

**'THROUGH ALL THEM FOUR LETTERS, CHANGES EVERYTHING': AN  
EXPLORATION OF THE LIVED EXPERIENCE OF CHILDREN, WITH A  
DIAGNOSIS OF ADHD, AND THEIR PARENTS**

by

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## **Abstract**

This study explored the 'phenomenological' stories of children and their parents about their experiences of having ADHD in their lives. As one of the most common and highly contested mental health diagnoses given to children, it is a significant topic for research.

In the spirit of narrative therapy, this study sought to 'separate the person from the problem' to explore the effects of the ADHD, including ways in which it had become 'shaping of their lives'.

The study employed a qualitative methodology. Individual semi-structured interviews were conducted with four children who had received a diagnosis of ADHD, and one of the parents of each child. Data were analysed using Interpretative Phenomenological Analysis.

ADHD was understood within the discourse of problem behaviour and children's personal experience tended towards 'being', rather than 'having' ADHD. Adult-orientated systems appeared to operate, with children's voice and participation rendered invisible.

Living with ADHD was described as stressful. Parents were in a constant cycle of action to meet their child's needs and to defend against stigmatising forces placing them within a naughty child/bad parent dyad. There was

dissatisfaction with post-diagnostic care and a sense that a more holistic approach would be helpful.

Consideration is given to the implications for future research and for practice.

## **Dedication**

To my parents for their love and continuous support

## **Acknowledgements**

Many thanks are owed to the young people and parents who kindly volunteered to take part in this research. The stories you shared are profound and moving, and contribute greatly to a growing body of 'insider knowledge' about ADHD.

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## CHAPTER ONE: INTRODUCTION

*'Many tales have more than one meaning'*

Mary Catherine Bateson (1994, p.11)

### 1.1 Introduction

Attention deficit hyperactivity disorder (ADHD) is a developmental disorder (American Psychiatric Association, 2013) characterised by a pattern of behaviours including inattention, hyperactivity and impulsivity (Hill and Turner, 2016). It is the most common mental health diagnosis given to children, and the most studied (Baldwin 2000; Barkley, 2005; Graham, 2008; Timimi and Leo, 2009).

It is reported that there has been an exponential rise in the number of children and young people receiving a diagnosis of ADHD (Timimi, 2004; Traxson, 2010), and parallel with this rise has been an increase in prescriptions for psychostimulant medication (Graham, 2008; Timimi, 2009; Hill, 2013). Whilst this medication is reported to have beneficial effects on improving attention and reducing hyperactivity in the short term, there is concern about the paucity of 'good evidence' regarding its efficacy with long-term use (Moncrieff, 2009). In addition, there is significant concern about the harmful side effects of these drugs (Timimi, 2004; Moncrieff, 2009; Traxson, 2010).

ADHD is a complex phenomenon with diverse and competing perspectives related to its definition, causality and treatment. These differing views

continue to fuel debate surrounding it, which has led to ADHD becoming the most controversial mental health label (Mayes and Rafalovich, 2007; Visser and Jehan, 2009; Horton-Salway, 2011). However, amidst the conflict and controversy are individual stories of children, young people and families whose views and experiences have become overshadowed by the ‘fuzziness’ (Horton-Salway, 2007) of this changeable and contested diagnostic label.

ADHD has tended to be positioned within the empiricist position of medical and psychological research (Timimi and Radcliffe, 2004), contributing to an abundance of quantitative research exploring a biological basis of ADHD and efficacy of drug treatment (Timimi and Radcliffe, 2004; Singh *et al.*, 2010; Dunne and Moore, 2011). There has been concern, however, that in dominating the research landscape, this focus has led to alternative descriptions and explanations becoming marginalised (Brady, 2004; Dunne and Moore, 2011). Furthermore, individual experiences have become lost amongst ‘clinical descriptions of “disordered” groups’ (Lewis *et al.*, 2015, p. 32).

An increasing number of children are living with diagnostic labels (Bringewatt, 2013). However, for many years, children’s voice and participation within the assessment and diagnostic process have been largely absent, raising questions as to how these children come to understand and experience their diagnosis (ibid, 2013). By inviting children, and parents, into the discussion, both in research and in practice, we can give voice to, and learn from, their

personal experiences and perspectives, and so understand what it means for them to have ADHD in their lives.

## **1.2 Research aim**

Singh (2011) has argued that much of the research on ADHD has tended to 'silence' children, because their voices and experiences have been largely ignored. This study acknowledges that children are active participants in their social worlds and that their views and perspectives are worthy of study. As Prout and James (1990) argue, children may have a different view, but it is no less valid.

Seeking and listening to children's views is not a new concept, the public policy context in England has long emphasised the importance of attending to the perspectives of service users in their capacity as 'experts by experience' (Corrigan, 2014; Norwich and Eaton, 2015). In education, health and social care in particular, the rights of children and young people to be consulted meaningfully in decisions made about them has been documented:

- in education (e.g. from the Children Act 1989, through to its most recent iteration, the Children and Family Act 2014 and subsequent *Special Educational Needs and Disability Code of Practice: 0 to 25 Years* (DfE/DH, 2014);
- and in health (the Department of Health White Paper, *Valuing People* (DoH, 2001) and Department of Health guidance, *Person-Centred Planning: advice for using person-centred thinking, planning and reviews in school and transition* (DoH, 2010)) policy.

However, despite long-standing recognition of children's rights and of their valuable contribution, findings from research exploring children's participation in their health care, have consistently shown that they remain on the periphery during assessment, diagnosis and treatment, and are rarely consulted directly (Kendall *et al.*, 2003; Travell, 2005; Davies, 2009; Stafford *et al.*, 2016).

The purpose of the current study is to contribute to knowledge about children's and parents' understandings and experiences of ADHD. Despite several researchers contributing to this area over the last 10 years, there is still minimal attention given to the child's perspective and the meanings which they give to living with such a diagnosis (Brady, 2014). In seeking the views of parents, I am interested in exploring how they understand and experience the 'disorder' and whether their stories are reflected in those of their children. As Bracken (2014) describes, particular experiences can only be grasped through an understanding of the context.

Hearing the stories of those with experience of ADHD is crucial, as one of the participants who took part in this research study described:

Netty (101p27): *... you go and get a book: it'll be nothing like I'm telling you, because this book makes it like dead like bull... bullet point and, you know, dead blank and things like that. It doesn't tell you the dark side to it: the things that you go through and the fears and things like that. You can only get that from, from asking a person. And none of the people ask, you know. I'm lucky.*

This small-scale 'phenomenological' study harnessed individual semi-structured interviews with four children who had received a diagnosis of ADHD, and one of the parents of each child. Data were analysed using interpretative phenomenological analysis: a methodological approach selected for its commitment to the detailed exploration of personal meaning and lived experience (Smith and Osborn, 2015).

Through this research endeavour, my hope was that the outcomes would:

- add to a body of knowledge still in its infancy on what it is like to live with ADHD;
- help to inform local policy decisions regarding ADHD interventions and the future training needs of teachers and other professionals working with children;
- help to improve services and support for children and their families; and
- offer other children and young people with ADHD in their lives an opportunity to learn from a growing body of 'insider knowledge' about what it is like to live with ADHD. In the spirit of narrative therapy, it was hoped that as people join their voices together, they would be more likely to be heard and in doing so, become less marginalised (Freedman and Combs, 2012).

### **1.2.1 Orientation and definitions**

For the purposes of this research, ADHD is understood to be a label applied by qualified health professionals to certain individuals presenting behaviours which include inattentiveness, hyperactivity and impulsivity. Within the context of carrying out the procedure (individual semi-structured interviews with children and parents) of this research study, no prior assumptions or meanings were attached to the term ADHD. As described, the focus of this study was to explore the individual meaning and experiences from the perspectives of the children and parents who took part.

### **1.3 Professional context**

I have been practising as a local authority educational psychologist for 10 years, having qualified in 2006. Prior to this I worked as a teaching assistant and primary school teacher, working with children, families and schools for 17 years.

This research study was conducted as part of a post-qualification doctorate in educational psychology. This professional doctorate has included six taught modules and a final research study; assessed through module assignments and a final thesis. Throughout the period of course registration I have worked as a local authority educational psychologist, during which my professional experience has included work with children and young people diagnosed with a wide range of mental health disorders, including ADHD. For these children and young people, the match between observed behaviours and diagnostic criteria for mental health disorders formed the focus of service-user concerns.

In following scientist-practitioner model (Fallon *et al.*, 2010) my practice has been informed by focused literature searches and selective reading; some of which afforded foundations for the reading undertaken specifically to shape, and inform, this research study. This has included the completion of two module assignments (child and adolescent mental health and specialist research modules) focusing on narrative therapy and its application to educational psychology practice and exploration of the phenomenon of ADHD, both of which preceded this research study. For the latter, extensive scoping of theoretical, research, policy and professional literature relating to ADHD was undertaken. Hence, the literature review process (see literature search criteria, Chapter 3, section 3.1.1) for this empirical study formed the later development of a process which, originated several years before and which, has developed recursively through a series of iterations.

My interest in ADHD has developed during my practice as an educational psychologist, where use of the label has become common when concerns regarding challenging behaviour are described. Within my casework, I have observed how problems related to social and/or emotional difficulties seem to be quickly constructed as ADHD, often followed by a quest for a diagnosis. As I began to reflect on these experiences, I found it particularly striking that in many of these cases, within the family and within the school, challenging or 'difficult to manage' behaviours appear to be understood through the lens of a medical condition, and located within the child. In taking this view, there seemed to be an assumption that this behaviour had a biological aetiology.

This was particularly interesting to me as I recognise the complexity of ADHD and acknowledge the range of causal explanations.

Concern about these experiences increased following publication of the new *Special Educational Needs and Disability Code of Practice: 0 to 25 Years* (DfE/DH, 2014), which introduced the language of psychiatric disorder in its changes to the classification of 'social, emotional and behavioural' to 'social, emotional and mental health' needs. In this new Code of Practice, it is suggested that challenging behaviours 'may reflect underlying mental health difficulties', such as ADHD (*Special Educational Needs and Disability Code of Practice*, section 6.32). This stance seems to prompt understanding of these difficulties through a medical/biological lens and perhaps, inadvertently, the need to seek a diagnostic label to validate and legitimise the problem and ensure appropriate support and intervention. As Norwich and Eaton (2015) describe, 'there is a gap between general diagnostic categories and the particular individual characteristics and contexts of children' (p. 27). A focus on linking certain behaviours with mental health categories, thus leaning towards a biological position, risks silencing social, cultural and relational factors (Timimi *et al.*, 2004; Lewis-Morton *et al.*, 2014), which may be equally pertinent.

Alongside my interest in how certain presenting problems are constructed and understood within dominant discourse, has been a growing interest and practice of approaches from narrative therapy (as espoused by White and Epston, 1990). They believe that stories people tell about their lives, or about

the lives of others, can be constitutive in shaping their lives and relationships, and are open to interpretation and multiple meanings. By externalising the dominant 'problem-saturated' description or story of a person's life, the influence that problems have can be explored. Through a process of externalisation (by separating the person from the problem), people can begin to consider their relationships with problems; thus, the narrative motto: 'the person is not the problem, the problem is the problem'. Narrative therapy centres the person as an expert on their own life (Bennett, 2008) and focuses on the meaning people make of their experiences and how these come to affect their knowledge and practices (Zimmerman and Beaudoin, 2002).

From a narrative perspective, the term ADHD may invite parents and professionals to develop a deficit-saturated story about a child or young person, in which past, present and future events can become interpreted through the lens of the problem story (Nylund and Corsiglia, 1996); in so doing, events and behaviours outside the ADHD story may go unnoticed. White and Epston (1990) state that, once people see problems as separate from identity, the opportunity for change has been created. From this position, alternative stories can be created, by building on strengths, skills and experiences often rendered invisible by the dominant problem story.

## **1.4 Local context**

This research was conducted in a small unitary local authority located in the Midlands. [REDACTED]

[REDACTED]. According to Public Health England (June 2015), the health and well-being of children within the local authority are generally worse than the average for England.

According to the most recent census (2011), the population was recorded as [REDACTED]: the ethnic groups are reported as 'White British' (88%), Pakistani (4%), 'mixed ethnic groups' (3.4%), 'Asian other' (1.4%) and Black African (1.0%). There are approximately [REDACTED] children living within the local authority area.

## **1.5 Organisation of thesis**

A brief summary of each chapter is presented in Table 1.1 to assist in orienting the reader as their journey through the thesis commences.

Number	Summary of Chapter
Chapter Two	This chapter discusses the clinical approach to understanding ADHD (e.g. clinical definition, diagnosis and prevalence), examines prominent theories in relation to its construction and aetiology, and discusses common approaches for treatment and management of the disorder.
Chapter Three	In setting the scene for this research study, this chapter presents a review of qualitative studies exploring the views of children and parents regarding their experiences of ADHD. Issues relating to their research design are also discussed, including implications for this research study
Chapter Four	This chapter describes the process by which I decided on the methods to address my research aims and presents the chosen research methodology.
Chapter Five	Details regarding the research design, implementation and data analysis are presented. Ways in which I addressed trustworthiness and validity for my research findings are also discussed.
Chapter Six	This chapter presents a narrative account of the two superordinate themes that were constructed through the analysis of the individual interviews with the four child participants.
Chapter Seven	A narrative account of the three superordinate themes that were constructed through the analysis of the individual interviews with the four parent participants is presented. Discussion of similarities and differences between the child and parent accounts are also discussed.
Chapter Eight	In drawing the study to its conclusion, this chapter discusses the contribution of this research to existing understanding, considers the strengths and limitations of the study and presents implications for future research and practice.

Table 1.1: Summary of chapters.

## CHAPTER TWO: THE PHENOMENON OF ADHD

### 2.1 Introduction

Chapter 1 outlined the context, rationale and research aims of this research study. This chapter reviews the clinical approach to understanding the phenomenon of ADHD (including clinical definition, diagnosis and prevalence), examines prominent theories in relation to its construction and aetiology, and discusses common approaches for treatment and management of the disorder.

ADHD describes a pattern of behaviours including inattention, hyperactivity and impulsivity (Hill and Turner, 2016). As discussed in the previous chapter, it is subject to intense interest and, in terms of quantity of research, is one of the most studied childhood psychiatric conditions and amongst the most controversial (Schachar and Tannock, 1997; Breggin, 1999; Baldwin, 2000; Barkley, 2005; Graham, 2008; Timimi and Leo, 2009). As this chapter will demonstrate, ADHD is a complex phenomenon with diverse and competing perspectives.

This chapter does not seek to promote one theory over another, or to debate the existence of ADHD; however, I believe it is important to mention these positions in order to consider how they may influence the narratives of parents and children, including those involved in this research study. As Rafalovich (2004) has observed, people invest a tremendous amount of agency in how they interpret the disorder (p. 6). In addition, I believe it important to set out

the diagnostic process, including definition of the disorder and assessment, in order to understand and contextualise the experiences of the participants.

## **2.2 Defining ADHD**

In clinical guidelines (e.g. National Institute for Health and Clinical Excellence), ADHD is described as a 'heterogeneous behavioural syndrome characterised by the core symptoms of hyperactivity, impulsivity and inattention' (NICE, 2013, p. 4). Diagnostic criteria are provided by the International Classification of Mental and Behavioural Disorders 10<sup>th</sup> revision (ICD-10) and Diagnostic and Statistical Manual of Mental Disorders 5<sup>th</sup> edition (DSM-5); greater use being made of the latter within the UK (Conrad and Bergey, 2014).

Prior to publication of DSM-5, ADHD had been classified as a discrete member of the class of 'Disruptive Behaviour Disorders' (DSM-IV; APA, 1994, p. 48). In DSM-5 (APA, 2013), ADHD is understood as a neurodevelopmental condition that can persist throughout the lifespan, reflecting the way ADHD is currently conceptualised (Rabiner, 2013), and is thus within the 'Neurodevelopmental Disorders' section.

Similar to its predecessor, the DSM-5 identifies three subtypes of ADHD (see Appendix 2 for examples of behaviours); however, the terminology has since changed, and 'subtypes' are referred to as 'presentations'. The three presentations of ADHD are:

- predominantly inattentive presentation;

- predominantly hyperactive–impulsive presentation; and
- combined presentation.

If a child meets the criteria for both the inattentive and hyperactive–impulsive presentations, he or she may be diagnosed with what is called the combined presentation.

