHD.

Many staff in children's services are already showing a keen interest in this research and are eager to "get ADHD on the map" as one colleague put it. The Principal EP is also keen to explore how we can establish a more robust ADHD pathway, and bring about greater inter-service collaboration with our health colleagues in particular. I have also been contacted by the LA's ethics board, who have asked me to report the findings to them, as this study aligns with their core areas of development.

I am also eager to receive feedback from the participants of this study. I feel confident that many of them would like to be involved in the future development of services and training as experts by experience, which, from my perspective, is an exciting and meaningful prospect. This also aligns with the NHS's and LA's priorities to place a greater emphasis on family engagement and with the BPS Practice Guidelines who describe best practice as working collaboratively with experts by experience in developing and delivering all aspects of psychological services, policies, and guidelines (BPS, 2017b).

It feels incredibly rewarding to think that my research may have some impact on the services, and educational provision around CYPF with ADHD. Earlier in 2022, I delivered ADHD training, firstly to my SLST (Specialist Learning Support Teacher) colleagues, and then to a specialist provision, in collaboration with a SLST. This was very well received, with highly positive feedback. We are now hoping to deliver this to more schools as a part of the core consultations that we offer. This feels like a tangible way to effect change for CYPF living with ADHD. This presentation was observed by my fieldwork supervisor, who was incredibly positive about it, noting that my theoretical knowledge, in particular, was helpful in re-framing ADHD, which complimented my colleague who has substantial knowledge of practical classroom strategies in particular. However, I am mindful of some of the many challenges that exist in bringing about meaningful organisational change (Cooperrider & Sekerka, 2015), and why such efforts often fail (Kotter, in Gallos, 2006). Given this, I am now exploring ways in that systems change may be approached, including learning more about appreciative enquiry as a model of organisational change (Doggett & Lewis, 2013).

It feels as though there is still much re-framing needed to be done in our service alone, and there is a growing recognition amongst colleagues that ADHD appears to have been somewhat lost, sitting in the shadow of ASD, that (quite rightly) has its own dedicated ASD team. That said, I am acutely aware of the challenges that lie ahead: while my research will have some professional standing as it is written at doctoral level, it is still just one small-scale study, that was not designed to be generalisable. There is a danger that it could be a flash-in-the-pan study and is lost in the utter busyness and strain under which our services currently operate. What's more, my year 3 fieldwork supervisor was involved in an inter-agency ADHD working group, that made some headway in terms of inter-service collaboration and service improvement. However, for many reasons, this lacked longevity and slowly disbanded. She described one reason for this as the short-term employment contracts that NHS staff were placed on, meaning that key members of the group left, making it harder to maintain long-term group cohesion. I have already experienced this to a lesser extent. While, I am learning more about working within systems (Doggett & Lewis, 2013; Fox, 2009), this has predominantly focused on change within one system, rather than across multiple systems. This, I feel, is the area that will present with the most significant challenges, and I concede that I am quite daunted by this prospect, and will be looking to my senior colleagues for support and guidance in this.

In conclusion, I recognise the powerful position that I am placed in to bring about meaningful development in this area. While I am filled with personal and professional drive, I am also under no illusion about the huge challenges that lie ahead, especially given that I am at such an early stage of my EP career. That said, I do feel that positive change is possible, with the assistance of my knowledgeable, experienced, and dedicated colleagues in children's services. What's more, I hope that any future project to improve the experiences for CYPF living with ADHD, in this region, is likelier given its strong alignment with the service's improvement objectives.

References

ADDiSS. (ADHD Information Services). (2005). A report based on research amongst children and parents illustrating the impact of ADHD on the school day. Retrieved 26th March 2022, from: J05-1189_J05_1189_MJW (addiss.co.uk)

Ahmed, R., Borst, J., Wei, Y. C., & Aslani, P. (2017). Parents' perspectives about factors influencing adherence to pharmacotherapy for ADHD. *Journal of Attention Disorders*, *21*(2), 91–99. https://doi.org/10.1177/1087054713499231

Akinbami, L., Liu, Xiang, Pastor, P., & Reuben, C. (2011). Attention Deficit Hyperactivity Disorder Among Children Aged 5–17 Years in the United States, 1998–2009. *Centers for Disease Control and Prevention National Center for Health Statistics, 70*, 9.

Anderson, C., & Bushman, B. (2001). Effects of violent video games on aggressive behaviour, aggressive cognition, aggressive affect, physiological arousal, and prosocial behaviour: a meta-analytic review of the scientific literature. *Psychological Science, 8.*

Antshel K., Zhang-James Y., Wagner K.E., Ledesma A., Faraone S.V. (2016). An update on the comorbidity of ADHD and ASD: A focus on clinical management. *Expert Rev. Neurother.* 16:279–293.

Barkley, R. A. (2015). Emotional dysregulation is a core component of ADHD. In R. A. Barkley (Ed.), *Attention-deficit hyperactivity disorder: A handbook for diagnosis and treatment* (pp.81–115). The Guilford Press.

Beau-Lejdstrom, R., Douglas, I., Evans, S. J. W., & Smeeth, L. (2016). Latest trends in ADHD drug prescribing patterns in children in the UK: Prevalence, incidence and persistence. *BMJ Open*, *6*, 6.

Bedrossian, L. (2021). Understand and address complexities of rejection sensitive dysphoria in students with ADHD. *Disability Compliance for Higher Education*, *26*(10), 4–4.

Bélanger, S. A., Andrews, D., Gray, C., & Korczak, D. (2018). ADHD in children and youth: Part 1—Etiology, diagnosis, and comorbidity. *Paediatrics & Child Health*, *23*(7), 447–453. https://doi.org/10.1093/pch/pxy109

BERA (British Educational Research Association). (2018). Ethical guidelines for educational research.

Bhaskar, R. (1978). *A realist theory of science*. Routledge.

Biederman, J. (2005). Attention-deficit/hyperactivity disorder: A selective overview. *Biological Psychiatry*, *57*(11), 1215–1220.

Blackburn, C., Read, J., & Spencer, N. (2012). *Children with neurodevelopmental disabilities*. 13.

Booth, T., & Ainscow, M. (2011). Index for Inclusion: developing learning and participation in schools. *Published by the Centre for Studies on Inclusive Education (CSIE)* .

Boseley, S. (2018, August 3). UK children with ADHD wait up to two years for diagnosis, say experts. *The Guardian*. Retrieved 31st March 2022, from: https://www.theguardian.com/society/2018/aug/03/uk-children-adhd-wait-two-years-diagnosis-experts

BPS (British Psychological Society). (n.d.). Introduction to the PTMF (Power Threat Meaning Framework). Retrieved 28th November 2020, from: https://www.bps.org.uk/power-threat-meaning-framework/introduction-ptmf

BPS (British Psychological Society). (2011). Good practice guidelines on the use of psychological formulation.

BPS (British Psychological Society). (2013). Classification of behaviour and experience in relation to functional psychiatric diagnoses: Time for a paradigm shift DCP position statement.

BPS (British Psychological Society). (2017a). Declaration on equality, diversity and inclusion. Retrieved September 28th, 2019, from: https://www.bps.org.uk/sites/bps.org.uk/files/News/News%20-%20Files/INF278%20Declaration%20on%20equality%20v3.pdf

BPS (British Psychological Society). (2017b). Practice guidelines.

BPS (British Psychological Society). (2018). Code of ethics and conduct.BPS (British Psychological Society). (2018b). The power threat meaning framework towards the identification of patterns in emotional distress, unusual experiences and troubled or troubling behaviour, as an alternative to functional psychiatric diagnosis. Retrieved 03/12/2020, from: PTM Framework (January 2018)_0.pdf (bps.org.uk)

BPS (British Psychological Society). (2019). Division of educational and child psychology. Quality standards for educational psychology service.

BPS (British Psychological Society). (2022). Educational psychology is inherently political. *The Psychologist.* Retrieved 29th March 2022, from: 'Educational psychology is inherently political' | The Psychologist (bps.org.uk)

BPS (British Psychological Society). (2022b). Non-pharmacological interventions to support children who have difficulties with attention, activity and impulsivity.

Brady, G. (2014). Children and ADHD: Seeking control within the constraints of diagnosis. *Children & Society*, *28*(3), 218–230.

Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology. Retrieved 14th July, 2020, from:* https://www.researchgate.net/publication/235356393_Using_thematic_analysis_in_psychology

Bronfenbrenner, U. (1979). *The ecology of human development: Experiments by nature and design.* Harvard University Press.

Bruchmüller, K., Margraf, J., & Schneider, S. (2012). Is ADHD diagnosed in accord with diagnostic criteria? Overdiagnosis and influence of client gender on diagnosis. *Journal of Consulting and Clinical Psychology*, *80*(1), 128–138.

Bucci, S., Seymour-Hyde, A., Harris, A., & Berry, K. (2016). Client and therapist attachment styles and working alliance. *Clinical Psychology and Psychotherapy, 23,* 155-165.

Cassidy, J. (1994). *Emotion regulation: influences of attachment relationships*. 23. Retrieved 18th February 2021, from: Emotion Regulation: Influences of Attachment Relationships on JSTOR (oclc.org)

CD (Cambridge Dictionary). (n.d. 2) Online search for the word 'aetiology'. Retrieved 27th February 2021, from: AETIOLOGY | meaning in the Cambridge English Dictionary

CD (Cambridge Dictionary). (n.d.) Online search for the word 'treatment'. Retrieved 14th February 2021, from: TREATMENT | meaning in the Cambridge English Dictionary

CDC (Centers for Disease Control and Prevention). (2019). Retrieved 19th April 2022, from: Research on ADHD | CDC

Children and Families Act. (2014). Retrieved October 4th 2019, from: http://www.legislation.gov.uk/ukpga/2014/6/contents/enacted

Christakis, D. A., Zimmerman, F. J., DiGiuseppe, D. L., & McCarty, C. A. (2004). Early television exposure and subsequent attentional problems in children. *Pediatrics, 113,* 708–713.

Clarke-Carter, D. (2010). *Quantitative psychological research the complete student's companion*. Psychology Press.

Clark, L. A., Cuthbert, B., Lewis-Fernández, R., Narrow, W. E., & Reed, G. M. (2017). Three approaches to understanding and classifying mental disorder: *ICD-11, DSM-5* , and the national institute of mental health's research domain criteria (RDoC). *Psychological Science in the Public Interest*, *18*(2), 72–145.

Clifford, D. (2021). Disparities by deprivation: The geographical impact of unprecedented changes in local authority financing on the voluntary sector in England. *Environment and Planning A: Economy and Space*, *53*(8), 2050–2067.

Cohen, L., Manion, L., & Morrison, K. (2011). *Research methods in education.* Routledge.

Cooper, P., & Ideus, K. (1996). *Attention deficit/hyperactivity disorder: A practical guide for teachers (Resource materials for teachers).* UK: David Fulton Publishers.

Cooperrider, D., & Sekerka, L. (2015). Towards a theory of positive organisational change. *ResearchGate.* Retrieved 13th April 2022, from: Inquiry_into_the_Appreciable_World_Toward_a_Theory.pdf

Corcoran, J., Schildt, B., Hochbrueckner, R., & Abell, J. (2017). Parents of children with attention deficit/hyperactivity disorder: A meta-synthesis, part II. *Child and Adolescent Social Work Journal*, *34*(4), 337–348. https://doi.org/10.1007/s10560-017-0497-1

Cortese, S., & Coghill, D. (2018). Twenty years of research on attention-deficit/hyperactivity disorder (ADHD): Looking back, looking forward. *Evidence-Based Mental Health*, *21* (4), 173–176.

CQC (Care Quality Commission). Report details removed for anonymity

CQC (Care Quality Commission). Report details removed for anonymity

CQC/Ofsted (Care Quality Commission/Office for Standards in Education). Report details removed for anonymity

Cromby, J. (2020). Meaning in the power threat meaning framework. *Journal of Constructivist Psychology*, 1–13. https://doi.org/10.1080/10720537.2020.1773355

Darwin, C. (1998). *Darwin: The origin of species*. Wordsworth Publishers.

DFE (Department of Education). (2018). Working together to safeguard children.

DfE (Department for Education). (2019). Special educational needs in England, January 2019. Retrieved 18th March 2021, from: Special educational needs in England: January 2019 - GOV.UK (www.gov.uk)

DfE (Department for Education). (2019). Statements of SEN and EHC plans: England, 2019. Retrieved 20th February 2021, from: SEN2_2019_text.pdf (publishing.service.gov.uk)

DfE (Department for Education). (2019b). National and local authority tables. Retrieved 20th February 2021, from: Statements of SEN and EHC Plans: England 2019 - GOV.UK (www.gov.uk)

DfE (Department for Education). (2020). Special educational needs in England, 2020. Retrieved 20th February 2021, from: Special educational needs in England, Academic Year 2019/20 – Explore education statistics – GOV.UK (explore-education-statistics.service.gov.uk)

DfE (Department for Education). (2022). SEND Review. Right Support, Right Place, Right Time: An inclusive education system: the green paper.