### **2.3 Diagnosing ADHD**

In order for an accurate diagnosis of ADHD to be made, NICE recommends that specialist psychiatrists, paediatricians or other appropriately qualified healthcare professionals with expertise in the diagnosis of ADHD, undertake the assessment (2013, p. 20). Protocols relating to the components of a specialist assessment for ADHD have been provided by National Health Service (NHS) (e.g. NICE (2013)) and Scottish Intercollegiate Guidelines Network (SIGN; 2009) guidelines. SIGN advises that assessment should include:

- parent or carer interview (to gather information pertaining to the child’s presentation and development, a family history and family functioning);
- child/young person interview (to understand the child’s perception of the problem);
- observations and questionnaires (e.g. Conners’ Rating Scales; Conners, 1997);
- psycho-educational assessment (including tests of attainment in basic skills areas, e.g. reading);
- clinical examination (to consider any underlying medical problems,

- including neurological signs and minor physical anomalies); and
- ancillary (physical, psychiatric and psychological) assessments (2009, p.7).

The aim is to ensure a reliable diagnosis of ADHD is made on the basis of a comprehensive assessment, drawing on evidence from professionals from different disciplines, as outlined above. From this, the guidelines recommend development of a multimodal treatment plan, including psychological, behavioural and educational advice and interventions, and which may also involve medication. Counter to these recommendations, however, evidence has shown that many children are assessed and treated for ADHD without undergoing these multiple methods of assessment (Baldwin and Anderson, 2000; Brown, 2000; Curtis, 2004) and that medication has been prescribed as a first-line treatment (Travell, 2005; Dixon, 2013; Brady, 2014).

A complicating factor in diagnosing ADHD is that despite widely researched biological theories, there is no objective diagnostic test that can establish conclusively that a person has ADHD (Carpenter-Song, 2009; Furman, 2009; Timimi, 2013). As Breggin has described, 'there are no physical symptoms, neurological signs, blood tests, brain scan findings or chemical imbalances which can verify that a child has ADHD' (1998, p. 138). Diagnosis is made using diagnostic criteria which include the presentations detailed in section 2.2, and which Diller (2006) contends 'are not based on any scientific data, but on panels of experts' opinion' (p. 8). The evidence for diagnosis is often reliant upon the observation of behaviour using checklists, where the basis for

ratings may be highly subjective in nature (Furman, 2009). There is concern (e.g. Timimi and Radcliffe, 2004) that these questionnaires and checklists omit layers of experience and context that could contribute to a more thorough understanding of the observed behaviour and the possibility of establishing alternative meanings for this behaviour.

NICE (2013) recommends that for a child or young person to be diagnosed with ADHD, the symptoms of hyperactivity, impulsivity and/or inattention should meet the diagnostic criteria presented in DSM-5 or ICD-10 (see section 2.2), be associated with at least a moderate degree of psychological, social and/or educational impairment, and be present in multiple settings (e.g. social, familial, educational). Symptoms of ADHD are said to begin before the age of 12 (previously 7) years and can persist throughout the lifespan (DSM-5; APA, 2013). Establishment of the severity of the disorder is considered to be a matter of clinical judgement, which takes into account the severity of the impairment, pervasiveness, individual factors, and family and social context (NICE, 2013). The DSM-5 recommends that clinicians specify the severity level using the terms 'mild' (few, if any, symptoms beyond those required to make a diagnosis, and no more than minor impairment in functioning), 'moderate' (symptoms or functioning impairments between mild and severe) and 'severe' (many symptoms in excess of those required for diagnosis, and marked impairment). However, as the classification of these levels is a matter for clinical judgement, variation in practice is inevitable; as Furman (2005) argues, 'the impact of subjectivity on symptom assessment is considerable' (p. 997).

## 2.4 Prevalence

Epidemiological data suggest America is the 'epicentre of the ADHD diagnosis in children' (Lloyd *et al.*, 2006, p. 5), with approximately 9% of American children and young people aged 4–17 years having a diagnosis of ADHD (Kessler *et al.*, 2006). In the United Kingdom, ADHD is thought to affect about 3–9% of school-age children and young people (NICE, 2013), making it the most prevalent behaviour disorder. It is estimated that 1 in 100 UK children (aged 5–16 years) manifest the most severe symptoms, whilst about 5 in 100 children exhibit less severe symptoms (NICE, 2013).

Studies have found diagnosis of ADHD to be 3–4 times more likely if the DSM criteria are used (Rohde *et al.*, 2005). It has been suggested that the ICD-10's emphasis on impairment, requirement for more symptoms to be present and preclusion of co-morbidity with other childhood psychiatric conditions account for the discrepancy (Lee, 2008).

Whilst the diagnosis rate in the UK has remained lower than in America, over the last decade, there has been an exponential rise in the number of children and young people receiving a diagnosis (Timimi, 2004; Traxson, 2010). Parallel to the rise in diagnosis, has been the prescribing of psychostimulant medication (Timimi, 2004; Graham, 2008; Hill, 2013). When the UK Government was asked to provide data regarding changes in the level of dispensed prescriptions for Ritalin (a psychostimulant used in the treatment of ADHD) between 1997 and 2010, the then Health Minister, Simon Burns MP,

reported a 618.4% increase in the number of prescriptions from 92,079 in 1997 to 661,463 in 2010 (Whitehouse 2012, February 20<sup>th</sup>).

The prevalence of ADHD has been found to be higher among boys than girls (Hartung *et al.*, 2002; Ohan and Visser, 2009; Holden *et al.*, 2013) and a number of hypotheses have been presented regarding this difference; for example, Holden *et al.* (2013) have suggested that females present with different symptoms and Berry *et al.* (1985) have proposed that girls are less likely to have coexisting disruptive behaviours. It is suggested that as disruptive behaviours often trigger referral for an ADHD assessment, this may explain the discrepancy in male to female ratios (Biederman, 2005); however, consensus on this matter has not been reached (NICE, 2013). Interestingly, in adults diagnosed with ADHD, the male to female ratio has been reported to be approximately equal (Kooij *et al.*, 2004; Moffitt *et al.*, 2015).

ADHD is considered a persisting disorder, with most young people continuing to experience difficulties into adulthood (NICE, 2013). In recent years, the number of adults receiving a diagnosis has increased, including growing numbers of adults who were never diagnosed as children (Moncrieff and Timimi, 2011). NICE (2013) reported that ADHD is thought to affect 2% of adults, although current estimates are that between 5–9% of the adult population may have the condition (Kessler *et al.*, 2006; Simon *et al.*, 2009).

## **2.5 Co-morbidity: ADHD and other conditions**

ADHD is characterised by a cluster of behavioural symptoms that are considered separate from, but highly correlated with, other conditions (Singh, 2008). It is estimated that over 65% of children and young people with a diagnosis of ADHD also have one or more coexisting disorders, including: dyslexia, learning disability, developmental co-ordination disorder, Tourette's syndrome, an autistic spectrum condition, mood disorder, anxiety disorder, conduct disorder and oppositional defiance disorder (Kadesjo and Gillberg, 2001; Harpin, 2005; Furman, 2009; Hill and Turner, 2016).

## **2.6 Aetiology of ADHD: a complex phenomenon**

There is considerable uncertainty about the origins of ADHD. Researchers have proposed multiple risk factors, including genetic (Tannock, 1998) and neurological factors (Tannock, 1998; Barkley, 1990, 1997; Sonuga-Barke *et al.*, 1996), which they suggest can lead to the development of ADHD behaviours. Other researchers postulate the social influence of family factors (Breggin, 1994; Lange *et al.*, 2005), a biopsychosocial condition (Cooper, 1997; Thapar and Thapar, 2003) and a socially constructed illness (Baldwin and Anderson, 2000; Timimi, 2002).

The theories of ADHD presented in the research literature suggest ADHD is a complex phenomenon that can be understood in many different ways. In their review of ADHD, the British Psychological Society (BPS) concluded that it is an 'evolving' concept, with many theoretical, empirical and practical questions yet to be resolved (1996, p. 10). Whilst 20 years have passed since this

review took place, it could be argued that the conceptualisation of ADHD continues to evolve. What is evident in the literature, however, is a shift from reductionist explanations that have defined ADHD through a biological lens towards investigating the complex interaction of a range of factors; as Kinderman *et al.* (2013) assert, there are 'complex, individual, interactions between biological, social and psychological factors'. However, the greatest proportion of research on ADHD continues to be focused on exploring biological processes linked to the aetiology of ADHD and the efficacy of pharmacological treatment (Singh, 2003; Visser and Jehan, 2009; Moses, 2010; Timimi, 2013). It is argued that much of this research has been promoted and, in many cases, funded by large pharmaceutical companies (Moncrieff, 2009; Traxson, 2010). The vast amount of research produced has led some to suggest that acceptance of ADHD as a neurodevelopmental disorder has acquired scientific status and legitimacy (Brown, 2004), which has then been reinforced in the views of mental health professionals and health guidelines, and subsequently the wider population; marginalising other descriptions and explanations (Brady, 2004).

### **2.6.1 The biomedical story**

This story asserts that ADHD is a disease caused by biomedical factors, particularly within the modalities of neurology and genetics. There has been a long history of ADHD being understood through a biomedical lens, although differing explanations have been presented regarding the source of the differences and abnormalities proposed by researchers. In their critical review of the evolution of ADHD since the 1900s, Mayes and Rafalovich (2007)

noted over twenty diagnostic terms for the behaviours we have now come to understand as ADHD. Many of these terms imply a biomedical aetiology and include: encephalitis lethargica, minimal brain damage, mild retardation, minimal brain dysfunction and hypokinetic impulse disorder.

ADHD is considered one of the most heritable psychiatric conditions (Faraone *et al.*, 2005), with heritability estimates from twin and family studies of around 0.7 (Tarver *et al.*, 2014). According to Barkley (1998), twin studies furnish ‘the most inclusive evidence that genetics can contribute to ADHD’ (p. 68). However, although many of the twin studies (e.g. Thapar *et al.*, 1995; Sherman *et al.*, 1997; Heiser *et al.*, 2006) conclude that monozygotic twins are more concordant for ADHD, critics (e.g. Joseph, 2009) have argued that researchers have based their conclusions on a traditional assumption that the environments of monozygotic and dizygotic twins are equal. As highlighted by Cooper (1999), there are difficulties in controlling experiential influences that are commonly shared by members of the same family.

Studies seeking to identify the genetic causes of ADHD have employed two approaches: the genome scan, surveying all genes unselectively; and the candidate genome approach, which has focused specifically on the genes related to the mechanism of action of the medication used to treat ADHD (e.g. dopamine and norepinephrine transporter and receptor genes) (Franke *et al.*, 2009). In particular, research has focused on genes involved with the brain’s dopamine receptors, and it has been suggested that there is a dopamine deficiency in children with ADHD (Spencer *et al.*, 2005). Researchers

supportive of this hypothesis emphasise the therapeutic benefits of methylphenidate, known to be a dopamine agonist: Gizer *et al.* (2009) conducted a meta-analysis of commonly studied candidate genes and found candidate gene polymorphisms in the dopaminergic and serotonergic systems, which they describe as moderately associated with ADHD. However, these genome-wide scans have not identified any regions that are consistently implicated, and researchers have acknowledged that this is not surprising given that ADHD is so 'phenotypically variable' (Furman, 2009).

In summary, no single genetic risk factor has been identified, making it likely that ADHD develops as the result of the interaction between multiple genetic risk variants, each of small effect (Thapar *et al.*, 2013).

Research has also been directed towards finding a neuroanatomic locus for the disorder, with ADHD being associated with a number of morphological brain abnormalities (Tarver *et al.*, 2014). These proposed abnormalities have been identified through use of neuroimaging techniques such as magnetic resonance imaging (MRI) and computerized transaxial tomography (CTT), comparing the brains of children with ADHD with those of children who do not meet the criteria for a diagnosis. Studies have associated ADHD with reduced global brain volume (Castellanos *et al.*, 2002), reduced grey matter in regions forming part of the fronto-striatal circuits (involving executive functions) (Bush *et al.*, 2005; Nakao *et al.*, 2011), cortical thinning (Batty *et al.*, 2010) and delayed cortical development (Shaw *et al.*, 2007). However, critics have argued that these studies have failed to control for potentially critical

confounders known to affect brain imaging results (Furman, 2009), including prior or current medication use, pre- and perinatal complications, effects of co-morbidity and treatment effects in participants with multiple diagnoses, and generally inadequate use of control populations with other pathologies.

Barkley (1990, 1997, 1998), a prominent researcher in the field of ADHD, identifies important relationships between behavioural inhibition, executive mental functions and self-control, which he has linked to a 'developmental failure in the brain circuitry'. His theory suggests that the onset of ADHD is related to deficiencies in key areas of the brain, including working memory, internalised speech and motivational appraisal, leading to difficulties with self-regulation and impulse control. He asserts that deficiencies in these areas lead to poor response inhibition, which narrows children's range of options and choices of actions. Cortese (2012) also suggests that ADHD is likely to be the result of structural abnormalities in a complex network of brain regions and connecting circuitry.

Whilst it is not the intention of this chapter to provide a detailed account of all biomedical theories, it is accepted that within this domain, ADHD has also been linked to biological risk factors, including maternal smoking during pregnancy (Langley *et al.*, 2005), low birthweight (Johnson *et al.*, 2010) and nutritional deficiencies (Stevens, 1995; Arnold, 2005; Cortese *et al.*, 2012).

In summary, neurobiological theories are far from conclusive, particularly as neurological research has been limited to a small percentage of the general

population (Doggett, 2004). Doggett, who conducted a review of research into the brains of individuals diagnosed with ADHD, concluded that 'while ADHD brains are different, they also have many of the same developmental and neurological features as other types of brains...therefore, scientists cannot agree with certainty that ADHD children have a unique and identifiable brain blueprint' (2004, p. 74). Given its heterogeneity, it is perhaps unlikely that there is a single identifiable genetic or neurological cause of ADHD; rather, it is more probable that children and adults with similar symptoms have different underlying problems that may not result from a single cause. As Rafalovich has cautioned, 'it would be premature to say that neurology has found the answer' (2004, p. 414).

### **2.6.2 The ecological story**

The ecological story of the causes of ADHD has focused on the interaction between child characteristics and family circumstances. This approach is consistent with Bronfenbrenner's (1995, 2005, 2006) ecological systems/bioecological model, which, inter alia, promotes the bidirectional nature of the parent-child relationship, asserting that the family is an important context for development, influencing, and influenced by the developing child's characteristics and behaviour. Whilst the model theorises that development is shaped by multiple interacting systems that are multi-directional and reciprocal in nature (Pham, 2015), the literature presented herein specifically relates to the family microsystem.

Podolski and Nigg (2001) suggest that a child's challenging behaviours can increase parental distress, whilst an adverse family environment can exacerbate symptoms of ADHD. This story of ADHD has become less popular over time due to concern about a unidirectional hypothesis leading to parent blame, particularly of mothers (Singh, 2002). Furthermore, critics have emphasised the limited research on the extent to which such parenting practices are causal or contributory factors in ADHD, or rather, responsive to negative child behaviour (Howe, 2010; Tarver *et al.*, 2014).

Crea *et al.* (2013) assert that the term 'family environment' encompasses multiple, closely related concepts, which include: family cohesion (Moos and Moos, 1994), family coherence and adaptability (Antonovsky and Sourani, 1988) and family conflict (Jaycox and Repetti, 1993; Burt *et al.*, 2003). Positive family environments provide a vital context for the development of children's emotional and behavioural well-being, and may also buffer development of ADHD (Crea *et al.*, 2013), whereas it has been argued that adverse family environments and parenting practices are commonly observed in families of children with ADHD (Johnston and Mash, 2001; Hinshaw, 2002; Seipp and Johnston, 2005; Dallos *et al.*, 2012; Keown, 2012). Despite his strong views about internal individual effects, Biederman (2005) concedes that psychosocial adversity in the family may trigger an underlying predisposition. This position appears to fit within the epigenetic model of gene–environment interaction, which acknowledges the interplay between an individual's genes and his or her environment (Banerjee *et al.*, 2007). Within

this model, environmental factors are understood as 'enhancing' or 'attenuating' the expression of a given gene (Daley *et al.*, 2008).

More recently, the high heritability rates of ADHD have led some to conclude that it is possible that parents attending clinics may have ADHD themselves, and that their symptoms are likely to affect their parenting skills (Harvey *et al.*, 2003; Daley, 2006; Tarver *et al.*, 2014). Parental ADHD is associated with more adverse discipline practices and higher levels of family chaos (Johnston *et al.*, 2012; Keown, 2012).

Several studies indicate higher rates of family dysfunction (Crea *et al.*, 2013). In particular, research has identified the following: problems in communication, relationships and problem-solving (Cunningham and Boyle, 2002); increased family conflict and difficulties with organisation (Foley, 2010; Mulligan *et al.*, 2011); more marital/partner discord (Hurtig *et al.*, 2005; Wymbys *et al.*, 2008; Heckel *et al.*, 2009); and increased stress, lower levels of social support, reduced quality of life and higher levels of authoritarian parenting (Lange *et al.*, 2005; Keown, 2012). Counts *et al.* (2005) found symptoms of oppositional defiance disorder (ODD) in children with ADHD to be related to poor maternal mental health and marital conflict.

There has also been some evidence to suggest that early neglect and abuse may be risk factors for later ADHD symptoms, with researchers drawing attention to work undertaken by Rutter *et al.* (2001). Rutter *et al.* (2001) found that the severe deprivation and neglect experienced by children in Romanian

orphanages was associated with later inattention and overactivity. More recently, a number of studies have drawn upon attachment theory (Bowlby, 1969, 1988) to explore attachment interactions within family systems (Vetere and Cooper, 2005; Dallos and Smart, 2011, Dallos *et al.*, 2012). The impact of domestic violence has also been considered (Vetere, 2004; Vetere and Cooper, 2005). Marvin (2009) suggests, from these perspectives, difficulties reside in the relationship between the child and their caregiver (e.g. parent), rather than solely within the child. However, Dallos and Smart (2011) add caution, emphasising the importance of the multidirectional nature of relationships (which they describe as triadic configurations); as Thapar *et al.* (2013) suggest, care is needed in ascribing direction of effects, causality and potential blame.

In summary, as Bronfenbrenner's (1995, 2005, 2006) model describes, ADHD is likely to be shaped by multiple interacting systems, including biological, psychological, social and cultural, which are bidirectional and reciprocal in nature. Symptoms of ADHD do not emerge, grow or take shape solely as a consequence of biological deficits (Singh *et al.*, 2011) or solely within the family microsystem. As Rutter *et al.* (1997) caution, 'researchers who ignore genetic effects do so at their peril...researchers who ignore environmental influences also do so at their peril' (p. 336).

### **2.6.3 The biopsychosocial story**

Proponents of the biopsychosocial story believe that this is an approach which promotes a more balanced, holistic understanding of ADHD; one that moves

away from the polarising nature versus nurture perspectives, against which Rutter *et al.* (1997) caution, that attribute the cause of ADHD as either 'primarily volitional in nature or the product of neglectful or deviant parenting' (Baldwin and Cooper, 2000, p. 599). This does not offer a qualitatively different lens to the aforementioned ecological story but rather, places greater emphasis on social determinants and how these are psychologically and biologically mediated. The biopsychosocial story was initially developed by Cooper (1997); however, similar views have been espoused by others working within the field of ADHD (e.g. Teeter, 1998; Singh, 2002; Thapar and Thapar, 2003).

Cooper (1999) proposed that ADHD should be more accurately seen as a condition with a likely biological element which interacts with psychosocial factors in the individual's environment. Whether ADHD develops, and the nature of that development, depends upon 'the complex interaction' and 'intricate interplay between complex human systems' (Cooper, 1999, p. 7). This model provides fuller elaboration of the stories discussed previously, in which elements of both are acknowledged. From this perspective, ADHD originates from the theoretical underpinning of biological, psychological and sociological factors.

In relation to ADHD, Cooper (2001) views biology as 'creating propensities' (p. 391): in other words, the likelihood of developing ADHD is increased by the presence of certain genetic and neurological factors. Cooper (2008) argues that evidence from cognitive, neurobiological and genetic research provides a

compelling argument. Furthermore, he argues that these biological propensity factors are themselves influenced by social/physical environmental factors. Goldstein and Naglieri (2009) describe ADHD as a condition with a neurological basis, but one that is environmentally driven.

For Cooper (2008), the biopsychosocial understanding of ADHD provides a sound base for a multimodal approach to intervention, which combines medical, psychological and educational dimensions. Aspects of this approach are recognised within health guidelines on ADHD (e.g. NICE, 2013). In particular, Cooper (2008) calls for the development of effective educational practice (e.g. changing the educational context to accommodate the child with ADHD, providing training for school staff), which he believes may reduce the need for medication.

Whilst the multimodal approach is popular in the literature, its effects in practice are not so clearly seen; for example, Hazelwood *et al.* (2002) conducted interviews with professionals working in the field of ADHD to explore the meaning of the multimodal perspective, and their findings suggested that whilst this approach was supported, there was no clear definition of its implementation in practice. The authors also noted that the professionals' practice used a particular set of values, ethics and methods that reflected their discipline's theoretical and philosophical perspective. Research by Hughes (2007) and Moldavsky and Sayal (2013) produced similar findings, suggesting that the different philosophical and professional

perspectives appear to influence assessment and intervention practices, and provide a barrier to a successful multi-agency and holistic way of working.

#### **2.6.4 The postmodern story**

The postmodern story views ADHD as a socially constructed illness, which can be culturally defined. Timimi (2002), a child psychiatrist, argues that the mainstream literature on ADHD is 'contaminated' and 'misleading', and proposes that ADHD is best viewed through a cultural lens. There has been great concern that the focus on internal individual factors for presenting behaviours has separated the person (in this case, the child with a diagnosis of ADHD) from their context. In addition, it is feared that the lack of acknowledgement of the subjective nature of psychiatric practice leaves it open to abuse (Kopelman, 1990; Kinderman *et al.*, 2013).

It is argued that ADHD exists as a concept because it has been positioned within the empiricist tradition of medical and psychological research, which has been made meaningful through powerful, high-status opinions of doctors, thus minimising opposition (Timimi and Radcliffe, 2005). Furthermore, when ADHD is linked with biological processes, it provides further credence (Boyle, 2002), whilst other accounts are ignored or rejected; for example, ADHD is claimed to be a proven 'medical' disorder and psychotropic medication as well-founded effective treatment, when there is little evidence to show long-term effects (Schachter *et al.*, 2001).

The postmodern critique of the medical model has been attributed to the 1970s' anti-psychiatry movement, based on the work of psychiatrist Thomas Szasz (1974), who suggested that mental illness is a metaphor for culturally disapproved thoughts, feelings and behaviours (Bracken and Thomas, 2010). However, whilst those arguing from a critical psychiatry position may concur with Szasz's refusal of a purely medical framing of mental illness, the mind and body are not understood as being separate entities. Critical psychiatry draws on the work of Foucault (1988) in seeking to understand how mental illness is experienced in all our lives (Bracken and Thomas, 2010; Moncrieff and Timimi, 2013).

There is concern about the power given to certain forms of knowledge in claiming exclusive authority about the truth of ADHD (Moncrieff and Timimi, 2013); for example, the wide-ranging definitions, which it is argued are dependent upon the dominant and most widely accepted current theory about underlying aetiology, and revisions of the DSM classification system, that produce higher numbers of children potentially deemed to have the disorder (Kinderman *et al.*, 2013; Prosser and Reid, 2013). In addition, proponents of the postmodern story highlight concerns about the involvement of pharmaceutical companies in illness promotion (e.g. funding parent support groups) and their influence on research activities through financial incentives (Breggin, 2001; Moncrieff, 2009).

Timimi (2002) has argued that prevailing cultural conditions, including loss of extended family support, breakdown in the authority of adults, change in

family life and a profit-dependent pharmaceutical industry have spawned and 'propagated' the ADHD construct. In response, critics of the postmodern story argue that this stance positions ADHD within the context of uncommitted parents, incompetent teachers and rapacious pharmaceutical companies (Singh, 2002). Singh (2002) criticises this approach for sacrificing the individual to radical social and political agendas; however, she also criticises the biomedical approach for sacrificing the individual and social context to biology and genes. In response to the 'either/or' critique, many of those who take a postmodern position make clear that they are not opposed to the involvement of medicine in the lives of those who experience mental illness, but suggest that by critiquing current ideas and practices, they open the field to different ways of understanding, framing and responding to such experiences (Bracken and Thomas, 2010).

As discussed in the previous subsections, many theories have been presented about the causes of ADHD; however, despite being one of the most studied psychiatric disorders, the exact cause remains unknown (Thapar *et al.*, 2013). More recently, emerging aetiological research has focused on possible interactions and correlations between inherited and non-inherited factors (Tarver *et al.*, 2014): in other words, a belief that ADHD is caused by an inherited predisposition combined with exposure to environmental triggers (Curatolo *et al.*, 2010; Thapar *et al.*, 2012). However, despite the epistemological uncertainty, biomedical theories remain the dominant story (Moses, 2010; Timimi, 2013; Brady, 2014).

## **2.7 Outcomes for children and young people diagnosed with ADHD**

Children who are diagnosed with ADHD have been shown to be at a higher risk for learning, behavioural and emotional problems throughout childhood. Research on long-term academic outcomes suggests that children diagnosed with ADHD are likely to have poor educational prospects (Barbaresi *et al.*, 2007), more likely to be receiving special education, have a history of suspension or permanent exclusion and attain lower levels of academic achievement compared to controls (Bauermeister *et al.*, 2007). Research suggests that this negative trajectory continues, with adolescents leaving school with few or no qualifications and the likelihood of lower employment attainment (Mannuzza *et al.*, 1993). It has also been suggested that young people with ADHD are at increased risk of being engaged in criminal behaviour, and drug and alcohol misuse (Barkley *et al.*, 2006). However, as has been discussed, there are many causal factors and it would be unhelpful, and rather simplistic, to suggest that having ADHD *per se* leads to this increased risk (Schmidt and Petermann, 2009). As Hazelwood *et al.* (2002) describe, ADHD is characterised by heterogeneity and ambiguity, and confounded by co-morbidity.

Research has indicated similar long-term negative experiences within the social domain. Studies have shown that children and young people with ADHD are more likely to experience difficulties with peer relationships and have fewer reciprocal friendships (Hoza *et al.*, 2005); are often rejected by their peers (Harpin, 2005); and rated lower on social preference (Hoza *et al.*, 2005). However, Harpin (2005) counters these somewhat deterministic

projections, suggesting that such outcomes vary with family and school resources, as well as with age, cognitive ability and insight of the child or young person. This once again points to the complex interplay of a range of biological, psychological and environmental factors.

## **2.8 Treatment and management of ADHD**

A multimodal approach to the treatment and management of ADHD has been proposed (BPS, 2000; SIGN, 2009; NICE, 2013). This approach recommends that psychological, behavioural and educational advice and interventions be implemented alongside the use of any pharmacological treatments (e.g. prescription of stimulant medication). Whilst it is accepted that medication often controls the core symptoms of ADHD, difficulties such as parent–child relationships, peer relationships and internalising behaviours (e.g. anxiety, low mood) are likely to respond to a multimodal approach (MTA Cooperative Group, 1999), particularly where these are key targets for intervention (Pelham, 2005).

From the literature, however, the provision of treatments and interventions for children, young people and their families appears to vary within and between countries. For example, in North America, the advice of the professional association, the American Academy of Pediatrics, is that stimulant medication should be prescribed when any subtype of ADHD is diagnosed. In contrast, within the UK, specific guidance is provided in relation to the age of the child and severity of the ADHD (SIGN, 2009; NICE, 2013): medication is not recommended as first-line treatment when ADHD is deemed to be *moderate*;

however, in cases of severe ADHD (including hyperkinetic disorder), medication is recommended; whilst the use of drug treatment for preschool children is not advised. Despite these recommendations, there has been a considerable rise in the number of prescriptions given to children and young people in the UK, with little evidence to suggest an increase in the severity of the disorder. It has been argued that emphasis on clinical judgement when evaluating the severity of ADHD (Carey, 2002; Stolzer, 2009), limited adherence to the guidelines (Travell, 2005; Brady, 2014) and reliance on parent and/or teacher ratings for outcome measures (Hoza *et al.*, 2007) may be contributing to this rise. In addition, it has been suggested that parents may favour the immediate effects or 'quick fix' of medication (Baggini, 2005, Schmidt Neven, 2008).

The pharmacological treatment prescribed for children and young people with ADHD includes stimulants, e.g. methylphenidate (Ritalin, Cephalon UK Ltd.; Concerta, Janssen-Cilag Ltd.) and dexamfetamine (Dexedrine, USB Pharma Ltd.), and non-stimulants, e.g. atomoxetine (Strattera, Eli Lilly & Co.), which operates as a noradrenalin reuptake inhibitor. The medication can be administered in long- or short-acting forms, with long-acting forms more often prescribed as effects remain for 8–10 hours (Singh, 2008). Psychostimulants are reported to have a beneficial effect on reducing children's inattentive behaviours, although the exact way they achieve this is unclear. NICE (2013) has concluded that these medications are effective in controlling the symptoms of ADHD relative to no treatment. Interestingly, the effects of stimulants are not specific to children with ADHD: children without a diagnosis

and those with other diagnoses (e.g. conduct disorder) also show a reduction in activity level in response to psychostimulants (Carr, 1999). These observations challenge a disease-centred model (Moncrieff and Cohen, 2005) that seeks to understand drug treatment as acting on the underlying neurological abnormalities, thus confirming the diagnosis: the medication appears to enhance performance, rather than treating specific psychopathology (Singh, 2008).

Stimulant drug treatment has been presented as relatively safe (Biederman and Faraone, 2005; Bates, 2009), although known side effects are reported to include: appetite suppression, abdominal pain, headache, sleep difficulties, tics, itchy skin, rashes, a feeling of depression, mood change or nausea (Cooper and Bilton, 2002). Over recent years, however, more serious long-term side effects have been reported (Breggin, 1999, 2002; Baughman and Hovey, 2006) prompting questions about the ethics of pharmacological treatment: for example, cardiovascular effects, growth suppression, development of psychosis and, in rare cases, sudden death have been reported (Singh, 2008; Jackson, 2009). In addition, withdrawal from psychostimulants has been known to cause depressive symptoms resembling a major depressive episode (American Academy of Child and Adolescent Psychiatry, 2002); side effects that may be exacerbated by the increasing use of a combination of psychotropic drugs (Singh, 2008; Traxson, 2010).

The efficacy of psychostimulants in reducing core symptoms of ADHD, in the short-term, is well documented: findings from a wide-scale meta-analysis of

randomised controlled trials of methylphenidate demonstrated short-term clinical effect in treatment of ADHD (Schachter *et al.*, 2001). Long-term effectiveness when compared with other treatment modalities is inconclusive, however (Jensen *et al.*, 2007): the meta-analysis conducted by Schachter *et al.* (2001) found effects of psychostimulants did not remain beyond four weeks. In addition, they cited concerns with research design: inconsistencies within rating scales, problems with side effects and observed publication bias.

One of the most frequently cited studies regarding long-term effectiveness of medication is The Multimodal Treatment Study of Children with ADHD (MTA) (MTA, 1999). This study has been highly influential in the development of treatment guidelines and insurance coverage policies (Hoza *et al.*, 2007). A sample of 579 children between 7 and 10 years old took part in the study, which initially lasted for 14 months. Participants were assigned to one of four treatment modes: intensive behaviour therapy; intensive 'medication management' treatment regime, including regular reviews with a doctor; combination of behavioural therapy and medication management; and, 'routine community care'. Data from the initial follow-up at 14 months showed that children receiving medication alone or a combination of medication and behavioural therapy showed greatest improvements in core ADHD symptoms. Although medication was noted to be superior in relation to core ADHD symptoms, this did not extend to other important areas of functioning, such as oppositional behaviour (previously mentioned as commonly co-occurring), peer relations and academic achievement.

At the three year follow-up, there appeared no significant difference in primary outcomes between children who received 'medication management' and those who received behaviour therapy or 'routine community care' (Jensen *et al.*, 2007). Despite these findings, prescriptions for stimulant medication reportedly increased following publication of the study's earlier results. In response, Hoza *et al.* (2007) suggest that researchers refrain from publishing data in the order they become available, to ensure a more balanced picture of results is presented. This has significance for public and professional understanding and practice regarding the selection and promotion of certain treatments: misinterpretation of findings could lead to increased use of a particular treatment modality with other treatments becoming marginalised. For example, in her review of evidence for the benefits of stimulants, Moncrieff (2009) reported that the NICE guideline on ADHD 'acknowledge that there is practically no basis for the use of stimulants in children' (p. 214). This is also important given the link between effectiveness of medication and evidence of a biological aetiology, as Moncrieff and Cohen (2005) have cautioned.

Psychological, behavioural and educational interventions are often referred to as non-pharmacological treatments. These interventions vary between those directed specifically towards the child or young person and those where parents are the recipients. Such interventions include: psycho-educational input (e.g. school-based programmes, social skills training, parent training), behavioural therapy and family therapy (Fonargy *et al.*, 2002; Taylor *et al.*, 2004). In the most recent NICE (2013) guidance, behavioural therapy is

recommended as first-line treatment for less severe ADHD, with parent training being given as the primary intervention for preschool children.