Doernberg, E., & Hollander, E. (2016). Neurodevelopmental disorders (ASD and ADHD): DSM-5, ICD-10, and ICD-11. Retrieved 16th February 2021, from: Neurodevelopmental Disorders (ASD and ADHD): DSM-5, ICD-10, and ICD-11 | CNS Spectrums | Cambridge Core (oclc.org)

Doggett, C., & Lewis, A. (2013). Using Appreciative Inquiry to facilitate organisational change and develop professional practice within an Educational Psychology Service. *Educational & Child Psychology,* Vol. 30 No. 4.

DoH/DfE (Department of Health and Department of Education). (2015). Special Educational Needs Code of Practice: 0-25 years.

DoH/DoE (Department of Health/Department of Education). (2017). Transforming children and young people's mental health provision: a green paper. Retrieved 16th February 2021, from: Transforming_children_and_young_people_s_mental_health_provision.pdf (publishing.service.gov.uk)

DSM-V (Diagnostic and Statistics manual of Mental Disorders, fifth edition). (2013). *American Psychiatric Association.*

Elliot, J, & Grigorenko, E. (2014). The end of dyslexia. *The Psychologist.* Retrieved 5th March 2020, from: The end of dyslexia? | The Psychologist (bps.org.uk)

Esteller-Cucala, P., Maceda, I., Børglum, A. D., Demontis, D., Faraone, S. V., Cormand, B., & Lao, O. (2020). Genomic analysis of the natural history of attention-deficit/hyperactivity disorder using neanderthal and ancient Homo sapiens samples. *Scientific Reports*, *10*(1), 8622. https://doi.org/10.1038/s41598-020-65322-4

Férat, V., Arns, M., Deiber, M.-P., Hasler, R., Perroud, N., Michel, C. M., & Ros, T. (2021). Electroencephalographic microstates as novel functional biomarkers for Adult Attention-Deficit/Hyperactivity Disorder. *Biological Psychiatry: Cognitive Neuroscience and Neuroimaging*. https://doi.org/10.1016/j.bpsc.2021.11.006

Finfgeld, D. L. (2003). Meta-synthesis: the state of the art—so far. *Qualitative Health Research,* 13, 893–904.

Flack, E. (2018). Exploring boys' experiences of ADHD and good practice in mainstream secondary schools; a multi-informant study. Doctoral thesis, UCL Institute of Education

Ford, T., Parker, C., Salim, J., Goodman, R., Logan, S., & Henley, W. (2018). The relationship between exclusion from school and mental health: A secondary analysis of the British Child and Adolescent Mental Health Surveys 2004 and 2007. *Psychological Medicine*, *48*(4), 629–641.

Foreman, D. M., & Ford, T. (2008). Assessing the diagnostic accuracy of the identification of hyperkinetic disorders following the introduction of government guidelines in England. *Child and Adolescent Psychiatry and Mental Health*, *2*(1), 32.

Fox, M. (2009). Working with systems and thinking systemically – disentangling the crossed wires. *Educational Psychology in Practice*, *25*(3), 247–258. https://doi.org/10.1080/02667360903151817

Franke, S., Kissgen, R., Krischer, M., & Sevecke, K. (2017). Attachment in children with ADHD. *Journal of Behavioral and Brain Science*, *07*(11), 497–510. https://doi.org/10.4236/jbbs.2017.711035

Frith, C., & Frith, U. (2005). *Advances in Clinical Neuroscience & Rehabilitation.*

Gallos, J (Ed.). (2006). *Organization development.* A Jossey-Bass Reader.

Galves, A.O., Walker, D., Cohen, D., Schneider, K.J., Greening, T., Karon, B., Dunlap, M., Wetzel, N.A., Friedman, H., Duncan, B., & Johnson, T. (2003). *A letter to APA by 11 psychologists*. Retrieved 14th March 2020, from: http://psychrights.org/articles/replytorubenstein.pdf

Glasser, W. (1997). A new look at school failure and school success. *The Phi Delta Kappan*, 78(8), 596–602.

Gnanavel, S., Sharma, P., Kaushal, P., & Hussain, S. (2019). Attention deficit hyperactivity disorder and comorbidity: A review of literature. *World Journal of Clinical Cases*, *7*(17), 2420–2426.

Gov.UK (2014). Atomoxetine (Strattera) increases in blood pressure and heart rate. Retrieved 7th February 2021, from: Atomoxetine (Strattera▼): increases in blood pressure and heart rate - GOV.UK (www.gov.uk)

Greene, R. W., Beszterczey, S. K., Katzenstein, T., Park, K., & Goring, J. (2002). Are students with ADHD more stressful to teach?: Patterns of teacher stress in an elementary school sample. *Journal of Emotional and Behavioral Disorders*, *10*(2), 79–89.

Greenway, C., & Rees-Edwards, A. (2020). Knowledge and attitudes towards attention-deficit hyperactivity disorder (ADHD): A comparison of teachers and teaching assistants. *Australian Journal of Learning Difficulties, 25(1),* 31-4. Retrieved 22nd April 2022, from: Knowledge and attitudes towards attention-deficit hyperactivity disorder (ADHD): a comparison of teachers and teaching assistants (oclc.org)

Grieg, A., Taylor, J., & Mackay, T. (2013) *Doing research with children: a practical guide.* Sage.

Groen, Y., Priegnitz, U., Fuermaier, A. B. M., Tucha, L., Tucha, O., Aschenbrenner, S., Weisbrod, M., & Garcia Pimenta, M. (2020). Testing the relation between ADHD and hyperfocus experiences. *Research in Developmental Disabilities*, *107*, 103789. https://doi.org/10.1016/j.ridd.2020.103789

Grotewiel, M. M., Crenshaw, M. E., Dorsey, A., & Street, E. (2022). Experiences of hyperfocus and flow in college students with and without Attention Deficit Hyperactivity Disorder (ADHD). *Current Psychology*. https://doi.org/10.1007/s12144-021-02539-0

Guba, E. G., & Lincoln, Y. S. (1994). Competing paradigms in qualitative research. In Denzin, N. K., & Lincoln, Y. S (Eds.), *Handbook of qualitative research* (pp.105-117). Sage. Retrieved 20th March 2021, from: Guba & Lincoln 1994.pdf (uoa.gr)

Harpin, V. A. (2005). The effect of ADHD on the life of an individual, their family, and community from preschool to adult life. *Archives of Disease in Childhood*, *90*.

Hartmann, T. (2019). *A hunter in a farmer's world.* Inner Traditions Bear and Company.

HCPC (Health and Care Professionals Council). (2015). Standards of proficiency.

HCPC (Health and Care Professionals Council). (2016). Standards of conduct, performance and ethics.

Hefferon, K., & Gil-Rodriguez, E. (2011). Methods: Interpretative phenomenological analysis. *The Psychologist*. Retrieved January 21, 2022, from: https://thepsychologist.bps.org.uk/volume-24/edition-10/methods-interpretative-phenomenological-analysis

Heidegger, M. (1962/1972). *Being and Time.* Blackwell.

Hemming, G. L. (2017). *Understanding the experiences of students and teachers of students diagnosed with ADHD: an interpretative phenomenological analysis of the ADHD label in schools*. 167. Doctoral thesis, The University of Birmingham.

Hidalgo, M. (2018). Defying the odds: one mother's experience raising a twice-exceptional learner. *Research Issues in Contemporary Education, 3,1.*

Hill, V. (2017). The rise of ADHD: An educational psychology perspective. *The BPS.* Retrieved April 15, 2022, from: https://www.bps.org.uk/news-and-policy/rise-adhd-educational-psychology-perspective?msclkid=aab2048fbcd011ec91649b2d4578cb91

HMIoE (Her Majesty's Inspectorate of Education, Scotland). (2007). Quality management in local authority educational psychology services 2: self-evaluation toolkit. Retrieved 12th July, 2020, from: https://archive.org/details/ERIC_ED541218/page/n1/mode/2up

Hoffmann, H. (1845). *Der struwwelpeter. Retrieved 27th March 2021, from:* The Story of Fidgety Philip (vcu.edu)

Holbrook, J., Danielson, M., Bitsko, R. H., Cuffe, S. P., O'Banion, D., & McKeown, R. E. (2017). Parent-reported benefits and side effects from attention-deficit/hyperactivity disorder (ADHD) medication in a nationally drawn sample of school-aged children diagnosed with ADHD. *Journal of the American Academy of Child & Adolescent Psychiatry*, *56*(10).

Honkasilta, J. (2016). Voices behind and beyond the label. The master narrative of ADHD (de)constructed by diagnosed children and their parents. Retrieved 5th March 2020, from: (PDF) Voices behind and beyond the label : the master narrative of ADHD (de)constructed by diagnosed children and their parents (researchgate.net)

Hooft, M.-N., Denis, C., & Pitchot, W. (2016). Controversies around the diagnosis of ADHD. *Revue Medicale De Liege*, *71*(3), 141–146.

Hou, Y., Xiong, P., Gu, X., Huang, X., Wang, M., & Wu, J. (2018). Association of serotonin receptors with attention deficit hyperactivity disorder: A systematic review and meta-analysis. *Current Medical Science*, *38*(3), 538–551. https://doi.org/10.1007/s11596-018-1912-3

Howitt, D., & Cramer, D. (2007). *Introduction to research methods in psychology*. Pearson Education.

ICD-10 (International Statistical Classification of Diseases and Related Health Problems, 10th edition). (2010). Retrieved 4th December 2020, from: ICD-10 Version:2010 (who.int)

ICD-11 (International Statistical Classification of Diseases and Related Health Problems, 11th edition). (2022). Retrieved 4th May 2022, from: ICD-11 (who.int)

Johnstone, L. (2017). Psychological formulation as an alternative to psychiatric diagnosis. *Journal of Humanistic Psychology, 58.*

Johnstone, L., & Boyle, M. (2018). The Power Threat Meaning Framework: An alternative non-diagnostic conceptual system. *Journal of Humanistic Psychology*, 002216781879328. https://doi.org/10.1177/0022167818793289

Jones, K., & Tymms, P. (2014). Ofsted's role in promoting school improvement: The mechanisms of the school inspection system in England. *Oxford Review of Education*, *40*(3), 315–330. https://doi.org/10.1080/03054985.2014.911726

Jutel, A. (2009). Sociology of diagnosis: A preliminary review. *Sociology of Health & Illness*, *31*(2), 278–299. https://doi.org/10.1111/j.1467-9566.2008.01152.x

Kadesjo, B., & Gillberg, C. (2001). The comorbidity of ADHD in the general population of Swedish school-age children. *J. Child Psychology & Psychiatry*, 42.

Keer, M. (2022). Publication day: your first look at what's in the SEND green paper. *Special Needs Jungle. Retrieved 20th April 2022, from:* Publication day: Your first look at what's in the SEND Review Green Paper. - Special Needs Jungle

Kelly, B., Marks Woolfson, L., & Boyle, J. (2017). *Frameworks for practice in educational psychology*. Jessica Kingsley Publishers.

King, N., Reid, D., & Dingle, A. D. (2013). Making ethical treatment decisions in ADHD: psychotropic medication use in child and adolescent populations. *Child and Adolescent Psychopharmacology News*, *18*(2), 1–4. https://doi.org/10.1521/capn.2013.18.2.1

Kooth. Retrieved 3rd April 2020, from: Home - Kooth

Kos, J., Richdale, A., & Hay, D. (2006). Children with Attention Deficit Hyperactivity Disorder and their teachers: A review of the literature. *International Journal of Disability Development and Education*, *53*, 147–160.

Lambek, R., Tannock, R., Dalsgaard, S., Trillingsgaard, A., Damm, D., & Thomsen, P. H. (2011). Executive dysfunction in school-age children with ADHD. *Journal of Attention Disorders*, *15*(8), 646–655. https://doi.org/10.1177/1087054710370935

Langberg, J. M., Arnold, L. E., Flowers, A. M., Altaye, M., Epstein, J. N., & Molina, B. S. G. (2010). Assessing homework problems in children with ADHD: validation of a parent-report measure and evaluation of homework performance patterns. *School Mental Health*, *2*(1), 3–12. https://doi.org/10.1007/s12310-009-9021-x

Lauchlan, F., Boyle, C., Gibbs, S., & Resing W. (2017). Labelling and diagnosis. *Educational & Child Psychology Vol. 34 No. 4.*

Lauckner, H., Paterson, M., & Krupa, T. (2012). Using constructivist case study methodology to understand community development processes: proposed methodological questions to guide the research process. *The Qualitative Report,*17, 1-22.

Lee, M., Chou, M., Chou, W., Huang, C., Kuo, H., Lee, S., & Wang, L. (2018). Heavy metals' effect on susceptibility to attention-deficit/hyperactivity disorder: implication of lead, cadmium, and antimony. *International Journal of Environmental Research and Public Health*, *15*(6), 1221.

Leitch, S., Sciberras, E., Post, B., Gerner, B., Rinehart, N., Nicholson, J. M., & Evans, S. (2019). Experience of stress in parents of children with ADHD: A qualitative study. *International Journal of Qualitative Studies on Health and Well-Being*, *14*(1).