As reported, studies have shown improvements in core symptoms of ADHD (e.g. increased on-task behaviour; reduced fidgeting, finger tapping and interrupting; reduced impulsive responding; reduced aggression; and increased compliance) following treatment with stimulant medication (Barkley, 1997; Swanson *et al.*, 1998), and it has been argued that these effects provide a 'window of opportunity' for the child or young person to be more receptive to learning opportunities. Findings from a meta-analysis of 74 studies (Purdie *et al.*, 2002) have suggested some caution, however: whilst overall effect size for pharmacological interventions was higher than that achieved by other approaches for behavioural outcomes, there appeared little effect on educational outcomes. Many of the symptoms of ADHD are evident in the classroom and it is argued that teachers play a key role in the management of ADHD through the implementation of a range of behaviour management strategies and techniques (e.g. Cooper and Bilton, 2002; Cooper, 2005; Hughes and Cooper, 2007). Interestingly, consumer satisfaction data from the MTA study (Pelham *et al.*, 2005) indicated that teachers and parents reported greater satisfaction following use of behavioural interventions than from those involving medication alone. Furthermore, Hinshaw (2007) has suggested that changes in family environment following access to parenting interventions appear crucial to the improvement of social skills and reductions in disruptive behaviour.

Rose has cautioned that 'Ritalin no more 'cures' ADHD than aspirin cures toothache' (2005, p. 263). He warns that whilst medication can provide a useful breathing space for parents, teachers and the child to regulate a new and better relationship, if the opportunity is not seized, then 'we will once again find ourselves trying to adjust the mind rather than adjust society'. In a similar vein, Travell (2005) has questioned whether the use of medication may be 'a chemical solution designed to produce compliance in a group of children for whom the current education system is ill-designed and not prepared to change to accommodate' (p. 64). Children and young people exist in multiple contexts, most notably, home and school; therefore, ideally treatments should be implemented in both of these contexts (Pelham *et al.*, 1998), and take account of differing risk and/or protective factors that exist within these (Mash, 1998). This is a view shared by Young and Amarasinghe (2010), who highlight the importance of tailoring treatments to an individual's specific needs, and implementing them consistently over the long-term in all settings where the difficulties are present.

In summary, the message appears to be that medication is not a panacea and that treatment, as Young and Amarasinghe (2010) suggest, should be individualised to the child or young person's needs, agreed with them and include all agencies involved in their care.

## 2.9 Summary

In providing an introduction to the phenomenon of ADHD, this chapter has discussed the clinical approach to understanding the disorder, examined prominent theories in relation to its construction and aetiology, and presented an overview of common approaches for treatment and management. The literature presented has demonstrated the complexity and ambiguity of this most studied and controversial disorder. As Tarver *et al.* (2014) describe, 'ADHD is a heterogeneous disorder; aetiological factors, clinical presentation and response to treatment are likely to vary greatly between individuals' (p. 768).

These diverse and competing perspectives have implications for the ways in which ADHD is understood and managed for the individuals and professionals involved, and within wider social and cultural domains. As discussed, certain theories have tended to receive more credence than others and thus become more dominant, resulting in a number of 'taken-for-granted' assumptions (Carrey, 2006), which affect the narratives that are produced and reproduced. These dominant, or taken-for-granted, stories have the potential to shape how people come to understand ADHD and their experiences (White and Morgan, 2006).

In moving the spotlight to the lived experience of ADHD, the following chapter presents a review of qualitative studies exploring children's and parents' perceptions and experiences. Issues relating to their research design are also discussed, including implications for this research study.

## **CHAPTER THREE: THE LIVED EXPERIENCE OF THE PHENOMENON OF ADHD**

### **3.1 Introduction**

Chapter 2 discussed the clinical approach to understanding ADHD (e.g. clinical definition, diagnosis and prevalence), examined prominent theories in relation to its construction and aetiology, and discussed common approaches for treatment and management of the disorder. The literature review demonstrated that ADHD is a complex phenomenon with diverse and competing perspectives related to its definition, causality and treatment. These differing views continue to fuel debate surrounding the disorder, which has led to ADHD becoming one of the most controversial mental health labels (Mayes and Rafalovich, 2007; Visser and Jehan, 2009; Horton-Salway, 2011).

Whilst the ambiguity of disorders such as ADHD can pose a challenge for researchers, Carpenter-Song proposes that this uncertainty and lack of consensus regarding the nature of these problems are themselves 'ripe conditions for inquiry', in terms of understanding the various meanings that these diagnoses take on from the perspectives of those who are experiencing them (2009, p. 62). As Prosser notes, 'whatever one's view on its "reality", ADHD is "real" in its consequences' (2006, p. 2).

The concept of ADHD has tended to be positioned within the empiricist position of medical and psychological research (Timimi and Radcliffe, 2004). This appears to have contributed to an abundance of quantitative research literature exploring the physical basis of ADHD and efficacy and side effects

of drug treatment (Timimi and Radcliffe, 2004; Singh *et al.*, 2010; Dunne and Moore, 2011). There has been increasing concern that medicalised discourse has dominated the research landscape and, as a consequence, has marginalised differing descriptions and explanations (Brady, 2004; Dunne and Moore, 2011). Over the last two decades there has been a call for qualitative research to explore the meaning of how people make sense of and experience mental health disorders such as ADHD (Brady, 2004; Dunne and Moore, 2011; Singh, 2011; Bringewatt, 2013). As Willig (2008) states, such research focuses on the quality and texture of relationships, rather than cause–effect. Furthermore, Brady (2004) asserts that the voices of children and young people (and their parents) have an important story to tell.

The literature presented in Chapter 2 is important in order to understand and contextualise the experiences of the participants and to consider how different stories regarding its aetiology may influence the narratives of parents and children, including those involved in this research study. White and Morgan (2006) suggest that dominant or most-accepted stories have the potential to become a story of identity, which can shape how people come to understand their experiences.

### **3.1.1 Literature search criteria**

Relevant published literature was identified through searches of the following electronic databases: PsycINFO, PsychARTICLES, ERIC, PubMed, Web of Science for the years 2000-2013, initially. This was accompanied by the use of FindIt@bham (University of Birmingham’s electronic search system for the

library) and Google Scholar. Key words in all multi-field searches were 'ADHD' (in all possible combinations, e.g. Attention Deficit Hyperactivity Disorder, ADD, Attention Deficit Disorder) with 'adolescen\*', 'child\*', 'young person', 'parents', 'family', 'experience\*', 'perceptions', 'beliefs', 'stigma', 'identity', 'qualitative', 'interviews', 'IPA', 'interpret\* phenomenological analysis'. Relevant literature from the reference lists of identified articles were also followed-up. Literature was obtained through the University of Birmingham electronic library and orders from the British Psychological Society archives. Papers were selected for review if they were original articles, peer reviewed and written in English. Searches were updated in 2015 and 2016 to ensure more recent literature had not been overlooked between initial planning and preparation for the study and subsequent data collection (see also Chapter 1, section 1.3).

As discussed in the previous chapter there is no definitive test, which can establish exclusively the existence of ADHD in an individual (Carpenter-Song, 2009; Wheeler, 2010). Diagnosis is made using diagnostic criteria described in diagnostic classification manuals, such as the ICD-10 and DSM-5 (see Chapter 2, section 2.2), and is based on subjective expert judgments (Wheeler, 2010), taking place within different cultural contexts (Singh, 2011); leading to variability in symptoms in individuals diagnosed with the disorder (Wheeler, 2010) and in the conceptualisation of ADHD, both within and between countries (Timimi, 2004; Singh, 2011). Such differences are likely to influence how ADHD is experienced and therefore differences in lived experience may be evident in research within and between countries. Whilst

experiential differences may be observed, however, those who have the disorder share experiences of identified difficulties with inattention, hyperactivity and impulsivity (see Chapter 1, section 2.2). Rather than being viewed as a limitation, findings from national and international studies enable understanding of the various meanings that these diagnoses take on from the perspectives of those who are experiencing them, as Carpenter-Song (2009) asserts.

### **3.2 Children and young peoples' views and experiences of ADHD**

Children and young people's voices can be silent within the assessment, diagnosis and treatment of ADHD, and indeed, in research about ADHD and its effects. In contrast with most medical conditions, in the case of ADHD (and other mental health disorders), it is those around the child who notice differences in the child's development and seek help from education and/or health services (Stranger and Lewis, 1993). This can present challenges because, as Nylund (2000) suggests, many children struggle to identify with or understand a mental health label.

There remains very little research documenting the views of children and young people, despite several researchers highlighting this gap (McNeal *et al.*, 2000; Kendall *et al.* 2003; Meaux *et al.* 2006; Travell, 2005; Brady, 2014; Kendall, 2016). Where research has focused on children's views, this often relates to their experiences of taking medication (Moline and Frankenburg 2001; Knipp, 2006; Meaux *et al.*, 2006; Singh *et al.*, 2010), rather than their overall lived experience of having ADHD in their lives (Brady, 2014). An

overview of eight studies that have sought to give value to these stories is provided below. These were selected in order to illustrate children and young people's lived experience of ADHD in relation to diagnosis and treatment, and the experience of living with the disorder and its effects within school and familial environments; thus, presenting a diverse set of stories about what it is like to experience ADHD.

One of the first studies to explore young people's perceptions of ADHD was undertaken by Cooper and Shea (1998). Their small-scale study investigated the experiences of 16 (ten boys and six girls) young people (aged 11–16 years), with a diagnosis of ADHD, attending an independent day special school for students with learning and behavioural problems. This UK study focused on the students' perceptions of ADHD and attempted to construct 'authentic accounts' of the disorder (ibid, 1998, p. 46), using one-to-one informant interviews. The authors found that there were conflicting attitudes towards ADHD: participants, particularly boys, spoke of difficulties in controlling verbal loudness and feelings of anger; they also spoke of feelings of 'oppositonality' and aggression, which they associated with a lack of control and a sense of 'dangerousness' (ibid, 1998, p. 39).

Participants spoke of the stigmatising effects of an ADHD diagnosis, which they attributed to its association with extreme and disruptive behaviour. They reported generally positive attitudes towards medication; however, the authors cautioned that this positive view was part of a broader and more complex pattern of attitudes towards medication. The use of medication was described

as a 'trade-off': on the one hand, welcomed by participants as a means to increase school success; on the other hand, making them less sure of themselves and their identities. The authors expressed concern about the pupils' perceptions of ADHD as a biologically determined phenomenon, and proposed that pupils may benefit from being introduced to a more balanced view – one that would acknowledge the interactions between biological, psychological and social forces, and, according to the authors, help to restore pupils' self-esteem and their sense of power and control over the disorder. The study cannot be said to be representative of the experiences of children and young people with ADHD, the majority of whom attend local state mainstream schools (unlike the participants in Cooper and Shea's study) with larger class sizes and higher pupil-to-teacher ratios. However, the qualitative methodology, as the authors assert, provided accounts that represent something of young people's genuine thoughts, experiences and concerns about ADHD.

Krueger and Kendall (2001) conducted a qualitative exploratory study in the USA to investigate how ADHD is experienced, perceived and managed by young people who have been diagnosed with the disorder. The sample consisted of 11 adolescents (eight boys and three girls) who ranged in age from 13 to 19 years old. Interviews were used to gain an account of the participants' experiences within the context of family, peer group, school and wider social networks. The authors found that the participants defined themselves in terms of their ADHD symptoms and tended not to view themselves as being distinct from the disorder: a process the authors' referred

to as an 'ADHD-defined self'. The experience of ADHD for these participants appeared to be entwined with their identity. Interestingly, the authors noted gender-related differences in the vocabulary participants used to describe themselves: for example, girls described themselves as 'inadequate', whilst boys described themselves in terms of 'anger' and 'defiance'. The authors concluded that 'they were their ADHD and their ADHD was them' (ibid, 2001, p.65). This determinist narrative may pose difficulties in relation to exploring different treatment options, as it implies requiring approaches based on changing the child/young person (e.g. via medication) and risks rendering invisible the child/young person's sense of agency and control, as Tait (2003) has cautioned.

Akin to the views held by their participants, the authors appear to subscribe to a biomedical story of ADHD, in which they recommend one-to-one therapeutic treatment for the young person. Their understanding of ADHD appears to suggest a 'within-person' condition (e.g. a brain-based disorder), thus requiring 'within-person' solutions and seeming to overlook interventions aimed at changing the young person's environment (e.g. home and school). This biomedical position may reflect their professional backgrounds as nurses.

An important aspect of their study is their recommendation that ADHD be reframed as a developmental disorder. This is interesting given the recent change in the conceptualisation of ADHD as a neurodevelopmental disorder, following publication of the DSM-5 (see Chapter 2, section 2.2). The authors

suggest that understanding ADHD as a developmental disorder would not only help parents and teachers to accept that improvements in self-control are likely to develop over a longer time period but also seem helpful in encouraging them to measure their child’s progress over time.

Kendall *et al.* (2003) studied the perceptions of 39 (26 boys and 13 girls) children and adolescents (aged 6–17 years), from diverse ethnic and socio-economic backgrounds in the USA, who had been diagnosed with ADHD. Semi-structured interviews were used to explore children’s perceptions of experiences within their everyday lives; data – a subset of qualitative data from a large mixed-method study of 157 families with children diagnosed with ADHD – were analysed using a constant comparative analysis (Strauss and Corbin, 1998). Similar to the previous study, the authors’ professional backgrounds were in school nursing.

The six themes abstracted from the data by Kendal *et al.* are presented in

Table 3.1.

Themes	Brief Summary of Themes
‘problems’	Participants identified numerous everyday problems related to what they saw as ADHD. These problems were described as learning/thinking (e.g. their slower rate of learning and feeling constantly distracted), behaving (e.g. problems following the rules and getting along with others) and feeling (e.g. participants described feeling sad, mad, frustrated and ashamed.). The authors reported that participants ‘parroted’ negative descriptions they had heard about themselves.
‘meaning and identity’	Similar to the studies presented previously, the authors found that participants talked about ADHD in terms of who they were (e.g. hyper, bad/trouble/weird), rather than the symptoms they experienced, as if ADHD had come to define them (e.g. an ‘ADHD identity’).

'pills'	Participants understood that 'the pills' were a way to help them with the problems they were experiencing, although there appeared some confusion because, for some, ADHD meant the pills themselves. The participants reported positive (e.g. controlling hyperactivity, increasing concentration and improving grades) and negative (e.g. the taste, side effects such as headaches and stomach ache, and fear and shame) effects in relation to their medication. However, despite their ambivalence, participants indicated medication helped the most out of all the treatments they had experienced.
'Mom'	Participants often talked about the importance of their families, particularly their mother. They reported that their mother kept them safe, understood and helped them the most.
'causes'	Participants offered a variety of explanations regarding the cause of their ADHD, including: genetic; neurological (e.g. 'how my brain works'); prenatal (e.g. a result of their mother using drugs and alcohol during pregnancy); and psychosocial adversity (e.g. family tragedies).
'ethnicity/race/racism'	The authors reported that they did not identify differences in the data related to gender, age or parental income. However, they noted differences regarding children's self-appraisal in relation to ethnicity and race (e.g. African American children tended to use the term 'bad' when describing themselves; Hispanic children more frequently discussed the meaning of ADHD in terms of getting into trouble; and Caucasian children tended to mention being 'weird' or 'whacko').

Table 3.1: A brief summary of Kendall *et al.*'s (2003) six themes.

Kendall *et al.* concluded that children diagnosed with ADHD and their families suffer real difficulties, and that the continued debate and dissent surrounding the existence of the disorder has meant that their developmental, emotional and behavioural needs are not being met. Although the authors do not explain the exact nature of these needs, their view appears to be that failure to accept the 'problems' as being a result of a disorder rather than the child's free will may prevent appropriate understanding and intervention for the child and their

family. This appears to be supported by the authors' call for professionals to focus on ADHD as an illness, in order to replace blame and criticism with understanding and support. They suggested that this would help to stabilise the family unit and contribute to a reduction in the symptoms of ADHD itself.

Interestingly, there appears little recognition of the child's position as passive observer or object of the diagnostic process, and its possible impact on 'meaning and identity'. Furthermore, they concluded that medication for many children and adolescents could be helpful and effective, which, similar to Krueger and Kendall (2001), seemed to reflect 'within-person' solutions. Despite participants reporting feelings of 'difference' and of difficulties fitting in with expectations (e.g. within the school context), there appeared little recognition of possible environmental influences and interventions. The authors commented on the children's wider context, but this related to the need for others to be 'compassionate' and of 'looking out' for the child, which could risk further feelings of difference. The authors reported that the difficulties the participants described corresponded to the DSM criteria, which they appear to infer as supporting the status of ADHD as a legitimate disorder.

The studies examined so far have focused on how ADHD is experienced, perceived and managed within the children's everyday lives. What is striking is the influence of ADHD on their sense of self, whereby the ADHD came to define them. Linked with their negative sense of self were the reactions from others (e.g. blame and criticism), which participants experienced as

stigmatising. Ambivalent attitudes were expressed in relation to medication; however, the positive case presented appeared to relate to being able to comply with the demands of school (e.g. increasing concentration and improving behaviour). In the Kendall *et al.* (2003) study, the authors described how on being 'told' they had ADHD, it was the adults in authority who constructed the 'reality of ADHD' for the children and young people. The experience of assessment, diagnosis and treatment are explored further in the following study.

Travell (2005) focused more specifically on young peoples' and parents' experiences of diagnosis and treatment, and examined the longer-term outcomes of such. This small-scale UK study explored participants' experiences and perspectives in five dimensions: 'symptoms' of ADHD and their consequences; the process of diagnosis and treatment; interventions; a personal diagnosis (including whether the participants agreed with the diagnosis, and their views about the causes of ADHD and the treatment offered); and participation and voice. Seventeen (16 boys and one girl) young people (aged 11–16 years) were interviewed at school and at least one of their parents interviewed at home. A semi-structured interview format was employed and results were analysed using a constant comparative method (Strauss and Corbin, 1998). At the time of the study the author was employed as an educational psychologist, and the research undertaken in the Midlands borough where he worked.

The findings prompted the author to question whether longer-term negative psychological effects of treatment with medication outweighed the short-term benefits. Responses appeared to contradict some of the available literature that the side effects of medication are insignificant and short-term. The young people interviewed reported suppression of appetite, sleeplessness, tics, depression and head-/stomach aches, which had, in some cases, continued for 5 years, suggesting they were not 'minimal and short-lived' as indicated in the health guidelines. Positive aspects of medication were reported, including: reduction in getting into trouble, being more able to concentrate on schoolwork and improved schoolwork. However, participants appeared to face a dichotomy, similar to the 'trade-off' effect noted by Cooper and Shea (1998): to take the medication or continue to be reprimanded for their behaviour.

The study highlighted the importance of considering the views of the young person in assessment and intervention processes. The young people reported being involved during the process of diagnosis; however, this was at the level of being told they had ADHD and about the need for medication, together with some attempts to gain their consent to take it. Participants indicated that they did not feel adequately consulted or listened to during the diagnostic process or in the negotiation of a treatment plan within which potential risks and benefits were accurately presented to them. The experiences described by participants indicated practitioners' limited adherence to health guidelines (e.g. NICE, 2013), and is concerning. For example, medication was prescribed frequently as a first-line treatment despite few participants displaying the complete range of symptoms that would indicate severe ADHD,

little evidence of the use of multimodal approaches and lack of consultation between the psychiatrist and other professionals (to draw on multiple sources of information). In addition, there appeared to be a lack of informed consent from the young people regarding treatment with medication; as LeFrancois (2008) has argued, despite the rhetoric of empowerment and children's rights, children continue to be passive recipients of care.

Drawing on his findings, Travell asserted that challenging behaviour should be interpreted and addressed from a broad theoretical perspective, which takes into account biological, psychological, social and cultural factors. In the author's view, diagnosis and treatment with medication risks limiting the adoption of this holistic perspective. These views contrast with those of Kendall *et al.* (2003) who argued for professionals to focus on ADHD as an illness, and Krueger and Kendall (2001) who argued for 'within-person' solutions.

Most participants assumed a biomedical position in explaining the aetiology of ADHD, which, similar to Cooper and Shea (1998), in the author's view, appeared to impair the potential efficacy of psychosocial interventions. A key finding from this study indicated that there is more work to be done with young people, particularly during the diagnostic and treatment process.

In exploring adolescents' experiences of being diagnosed with ADHD, O'Leary (2007) focused on the perceptions of change and continuity following receipt of a diagnosis. Semi-structured interviews were used to gain the experiences of eight young people (six boys and two girls), aged 15–17 years, to capture the multiple ways of understanding ADHD. This UK study formed the research component of the author's doctorate in clinical psychology at the University of East London. Six superordinate themes were constructed using an interpretative phenomenological analysis, as follows:

- 'what others think of me and what I think of myself';
- 'emotions are everywhere';
- 'I need to be active';
- 'dismissive of diagnosis';
- 'how can I keep things under control?'; and
- 'turning points'.

The participants spoke of how their view of themselves was linked to how they were perceived by those around them (e.g. family members, teachers, peer group). If they believed the people around them to understand their difficulties and to value their opinions, they felt less marginalised and more supported. The author highlighted the importance participants placed on 'fitting in' and 'not standing out', which conflicted somewhat with their belief that it was acceptable to be different. Participants reported feeling stigmatised by their diagnosis and attributed incidents of bullying to the ADHD. In addition, they expressed concern that the diagnosis may affect their employability (e.g. joining the armed forces).

Participants described many of the core symptoms of ADHD (e.g. being active and easily bored), which they perceived to be part of their personality. In addition, they spoke of being sporty and successful at sport, which they attributed to the ADHD. O'Leary described how participants posited a variety of reasons for their behaviours (e.g. family problems, relationships with parents), although many of these appeared to have been silenced or overshadowed by the ADHD diagnosis.

Overall, participants assumed a biological position in understanding ADHD and believed that medication was the main way to keep it under control. Despite this, and consistent with findings from previous studies, there was ambivalence in their views about medication (e.g. medication kept them from losing control and helped them get through school, but it also affected their personality and they felt less keen to participate in lessons); some associated ceasing medication treatment with increased self-control and becoming more independent.

Whilst the longevity of the disorder (as a lifelong condition) is recognised in the most recent DSM (exemplars of symptoms are provided for older adolescents and adults), and there has been reported increase in adults being diagnosed with the disorder (Moncrieff and Timimi, 2011), the experiences of the participants in O'Leary's study suggested that the effects of ADHD diminished as they entered mid-adolescence (e.g. calming down, improved relationships with family members). However, it is unclear whether these

outcomes were related to specific interventions they had accessed, including and/or alongside their medication.

Gallichan and Curle (2008) conducted a qualitative study to explore young people's perspectives on ADHD, with particular reference to social context and coping. This UK study formed the research component of the first author's doctorate in clinical and community psychology at the University of Exeter. Gallichan and Curle argue that previous studies examining children and young peoples' views on ADHD have tended to focus on describing phenomena rather than the possible processes that underlie those phenomena. Twelve young people (ten boys and two girls), aged 10–17 years, living in south-west England (in either rural locations or small towns or cities), took part in the study. Semi-structured interviews were used and data were analysed using Charmaz's (2006) version of grounded theory, which the authors have suggested emphasises understanding over explaining.

The participants defined themselves as 'different' through their interaction with the social world and comparisons with others, both in academic and social spheres. Similar to the experiences of O'Leary's participants, those in this study highlighted the challenges faced when they struggled with not fitting in to conventional society (like square pegs trying to fit round holes), prompting the authors to suggest that a more comfortable fit could be achieved if adaptations were made to both the young person and their environment. If the participants felt forced to change (e.g. by taking tablets) without the environment altering, they appeared resentful and found themselves in a

'vicious cycle' of trying to fit into conventional society. These experiences provide further impetus for the need to consider a systemic or 'holistic' perspective (Prior, 1997; Travell, 2005).

Gallichan and Curle found that many participants perceived some benefit from their tablets, as the medication enabled them to function in a more conventional manner (e.g. calming, helping them focus). However, the practical, physical, psychological and social side effects meant that participants' relationship with medication was often ambivalent. The authors suggested that the medication could threaten their sense of self, as participants felt controlled by their tablets. However, if others (family members, adults in schools, health professionals and peers) were flexible, supportive and accepting, the young people's accounts spoke of competence, motivation, a sense of agency and higher self-esteem. Making sense of the situation was also an important process in helping the young people to establish a more comfortable fit into conventional society (e.g. the virtuous cycle), as could changes both outside the person (e.g. school) and within the person (e.g. feeling competent). The authors suggested that when the environment was adaptable, the influence of ADHD as a problem diminished. Furthermore, they suggested their model (of square pegs and round holes) offers an understanding of how young people may respond to the challenges posed by ADHD.

A phenomenological study by Davies (2009) sought to answer her key research question: 'What does it mean to have a diagnosis of ADHD?' This UK study formed the research component of the author's doctorate in educational psychology at the University of Bristol. Semi-structured interviews were employed to gain the experiences and perceptions of six young people (five boys and one girl), aged 11–16 years. Three superordinate themes emerged from an interpretative phenomenological analysis: ADHD and medication; ADHD and inclusion; and ADHD and identity. Weaved within these themes is the participant's hidden voice and sense of being silenced – familiar themes in the studies presented previously. These findings are concerning, given that this study was conducted some years after those of Kendall *et al.* (2003) and Travell (2005), and within a context where children and young people's participation and involvement has a high profile in policy terms (Day, 2008).

A summary of the key findings is presented in Table 3.2.

Themes	Brief Summary of Themes
ADHD and medication	Akin to Travell's (2005) findings, participants described how they did not feel adequately consulted or listened to. Their visit to the clinic appeared to confirm a decision that had already been made (by parents and other professionals), and they reported being 'sidelined' when it came to discussing their own health and behaviours. Furthermore, as described in Travell's study, key adults appeared to prompt the young people to take their medication. The young people's response to medication was mixed: on the one hand, they recognised positive effects (e.g. better concentration, feeling calmer and keeping hyperactive behaviours in check); but on the other, they described negative physiological (e.g. sleep, appetite, mood) and psychological (e.g. their identity changed) effects.
ADHD and inclusion	Participants described how school life was punctuated by provocation and provocative relationships (e.g. verbal teasing, threats, physical violence), which left them struggling to feel accepted and became a barrier to establishing positive relationships. They spoke of their experience of isolation at a personal (e.g. exclusion from their peer group) and organisational level (e.g. exclusion from school), which had an impact on their emotional well-being and feelings of belonging and acceptance. The participants highlighted the importance of being listened to, feeling understood and having their voices heard.
ADHD and identity	Similar to findings from previous studies (e.g. Cooper and Shea, 1998; Kruegar and Kendall, 2001; Kendall <i>et al.</i> , 2003), participants described ADHD as internal and intrinsic to them, and assimilated into their identity. This ADHD identity was often conflicted, and fluctuated according to the situation and context. They understood ADHD as being 'hyper' and 'out of control', and spoke of how the ADHD was a barrier to full inclusion and participation in school (e.g. stopping them from doing things such as work experience). Interestingly, the author highlighted participants' need for attention, rather than a deficit of attention as described in classification manuals. As Travell (2005) has argued, the behavioural difficulties that trigger a diagnosis of ADHD have complex causal routes, which may not be related to core symptoms of the disorder. Despite describing negative aspects of an ADHD identity, participants also spoke of their skills and talents (e.g. football and singing), and of positive aspects of ADHD (e.g. having more energy than others and certain entitlements, such as going to lunch early and adult support).

Table 3.2: A brief summary of Davies' (2009) three superordinate themes.

Meanwhile, focusing on the family microsystem, Grant (2009) conducted a qualitative study to explore young people's experience of living with a diagnosis of ADHD, within the context of their families. This UK study formed the research component of the author's doctorate in clinical psychology at the University of East London. Semi-structured interviews were used to gain the experiences of eight young people (seven boys and one girl), aged 11–18 years. Particular attention was given to their experiences of the support they received.

Participants spoke of feeling like 'an outsider' as they struggled to integrate into their school, family and peer group. They also reported being 'the target of blame' for incidents on the basis of having ADHD, and spoke of incidents of bullying because the ADHD set them apart from others. Grant described how fear of alienation and risks to belonging appeared to contribute to participants declining any additional support offered to them.

ADHD appeared to play a central part in the participants' identities, and they grappled with the extent to which the label defined them (e.g. 'hyper-self' that led them into trouble) or determined their behaviour (e.g. mad, bad and out of control). Participants spoke of an awareness of the effects their behaviour had on their families, and some perceived themselves to be a burden.

The participants reported positive traits, which they believed to be inherent to ADHD (e.g. creativeness, a good imagination, quirkiness). Remarkably, despite the internalised locus of ADHD, the participants spoke of their growing

ability to understand other people through their own difficult experiences. Most of the participants held a biomedical understanding of ADHD.

Grant described that medication was viewed as controlling an undesirable aspect of 'self' (e.g. improving their behaviour and the ability to complete schoolwork), which enabled the participants to be seen as more than just the negatives associated with their ADHD. The value of their medication was further reinforced by the positive responses they received from adults in authority. Whilst negative aspects of medication (e.g. side effects) were reported, participants believed this to be a 'price worth paying'. The participants perceived support systems as providing a boundary for behaviour, and located the primary responsibility for controlling their actions externally.

### **3.2.1 Summary of research exploring children's views and experiences**

The qualitative studies presented in section 3.2 have explored children's and young people's lived experience of ADHD. All utilised semi-structured interviews, but different methods were employed for analysis. Whilst a diverse set of themes were constructed, related to the nature of the study and research questions, there appeared striking similarities in the children's and young people's stories. These related to: the effects of ADHD on their sense of self (consistent with findings from recent research by Kildea *et al.* (2011) and Byrne and Swords (2015)); their experiences of stigma; the ambivalence felt about taking medication; a sense of being silenced and sidelined during decision-making at diagnosis and treatment (consistent with literature relating

to children's participation in mental health services by Davies and Wright (2008), LeFrancois (2008), Worrall-Davies and Morino-Francis (2008), Weil *et al.* (2015) and Stafford *et al.* (2016)); and difficulties in adapting to environments that appeared intent on changing the child, and consequently emphasised their difference. In addition, a biomedical position remained dominant and was the explanation most often reproduced.

Whilst the findings present a bleak picture, positive aspects of having ADHD were reported by some of the studies; perhaps reflecting themes of interview questions and/or the participants' decision to share these as part of their overall experience. These positive aspects of ADHD related to skills and talents that the participants associated with the disorder and improvement in symptoms over time, which participants linked to maturation and development of personal strategies.

Most of the studies focused on young people of secondary school age, and I was interested in whether there may be differences in the experiences of primary school-aged children. I therefore decided to concentrate on the upper (Key Stage 2) primary school age group, as there appeared to be a smaller amount of literature within this age range. All but one of the studies stated that the participants had received a formal diagnosis of ADHD and whilst not stated directly, many were recruited from within services where the researchers were based, allowing for some validation of diagnosis. I believed this important for my own study to ensure a method of confirming diagnosis and homogeneity of the sample in relation to the phenomenon being studied

(Smith *et al.*, 2009). The majority of participants were boys, reflecting prevalence of the disorder; however, this prevented exploration of differences in the findings from girls, which was tentatively offered in some of the studies. Whilst my aim was to recruit a more gender-balanced sample, I noted the recruitment difficulties reported by some of the researchers. Some participants were reported to have a co-morbid diagnosis, which may have impacted upon their unique experiences, and only Cooper and Shea's (1998) study referred to different ADHD presentations within their analysis. However, as O'Leary (2007) states, these different presentations and co-morbidities reflect the complexities of ADHD.

Gallichan and Curle (2008) have been critical of some qualitative studies, arguing that there has been a tendency to describe rather than understand the phenomenon of ADHD. They suggest that grounded theory methods enabled them to focus on processes that underlie the experience of ADHD in order to develop explanatory theories. Like O' Leary (2007) and Davies (2009), interpretative phenomenological analysis has been chosen for this research study to enable an in-depth exploration of participants' experiences.

Whilst interview schedules are informed by research questions, one study in particular constructed themes quite similar to their research questions. Brocki and Weardon (2006) warn that researchers must be careful not to structure the analysis before data collection begins; however, all findings appeared to be grounded in the data, with transcripts from the data set used to support interpretation and conclusions. Most authors used peer validation to enhance

rigour, but some used respondent validation of themes, via a second interview or response to written reports of initial themes. My aim has been to seek respondent validation, in keeping with my focus of prioritising children's and parent's views and experiences.

### **3.3 Parents' views and experiences of ADHD**

As discussed in Section 3.2, a growing number of studies have sought to address the gap in the literature pertaining to the views and experiences of children and young people who have ADHD in their lives; however, many of these studies have omitted to explore the views and experiences of parents. Researchers such as Johnston and Mash (2001), Peters and Jackson (2009), Firmin and Phillips (2009) and McIntyre and Hennessy (2012) endorse the need to consider the interaction between child characteristics and family circumstances in order to understand fully the experience of ADHD. This approach fits with Bronfenbrenner's (1995, 2005, 2006) systems/bioecological model, which promotes the multidirectional nature of the parent-child relationship and recognises the family as an important context for development. As Lewis-Morton *et al.* (2014) argue, whilst mental health classification systems (such as the DSM-V and ICD-10) provide guidance to distinguish whether or not a child or young person has ADHD, it does not provide a contextual basis from which to understand the behaviour: a position that has been endorsed by others (e.g. Travell (2005); Timimi (2009)). An overview of four studies that have sought to understand the experience of ADHD within the context of the family is now presented.

Peters and Jackson (2009) conducted a qualitative study to explore the perceptions and experiences of mothers parenting a child with ADHD in New South Wales, Australia. At the time of the study, the authors were qualified nurses and lecturers at the University of Western Australia. A narrative-based, feminist approach was used to 'illuminate, substantiate and authenticate women's experiences, concerns and ways of being' (Jackson and Mannix, 2003, p. 31). The mothers (n = 11) were recruited via a newspaper advertisement and selected on the basis that they met the researchers' inclusion criteria (primary carers of children with a medical diagnosis of ADHD who could converse fluently in English); interviews were used to elicit the mothers' perceptions and experiences.