Leno, V. C., Charman, T., Pickles, A., Jones, C. R. G., Baird, G., Happé, F., & Simonoff, E. (2015). Callous–unemotional traits in adolescents with autism spectrum disorder. *The British Journal of Psychiatry*, *207*(5), 392–399. https://doi.org/10.1192/bjp.bp.114.159863

Linnet, K. M., Dalsgaard, S., Obel, C., Wisborg, K., Henriksen, T. B., Rodriguez, A., Kotimaa, A., Moilanen, I., Thomsen, P. H., Olsen, J., & Jarvelin, M.-R. (2003). Maternal lifestyle factors in pregnancy risk of attention deficit hyperactivity disorder and associated behaviours: Review of the current evidence. *American Journal of Psychiatry*, *160*(6), 1028–1040. https://doi.org/10.1176/appi.ajp.160.6.1028

Mahone, E. M., Cirino, P. T., Cutting, L. E., Cerrone, P. M., Hagelthorn, K. M., Hiemenz, J. R., Singer, H. S., & Denckla, M. B. (2002). Validity of the behaviour rating inventory of executive function in children with ADHD and/or Tourette syndrome. *Archives of Clinical Neuropsychology*, 20.

Manohar, H., Kuppili, P. P., Kandasamy, P., Chandrasekaran, V., & Rajkumar, R. P. (2018). Implications of comorbid ADHD in ASD interventions and outcome: Results from a naturalistic follow up study from south India. *Asian Journal of Psychiatry*, *33*, 68–73. https://doi.org/10.1016/j.ajp.2018.03.009

Mary, A., Slama, H., Mousty, P., Massat, I., Capiau, T., Drabs, V., & Peigneux, P. (2016). Executive and attentional contributions to Theory of Mind deficit in attention deficit/hyperactivity disorder (ADHD). *Child Neuropsychology: A Journal on Normal and Abnormal Development in Childhood and Adolescence*, *22*(3), 345–365. https://doi.org/10.1080/09297049.2015.1012491

Masi, G., Fantozzi, P., Muratori, P., Bertolucci, G., Tacchi, A., Villafranca, A., Pfanner, C., & Cortese, S. (2020). Emotional dysregulation and callous unemotional traits as possible predictors of short-term response to methylphenidate monotherapy in drug-naïve youth with ADHD. *Comprehensive Psychiatry*, *100*, 152178.

Maslow, A. H. (1943.). *A Theory of human motivation*. 27. Retrieved 14th March 2021, from: Maslow, A. H. (1943). A theory of human motivation. Psychological Review, 50, 370–396. - Bing

McCubbin, M., & Cohen, D. (1999). Empirical, ethical, and political perspectives on the use of methylphenidate. *Ethical Human Sciences and Services,* 21.

McElearney, C., Fitzpatrick, C., Farrell, N., King, M., & Lynch, B. (2014). Stimulant medication in ADHD: What do children and their parents say? *Irish Journal of Psychological Medicine*, *22*(1), 5–9. https://doi.org/10.1017/S0790966700008715

Mind. (2016). GPs and practice nurses aren't getting enough mental health training. Retrieved 20th February, 2020, from: GPs and practice nurses aren't getting enough mental health training | Mind

Mueller, A. K., Fuermaier, A. B. M., Koerts, J., & Tucha, L. (2012). Stigma in Attention Deficit Hyperactivity Disorder. *Attention Deficit and Hyperactivity Disorders*, *4*(3), 101–114.

Murray, S., & Leadbetter, J. (2018) Video Enhanced Reflective Practice (VERP): supporting the development of trainee educational psychologists' consultation and peer supervision skills. *Educational Psychology in Practice.*

Nijmeijer, J. S., Minderaa, R. B., Buitelaar, J. K., Mulligan, A., Hartman, C. A., & Hoekstra, P. J. (2008). Attention-deficit/hyperactivity disorder and social dysfunctioning. *Clinical Psychology Review*, 28(4), 692–708. doi:10.1016/j.cpr.2007.10.003

NHGRI (National Human Genome Research Institute). (n.d.) Researchers identify gene associated with ADHD susceptibility. Retrieved 3rd December 2020, from: Researchers Identify Gene Associated with ADHD Susceptibility (genome.gov)

NHS (National Health Service). (2021). ADHD Treatment. Retrieved 10th April 2020, from: Attention deficit hyperactivity disorder (ADHD) - Treatment - NHS (www.nhs.uk)

NICE (National Institute for Health and Care Excellence). (n.d.). History of NICE. Retrieved 27th February, 2021, from: History of NICE | Who we are | About | NICE

NICE. (National Institute for Health and Care Excellence). (2014). Developing NICE guidelines: the manual. Retrieved 30th March 2020, from: 5 Identifying the evidence: literature searching and evidence submission | Developing NICE guidelines: the manual | Guidance | NICE

NICE (National Institute for Health and Care Excellence). (2018). Attention Deficit Hyperactivity Disorder: diagnosis and management. Retrieved 3rd March 2021, from: www.nice.org.uk/guidance/ng87

NICE (National Institute for Health and Care Excellence). (2019). Attention Deficit Hyperactivity Disorder: diagnosis and management. Retrieved 17th February, 2021, from: https://www.nice.org.uk/guidance/ng87/chapter/Context

Nigg, J. T., Karalunas, S. L., Gustafsson, H. C., Bhatt, P., Ryabinin, P., Mooney, M. A., Faraone, S. V., Fair, D. A., & Wilmot, B. (2020). Evaluating chronic emotional dysregulation and irritability in relation to ADHD and depression genetic risk in children with ADHD. *Journal of Child Psychology & Psychiatry*, *61*(2), 205–214.

Nikkelen, S. W. C., Valkenburg, P. M., Huizinga, M., & Bushman, B. J. (2014). Media use and ADHD-related behaviours in children and adolescents: A meta-analysis. *Developmental Psychology*, *50*(9), 2228–2241.

Nolen, S. B. (2020). Challenging research norms in educational psychology. *Educational Psychologist*, *55*(4), 267–272.

Oxley, L. (2016). An examination of Interpretative Phenomenological Analysis (IPA). *Educational & Child Psychology. 33*(3), 9.

Parens, E., & Johnston, J. (2009). Facts, values, and attention-deficit hyperactivity disorder (ADHD): An update on the controversies. *Child and Adolescent Psychiatry and Mental Health*, *3*(1), 1. https://doi.org/10.1186/1753-2000-3-1

PHE (Public Health England). (2016). Mental health of children in England. Retrieved 14th February 2021, from: Mental health of children in England (publishing.service.gov.uk)

Pickersgill, M. D. (2014). Debating DSM-5: Diagnosis and the sociology of critique. *Journal of Medical Ethics*, *40*(8), 521–525.

Pickett, J. (2016). Management of ADHD in children and adolescents: ADHD. *Prescriber*, *27*(2), 17–23. https://doi.org/10.1002/psb.1432

Pliszka, S. (2003). The comorbidity of ADHD in the general population of Swedish school-age Children. *Therapy in Practice.*

Polanczyk, G., de Lima, M. S., Horta, B. L., Biederman, J., & Rohde, L. A. (2007). The worldwide prevalence of ADHD: A Systematic review and meta-regression analysis. *American Journal of Psychiatry*, 7.

Polanczyk G., Willcutt, E., Salum, G., Kieling C, Rohde L. (2014). ADHD prevalence estimates across three decades: an updated systematic review and meta-regression analysis. *International Journal of Epidemiology,* 43, 434–42.

Radley, A., & Chamberlain, K. (2001). Health psychology and the study of the case: from method to analytic concern. *Social Science & Medicine* 53 (321–332).

Rice, D, & Barone Jr, S. (2000). Critical periods of vulnerability for the developing nervous system: Evidence from humans and animal models. *Environmental Health Perspectives.*

Ringer, N., Wilder, J., Scheja, M., & Gustavsson, A. (2020). Managing children with challenging behaviours. Parents' meaning-making processes in relation to their children's ADHD diagnosis. *International Journal of Disability, Development and Education*, *67*(4), 376–392. https://doi.org/10.1080/1034912X.2019.1596228

Roughan, L. A., & Stafford, J. (2019). Demand and capacity in an ADHD team: Reducing the wait times for an ADHD assessment to 12 weeks. *BMJ Open Quality*, *8*(4).

Roy, M., Rivest, M.-P., Namian, D., & Moreau, N. (2019). The critical reception of the *DSM-5*: Towards a typology of audiences. *Public Understanding of Science*, *28*(8), 932–948.

Ruddle, A., & Dilks, S. (2015). Opening up to disclosure. *The Psychologist.* Retrieved 27th May 2021, from: Opening up to disclosure | The Psychologist (bps.org.uk)

Sayal, K., Prasad, V., Daley, D., Ford, T., & Coghill, D. (2018). ADHD in children and young people: prevalence, care pathways, and service provision. *The Lancet Psychiatry*, *5*(2), 175–186. Retrieved 14th February 2021, from: https://doi.org/10.1016/S2215-0366(17)30167-0

Schwartz, A. (2016). *ADHD nation. The disorder. The drugs. The inside story.* Little Brown.

Scotland, J. (2012). Exploring the philosophical underpinnings of research: relating ontology and epistemology to the methodology and methods of the scientific, interpretive, and critical research paradigms. *English Language Teaching, 5, 9.*

Shareghfarid, E., Sangsefidi, Z. S., Hosseinzadeh, M., Salehi-Abargouei, A., & Mohammadi, M. (2020). Comparison of nutrients\intakes in children with and without attention deficit hyperactivity disorder. *Journal of Nutrition and Food Security*, *5*(2), 132–140.

Shaw, P., Stringaris, A., Nigg, J., & Leibenluft, E. (2014). Emotional dysregulation and Attention-Deficit/Hyperactivity Disorder. *The American Journal of*

Psychiatry, *171*(3), 276–293. https://doi.org/10.1176/appi.ajp.2013.13070966

Singh, I. (2012). Voices: voices on identity, childhood, ethics and stimulants. Children join the debate. *ADHD Voices.* Retrieved 22nd April 2022, from: 12_0819_Voices_Report_LR-72dpi-GREY_V4.pdf (adhdvoices.com)

Slattery, C., Egan., & Brophy, T. (2022). An exploration of the assessment for intervention model in an Irish educational context. *Educational Psychology in Practice*, 38, 1-19.

Smith, P., Cowie, H., & Blades, M. (2007). *Understanding children's development.* Blackwell Publishing.

Smith, J., Flowers., & Larkin, M. (2012). *Interpretative Phenomenological Analysis, theory, method and research.* SAGE Publications Ltd.

Srinath, S., Jacob, P., Sharma, E., & Gautam, A. (2019). Clinical Practice Guidelines for Assessment of Children and Adolescents. *Indian Journal of Psychiatry*, *61*(Suppl 2), 158–175. https://doi.org/10.4103/psychiatry.IndianJPsychiatry_580_18

Stanbridge, J., & Mercer, E. (2018). Mind your language: why the language used to describe children's SEMH needs matters. *International Journal of Inclusive Education.*

Swanepoel, A., Music, G., Launer, J., & Reiss, M. J. (2017). How evolutionary thinking can help us to understand ADHD. *BJPsych Advances*, *23*(6), 410–418. https://doi.org/10.1192/apt.bp.116.016659

Teddlie, C., & Tashakkori, A. (2009). *Foundations of mixed methods research*. Sage, chapter 2.

Thapar, A., Cooper, M., Eyre, O., & Langley, K. (2013). Practitioner review: what have we learnt about the causes of ADHD? *Journal of Child Psychology and Psychiatry*, *54*(1), 3–16. https://doi.org/10.1111/j.1469-7610.2012.02611.x

Timimi, S. (2005). *Naughty boys: anti-social behaviour, ADHD and the role of culture*, Palgrave Macmillan. Retrieved 3rd December 2020 from https://ebookcentral.proquest.com/lib/uea/detail.action?docID=4762703.

Tracy, S. (2015). Qualitative quality: eight “big-tent” criteria for excellent qualitative research. *Qualitative Inquiry,* 16(10) 837–851.

Tyrer, P. (2014). A comparison of DSM and ICD classifications of mental disorder. *Advances in Psychiatric Treatment*, *20*(4), 280–285. https://doi.org/10.1192/apt.bp.113.011296

UN (United Nations). (1989). *Convention on the rights of the child*. Retrieved 20th April 2022, from: Convention on the Rights of the Child | OHCHR

Vuori, M., Martikainen, J. E., Koski-Pirilä, A., Sourander, A., Puustjärvi, A., Aronen, E. T., Chudal, R., & Saastamoinen, L. K. (2020). Children’s relative age and ADHD medication use: A Finnish population-based study. *Pediatrics*, *146*(4), e20194046.

Wang, P., Zhang, X., Fu, T., Li, S., Li, B., Xue, W., Yao, X., Chen, Y., & Zhu, F. (2017). Differentiating physicochemical properties between addictive and nonaddictive ADHD drugs revealed by molecular dynamics simulation studies. *ACS Chemical Neuroscience*, *8*(6), 1416–1428. https://doi.org/10.1021/acschemneuro.7b00173

Waters, E., Crowell, J., Elliott, M., Corcoran, D., & Treboux, D. (2002). Bowlby’s secure base theory and the social/personality psychology of attachment styles: work(s) in progress. *Attachment & Human Development*, *4*(2), 230–242.

Wegmann, J. (2015). *Psychopharmacology, straight talk on mental health medications*. PESI Publishing.