The findings revealed that the participants were exhausted by the 'mothering role' and overwhelmed by the demands of their children; many described their focus on preventing or arresting negative behaviour. They reported receiving minimal practical support from family, friends and community services (e.g. a reluctance to look after their children or involve their children in social activities), and this in turn meant their child's and their own social activities were restricted. The mothers reported a lack of resources available at school to meet their child's learning needs, and some felt obligated to school their children at home. Several expressed sadness and disappointment at missing what they perceived to be a normal parenting experience. The mothers reported that their children were stigmatised by the ADHD diagnosis, and that in their role as parents, they were scrutinised and negatively judged, which had an effect on their emotional well-being. Participants reported the need to

act as advocates for their children, particularly in relation to medical treatment and schooling (to ensure their special needs were considered), and highlighted the negative impact on their child's self-esteem when their child's needs were not being met. These views link with findings from Hughes (2007b) and Gallichan and Curle (2008), who have stressed the importance of the social context and adaptations to the environment.

Whilst the authors acknowledge that their study captured perspectives from middle-class mothers who belonged to the dominant culture, making findings difficult to generalise, their findings are supported and confirmed by other studies exploring parents' perspectives (e.g. Harborne *et al.*, 2004; Singh, 2004; Moses, 2010; Kildea *et al.*, 2011). In drawing conclusions, the authors suggest that long-term therapeutic management, participation in support groups and advocacy support may be beneficial to parents.

Dennis *et al.* (2008), who had a professional background in nursing, conducted a study to examine the views of parents (of children with a diagnosis of ADHD) and professionals (experiencing ADHD in their classrooms) in two north London boroughs. In particular, this qualitative study focused on beliefs regarding the causes of ADHD and perceptions of service provision. Six GP practices and two voluntary groups contacted prospective parent participants, and a purposive sampling strategy then sought to ensure an age range of children; professionals were recruited via community networks. Forty-six parents (of children aged 6–14 years) and 29 professionals (including paediatricians, psychiatrists, teachers, school nurses

and educational psychologists) took part in the study. In contrast with the abovementioned study, the sample included participants from a variety of ethnic backgrounds. Focus groups were used to elicit parents' views, and individual interviews, constructed from themes emerging from the focus groups, were completed with the professionals. Following this, a subsample of parents was interviewed, using open-ended questions to address beliefs regarding causes of ADHD and concerns and treatment. Data were analysed using a constant comparative technique.

The six themes abstracted from the data are presented in Table 3.3.

Themes	Brief Summary of Themes
'beliefs about ADHD'	Parents' views about the causes of ADHD.
'disconnected encounters'	Parents cited problems with communication from professionals, which were compounded by the number of professionals involved.
'crisis-orientated system'	The decision to seek help was frequently made by the mother in response to a crisis (e.g. school exclusion).
'trial-and-error management'	Professional advice was tested and adapted to fit parents' own understanding and in relation to their everyday lives.
'impact on family'	Findings indicated that ADHD impacts heavily on family life, causing stress and disruption.
'support'	Parental satisfaction with the management of ADHD was influenced by many factors, including good support systems and the availability of treatment (e.g. school-based interventions and advocacy).

Table 3.3: A brief summary of Dennis *et al.*'s (2008) six themes.

Parents cited a variety of causes of ADHD, with many reporting more than one possible cause. The dominant view was that ADHD had both biological and social causes, and that the condition was not permanent. Ethnic minority mothers were more likely to attribute ADHD to a lack of 'cultural understanding' of their child's presentation and overwhelmingly preferred treatment options other than medication (although the authors provide no information about the treatment options mentioned by these parents). The findings suggested that, overall, parents viewed a diagnosis of ADHD positively, as it removed the notion of blame and the label of 'bad parents'. However, Singh (2004) suggests that the 'mother-blame', 'brain-blame' binary often brings only short-term relief.

Dennis *et al.* reported that most parents were hesitant to allow their child to use medication, due to concerns about safety and side effects; however, positive and negative effects were noted. Parents' understanding appeared to influence their compliance with treatment. Similar to findings by Johnston *et al.* (2005), different beliefs about ADHD management explained a parent's decision not to follow professional advice, though misconceptions regarding medication were reportedly more prevalent among parents from ethnic minorities (however, these were not documented). All parents highlighted a lack of treatment choice: the two current treatments, psychostimulants and behaviour therapy, were not viewed as having long-lasting effects.

The authors stress the importance of professionals gaining a greater understanding of parental views about treatment, which they suggest will increase the likelihood of their adhering to treatment. Whilst it would be questionable and unethical to provide treatment based solely on parental request, parents' views and, most importantly, the views of the children and young people at the centre should be considered. This recommendation is congruent with advice for mental health professionals (Wolpert *et al.*, 2006), which suggests there is no 'one size fits all' for individuals with similar problems, and a range of factors should guide decision-making (p. 5). Similarly, findings from a study by Kildea *et al.* (2011) indicated that parents wanted a 'holistic service', where a range of interventions could be customised to the individual and the family.

The majority of parents described ADHD as impacting heavily on family life, causing stress and disruption, which the authors suggested may be due to a lack of support. Furthermore, parents' coping ability appeared to be dependent upon the level of support they received. Similarly, Kildea *et al.* (2011) found that parental distress was greater when parents experienced limited support and believed themselves to be isolated. Parents reported problems with communication, which they attributed to the number of professionals involved and professionals 'not knowing the family'. Mothers frequently instigated the involvement of professionals following a crisis, but there was consensus that professionals should recognise problems earlier.

Whilst this qualitative study provided some insight into the impact of ADHD on the family, there remained a strong focus on the causes of ADHD and treatment. As Prosser (2006) suggests, in trying to understand ADHD (either as a social or as a medical phenomenon), if we ask only medical questions, we only get medical answers (and more drug treatment).

In seeking to understand more fully the daily experiences of families with children with ADHD, Firmin and Phillips (2009) conducted a phenomenological study of 17 American families. In-depth interviews were conducted, using Segal's (1998) open-ended qualitative research methodology, to explore the challenges faced in raising children diagnosed with ADHD. The authors argue that familial contexts should be considered in order to increase the chances of successful intervention programmes. The study had two main aims: firstly, to replicate previous research conducted by Segal (1998) as part of a qualitative validation process (to find whether Segal's conclusions would be consistent with a sample of similar families from the United States); and secondly, to identify which elements of the ADHD criteria were most salient for these families. Participating families were members of the national support group from Children and Adults with Attention-Deficit/Hyperactivity Disorder (CHADD).

The three themes abstracted from the data are presented in Table 3.4.

Themes	Brief Summary of Themes
'vigilant familial involvement'	Parents were described as demonstrating a high degree of involvement in their children's lives, and appeared informed and knowledgeable regarding a wide range of issues relating to their child's well-being. They were vigilant and attentive to their children, both at home (e.g. making adaptations when required to accomplish family objectives) and school (e.g. keeping in contact with teachers and initiating meetings), in order to pre-empt problems. The authors found parents to be 'familiar with clinical aspects' of ADHD and noted that they used specific medical terminology (e.g. 'biological disorder', 'chemical imbalance in the brain', 'neurological condition') when describing the disorder. The authors considered whether parents who attend ADHD support groups (e.g. CHADD) are more informed about ADHD.
'difficult times of the day'	Routine and preparation were identified as helpful strategies, and the parents identified relational effects as triggers to their child's behaviour (e.g. the impact of a parent's tiredness and having less patience).
'use of structure and routines'	The authors reported that parents were attuned to their children's behaviours and employed strategies of routine and structure to alleviate difficult times during the day. The families developed their own methods to create structure (e.g. use of organisers, notebooks and planners; instructions; sticker and reward charts; verbal rewards), and parents reported that their children seemed to recognise the benefit of these. Overall, the authors suggest that their sample of parents did not view family members independently, but rather as a complete structure in which each member has his or her own role as part of a larger family system.

Table 3.4: A brief summary of Firmin and Phillips' (2009) three themes.

The authors acknowledge the limitations of their study, including its small homogenous sample. In addition, participating families were all associated with CHADD groups and, therefore, may represent a subset of families that may differ from non-CHADD families. Whilst somewhat constrained in terms of interview content (in order to replicate a previous study), this interesting study provided parents an opportunity to talk about issues important to them within their lived experience. Although most of the children were taking stimulant medication, and parents held a biomedical perspective (in

understanding ADHD), this sample of parents considered relational and environmental factors in relation to their child's behaviour and made adaptations to support these.

McIntyre and Hennessy (2012) conducted a study to explore the experiences of parents of children with ADHD; the study was part of a larger project investigating the experiences of boys with ADHD in Ireland. Eighteen parents of boys (aged between 7 and 12 years) with a diagnosis of ADHD took part. Parents were recruited through two national support groups; a snowball method of recruitment was also implemented, whereby already participating families were asked to pass on details of the research to other parents who were interested in taking part. Open-ended interviews were used to capture the parents' experiences, with the authors suggesting that this allowed parents to raise issues that they felt were important and facilitated a broader exploration of parents' experiences. A demographic questionnaire and ADHD rating scale were also completed: the latter to ensure the experiences reported truly represented the experiences of parents of children with ADHD (McIntyre and Hennessy, 2012).

Table 3.5 presents the six major themes identified following a thematic analysis.

Themes	Brief Summary of Themes
'getting your head around ADHD'	Participants reported that parenting a child with ADHD was not an easy role and that they struggled to make sense of their sons' behaviour. Several reported making comparisons with other children in attempting to understand the relationship between their role and their child's behaviour. In making such comparisons, the authors suggested that parents were able to relinquish blame.
'the child takes over'	Parents described the demanding nature of their child and the impact on their own work life (e.g. giving up work to focus on the child), health (e.g. feeling physically exhausted) and family relationships (as their other children 'barely got a look in').
'emotional impact'	Parents described a range of worries and concerns by which they were regularly plagued, such as concerns about the future, social and academic difficulties, medication and transition to secondary school. They continually questioned whether they were 'doing the right things' and reported feeling lonely, depressed and overwhelmed.
'ignorance and discrimination'	Parents spoke of a lack of understanding (from family members, friends, schools, members of the public) about ADHD due to misconceptions about the condition (e.g. an excuse for poor parenting). These misconceptions led to prejudice and discrimination, and resulted in parents becoming increasingly isolated (e.g. losing friends, being unable to turn to family members for support, avoiding situations where they may feel judged by others).
'inconsistency of structural supports for ADHD'	Parents expressed dissatisfaction with the quality of services they and their child had received (e.g. the lengthy assessment and diagnostic process, travelling long distances to access services, inadequate monitoring of medication, no alternatives to medication as treatment for ADHD, not enough one-to-one support), and spoke of 'having to fight' for basic services. Parents described feeling forced to seek private help and, in some cases, having no other choice but to consider specialist schools to ensure that appropriate support was provided.
'it's not all bad'	Despite the challenges, all parents had something positive to say about their child with ADHD (e.g. kind, caring, funny, individual, full of zest for life). Some spoke of the positive side of 'difference', by looking to the individuality of their own child and focusing on their strengths, and believed that their children would do well if their child's unique skills were 'honed and developed'.

Table 3.5: A brief summary of McIntyre and Hennessy's (2012) six themes.

Whilst these findings reflect the experiences of a small group of parents in Ireland, they support conclusions drawn from other research (Johnston and Mash, 2001; Harborne *et al.* 2004; Peters and Jackson, 2008; Firmin and Phillips, 2009; Wheen, 2011; Davies, 2014) exploring parents' experiences of ADHD. For example, the demanding nature of parenting a child with ADHD, the emotional distress caused, the experience of stigma and limitations of services.

The study did not consider the presence of other related disorders or family stressors, which may have influenced the findings, and the analysis did not account for the variability of experiences associated with different presentations of ADHD; however, the latter potential limitation characterises previous studies. It is also possible that participating parents had an agenda or were biased in their reporting of their experiences: the authors noted Peters and Jackson's (2008) suggestion that parents who act as advocates for their children may not see the point in talking about their positive experiences. In contrast, all parents had something positive to say and 'nearly all' reported improvements in their sons' behaviour over the years. Given the bidirectional nature of the parent-child relationship, the authors recommend a family-centred approach to the treatment of ADHD. Furthermore, they recommend increasing societal understanding to reduce the stigmatising experiences of parents and children.

### **3.3.1 Summary of research exploring parents' views and experiences**

Studies presented in section 3.3 have focused on various aspects of parenting experiences, including perceptions and experiences of parenting a child with ADHD, impact on the family microsystem and perceptions of service provision. These studies used semi-structured or open-ended interviews in order to capture the parent's unique experiences.

A mixed sample of mothers and fathers were recruited; however, the majority of participants were mothers. Whilst this may reflect a more 'traditional' mother role, there has been critique that research focusing on mothers' experiences has tended to emphasise mothers' duty and responsibility, contributing to a culture of mother-blame (Singh, 2004; Davies, 2014).

From the themes constructed, there were similarities in the parents' experiences. These related to their more intense parenting role, experiences of stigma and blame, crisis-oriented service provision and lack of early intervention, and 'trial-and-error' management.

The parents spoke of the stressful and demanding nature of parenting a child with ADHD, due to the extra care their child required. This is consistent with literature exploring the experiences of parenting children with ADHD and those diagnosed with other complex needs, such as learning disability, Down syndrome and autism (e.g. Kildea *et al.*, 2011; Neely-Barnes *et al.* 2011; Nurullah, 2013; Woodgate *et al.*, 2015). Parents described the need to become more informed and knowledgeable about the disorder in order to pre-

empt and prevent problems arising as a result of their child's difficulties. They also spoke of the stress placed on the whole family, and of the guilt experienced due to the child with ADHD receiving more attention. These familial experiences are reflected in other research seeking the views of parents who have children with complex needs, including ADHD (e.g. Neely-Barnes *et al.*, 2011; Nurullah, 2013; Doubet and Ostrosky., 2015, Stapley *et al.*, 2016).

Experiences of being stigmatised and scrutinised weaved through the themes presented by the researchers. Malacrida (2001) has suggested that these stigmatising experiences are perpetuated by popular discourses that portray ADHD as an ambiguous diagnosis, associated with controversy and doubt. Parents spoke of being isolated and alienated by family members, other parents and the general public, and of actively avoiding situations to minimise exposure to ridicule and blame. Consistent with these experiences, O'Driscoll *et al.* (2012) have suggested that ADHD is more explicitly stigmatised than other conditions. A possible explanation is provided by Broomhead (2013) and Lee *et al.* (2015), who have suggested parents of children who have social and emotional difficulties are viewed differently, as the difficulties tend to be associated with ineffective parenting.

In exploring the experiences of stigmatisation in relation to mental health disorders (such as ADHD), Hinshaw (2005) identified four aspects that he believed to increase the likelihood of individuals being stigmatised. These are described as: 'concealability' (whether the condition is visible or hidden);

'chronicity' (the duration of the illness and associated negative characteristics); 'threat' (how the condition is represented, e.g. through the media); and 'controllability' (whether or not the behaviours associated with the condition are deemed to be under the person's control). In relation to ADHD, it could be argued that all four of these aspects are applicable: in relation to 'concealability', ADHD is not physically visible and therefore the reasons for the behaviour of the individual may not be apparent to others (as described by Weiner *et al.*, 2012); ADHD has been described as a lifelong condition, therefore increasing its 'chronicity'; in relation to 'threat', a review of media representations conducted by Slopen *et al.* (2009) suggested antisocial behaviour and dangerousness of individuals with mental illnesses to be primary themes when reporting on psychiatric disorders; and Mueller *et al.* (2012) have argued that doubts about the aetiology of ADHD strengthen misconceptions that either the individuals themselves or their environments are to be blamed for their condition (e.g. poor parenting), increasing the likelihood of ADHD being viewed as controllable.

In relation to parents' experience of health services, findings from the studies reviewed indicated difficulties in gaining access and the crisis-oriented nature of provision. Accounts spoke of lengthy and arduous assessments, lack of alternatives to medical treatment and professionals' disregard of parents' views as experts on their child. These findings are consistent with other research (e.g. Kildea *et al.*, 2011; Novak *et al.*, 2011; Woodgate *et al.*, 2015; Parker *et al.*, 2016).

### **3.4 Summary**

In reviewing qualitative studies focusing on the experiences and perceptions of children and parents, this chapter has begun to set the scene for this research study. The literature presented has identified the negative influence of ADHD on children's sense of self, the demanding nature of parenting a child with ADHD and the dissatisfaction with mental health services due to their lengthy assessments and crisis-oriented approach. In addition, findings from research exploring children's views suggest that these services have tended to silence and sideline children's voice and participation.