WHO (World Health Organisation). (2011). Children and neurodevelopmental behaviour and intellectual disorders. Retrieved 14th February 2021, from:

Microsoft PowerPoint - Children & neurodevelopmental disorders.ppt (who.int)

Wienen, A. W., Sluiter, M. N., Thoutenhoofd, E., de Jonge, P., & Batstra, L. (2019). The advantages of an ADHD classification from the perspective of teachers. *European Journal of Special Needs Education*, *34*(5), 649–662. https://doi.org/10.1080/08856257.2019.1580838

Willcutt, E. G. (2012). The prevalence of DSM-IV attention-deficit/hyperactivity disorder: A meta-analytic review. *Neurotherapeutics*, *9*(3), 490–499. https://doi.org/10.1007/s13311-012-0135-8

Williams, A., Billington, T., Goodley., and Corcoran, T. (2017). *Critical educational psychology.* (Eds.) John Wiley & Sons.

Yin, R. (2003). *Case study research and applications: design and methods*. Sage Publications.

Zola, I. (1983). Socio-medical inquiries: recollections, reflections and reconsiderations. Temple University Press.

Appendices

Appendix 1.0: Eight Orientations Towards ADHD that Remain Relevant Today (Cooper & Ideus, 1996)

Cooper & Ideus (1996) conducted an extensive literature review to learn more about the pervasive cultural attitudes towards ADHD in the UK and USA. The eight orientations that they discovered were:

1. Moral Ethical view: ADHD and associated behaviours are deliberate anti-social actions. By labelling such behaviours, we are diminishing individual accountability and responsibility.
2. Allopathic-Medical: ADHD stems from a medical problem, or neurological dysfunction. This eschews environmental factors for biological determinism
3. Political-Ideological: ADHD has been created to serve social control. Diagnoses can therefore be used to further marginalise certain social demographics.
4. Pragmatism: the view that people will accept a medical diagnosis at face value, without criticality.
5. Holistic-Medical: ADHD is a response to environmental factors such as diet and toxins.
6. Cognitive style: ADHD is not a disorder/deficit, but a cognitive style, that is superior to others.
7. Socio-cultural: there is nothing abnormal about people with ADHD, rather it is only problematised through social and cultural expectations and interpretations.
8. Systematic-Eclectic: a position that explains ADHD from a multi-perspectival view: i.e. a bio-psycho-social position.

(Cooper & Ideus, 1996, pp.79-80).

Appendix 2.0: Other Aetiological Hypotheses around ADHD

Other potential aetiological explanations of ADHD include exposure to: maternal alcohol consumption in utero (Linnet et al. 2003; Rice & Barone, 2000); toxins, including nicotine, in utero (Linnet et al. 2003); pesticides (Rice et al. 2000); heavy metals (Lee et al. 2018); x-ray radiation (Rice et al. 2000); intrauterine stress (Linnet et al. 2003); lower consumption of macronutrients (Shareghfarid et al. 2020), and “reduced brain volume” (DSM-5, 2013, p.61).

The scan-and-shift hypothesis and the fast-pace arousal hypothesis posit that the pervasive consumption of short, fast-paced, highly edited media develops attentional difficulties (Nikkelen et al. 2014). While the displacement hypothesis posits that high consumption of media, reduces the time otherwise spent engaging in social and cognitive activities, potentially reducing attentional capabilities (Christakis et al. 2004).

Hartmann (2019) suggests an evolutionary explanation for ADHD, in the hunter vs farmer hypothesis. This puts forward that people with ADHD may have evolved from members of hunter-gatherer societies, rather than those from farmer societies, and whose genetic make-up is misplaced, and misunderstood in modern (educational) settings.

Appendix 3.0: The LA ‘A’s Area SEN Strategy Key Priorities

- To ensure greater parental input in the co-production of services.
- To provide timely and easy access to services and improve effectiveness of interagency working.
- To improve the development of the co-production of services and family engagement.
- To focus on early identification of SEND and early intervention .
- To improve the level of inclusion for CYP with SEND and improve their outcomes.

(references removed).

Appendix 4.0: Child and Parent Semi-structured Interview Schedules

Child Semi-structured Interview Schedule

The questions in red font represents additional questions that may, or may not be used.

Area of focus	**Core Questions**	**Potential areas of exploration**
Aetiology	• What is ADHD? • Why some people have it? • Feelings?	• Why they feel this? • Sources of information?
Lived experience	• Can you tell me about your experiences (pre-diagnosis) and how it has affected you (and others)? • How do you think others viewed/treated you at that time? • How did you feel about yourself pre diagnosis?	• Affect ADHD has on lives/family (more broadly)?
Assessment and diagnosis	• Tell me about how they assessed you for having ADHD? • Have others treated you differently since you were diagnosed? • How did it feel to hear that you have ADHD?	• Diagnosis impact on school
Medication and treatment	• Do you take medication? • If no – why? • If yes – why? • Differences on and off medication • How do you feel about being on medication? • What else to manage your ADHD?	• Decision making process • **What do you think the medication does?** • How long do you think you will be on medication for?
Support	• Tell me about the support you have received before you were diagnosed? • And after diagnosis? • Enough support? • What more could be done? • Explore feelings about the support you receive/d? (Added 2/10/21)	
Other	• Is there anything else you would like to tell me about your experiences of having ADHD? • Feelings following interview?	

Parent/Carer Semi-structured Interview Schedule

(Additional Questions are in Red)

Area of focus	Core Questions	Potential areas of exploration
Aetiology	• What is ADHD? • Why some people have it? • Feelings?	• Why they feel this? • Sources of information?
Lived experience	• Can you tell me about your experiences (pre-diagnosis) and how it has affected you (and others)? • How do you think others viewed/treated your child at that time? • How did you feel about your child pre diagnosis?	• Affect ADHD has on lives/family (more broadly)?
Assessment and diagnosis	• Tell me about how they assessed your child for having ADHD? • Have others treated your child differently since diagnosis? • Do you treat your child differently post diagnosis? • How did it feel to hear that your child has ADHD?	• Diagnosis impact on school
Medication and treatment	• Do you take medication? • If no – why? • If yes – why? • Differences on and off medication • How do you feel about your child being on medication? • What else to manage your child's ADHD?	• Decision making process • **What do you think the medication does?** • How long do you think you will be on medication for?
Support	• Tell me about the support you/your child have received before you were diagnosed? • And after diagnosis? • Enough support? • What more could be done? • Explore feelings about the support you receive/d? (Added 2/10/21)	
Other	• Is there anything else you would like to tell me about your experiences of having ADHD? • Feelings following interview?	

Appendix 5.0: University Ethical Approval Letter

EDU ETHICS APPROVAL LETTER 2021-22

APPLICANT DETAILS	
Name:	Paul Codling
School:	EDU
Current Status:	**EdPsyD Student**
UEA Email address:	P.Codling@uea.ac.uk
EDU REC IDENTIFIER:	**2021_06_PC_AH_Updated**

Approval details	
Approval start date:	**28.09.2021**
Approval end date:	**31.05.2022**
Specific requirements of approval:	

Please note that your project is only given ethical approval for the length of time identified above. Any extension to a project must obtain ethical approval by the EDU REC before continuing. Any amendments to your project in terms of design, sample, data collection, focus etc. should be notified to the EDU REC Chair as soon as possible to ensure ethical compliance. If the amendments are substantial a new application may be required.

Victoria Warburton EDU Chair Research Ethics Committee

Appendix 6.0: CYP Post-Interview Support Sheet

Thank you for taking the time to talk with me today. It was really helpful!

Talking and reflecting upon your experiences can be challenging sometimes.

If you do feel a bit upset, or down, speak to your parent, carer, teacher, or trusted friend and let them know how you are feeling. You might find it helpful to write down your thoughts on paper. It may also be good to do some things that you enjoy.

If you still feel like you need a bit more help…

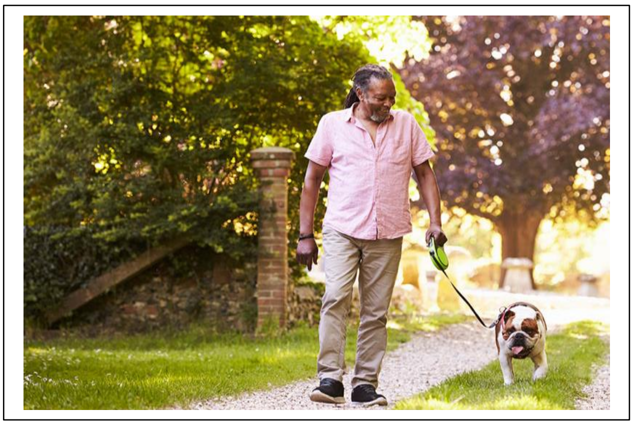
- You can get support through **Young Minds,** by texting YM to 85258. Texts are free from EE, O2, Vodafone, 3, Virgin Mobile, BT Mobile, GiffGaff, Tesco Mobile and Telecom Plus.
- You can also access a support team called **'Kooth'**. You can call them on 0203 984 9337 download the app here: Signup - Kooth or download the app.
- You can also talk with your **doctor**.

Appendix 7.0: Adult Post-Interview Support Sheet

Thank you for taking the time to talk with me today.

Talking and reflecting upon your, and your family's experiences can be challenging.

May I suggest that you take care of yourself over the next few days. Try to spend some time doing things that you enjoy.



You may find yourself thinking about the interview, and re-thinking your responses. This may have some bearing on your mood. This is perfectly normal.

However, if you have found this, or something else particularly difficult, there are a number of things you can do to help yourself:

1. Make time to speak to a trusted friend, or family member.
2. You may find it useful to write down your thoughts on paper.

If you feel that you would like more support than this. There are a number of services and charities that can help you:

- Speak to your GP – they will be able to sign-post you to the most appropriate services in your area.
- MIND can offer a confidential space to talk. They can be found at www.mind.org.uk or follow this link: Home | Mind or you can call them on 0300 123 3393.
- The Samaritans can offer support at any time, over the telephone, by calling 116 123, or by following this link: Contact Us | Samaritans
- XXX (XXX Foundation Trust) mental health services can also sign-post you to an appropriate service on this link (link removed)

Please also make time to check-in and monitor your child – they may need a little extra support too.

Appendix 8.0: A Short Study Description, May 2021

Would you be interested in taking part in a research project on ADHD, being undertaken by a trainee educational psychologist at the University of East Anglia?

The study aims to learn more about the lived experiences of children with ADHD, and their parents, and the affect/s it has had on their lives. It also aims to learn more about the experiences of seeking assessment and the quality of support that was received. The study will be used to shape the services that we offer.

If you agree to participate, you, your location, and anyone that you mention, will be fully anonymised in the study.

To take part you will need to be interviewed for approximately an hour. Your child would also need to be interviewed.

If you would like to take part, would it be OK for the researcher to contact you by email, or by telephone? He will be able to provide you with more details.

Your decision will not affect the work that we do with you, or your child in any way.

If you agree, but later change your mind, you are under no obligation to take part.

Appendix 9.0: Child Study Information Sheet and Consent Form

Study Information Sheet: ADHD and Me

My name is Paul.

I'm a 'Trainee Educational and Child Psychologist'.

I work with children and young people in school, and at home.

I'm doing a project at the University of East Anglia to find out more about what ADHD is and how it affects different children, young people, and their families.

I am asking you to take part in this project as you have ADHD and will know lots about what it is like living with ADHD.

I hope that by doing this project, we can let more people know what ADHD is and how it affects different people – like you.

You can decide if you want to take part in the study or not. You don't have to - it's up to you.

The sheets attached tell you what you will do if you decide to take part in the project. Please read it carefully so that you can make up your mind about whether you want to take part.

If you decide you want to be in the study, and then you change your mind later, that's ok. All you need to do is tell me that you don't want to be in the study anymore.

If you have any questions, you can just ask me, or your family/carers. My email address is p.codling@uea.ac.uk

What will happen if I say that I want to be in the study?

If you decide that you want to be in this study, I would…

1. Meet once, or twice, via Microsoft Teams.
2. I will ask you some questions about what it has been like for you having ADHD, and how others treat you because of it.
3. It's not a test – there's no getting it wrong 😊.
4. You can choose which questions you want to answer. If you don't want to talk about something, that's OK.
5. You can have an adult with you if you'd prefer.

6 You can stop talking to me at any time if you don't want to talk anymore.

7 You do not have to answer any questions that you do not want to answer. You can just say 'not that one' and I will move on to the next!'

8 I will need to record our voices, with a voice recorder, so that I can listen to it again later. (I won't record a video though).

9 I will then write about what you, and others, have told me.

10 I will not put your name or anyone else's name in what I write – so no-one will be able to tell it was you who spoke to me.

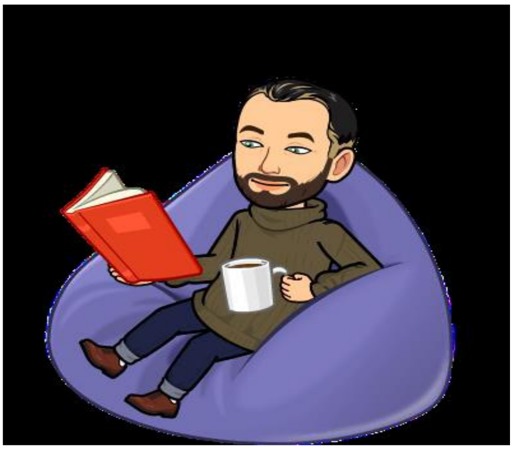
Will anyone else know what I say in the study?

I won't tell anyone else what you say except if you talk about someone hurting you, or about you hurting yourself or someone else. Then I might need to tell someone to keep you and other people safe.

All of the information that I have about you from the study will be stored in a safe place and I will look after it very carefully. I will write a report about the study and show it to other people but your name won't be in the report and no one will know that you were in the study, unless you want to tell them.

How long will the study take?

We will meet for about an hour. If that's too long for you to sit and talk in one go, we can break it up and do some fun things in between.



Are there any good things about being in the study?

I think you'll like talking about ADHD and it will be a chance to let others know more about it. I think it is really important for others to know what ADHD is and how it can affect people in the classroom and outside of school too. What I learn will also help to shape LA 'A's Educational Psychology service, and the way they work with children and families with ADHD.

Are there any bad things about being in the study?

This study will take up some of your time, but I don't think it will be bad for you.

Some children find it a bit challenging to talk about things like ADHD. If you're finding it difficult, we can stop at any time you want to. You can also talk with one of your trusted adults from school if you'd like to. I'll have their phone number with me. You may not want to of course!

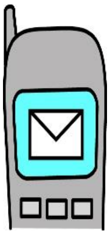
ADHD Medication

Please be aware that while we may discuss your experiences of medication, I am not a medical professional. As such I cannot offer you advice, or comment, on your past or current medical treatment in any way.

Will you tell me what you learnt in the study at the end?

Yes, if you want me to. There is a question on the next page that asks you if you want me to tell you what I learnt in the study. If you circle 'Yes', I will send you a copy of what I learnt.

What if I am not happy with the study or with you?



If you are not happy with how I am doing the study or how I treat you, then you or the person who looks after you can:

- **Call** the university on *01603 456161*
- Write an **email** to A.Honess@uea.ac.uk

If you would like to make a complaint to LA 'A' services you can:

- Contact XXX (Senior Educational Psychologist) on xxx or call Children's Services on xxx

If you don't want to take part, just let your parent/carer know, so they can tell me.

If you would like to take part, please fill in the two forms below and **give form number 1**

to your parent/carer to send back to me. **This letter and form number 2 are for you to keep. If you're still not sure, you can email me** - I'll be happy to talk with you about it a little bit more. My details are at the bottom of the forms…

ADHD and Me - Consent Form 1 (Paul's copy)

If you are happy to be in the study, please

1 **Write** your **name** in the space below

2 **Sign** your **name**, and put the **date** below

3 **Circle** your **2 choices** at the bottom of the page

You should only say 'yes' to being in the study if you know what it is about and you want to be in it. If you don't want to be in the study, don't sign it.

I, ……………………………………………………[PRINT NAME], am happy to be in this research study.

In saying yes to being in the study, I am saying that:

✓ I know what the study is about.

✓ I know what I will be asked to do.

✓ Someone has talked to me about the study.

✓ My questions have been answered.

✓ I know that I don't have to be in the study if I don't want to.

✓ I know that I can pull out of the study at any time if I don't want to do it anymore.

✓ I know that I don't have to answer any questions that I don't want to answer.

✓ I know that Paul won't tell anyone what I say when we talk to each other, unless I talk about being hurt by someone, hurting myself, or someone else.

Now I have 2 last questions for you (circle your choices):

Are you happy for me to **audio record** your voice?	**Yes**	**No**
Do you want me to tell you what I **learnt** in the study?	**Yes**	**No**

Sign your name ……………………………………………………

Today's date……………………………………………………**If you'd like to talk with me, email me at p.codling@uea.ac.uk**

Appendix 10.0: Parent/carer Information Statement and Consent Form

You (and your child) are invited to take part in a research study about your experiences of living with a child who has ADHD.

This statement tells you about the research study. Knowing what is involved will help you decide if you want to take part in the research or not. Please read this sheet carefully and then feel free to ask questions about anything that you don’t understand or want to know more about.

Who am I?

I am a trainee educational and child psychologist, completing my doctorate at the University of East Anglia. I am currently in practice, under supervision, working with children, young people, families and various services. I was a teacher for many years, and also worked for the NHS in both children’s, and adult’s mental health services.

This study will form my doctoral thesis and will, most likely, be published. I will also present the findings to my local authority educational psychology team, in a bid to further inform and shape the services that are offered to people living with ADHD in region ‘A’.

What is this study about?

This study is entitled: Case Studies Exploring the Lived Experiences of Children and Young People with ADHD, and the Lived Experiences of their Parents

The study will focus on a number of areas, namely:

- How families (including children/young people) attempt to make sense of what ADHD is.
- What it is like to have a child with ADHD, and how this has affected your lives.
- What led you to seek assessment and your experiences of this process.
- How you and your child are treated, and other’s perceptions of ADHD/your child.
- Your choices around treatment.
- The type and quality of support you received pre and post-diagnosis.
- What more could be done to support families, children/young people living with ADHD.

Who is running the study?

My name is Paul Codling, Trainee Educational Psychologist/ Postgraduate Researcher at the School of Education and Lifelong learning, University of East Anglia.

I am being supported by two research supervisors: Dr Andrea Honess, Educational Psychologist and UEA Course Director (for the Educational Psychology Doctoral programme) and Dr Kimberley Bartholomew, Lecturer in the School of Education and Lifelong Learning at the UEA.

What will the study involve?

For your child/young person, I will meet with them remotely over Microsoft Teams. I will spend about an hour with them asking them child-friendly questions about their experiences of having ADHD.

For you, the process will be similar – I will talk with you over Microsoft Teams about your experiences of having a child/young person with ADHD, as described above.

How much of my time will the study take?

Depending on how long your answers are, it is hoped that interviews will take approximately one hour to complete.

Does my child have to be in the study? Can they withdraw from the study once they've started?

To take part in the study, both you and your child/young person need to take part. Together, you will form ‘one case’. However, you can change your mind at any time. If you decide to let your child take part in the study and then change your mind later (or they no longer wish to take part), you/they are free to withdraw from the study at any time by simply telling me through email. Your decision to take part, or not, will not have any bearing on the service offered to you.

If you, or your child begins an interview, you/they are free to stop participating at any stage. If they (or you) decide at a later time to withdraw from the study, excluding their data will be possible up to the point in which analysis of the interviews begins. You/your child can choose to have the interview on your/their own, or with a trusted adult/friend, if preferred.

You and your child will not have to answer any questions that you don’t want to, and I will not pressure either of you to do so.

Are there any risks or costs associated with being in the study?

Aside from you and your child giving up your time, we do not expect that there will be any risks or costs associated with taking part in this study.

Please be aware that while we may discuss your experiences around medication, I am not a medical professional. As such I cannot offer you advice, or comment, on your past or current medical treatment in any regard.

Are there any benefits associated with being in the study?

There is a scarcity of research in this field, seeking out the voices of children, young people and families living with ADHD. While I cannot overestimate what this study may achieve, it is hoped that it will bring about a greater awareness of ADHD in this area. It has been agreed that the findings will be presented to the local authority Educational Psychology team. It is hoped that this will shape the way that ADHD is perceived, how the ADHD service pathways are structured, and how the services are offered to people living with ADHD.

What will happen to information that is collected during the study?

Your (and your child's/young person's) names, location/s and identity will not be disclosed in this study. Every effort will be made to ensure full anonymity and confidentiality.

By providing your consent, you are agreeing to us collecting personal information about your child for the purposes of this research study. Your/their information will only be used for the purposes outlined in this Participant Information Statement, unless you consent otherwise. Data management will follow the 2018 General Data Protection Regulation Act and the University of East Anglia Research Data Management Policy (2019). Your and your child's information will be stored securely, and your/their identity/information will be kept strictly confidential, except as required by law. Study findings may be published. Although every effort will be made to protect your child's identity, there is a risk that they might be identifiable due to the nature of the study and/or results. In this instance, data will be stored for a period of 10 years and then destroyed.

What if we would like further information about the study?

When you have read this information, I will be available to discuss it with you further and answer any questions you may have. You can contact me on p.codling@uea.ac.uk

Will I be told the results of the study?

You and your child have a right to receive feedback about the overall results of this study. You can tell us that you wish to receive feedback by ticking the relevant boxes on the consent form (below). This feedback will be in the form of a one-page summary, and you will receive this feedback after the study is finished. I can also send your child/young person a child-friendly version of the findings if they would like this. If published, you will, of course, be able to access the full article.

What if we have a complaint or any concerns about the study?

The ethical aspects of this study have been approved under the regulations of the University of East Anglia's School of Education and Lifelong Learning Research Ethics Committee. If you are unhappy about something, or there is a problem please let me know. You can contact me via email on p.codling@uea.ac.uk

If you (or your child) are concerned about the way this study is being conducted, please contact Andrea Honess in the first instance on a.honess@uea.ac.uk. You may also contact Kimberley Bartholomew on k.bartholomew@uea.ac.uk

If you wish to make a complaint to someone independent from the study, you could also contact the Head of the School of Education and Lifelong Learning, Professor Yann Lebeau at Y.Lebeau@uea.ac.uk.

If you wish to make a complaint to LA ‘A’ County Council services you can contact XXX (Senior Educational Psychologist) on xxx or call Children’s Services on xxx.

OK, I’m happy for me and my child to take part – what do I do next?

Please complete and return the consent form below. Please keep the information sheet for your records.

OK, I don’t want to/my child to take part – what do I do next? Please let me know via email if you/your child do not want to take part in this study.

This information sheet is for you to keep. Thank you for your time in reading this.

PARENT/CARER CONSENT FORM (This copy goes to the researcher please)

I, ... [PRINT PARENT’S/CARER’S NAME],

am willing for *my child/young person* ……………………………………………………………………………………….[PRINT CHILD’S NAME] to take part in this research study.

I, ... **am willing** to take part in this research study [PRINT YOUR OWN NAME]

Are you happy for me to **audio record** your/your child’s voice?

Yes **No**

Do you want me to tell you what we **learnt** in the study?

Yes **No**

Shall I send your child a child-friendly report of what we **learnt**?

Yes **No**

....
Signature

....
PRINT name

....
Date

Appendix 11.0: The Six Stage Process of IPA Analysis, Taken from Smith et al. (2012).

1 Reading and Re-reading

This involves the close reading, and re-reading of participant's transcripts. It is an iterative process, with an emphasis on avoiding reductionist readings, in which people can become accustomed. This process offers the researcher the opportunity to immerse themselves in the participant's account, and helps them to begin to understand the participant's experiences through their own subjective lens. This may involve listening to the audio transcript before moving on to the written version. At this stage, sections of the transcript were often read, many times over in a bid to make sense of what was being described.

2 Initial Note-taking

This is an extension of the process described above, but involves a closer analysis of the transcripts. In this study, the two stages inter-merged. The researcher sought to identify three areas, that were colour-coded in the following way:

Blue: Descriptive Comments. This was used to summarise sections, or points.

Green: Linguistic Comments. This focused, not only on the linguistic meanings that were being conveyed, but also on the way they were expressed. Particular focus was given to the use of figurative language, word-choice and repetition. Sections, phrases, and particular words were highlighted if they were felt to bear significant meaning to the participant.

Red: Conceptual Comments. This is a more time-consuming process taking greater reflection, to consider what is being conceptualised.

An example of the initial note-taking can be seen in Appendix 12.0.

3 Developing Emergent Themes

This aimed at recording emerging themes as they arose. This was done by writing potential themes in the left hand column of the transcript as seen in Appendix 12.0. When undertaking this stage of analysis, the researcher also engaged in bracketing: this involves moving away from the transcripts to record thoughts, and reflections. During this stage (and some of the others above) the researcher also engaged in a process of textual deconstruction. This meant, for example, considering how emerging themes and meaning may have been influenced by systems, including family, schools, governmental policy, historical, socio-economic, and cultural factors.

4 Searching for Connections Across Emergent Themes

This involved putting all of the emerging themes into a table. This study took the approach of recording possible themes in the left-hand margin. These were then recorded on a Word document the in order that they arose, accompanied by their line number. Following this, they were reduced to emerging themes and then consolidated again. An example can be found in Appendix 13.0. In keeping with Flowers et al. (2012) some of the potential themes were discarded at this stage. This was decided, more often than not, on the frequency in which it developed, and were likely discarded if the emerging theme only appeared once, i.e. if it did not appear to recur. If they did recur, they were more likely to be considered as potential emergent themes.

During this stage, the researcher, also continued to bracket, and also note areas of significant interest, for example, emerging themes that felt that they were particularly meaningful to the participant, or were specifically relevant to the RQs.

5 Moving to the Next Case

This means repeating the process above for the next case. In this instance, the researcher chose to move from parent to child, in the chronological order, in which the interviews were conducted.

The researcher became aware that the emergent themes that were arising in the later analyses were being influenced by what had arisen in the earlier cases. This meant that the researcher needed to adopt a reflexive and reflective position, to be mindful of this, and to allow new emergent themes to arise independently of the earlier cases.