In the following two chapters (Chapters 4 and 5), I describe the process by which I decided on the methods to address my research aims, present the chosen research methodology and design, and describe the process followed in analysing the data from interviews with the child and parent participants.

## CHAPTER 4: METHODOLOGY

### 4.1. Introduction

In the previous chapter I discussed outcomes from studies exploring views of children and parents regarding their experiences of ADHD. In my role as an educational psychologist, I have witnessed the increase in children receiving a mental health diagnosis such as ADHD and, through a narrative therapy lens, wondered about the impact such diagnostic labels can have in becoming 'totalising descriptions' of the person to whom these labels are ascribed. 'Totalising descriptions' is a term used by narrative therapists to describe the ways in which dominant stories about a person can become 'shaping of their lives and relationships' (White and Epston, 1990), resulting in vital aspects of lived experience being overlooked or neglected.

I also wondered about the experience of stigma. Findings from research discussed in Chapter 3 highlighted participants reporting the stigmatising effects of a diagnosis of ADHD (Cooper and Shea, 1998), including feelings of alienation (Grant, 2009) and of 'not fitting into conventional society' (Gallichan and Curle, 2008). In addition, parents have spoken of their experience of being stigmatised by association, known as courtesy stigma (Goffman, 1963). Parents have also reported feeling isolated (Kildea *et al.*, 2011), judged (Peters and Jackson, 2008) and labelled 'bad parents' (Dennis *et al.*, 2008).

It has been suggested that the vagueness of disorders such as ADHD, for which there is no definitive, objective or quantifiable test (for example, blood

glucose levels in the case of diabetes), poses a challenge for researchers (Carpenter-Song, 2009). However, in response, Carpenter-Song (2009) proposes that this uncertainty and lack of consensus regarding the nature of these problems are themselves 'ripe conditions for inquiry' (p. 62).

In carrying out this study I was interested in exploring the 'phenomenological' stories of children and their parents about their experiences of having ADHD in their lives. Kvale describes phenomenology as the study of 'subjects' perspectives on their world; ... [to attempt] to describe in detail the content and structure of the subjects' consciousness, to grasp the qualitative diversity of their experiences and to explicate their essential meanings' (1996, p. 53). In doing so, it is suggested that phenomenology contributes to a rich understanding of lived experiences, by exposing dominant assumptions about ways of knowing (Starks and Trinidad, 2007). I believed this to be an important aim of my research, as a vast amount of research on ADHD has been within a positivist, empirical paradigm (Timimi and Radcliffe, 2004).

As discussed in the introductory chapter, this research study draws on aspects of narrative therapy (White and Epston, 1990), which acknowledges the knowledge and skills present within the lived experience of participants. Narrative therapists do not treat people for their problems, they listen to their stories (Goddard *et al.*, 2000). In the spirit of narrative therapy, this study aimed to illuminate ways in which parents and children make sense of their lived experience of the phenomenon of ADHD, by listening to their personal accounts. It was envisaged that the sharing of these personal accounts would:

inform new ways of engaging children and young people in diagnostic and treatment decisions; inform professionals working with children, young people and their families; and document the 'insider knowledge' shared by participants, which can be drawn upon by others who have ADHD in their lives.

Qualitative studies explore phenomena within their natural contexts (Willig, 2008). Willig (2008) suggests that these studies tend to be holistic and explanatory rather than reductionist and predictive. Consistent with the descriptive nature of this research, and its emphasis on following a qualitative methodology, there are no specific hypotheses but rather a broad research question: what is it like to live with ADHD?

It is imperative for researchers to present the philosophical and methodological decisions for their chosen research, with particular reference to ontological, epistemological and methodological levels of enquiry (Proctor, 1998). In this chapter, I describe the process by which I decided on the methods to address my research aims and present the chosen methodological approach.

## **4.2. Philosophical and methodological position**

### **4.2.1 Ontological position**

This study sought to explore the participants' experiences of the phenomenon of ADHD and as such, subscribes to a relativist ontology. Willig (2008) defines a relativist ontology as one that 'questions the "out-there-ness" of the world

and it emphasises the diversity of interpretations that can be applied to it' (p. 13). This is in contrast to the realist approaches most commonly seen in the study of ADHD, and more widely, within medical categories associated with mental illness. A realist ontology sees the world as ordered and structured, with cause–effect relationships existing between these structures which can be measured and observed.

#### **4.2.2 Epistemological position**

Willig (2008) describes epistemological approaches within qualitative research as being positioned on a continuum from naïve realism (akin to positivism) to radical relativism. It is suggested that a range of positions fall within these extremes, which reflect the acceptance that knowledge and understanding of the world is affected to some degree by individuals interacting with the world (Willig, 2008). However, as Willig (2008) describes, researchers differ in their acceptance of the degree to which our understanding of the world can be objective and true (e.g. an absolute correct view).

As discussed in previous chapters, much of the research on ADHD has been within a positivist, empirical paradigm. This research has tended to focus on investigating the physical basis of ADHD (e.g. exploring neurological and genetic causality) and efficacy of drug treatment (Timimi and Radcliffe, 2004; Singh *et al.*, 2010; Dunne and Moore, 2011). From this positivist position, reality is understood to be independent of human cognition, and it is believed that there is a single reality that can be researched through the application of scientific methodology. In contrast, I take the position that knowledge is a

social and historical product that can be specific to a particular time, culture or situation (Robson, 2002).

#### **4.2.3 Methodological position**

According to Yardley (1997), a primary reason for adopting qualitative methodologies is 'a recognition that our knowledge and experience of the world cannot consist of an objective appraisal of some external reality, but is profoundly shaped by our subjective and cultural perspective, and by our conversations and activities' (p. 217). This research, in line with other qualitative studies, takes the view that the use of quantitative methods to explore ADHD has limitations in being able to capture adequately the quality and meaning of experiences of children and families who have ADHD in their lives (Hughes, 2007b; Gallichan and Curle, 2008). In contributing to this area of research, my aim has been to focus on children's and parents' subjective, experiential accounts of ADHD to explore personal meaning and lived experience; as Rafalovich (2004) observed, people 'assert a tremendous amount of agency in how they interpret the disorder' (p. 6). It is qualitative research methods that enable researchers to delve into questions of meaning (Starks and Trinidad, 2007).

#### **4.3. Qualitative approaches**

Narrative therapists work to create alternative stories to the dominant discourses that can become 'totalising descriptions' of people's lives. In assisting people to 're-author' thick descriptions of the 'problem', the alternative story is explored to support people in engaging in the construction

and performance of preferred identities, leading to a thickened new plot (Winslade and Monk, 1999). In adopting a qualitative approach, my aim was to explore thick descriptive accounts of the phenomenon of ADHD. Qualitative methodologies, however, do not present 'a homogenous entity' (Smith, 2015), and there are a number of different approaches offering different theoretical and methodological perspectives. Despite these different perspectives, commonalities exist, as their central purpose is to enrich our understanding of the phenomena in question (Elliott *et al.*, 1999). The qualitative approaches considered for this research study were narrative, discourse, grounded theory and phenomenology. A brief outline of each will be presented, prior to a brief account of my rationale for selecting the particular qualitative approach harnessed within this research study.

#### **4.3.1 Narrative analysis**

Narrative analysis provides the researcher with a means to understand how we make sense of the world and ourselves (Murray, 2015). Similarly to IPA, narrative researchers work with narrative accounts of particular experiences and are interested in meaning and understanding (Griffin and May, 2012). A narrative is an organised interpretation of a sequence of events in which the narrator organises the disorganised to give it meaning (Murray, 2015). A common theme in narrative research is the exploration of identity, with many narrative researchers interested in the social aspects of narrative (Griffin and May, 2012), rather than how the individual makes sense of their experiences. Like IPA, narrative analysis is interpretive, in that the researcher engages in

formulating meaning from the narrative; however, there is less structure in terms of how the analysis should proceed (Griffin and May, 2012).

#### **4.3.2 Discourse analysis**

Discourse analysis is concerned with 'how individuals accomplish personal, social and political projects through language' (Starks and Trinidad, 2007, p. 1374). There are two prominent versions of discourse analysis: discursive psychology and Foucauldian discourse analysis. Both share concern for the role of language in constructing social reality; however, they address different types of research questions (Willig, 2015). Discursive psychology studies how people use language, whereas Foucauldian discourse analysis is concerned with the ways in which discourse constructs subjectivity, self and power relations (Willig, 2008). Discursive representations are the unit of analysis in discourse analysis, whereas in IPA, the focus is on the individual and their meaning-making (Smith *et al.*, 2009). Smith *et al.* (2009) argue that both versions of discourse analysis demonstrate 'a stronger more singular commitment to social constructionism' (p. 195) than is the case for IPA.

Discourse analysts sample different groups who participate within a given discourse. A study may present a single person's account or use larger sample sizes to explore variations across persons and settings (Starks and Trinidad, 2007).

### **4.3.3 Grounded theory**

Grounded theorists inquire about how social structures and processes influence how things are accomplished through a given set of social interactions (Starks and Trinidad, 2007). Like IPA, it is an inductive approach; however, the goal is to develop an explanatory theory from a range of participants' experiences. In seeking to explain participants' perspectives in terms of wider social processes and their consequences, grounded theory does not have the same emphasis on analysis of individual experiences. Willig (2008) argues that this approach takes a view 'from the outside in', rather than the 'inside out' view taken by phenomenological research (p. 45). Like phenomenology, the researcher engages in a self-reflexive process of recognising and setting aside prior knowledge and assumptions. However, the role of the researcher is viewed differently, depending upon the version of grounded theory, as each follows contrasting theories of knowledge (Sutcliffe, 2016).

Grounded theory uses theoretical sampling to recruit participants with differing experiences of the phenomenon in order to explore multiple dimensions of the social processes under study (Starks and Trinidad, 2007). The researcher continues to add individuals to the sample until saturation is reached; according to Starks and Trinidad (2007), typical grounded theory studies report sample sizes of between 10–60 participants.

#### **4.3.4 Chosen methodological approach: phenomenology**

Phenomenology is 'interested in the world as it is experienced by human beings within particular contexts and at particular times' (Willig, 2007, p. 52). The aim is to contribute a deeper understanding of lived experience (Starks and Trinidad, 2007): what it was like to live the experience, not just the person's reaction to it (Munhall, 2007).

A number of approaches have been developed for phenomenological research: the descriptive and the interpretative (Willig, 2008). In seeking to describe the phenomenon under study, the former approach (e.g. Giorgi and Giorgi, 2008) requires the researcher to bracket their opinions and experiences about it (Reiners, 2012). The latter approach (e.g. IPA) focuses on interpretation and meaning rather than descriptions, and does not require the researcher to set aside their opinions and experiences (Reiners, 2012).

In both approaches, purposive sampling methods are used to recruit participants who have experienced the phenomenon under study (Starks and Trinidad, 2007); samples can range from 1 to 10.

Phenomenology has been described as a philosophical approach to the study of experience (Smith *et al.*, 2009). As such, I believed this to be the most appropriate theoretical approach to explore the lived experience of ADHD from the perspectives of both children who have received a diagnosis of the disorder and their parents. As discussed, a number of approaches have been developed for phenomenological research; 'all share the basic tenet of

phenomenology but each articulates an approach in a particular way' (Smith *et al.*, 2009, p. 200). Interpretative phenomenological analysis (IPA) was selected for this research study, my reasons for which are discussed below.

#### **4.4. Rationale for chosen methodological approach**

IPA involves the detailed exploration of personal meaning and lived experience (Smith and Osborn, 2015). As a research approach, IPA influences the approach to methodology: informing the formulation of research questions and data collection methods.

My rationale for selecting this approach is presented:

- IPA is concerned with experience which is of particular significance to the person. This approach enables the researcher to explore the meaning the participant ascribes to that experience, which is seen as representing the experience (Smith *et al.*, 2009).
- Within this research study, my focus was on understanding the particular significance for the participants of having ADHD in their lives. As Kendall (2016) asserts, individuals with ADHD are unique in terms of the impact of the disorder for them personally.
- IPA allows the researcher to explore multidimensional aspects of meaning (e.g. cognitive, linguistic, affective and physical) in order to produce a more holistic analysis.
- IPA takes an empathic and questioning stance, producing not just a description but also interpretation. The researcher is endeavouring to see what it is like from the participant's view, in order to represent their

experience, whilst also 'standing alongside' to provide interpretation and analysis (Smith *et al.*, 2009).

- IPA's idiographic stance allows the researcher to look at the particular (individual cases) and then to examine these within the shared experiences of the sample (highlighting similarity and differences across cases). I believed this to be particularly pertinent to the child participants, as a means of ensuring their unique experiences were captured (see also section 5.5 on research with children).
- As Larkin *et al.* (2006) have described, 'phenomenology is important because it returns people's perspectives and experiences to the forefront of psychological study' (p. 118).
- Research questions are open and exploratory, focusing on meaning rather than on identifying concrete 'causes' or 'consequences', which is reflected in much of the research on ADHD. IPA is concerned with an individual's personal account of an event or experience, not an attempt to produce an objective statement (Smith and Osborn, 2015).
- Due to the breadth of theoretical influences, IPA has been described as having 'epistemological openness' (Ware and Raval, 2007) that offers a means to accommodate a realist and relativist epistemological position.
- It does not impose a prescriptive approach and can therefore be adapted by individual researchers in light of their research aims (Eatough and Smith, 2006).

- IPA suits a relativist ontological position that assumes data tell us something about how an individual experiences the world, their orientation towards the world and how they make sense of it.

Whilst presenting my rationale for selecting this methodological approach, I remain mindful of the guidance of Elliott *et al.* (1999), who state: 'the value of any scientific method must be evaluated in its ability to provide meaningful and useful answers to the questions that motivated the research in the first place' (p. 216).

#### **4.5 Interpretative phenomenological analysis (IPA)**

IPA is a recently developed qualitative approach in psychological, sociological and health research (Smith, 2011). In relation to research on ADHD, there have been several recent studies using IPA, including: Tatum (2005); Young *et al.* (2008); Davies (2009); and Grant (2009). As discussed in the previous section, IPA has been chosen for its reported usefulness in capturing the lived experience of participants by focusing on their experiences and perceptions of a phenomenon (e.g. ADHD), and to understand how they make sense of these. IPA researchers are 'interested in what happens when the everyday flow of lived experience takes on particular significance for people' (Smith *et al.*, 2009, p. 1); in the case of my own study, the significance for the participants is having ADHD in their lives. The aim of IPA is to 'explore in detail how participants are making sense of their personal and social world' (Smith and Osborne, 2015, p. 25) by engaging with the individual's reflections,

thoughts and feelings (Smith *et al.*, 2009); this is done by ‘systematically and attentively reflecting on everyday lived experience’ (ibid, 2009, p. 33).

The philosophical basis of IPA is informed by concepts and debates from three areas of the philosophy of knowledge: phenomenology, hermeneutics and idiography. A detailed account of these core concepts is provided below:

- Phenomenology

IPA is informed by many of the principles and methods associated with phenomenology: a branch of philosophical thought that developed from the work of Edmund Husserl (1859–1938), which is concerned with ‘the world as it is experienced by human beings within particular contexts and at particular times’ (Willig, 2008, p. 52). The following definition captures the approach that this study has aimed to take: ‘phenomenological research is expressly interested in people’s experiences and particularly the experiences of those people who are usually ignored.’ (Levering, 2006, p. 457).

Phenomenology has undergone change and development since its inception 100 years ago (Willig, 2001). Transcendental phenomenology was formulated by Husserl in the early twentieth century and was concerned with the world as it presents itself to humans (Willig, 2008). For Husserl, phenomenological inquiry focuses on that which is experienced in the consciousness of an individual (Smith *et al.*, 2009). However, in order to identify the core structures and features of human experience, one must suspend all presuppositions and judgements about the phenomenon under investigation – a process known as

'bracketing' (Moustakas, 1994). This, he suggested, would allow the researcher to identify the qualities that give a specific experiential phenomenon its distinctiveness (Brooks, 2015). Heidegger (1889–1976), however, proffered a different view, suggesting that an interpretation can never be without influence from the researcher's prior experiences, preconceptions and assumptions: known as 'fore-conception' (Smith *et al.*, 2009). However, he suggested that if these experiences and preconceptions are acknowledged, they can become an important part of the interpretation (Smith *et al.*, 2009): to have an understanding of reality 'we need to understand both the detailed experience and the bigger picture' (Brooks, 2015, p. 642). Like Heidegger, IPA acknowledges that it is not possible to suspend all presuppositions and, instead, uses these to advance understanding (Willig, 2008). In this sense, research is never 'value-free', as our understanding can only be gained through 'the researcher's engagement with an interpretation of the participant's account' (Willig, 2008, p. 70). The analysis is therefore both phenomenological and interpretative.