6 Looking for Patterns Across Cases

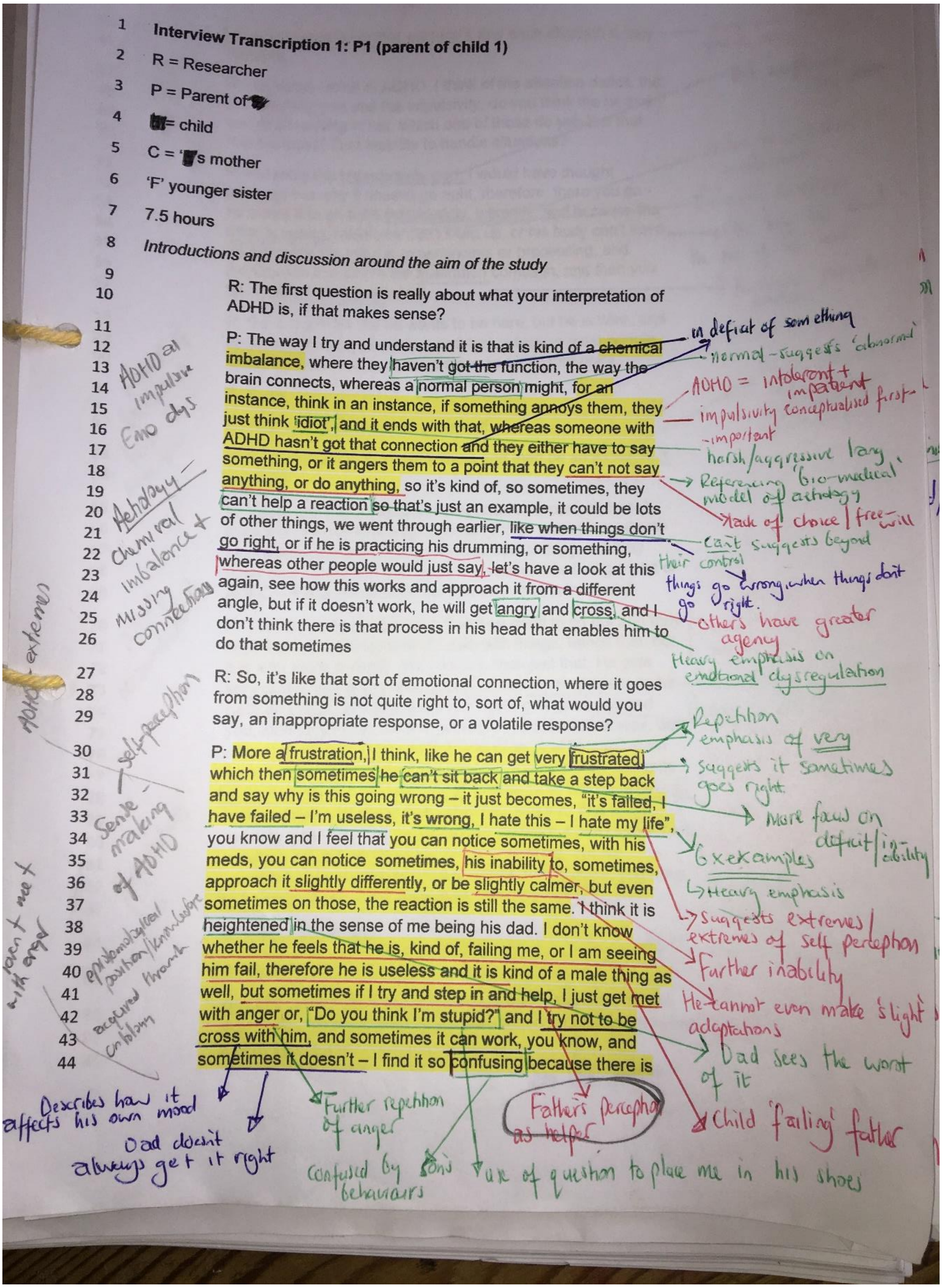
This involved looking for patterns, or thematic similarities/differences across the cases. In this instance, these were recorded on a large sheet of paper for both CYP and parent participants as seen in Appendix 14.0. This resulted in patterns across all five parent cases, and all five child cases being identified.

As well, as recording the themes, as they arose in this way, the researcher also began a process of abstraction, subsumption, polarization, contextualization and function as described by Smith et al. (2012). The authors also suggest the process of numeration but this was not employed preferentially, as it was felt that the focus of this study was not to place emphasis solely on the frequency with which a theme/topic appeared, over particularly meaningful, rich, or poignant expressions, and meaning making.

Finally a master table of subordinate themes developed across both CYP and parents as shown in Figure 1.0 and Figure 2.0.

From this, final, over-arching, or superordinate themes were identified as shown in Table 2.0.

Appendix 12.0: Example of Note-taking and Colour-coding in Peter's Transcript. The emerging themes can also be seen in the left hand column. This represents stages 1-3 of the IPA process (Smith et al. 2012).



Interview Transcription 1: P1 (parent of child 1)

R = Researcher

P = Parent of [redacted]

[redacted] = child

C = '[redacted]'s mother

'F' younger sister

7.5 hours

Introductions and discussion around the aim of the study

R: The first question is really about what your interpretation of ADHD is, if that makes sense?

P: The way I try and understand it is that is kind of a chemical imbalance, where they haven't got the function, the way the brain connects, whereas a normal person might, for an instance, think in an instance, if something annoys them, they just think 'idiot', and it ends with that, whereas someone with ADHD hasn't got that connection and they either have to say something, or it angers them to a point that they can't not say anything, or do anything, so it's kind of, so sometimes, they can't help a reaction so that's just an example, it could be lots of other things, we went through earlier, like when things don't go right, or if he is practicing his drumming, or something, whereas other people would just say, let's have a look at this again, see how this works and approach it from a different angle, but if it doesn't work, he will get angry and cross, and I don't think there is that process in his head that enables him to do that sometimes

R: So, it's like that sort of emotional connection, where it goes from something is not quite right to, sort of, what would you say, an inappropriate response, or a volatile response?

P: More a frustration, I think, like he can get very frustrated which then sometimes he can't sit back and take a step back and say why is this going wrong – it just becomes, "it's failed, I have failed – I'm useless, it's wrong, I hate this – I hate my life", you know and I feel that you can notice sometimes, with his meds, you can notice sometimes, his inability to, sometimes, approach it slightly differently, or be slightly calmer, but even sometimes on those, the reaction is still the same. I think it is heightened in the sense of me being his dad. I don't know whether he feels that he is, kind of, failing me, or I am seeing him fail, therefore he is useless and it is kind of a male thing as well, but sometimes if I try and step in and help, I just get met with anger or, "Do you think I'm stupid?" and I try not to be cross with him, and sometimes it can work, you know, and sometimes it doesn't – I find it so confusing because there is

ADHD as impulsive

Emo dys

Aetiology – chemical imbalance + missing connections

ADHD – extremes

self-perception

Sense making of ADHD

parent + me + with anger

epistemological position/knowledge acquired through criticism

in deficit of something

normal – suggests 'abnormal'

ADHD = intolerant + impatient

impulsivity conceptualised first – important

harsh/aggressive lang.

→ Referencing 'bio-medical' model of aetiology

lack of choice / free-will

Can't suggests beyond their control

things go wrong, when things don't go right.

others have greater agency

Heavy emphasis on emotional dysregulation

Repetition

emphasis of very

suggests it sometimes goes right

More focus on deficit/in-ability

6x examples

↳ Heavy emphasis

↳ Suggests extremes/ extremes of self perception

Further inability

He cannot even make 'slight' adaptations

Dad sees the worst of it

Child 'failing' father

Describes how it affects his own mood

Dad doesn't always get it right

Further repetition of anger

confused by son's behaviours

Father's perception ~~as helper~~

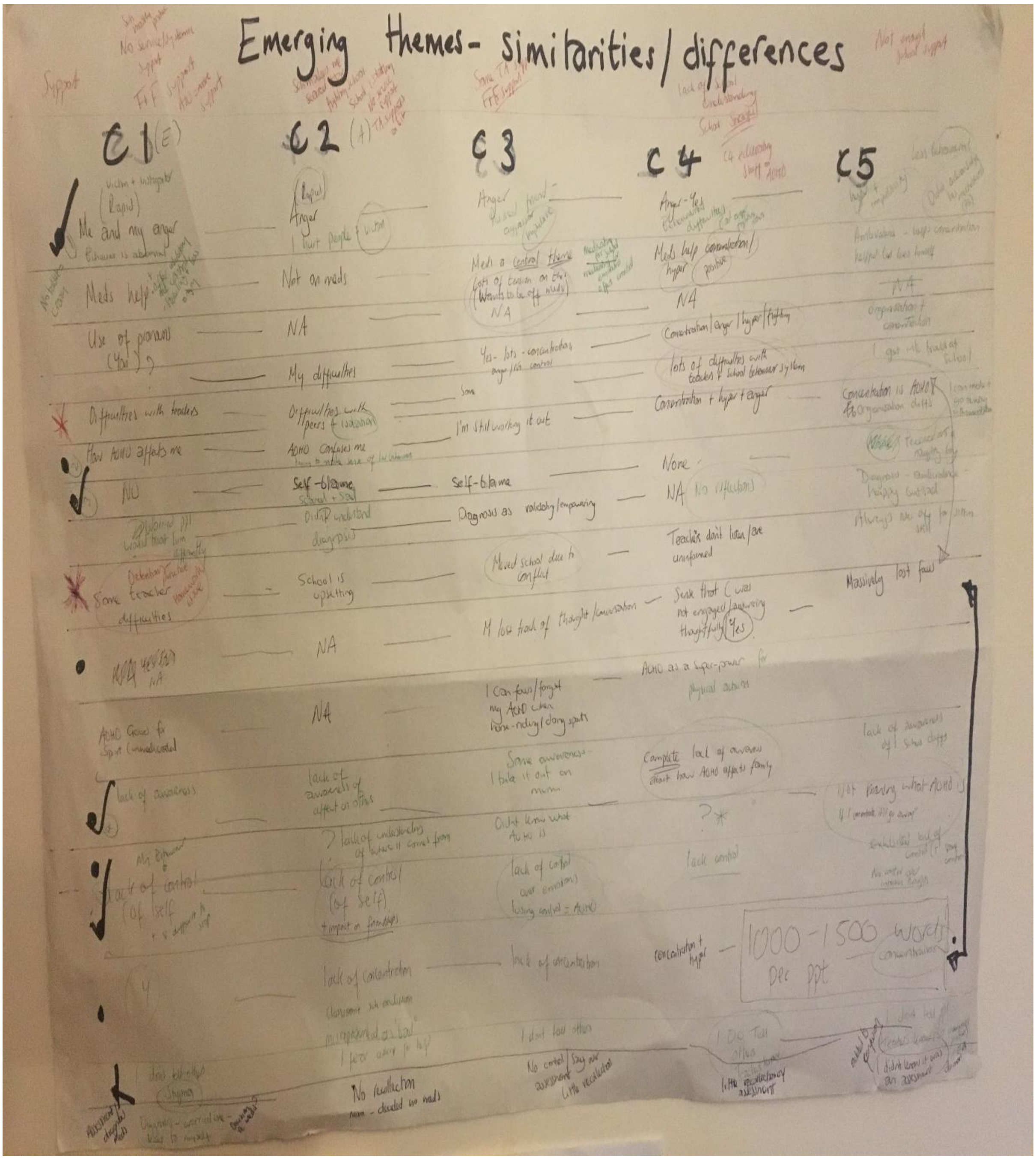
use of question to place me in his shoes

Appendix 13.0: An Example of Potential Emergent Themes (Left Column), Merged to Emergent Themes (Middle Column) and then to Consolidated Themes (Right Column). Taken from Peter's Data Analysis.

Potential Emergent Themes (presented in chronological order)	**Emergent Themes (grouped)** with frequency in brackets	**Consolidated Themes**
• Aetiology – chemical imbalance and missing connections (11-15; 23-26) • ADHD isn't 'normal' (13) • Symptoms of ADHD – intolerant; impatient; emotional dysregulation (11-46). • ADHD – lack of free-will/choice (17/18) • Children trying to make sense of ADHD (30 – 46). • Child failing father (39) • ADHD as extremes ('hate/ inability', 33, 35) • Very low sense of self - failure (30-44) • ADHD as confusing (44/45) • Parent met with anger (43/44/74) • Knowledge, or epistemological understanding is acquired fundamentally through ontological position (i.e. being in the world (30-44) • Parents as helper (41) • Superlatives used to understand child behaviours & ADHD (63) • health (549) • ADHD is misunderstood (556/562) • Diagnosis is helpful in… (571) • Drivers for assessment (580) • ADHD as hereditary (588) • ADHD: a difference or wrong? (600) • Impact on childhood (596-604)	• Making sense of ADHD and our child (20) • We get the worst of it: intolerance; impatience, and emotional dysregulation (9) • Our role as parents (7) • Friendship difficulties & social impact (7) • Navigating the assessment/diagnosis process (6) • Feeling lost in the world (5) • The perceptions and expectations of others (5) • School as supportive / collaborative (4) • Behaviour in school driving assessment (3) • Medication in supporting child and the school? (3) • Sibling relationships & family strain (3) • Stigma (3) • Knowledge of ADHD vs experience (epistemology) gained through experience (ontology) (3) • Stimulation seeking behaviours (3) • The role of support services (3) • Parent/s and child relationship (2) • ADHD/child strengths (2) • Our child's future (2) • Extremely challenging behaviours (2) • ADHD/child understood through extremes /superlatives (2) • Systemic pressure (school) (1) • Systemic pressures (societal) (1)	• Making sense of ADHD & our child & their behaviours (33) • The parental role, family relationships, conflict & strain (12) • We get the worst of it: intolerance, impatience, & emotional dysregulation (11) • The assessment/ diagnosis process (9) • Stigma & the expectations of others (8) • Friendship difficulties & social impact (7) • The school's influence (6) • Child strengths & their future (4) • Medication in supporting child & the school? (3) • The role of support services (3)

Appendix 14.0: Looking for Similarities and Differences across Participants

Children



Emerging themes- similarities / differences

Support

No service/systemic support

F+F support

Not enough school support

Some TA support

F+F support

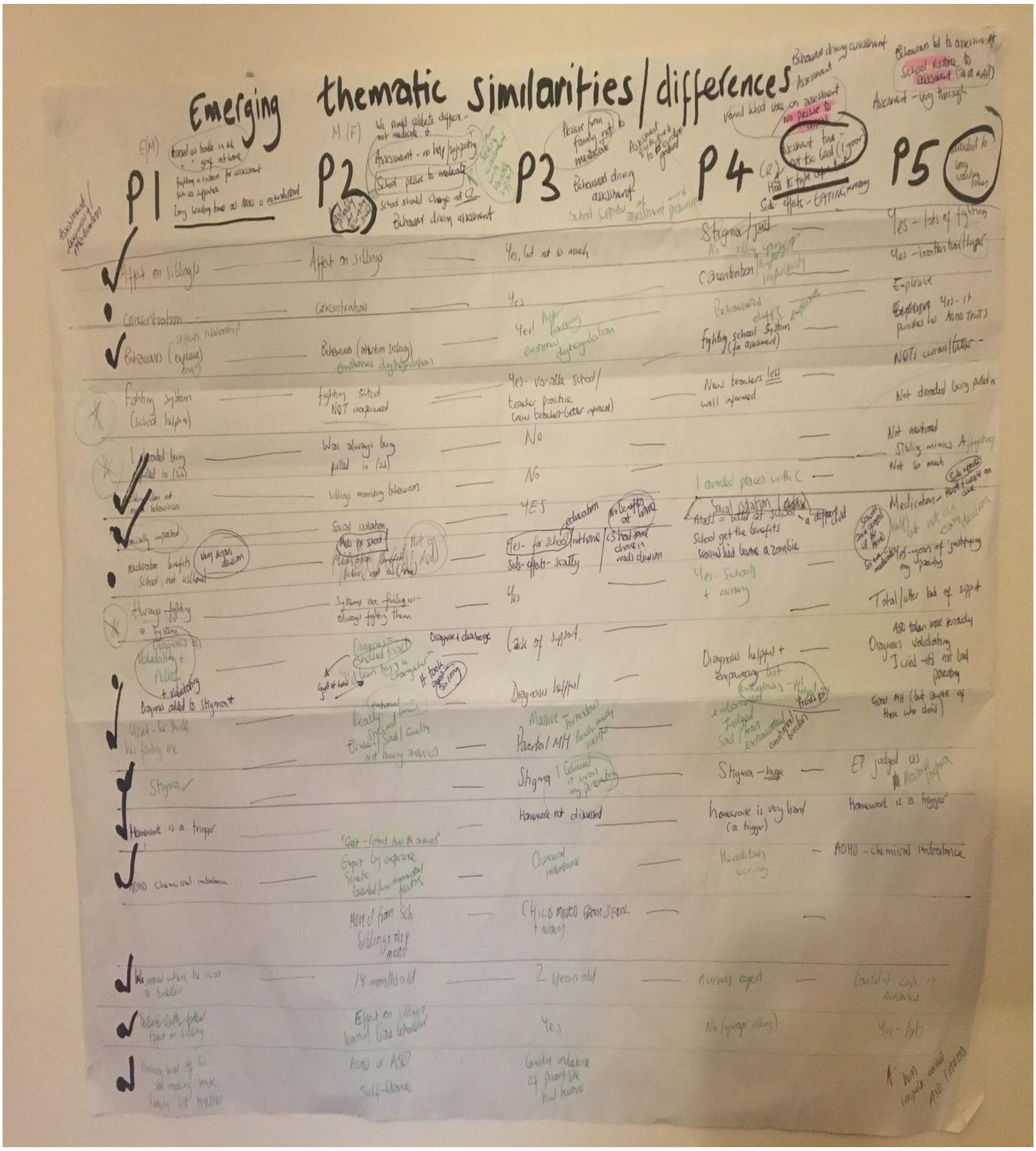
lack of school understanding

C1 (E)	C2 (A)	C3	C4	C5
Me and my anger	Anger I hurt people	Anger	Anger - Yes	hyper + impulsivity
Meds help	Not on meds	Meds a central theme Lots of tension on this (Wants to be off meds) NA	Meds help concentration/hyper positive	Ambivalence - helps concentration helpful but loses himself
Use of pronouns ('You')?	NA	Yes - lots - concentration anger/no control	NA Concentration/anger/hyper/fighting	NA organisation + concentration
	My difficulties	Some	lots of difficulties with teachers + school behaviour system	I got into trouble at school
Difficulties with teachers	Difficulties with peers + isolation	I'm still working it out	Concentration + hyper + anger	Concentration is ADHD Organisation diffs
How ADHD affects me	ADHD confuses me		None	
NO	Self-blame	Self-blame	NA No difficulties	Diagnosis - ambivalence - happy but sad
	Didn't understand diagnosis	Diagnosis as validating/empowering		
Some teacher difficulties	School is upsetting	Moved school due to conflict	Teachers don't listen/are uninformed	Massively lost focus
NA	NA	M lost track of thought/conversation	Sense that C was not engaged/answering thoughtfully Yes	
ADHD Good for Sport (unmedicated)	NA	I can focus/forget my ADHD when horse-riding/doing sports	ADHD as a super-power for physical activities	
lack of awareness	lack of awareness of affect on others	Some awareness - I take it out on mum	Complete lack of awareness about how ADHD affects family	lack of awareness Not knowing what ADHD is
	? lack of understanding of where it comes from	Didn't know what ADHD is	?	
lack of control (of self)	lack of control (of self) + impact on friendships	lack of control over emotions losing control = ADHD	lack control	
	lack of concentration	lack of concentration	concentration + hyper	concentration
	misunderstood as 'bad' I fear asking for help	I don't tell others	I Do Tell others	I don't tell
	No recollection mum - decided no meds	No control/say over assessment Little recollection	little recollection assessment	I didn't know it was an assessment

1000-1500 words per ppt

Appendix 14.0: Looking for Similarities and Differences across Participants

Parents



Emerging thematic similarities / differences

P1	P2	P3	P4	P5
E(M) Assessment / diagnosis + medication Viewed as trouble in sch / " " good at home fighting a system for assessment Sch as supportive Long waiting time at ADHD a misunderstood	M (F) We should celebrate difference - not medicate it Assessment - no help / signposting School pressure to medicate School should change not C2 Behaviour driving assessment	Pressure from family not to medicate Assessment quick [illegible] Behaviours driving assessment School supportive of assessment	(R) Behaviour driving assessment Assessment Varied school view on assessment No pressure to [illegible] Assessment time - not too bad (1 year) Had to fight Side-effects - EATING, memory	Behaviours led to assessment School pressure to assessment [illegible] Assessment - very thorough Needed to long waiting times
Affect on siblings	Affect on siblings	Yes, but not so much	Stigma / judged No - sibling younger	Yes - lots of fighting
Concentration	Concentration	Yes	Concentration Hyper impulsivity	Yes - inattention / hyper
Behaviours (explosive anger) attention relationship?	Behaviours (attention seeking) emotional dysregulation	Yes! hyper [illegible] emotional dysregulation	Behavioural difficulties explosive fighting school system (for assessment)	Explosive Yes - it pushes to ADHD traits NOTs currently better
Fighting system (school helpful)	fighting school NOT inexperienced	Yes - variable school / teacher practice (new teacher better informed)	New teachers less well informed	Not dreaded being pulled in
I dreaded being pulled in (sch)	Was always being pulled in (sch)	No		Not mentioned
Siblings does not mimic behaviours	siblings mimicking behaviours	No		Sibling mimics A fighting Not so much
Socially impacted	Social isolation	YES	I avoided places with C Social isolation	
Medication benefits school, not us (home) Very serious decision	Meds for school Medication benefits school, not us (home) Not on meds	Yes - for school not home education side-effects - scary No benefits at home C5 had some choice in meds decision	Meds = better at school - a different child School get the benefits Worried kid became a zombie	Medication - side effects help but not an easy decision 15 years of justifying my parenting
Always fighting a system	Systems are failing us - always fighting them	Yes	Yes - School + nursery	Total / utter lack of support
Diagnosis = validating + relief + validating Diagnosis added to stigma*	Diagnosis = [illegible] it took ages so long Diagnose + discharge	Lack of support. Diagnosis helpful	Diagnosis helpful + empowering but [illegible]	ASD taken more seriously Diagnosis validating I cried - it's not bad parenting
Upset - he thinks he's failing me	Really stressed emotional times Broken / Sad / Guilty not having answers	Massive - tremendous Parental MH	embarrassed judged Sad / tears exhausted continual burden	Good MH (but aware of those who don't)
Stigma ✓		Stigma ! Believed it was my parenting	Stigma - huge	EP judged us Massive stigma
Homework is a trigger		Homework not discussed	homework is very hard (a trigger)	Homework is a trigger
ADHD chemical imbalance	"Guilt - I don't have the answers" Expert by experience Genetic Parental / environmental factors	Chemical imbalance	Hereditary wiring	ADHD - chemical imbalance
	Moved from sch Siblings also moved	CHILD MOVED FROM SCHOOL + nursery		
We noticed when he was a toddler	18 months old	2 years old	nursery aged	Couldn't cope in nursery
Effect on sibling	Effect on siblings learned bad behaviour	Yes	No (younger sibling)	Yes - lots
[illegible]	ADHD or ASD Self-blame	Couldn't make [illegible] of parenting [illegible]		A [illegible] impulse control ASD [illegible]

Appendix 15.0: Examples of Reflections that Arose during the Process of Data Analysis

There are ongoing challenges in reducing the (vast) emerging themes into subordinate themes. For example, Bella’s subordinate theme of ‘exclusion and isolation’, has been coded under both green and red, in this instance. This is because it was felt that the exclusion and isolation that was described was occurring within the school setting, as well as being a lived experience, out of school.

There were also times, where some subordinate themes appeared to overlap, but were not jointly colour-coded. For example, the subordinate theme, ‘Difficulties with teachers’ (Tristan) seems to fall predominantly under the individual superordinate theme of ‘Systems, schools and support’. However, it is acknowledged that this, in itself, is somewhat of a simplification as the child’s difficulties with teachers may well have occurred in school, and as a part of his school experience, yet were undeniably an inevitable part of his lived experience too, meaning that it could, in many ways, have been jointly placed under the ‘My ADHD, my symptoms, and its impact’ theme. However, this was considered to be the best fit for this theme, as it was felt that this was overwhelmingly affecting him in the school for the most part. It is also accepted that there are arguments against this, yet, in the end, and in keeping with IPA analysis, and with my subjectivist epistemological position, a somewhat subjective decision needed to be made.

I have just completed first data analysis for both Peter and Tristan. I noticed and reflected upon how the descriptive comments (in blue), did not often tend to develop into a theme, and often acted as a way of describing a lot of information in a few succinct words. Some of the linguistic comments (in green) did develop into themes, as patterns emerged. These tended to be in relation to particular word choices, that felt really powerful, or difficult to overlook. For example, when referring to the stigma he has experienced, Peter referred to it as being “surrounded by stigma” (Peter, 547). This suggests that they were not experiencing stigma from a few isolated sources, rather they were being surrounded from all angles and all directions, creating an impression of it being inescapable and unavoidable. I noticed that the conceptual comments (in red) were the ones that were most likely to be encapsulated as themes, as such I tried to remain reflexive about my use of this category in particular.

After analysing Peter and Tristan, I felt somewhat concerned by the high number of potential themes I had recorded. I had some initial apprehensions about how these might be further reduced and consolidated. While challenging, the condensing of the themes, was therefore really useful as the data set felt as though it became more manageable. However, it felt somewhat arbitrary, in that, I felt that I could have grouped them in multiple different ways. This is in keeping with tensions around the double-hermeneutic, in that I was attempting to make sense of the participant, who was, in turn trying to make sense of their world (Smith et al. 2012). In attempting to do this, I felt that there were many grouping decisions that troubled me, depending on how I decided to view, or interpret the participant's expressions.

For example I felt that 'Homework' (for Tristan) warranted being put into its own theme, but, at the same time, it could have grouped with 'Frustration' (as it seemed to cause him a lot of frustration); 'Anger' (as it caused anger in the family home); 'Difficulties with teachers' (as they were the ones setting the homework); 'My behaviour' (as it affected his mood and behaviour) and so on. Therefore, while useful, this activity raised as many questions, as it did answers, and what felt to be most meaningful was not, so much, the quantity of times a topic/theme arose, rather, what was said about it and how it was expressed.

Additionally, there was another issue in seeking to consolidate the emerging themes: at times, participants might briefly mention a topic (medication for example) that potentially warranted inclusion as a theme, meaning it would be counted as being discussed once. However, at other times, the participant would talk about something at considerable length in one expression, meaning that there had been a much greater depth of discussion in this sense, but it was only captured as being discussed once in numerical form. This clearly does not account for the differences in length of discussion, or the rich/ shallow ways in which it was discussed during the interview.

It also noteworthy, that some of the emergent themes that were initially captured (in the left hand column of Appendix 13.0) were then removed in the process of condensing themes. This is because, while they were deemed interesting points and potentially worthy of inclusion, at that time, the participants did not seem to revisit them in any depth, meaning that they did not develop further into fully fledged themes. Some examples of those tentative themes, that were removed at the point of condensing (for Tristan) can be found below:

- ADHD is hereditary (71-73)
- The whole truth? (374)
- Self-esteem
- Others wind me up (112/114)
- Influence of friends (551)

It is noteworthy that after analysing emerging themes I then went back over the transcripts one more time, reflecting on the areas that I found most profound and that I wanted to try and report in the findings. I highlighted key sentences, phrases and expressions in yellow. The hand-written notes that I took at the time of interview were also useful as I had noted parts of the interview that I felt captured something particularly pertinent, or thought-provoking.

On analysing Jacqui’s data, I reflected on the micro-decisions that I was making around how to group her themes. It seemed harder with Jacqui – perhaps her thinking was broader and subsequently harder to pull together. For example, on the emerging theme: ‘I let others know she has ADHD’ (861), I put this into two themes: ‘Stigma and judgement’ (as she was telling other parents that Ellie had ADHD as she felt they were judging her behaviours), but also in the ‘The benefits of having a diagnosis’ as she only felt able to tell others that Ellie had ADHD as she had the diagnosis, which is therefore deemed to be a benefit. To leave this out of either theme felt uncomfortable, and on discussing this with my peer, it felt much more trustworthy and genuine to include it in both rather than to omit it from either of these themes. It should be noted, that this doubling-up on themes was not a common occurrence, but demonstrates some of the complexities of grouping emergent themes into wider themes.

My Perception vs the Findings

I thought that ‘The long wait for assessment/diagnosis’ was going to be a prevalent theme. However, on looking through the emergent themes, in chronological order, it transpired that Jacqui had only raised this twice, meaning that it took quite a lot of consideration as to whether this warranted being classified as its own theme. On reflection, the title was later broadened out further to ‘Challenges with the assessment process’ to accommodate two other emergent themes related to the assessment process, namely: ‘The assessment process was narrow’ and ‘I needed to be prepared for the assessment’.

Ellie’s data was difficult to categorise as there were many perceived inconsistencies in her responses. Many emerging themes did not neatly fit into the developing wider themes, without some tension, and often she later appeared to contradict herself. However, it may be that this was a reflection of her own confusion around such matters, or that she was still inherently attempting to make sense of ADHD, and herself. For example, she could see that taking medication was helping her to concentrate in school, but it had the side-effect of her not eating (much) in the school day. This, in turn, meant that she felt that she could not concentrate later in the school day, as she was hungry and was focusing on going home to eat.

I also reflected when grouping the themes into frequencies, for two reasons: firstly, the frequency was being affected by the number of questions I put to her in certain areas. Therefore, while I did not intentionally do this, if something was of particular interest to me during the interview, it is quite likely that I may have put further questions to her around this, subsequently meaning the thematic frequency would have increased, making it seem like more of a prevalent theme than it perhaps was.

Secondly, while some of the emergent themes were not as frequent as others, I felt that they were, in many ways, of greater significance. For example, the theme ‘friendships’ was counted approximately six times, yet the theme ‘Social exclusion’ was only counted three times. Yet, when considering the bearing that Ellie leaving her first primary school, must have had on her and her mother, it felt, in many ways, perhaps more significant and worthy of further discussion in comparison to the theme of ‘friendships’. However, it could be argued, of course, that my opinion is indicative of my subjective interpretative positioning, and in turn reflects tensions around the double hermeneutic (Smith et al. 2012).

Tommy

This was a difficult interview to analyse as it felt that, especially towards the end of the interview, Tommy was answering in a way that was contradictory with his own thinking. For example, earlier in the interview he talked about his difficulties with his sleep: “I have to take two bed-time tablets to help me get to sleep” (42). However, when asked, “so you must find it difficult to get to sleep?”, he replied: Yeah, sometimes, but not much” (648). This also conflicts with his mother’s view that “He doesn’t go to sleep” (366). It could be that Tommy simply did not perceive this to be as much of an issue as his mother did. Another example is that, earlier on in the interview, Tommy described, in quite some depth, how he felt that some teachers were not supporting him: “The school help me with…I don’t really know” (510). However, towards the end of the interview, he said that school staff listen to him, and that they are “more supportive than not” (548). He then went on to say that secondary school is less supportive than primary school. As a final example, Tommy told me: “No, there’s not really any side-effects…” (460), and then said, “The tablets kind of stunt my growth” (462). In short, I felt as though, his responses towards the end of the interview were shorter, and, in some ways, quite contradictory. This may of course be as he was struggling to maintain his focus, and is an inherent limitation of working with children with ‘attention deficit’.

I felt that it was interesting that Tommy repeatedly said that teachers “don’t understand about ADHD”, or “do enough for me” (34), and that the school system “doesn’t help me” (7). Yet, he only said he needs more support once (1). This again, seems incongruent, but could potentially be more indicative of a flaw in the/my thematic grouping.

Also, it is interesting just how much Tommy’s account differs from his mother’s. For example, Tommy commented that “It (ADHD) is not hard outside of school” (640), yet his mother placed a heavy focus on the challenges of managing his behavioural symptoms (outside of school) and how it has affected and strained her personally. It is plausible, of course, that this represents the extent to which she has shouldered the challenges herself and protected Tommy from them.

Caitlyn

Caitlyn felt like the hardest of all transcripts to sort into emerging themes. It felt like there was so much overlap and, at times, I was putting emerging themes into two or three groups. For example, with the emerging theme ‘He might not meet his potential x2 (1145/1148)’: I had to make a decision about whether this might be interpreted as fitting into the ‘My child’s behavioural symptoms and presentation’, or in the ‘Difficulties with school system and some teachers’. After some reflection, I decided to place in the latter. I did this as I felt that to place it in the former would suggest that him not reaching his potential would situate this as a within child issue, and given his reported potential, I did not feel that this was a fair reflection. I therefore situated it as a school difficulty as I felt they were unable to adapt in a way to help Bobby to realise his potential. This is in keeping with my position of critical realism, as it considers how the systems that Bobby sits within are influencing him, and thus takes into account the inequalities in the school system (that are, to some extent, in turn shaped by wider policy of course). This takes into account Bobby’s and his mother’s subjective experience of living with ADHD within the school system.

Bobby had significant difficulties in maintaining his focus in his interview, and was reportedly fidgeting and moving constantly (16). This enabled me to really get a sense of his difficulties, in that spending an hour talking to me (remotely) was clearly incredibly challenging for him. I could therefore feel first-hand how ADHD was affecting him during the interview and the extent of how it affected his concentration. This seems like a flaw in the study, and if I was to repeat this research, I would be more uncompromising about this and would use this experience to illustrate the importance of interviewing participants, with ADHD, face-to-face. This would also allow me to adapt the interview/s, and incorporate physical and sensory breaks into them.

On first reading of Bobby’s transcript, I felt that there were some potential inconsistencies in his responses. For example, he said, “I don’t have many difficulties in school” (80), but then went on to discuss his ‘difficulties in quite some length, including concentration, organisation, hyperactivity, impulsivity, (approximately thirty one times, in total) and ‘other difficulties in school, around writing and communication’, approximately sixteen times. This may be due to him losing his concentration and, at times, not thinking fully about his responses. This is also in keeping with his description that “I don’t think about what I’m saying, or doing (229)” and “my mind wanders”. There were other perceived inconsistencies, such as “I don’t tell people I have ADHD” (296) and “I tell people I have ADHD” (310). However, it may also be fair to suggest that such these are perhaps quite telling as they are potentially indicative of him, ontologically, attempting to make of himself in his world, and in doing so has demonstrated the complex, confusing and often contradictory nature of living with ADHD.

Appendix 16.0: Further Reflections around the Creation of Subordinate Themes

The creation of the master table of subordinate themes, and subsequently the superordinate themes leant itself to a clear order for presenting the analysis. The ordering of the frequencies, with the highest number towards the top, clearly indicated what themes were prevalent in the lived experiences of the participants. For example, across all child participants, the themes that arose most frequently were around their difficulties, or their ADHD symptoms. These all fall under the superordinate theme of ‘My ADHD, my symptoms, and its impact’. This is important as it suggests that their lived experiences of living with ADHD focus on their areas of difficulty. However, it can be seen, quite clearly, through the colour-coding that from here on in, the children focused, more frequently at least, on different areas. For example, Tristan placed significant emphasis on both medication and on the difficulties he had had with certain teachers and homework specifically. While, for Ellie, there was a greater frequency placed on the theme of support (‘The support I get and what I’d like more of’). Tommy spoke more frequently about ‘some teachers don’t understand ADHD, or do enough for me’.

While there was consistency in the most frequent subordinate theme, across the child participants, the frequencies within the parent participants tells a different story. Peter, Bella, and Rhonda spoke most frequently about their child’s behavioural presentation and/or symptoms. This was telling as it gave the impression that they felt a need for someone to listen, hear and understand just how challenging their child’s behaviours were. Even then though, there were some differences with Peter and Bella raising their child’s behavioral presentation 33 and 19 times respectively; Rhonda spoke of her child’s difficulties 94 times. It is felt this served to highlight the extent to which she felt that her child’s behaviours had impacted upon her, her family and her son. It therefore seems to be no coincidence that she also spoke 50 times about ‘My continual fight with school/nursery’ as though to emphasise, not only how her son’s “ADHD has really impacted our lives” (561), but that she, “just wanted to be listened to and supported”.

Interestingly, Caitlyn spoke most frequently about her ‘Difficulties with nursery/school system and teachers’ and her about ‘Support: our fight with services and lack of support services’. While she did speak about her son’s ADHD and associated presentation, or symptoms, she did this fewer times, suggesting that she felt the difficulties she has faced as a parent were less related to within-child factors, and more associated with difficulties around schools, educators, and the lack of support systems.

It is also noteworthy that Jacqui was the only parent to speak, most frequently, about ‘Medication, benefits and justifying its use’, with the ‘Absence of support and quality advice’ (plus some positive support’) second most frequently. This represents her perception of medication being a transformative factor in living with her daughter’s ADHD, and how the increased use of medication has made it “a hell of a lot easier” (56). She also placed a greater emphasis (or frequency at least) on the subordinate themes: ‘Absence of support/quality advice’, and ‘School and teacher differences in understanding and approach’, over her daughter’s behaviour and the impact it has had on her and her family, as seen in green in Figure 2.0.

Appendix 17.0: Earlier Draft of Interview Schedule (Parent/Carer Version)

Aetiology

1 What is your understanding of what ADHD is?
2 What is your understanding of the causes of ADHD?
3 Why do you think some people have ADHD, and some don't?

Lived experiences

4 When did you start to notice differences in your CYP?
5 How has ADHD affected yours/your child's life?
  5b How did you try and support X?
  5c What feelings did you have towards X's behaviour/s?
  5d Was X treated differently to other children?

Assessment and diagnosis

6 What were the reasons for assessing X for ADHD? (Prompt – did you feel any pressure to assess X? From whom? How?).
7 Can you describe the assessment process for me? (prompt – how did it make you feel?).
8 How did you feel when you found out that X had ADHD?
  8b Was it helpful, or unhelpful having a diagnosis of ADHD?
9 How does X having ADHD make you feel now?
  9b Has having a diagnosis changed the way you treat him/her?
  9c What were/are your main sources of information re ADHD?
10 Do people treat you/your child differently knowing X has ADHD? (prompt – what sort of things do people say about ADHD?)
11 What do other people think that ADHD is?
12 How did people treat X before they knew he/she had ADHD? (prompt – what about school?).
13 Do you tell people that X has ADHD (prompt – who? Why/why not?)
14 Do people treat you/your child differently since X was diagnosed?
15 How do your friends and family feel about X having ADHD?
16 Does having ADHD mean X can't help behaving in the way he/she does?

Medication and treatment

17 How do you try and manage/support X now?
18 Does X take medication for your ADHD?
19 What were the fundamental reasons for choosing to medicate X? (Prompt – did you feel any pressure to medicate X? From whom? How?).
20 What changes do you notice when X is on his/her medication?
21 How do you feel about X taking medication?
22 How much of a say did X have in decisions around medication?
23 How long do you think X will take medication for? (prompt – and what reasons would prompt decisions around cessation?).
24 Were you told about other ways to support CYP with ADHD besides medication?
25 How would you react if X wanted to stop taking your medicine?

Support

26 Do you think that X's school/teacher treat him/her differently now? (prompt – does he/she get any additional help now?).

27 What more could schools do to help CYP with ADHD?
28 Do you think you/X get enough service support to help X with his/her ADHD?
29 What more could be done to help CYPF with ADHD?
30 Do you feel involved in the way services help CYPF? (prompt – would you like to be involved in the way that services are offered to CYPF with ADHD?).
31 What would you do to help CYPF with ADHD if you had a magic wand?