- Hermeneutics

The second major theoretical underpinning of IPA comes from hermeneutics: the theory of interpretation. In IPA research, there is interaction between researcher and participant, and recognition that the researcher plays a fundamental role in interpreting and making sense of the participant's reflections on an experience. The analysis produced by the researcher is always an interpretation (Larkin *et al.*, 2006): to capture hidden meanings through the researcher's immersion in the data (Oxley, 2016).

The interpretative element of IPA has its roots in the work of the theorist, Heidegger. Heidegger's notion of 'Dasein' (1962/1927), which when translated means 'being in the world', emphasises that it is not possible to be fully objective, as experience, judgements and preconceptions cannot be suspended. Heidegger argued that our access to lived time and engagement with the world is always through interpretation (Smith *et al.*, 2009). IPA encourages the researcher to be reflexive and reflect on that which is brought to the act of perception through feeling, judging, thinking and remembering. IPA shares the view that human beings are sense-making creatures, and therefore the accounts which participants provide will reflect their attempts to make sense of their experience (Smith *et al.*, 2009). IPA also recognises that the researcher's access to experience is dependent on what participants share about that experience, and that the researcher then needs to interpret that account from the participant in order to understand their experience (Smith *et al.*, 2009). The IPA researcher is described as engaging in a double hermeneutic (two-stage interpretation) process, because the researcher is trying to make sense of the participant trying to make sense of an experience (Smith and Osborn, 2015). In this sense, the researcher has a 'dual role', because they are employing the same mental and personal skills and capacities as the participant – that of being a human being – whilst employing these skills more self-consciously and systematically (Smith *et al.*, 2009). The double hermeneutic factor of IPA links with Willig's (2008) argument that it is important to consider the differentiation between the phenomenological contemplation of an event as it presents itself to the researcher and the phenomenological analysis of an account of a particular experience presented

by a research participant: the participant's account 'becomes the phenomenon with which the researcher engages' (Willig, 2008, p. 54).

- Idiography

The third key influence upon IPA is idiography. Idiography is concerned with the particular, as opposed to making claims at the group or population level. IPA is committed to understanding how a particular event has been understood from the perspective of particular people, and as a result, the sample size is small and purposively selected in order to find a reasonably homogenous group, so that, within the sample, the IPA researcher can examine convergence and divergence in some detail (Smith *et al.*, 2009). Rather than starting with a theory, the aim of IPA is to inductively generate and construct the meaning of a situation through interaction with the participants. IPA has the capacity to reveal experiences that are unique to the individual as well as revealing the shared experiences across a sample of participants (Smith *et al.*, 2009).

IPA is centrally concerned with 'meaning-making', and the construction of narrative is one way of making meaning (Smith *et al.*, 2009). Smith *et al.* (2009) suggest that Bruner's model of narrative (1987), as an interpretative meaning-making endeavour, clearly resonates with the project of IPA. Furthermore, they suggest that those interested in the structure of people's stories (e.g. from the work of Gergen and Gergen, 1988, whose work influences some of the theoretical underpinnings of narrative therapy), and the

constraints and opportunities these story structures place upon human experience, have the potential for a fruitful exchange with IPA.

#### **4.5.1 Limitations of IPA**

IPA has received criticism for its lack of clarity at the descriptive level and, as suggested by Larkin *et al.* (2006), its flexible analytic approach has been mistaken for 'lack of rigour'. Consequently, novice researchers have tended to provide descriptive analysis rather than 'properly explore, understand and communicate the experiences and viewpoints offered by its participants' (Larkin *et al.*, 2006, p. 103). Conversely, there has been critique that IPA is overly dependent on structure when analysing data. However, Smith *et al.* (2009) do not prescribe a single 'method' but rather, offer a level of structure, particularly for novice researchers, which appears helpful in promoting accountability.

Willig (2008) has argued that whilst IPA provides 'rich descriptions', it does not attempt to further our understanding by explaining it, and therefore limits our understanding of phenomena. However, akin to Ware and Raval (2007), I believe IPA enables 'in-depth exploration of participants' experiences, providing a deep and textured account' (p. 563).

There has also been critique regarding IPA's reliance on 'the representational validity of language' (Willig, 2008, p. 66), resulting in difficulties in being sure the data reflect actual experience rather than the way participants talk about it (Ware and Raval, 2007). Language is seen as constructing rather than

describing reality and therefore, according to Willig (2008), interviews only tell how someone talks about a phenomenon rather than the experience itself. Eatough and Smith (2006) argue that IPA recognises the importance of language in influencing how individuals make sense of lived experience and the 'action-orientated' nature of language (p. 485). Furthermore, they argue that IPA's focus is on 'understanding, representing and making sense of people's ways of thinking, their motivations and actions' (ibid, 2006, p. 487). However, reliance on participants' abilities to articulate their thoughts and experiences is pertinent to this study, and is referred to in section 5.2.1.

In addition, IPA has received criticism for its guidance around reflexivity and researchers subjectivity (Willig, 2001). However, a critical evaluation of IPA in health psychology (Brocki and Weardon, 2006) reported that IPA has gone further than many other qualitative approaches in addressing these issues (see also section 4.5.2).

#### **4.5.2 Reflexivity in IPA**

Reflexivity requires the researcher to be aware of their contribution to the construction of meanings whilst conducting research, and to acknowledge the impossibility of their remaining 'outside of' the subject matter (Willig, 2008). Thus, reflexivity prompts the researcher 'to explore the ways in which a researcher's involvement with a particular study influences, acts upon and informs such research' (Nightingale and Cromby, 1999, p. 228).

A paradox is created within IPA, for whilst the participant is positioned at the centre of the research, it is acknowledged that the researcher plays a significant part in the interpretation and analysis process (Biggerstaff and Thompson, 2008). As Nagal (1974) stated, there is no such thing as 'a view from nowhere'. Therefore, reflection within IPA research is considered central (Oxley, 2016), and must be incorporated at each stage (Biggerstaff and Thompson, 1998).

In relation to this research, reflexivity included: my position as a researcher and my professional role (discussed in Chapter 1 and Chapter 4 section 4.5.3); awareness of the views I hold regarding the nature of ADHD (see Chapter 1 and Chapter 4 section 4.5.3); awareness of my prior knowledge of existing literature (Chapters 2, 3 and Chapter 4 section 4.5.3); ensuring themes were not in effect pre-constructed prior to analysis, by revisiting the data and grounding the analysis within the participants' accounts (see Chapters 5 Table 5.4, Chapter 6 and 7, and Appendices 10 and 11); and ensuring the transparency of the analysis by keeping a record of emerging themes and how these developed (see Appendices 10, 11 and 12). The last of these considerations is particularly pertinent, as the IPA researcher's role in the process of analysis (given its interpretative facet) means they have 'significant impact on the final narrative account' (Brocki and Weardon (2006, p. 92); however, this could be said for other qualitative approaches.

### **4.5.3 Self-reflexivity**

Qualitative researchers, then, are integral to the research process and influence the knowledge produced through the development of their research questions, selection of methods and analysis, and through their interpretation of data (Yardley, 2015). As Heidegger suggested the researcher's prior experiences, preconceptions and assumptions, which he referred to as their 'fore-ception', become an important part of the interpretation (Smith *et al.*, 2009).

During the process of this research I have remained committed to self-reflection in terms of the role I have taken in the planning of this research project, the gathering and evaluation of the data and the analysis there of. Further background information about my beliefs and experiences are presented below, so that my interaction with the research process can be reflected on. In doing so, I have taken account of the advice of Shaw (2010) who states that 'reflexivity, while paramount in making explicit all interpretative activities, should not be the objective of the research' (p. 241).

#### **4.5.3.1 Personal background**

In contrast to the participants in this study I have no personal experience of being ascribed a mental health diagnosis such as ADHD, and I have no personal experience of being a parent of a child with difficulties such as those described by the children and parents who took part in this study.

#### **4.5.3.2 Professional background**

My interest in ADHD has developed during my 10 years of practice as an educational psychologist, where use of the label has become common when concerns regarding challenging behaviour are described. Within my casework, I have observed how problems related to social and/or emotional difficulties seem to be quickly constructed as ADHD. For the children and young people at the centre, the match between observed behaviours and diagnostic criteria for mental health disorders formed the focus of service-user concerns. As I began to reflect on these experiences, I found it particularly striking that in many of these cases, within the family and within the school, challenging or 'difficult to manage' behaviours appear to be understood through the lens of a medical condition, and located within the child. In taking this view, there seemed to be an assumption that this behaviour had a biological aetiology. This was particularly interesting to me as I take a broader theoretical perspective, which takes into account biological, psychological, social and cultural factors (see Chapter 2).

Alongside my interest in how certain presenting problems are constructed and understood within dominant discourse, has been a growing interest and practice of approaches from narrative therapy (as espoused by White and Epston, 1990). They believe that stories people tell about their lives, or about the lives of others, can be constitutive in shaping their lives and relationships, and are open to interpretation and multiple meanings. From a narrative perspective, the term ADHD may invite parents and professionals to develop a deficit-saturated story about a child or young person, in which past, present

and future events can become interpreted through the lens of the problem story (Nylund and Corsiglia, 1996). These single-storied conclusions have the potential to become a story of identity, which can shape how children come to understand their experiences.

My experiences and personal values have informed my epistemological and theoretical orientation regarding the nature of knowledge and what can be 'known' (see also Chapter 4). I take the position that knowledge is a social and historical product that can be specific to a particular time, culture or situation (Robson, 2002).

In following scientist-practitioner model (Fallon *et al.*, 2010), my fore-knowledge has developed through extensive scoping of theoretical, research, policy and professional literature relating to ADHD (see Chapters 2 and 3). This theoretical knowledge and my personal and professional experiences will have influenced the interactions with each participant, the analysis procedure, and the co-construction of meaning. My familiarity with previous literature may have led to me focusing on certain comments in light of this previous knowledge and a different researcher may have elicited different responses and interpreted the data in a different way. As advocated by Yardley (2000), Elliott *et al.* (1999) and Smith *et al.* (2009), however, all themes have been grounded within the data, and furthermore, as recommended by Smith (2010), themes were supported by extracts from each participant to present 'breadth and depth' of the theme and to enhance rigour (p. 24) (see Chapter 8, section

8.4.1). An example of my personal reflection during the analytical process is shown in Appendix 12.

A number of guidelines have been produced for evaluating the quality and validity of qualitative research (Smith, 2011). These criteria aim to support the qualitative researcher in demonstrating that their study is 'trustworthy', 'legitimate' and 'useful' (Yardley, 2015). In Chapter 5, Table 5.4, I demonstrate ways in which I attempted to address Yardley's (2000) four principles for evaluating qualitative research.

## CHAPTER 5: RESEARCH DESIGN, IMPLEMENTATION AND DATA ANALYSIS

### 5.1 Research question

IPA is described as a suitable approach to explore how individuals perceive the particular situations they are experiencing: how they are making sense of their personal and social world (Smith and Osborn, 2015). In IPA, research questions are usually broad and exploratory to enable the researcher to explore, 'flexibly and in detail' (Smith and Osborn, 2015), people's experiences and/or understanding of a particular phenomenon. Questions are directed towards meaning and the detailed examination of lived experience, rather than difference or causality, as seen in studies taking a more positivist stance.

In keeping with the descriptive nature of this study and its emphasis on following a qualitative methodology, there is no specific hypothesis to be tested, but rather a broad research question: what is it like to live with ADHD? As Singh (2011) has described, my aim is to understand the phenomenon of ADHD as a lived experience in a local context, rather than in universally applicable generalisations. Consistent with a narrative therapy approach, I take the view that universal categories are unable to capture people's lives in all their complexity.

## **5.2 Research design**

### **5.2.1 Semi-structured interviews**

In order to produce a detailed account of the phenomena in question, IPA may incorporate a variety of data collection methods. For example, IPA studies have employed semi-structured interviews, focus groups, participant diaries and self-reporting tasks.

When choosing the appropriate research design, the aim is to enable participants to provide a detailed account of their personal lived experience (Smith, 2015). In-depth semi-structured interviews have been the exemplary method of conducting IPA, and most research using IPA has employed this method of data collection (Smith and Osborn, 2015). Smith (2015) suggests that interviews allow the researcher to 'hear the participant's account' and, in real time, decide 'where and when to probe further' (p. 645).

As with many IPA studies, and in particular those exploring the phenomenon of ADHD, the present study employed one-to-one semi-structured interviews. My rationale for selecting this method of data collection is summarised below:

- Semi-structured interviews are suited to in-depth personal discussion and, I believe, provide an effective forum for children and parents to express views that may be personal and sensitive.
- Initial questions can be modified in light of a participant's responses to 'capture "rich" and detailed aspects of individual experiences' (Westcott and Littleton, 2005, p. 150).

- As research questions in IPA are usually abstract, a pre-prepared schedule of questions enables the discussion of relevant topics, whilst also providing the freedom to probe interesting and important areas which may arise through the personal discussion.
- In relation to research with children, qualitative interviews provide a chance to check inconsistencies and contradictions, incorporate the language used and understood by the child, check for any misunderstandings and verify interpretations (Lobe *et al.*, 2008).
- Participants are part of the direction the interview takes and, in this way, the participant is viewed as the experiential expert on the subject (Smith and Osborn, 2015). This position fits with the principles of narrative therapy.
- Semi-structured interviews can elicit 'rich' data by providing an opportunity for participants to tell their stories, to speak freely and reflectively, and to develop their ideas and express their concerns (Smith *et al.*, 2009).
- Following the spirit of IPA, the researcher and participant can be active participants in the research process.
- Many of the qualitative research studies reviewed in preparation for this research study (see Chapter 3) have employed semi-structured interviews as their chosen method of data collection.

Randall and Phoenix (2009) suggest that whatever method we employ to gain access to the participant's world, we are ultimately glimpsing the story rather than the history. In their view, the information gathered through the interview is not the 'raw facts' within the person's mind waiting to be collected but

rather, their interpretations and their stories which have resonance (ibid, 2009). Smith *et al.* (2009) concur, suggesting that they do not assume a 'true' account is being accessed; rather, the researcher is committed to understanding the participant's perspective, whilst also understanding contextual factors that may influence the retelling of their experiences.

I acknowledge the limitations in choosing this method of data collection, particularly its reliance on language skills in order for participants to provide descriptions of their experiences. The information participants provide is heavily reliant upon their language use and vocabulary to express their thoughts, feelings and perceptions in words. This reliance on language to communicate the 'subtleties and nuances' of experiences could be seen as limiting (Willig, 2008, p. 67); however, this critique could be ascribed to many qualitative methods. Within IPA the focus is on understanding, representing and making sense of people's ways of thinking, their motivations and actions (Eatough and Smith, 2006).

When using semi-structured interviews, it is recommended that the researcher construct an interview schedule with a number of set questions. This schedule is used to guide, rather than dictate, the interview (Smith and Osborn, 2015). In the following section, I describe the process followed in constructing my interview schedule and present the questions selected.

### 5.2.2 Constructing the interview schedule

Interviews provide an opportunity for participants to talk about a particular aspect of their life or experience (Willing, 2008); they are described as a 'conversation with a purpose' (Smith *et al.*, 2009). IPA researchers usually use an interview schedule to facilitate the discussion of relevant topics (Smith *et al.*, 2009). However, in contrast to the controlled, structured and predictable nature of questions used in a structured interview, semi-structured interview schedules are more open-ended and non-directive, and used to guide rather than direct the conversation (Smith and Osborn, 2015). IPA informed the structure and type of questions used in this research, and was integral to my thinking and reflections about the researcher's role in the interview process.

In relation to conducting IPA research, Smith *et al.* (2009) have proposed the following advantages of constructing an interview schedule. These are:

- in case the interview becomes difficult;
- to help researchers to think about the broad range of issues they would like to cover;
- to enable the researcher to be more engaged and responsive, and to concentrate more thoroughly on the participants' stories;
- to place topics in the most appropriate sequence (e.g. leaving more sensitive topics until later in the interview);
- to consider probes and prompts specific to individual questions, to support participants who may struggle with less structured questioning;

- to think about ways of phrasing questions and consider the language used (e.g. in relation to my study, the appropriateness for the age range of the children); and
- to ensure questions are framed in an open form.

Whilst providing the researcher with a guide, the strategy is to encourage the person to speak about the topic with as little prompting as possible from the interviewer (Smith and Osborn, 2015). However, the researcher should ensure that the interview schedule does not become prescriptive, and thus restricting. Brocki & Wearden (2006) warn that if themes elicited are greatly similar to the topic areas to be covered, researchers are in effect structuring the analysis before the data collection begins. In a systematic literature review of published papers employing IPA, Brocki & Wearden (2006) found that whilst all the papers reviewed expressed a desire to provide an interview schedule, few described the process or provided copies of that schedule. They argue that this makes it difficult for the reader to judge the quality of the interview and any influence on the data obtained.

In semi-structured interviews, questions are open-ended and of a non-directive style. In this way, the interview schedule is used to facilitate participants to 'tell their story' in their own way. However, as discussed, it is important to acknowledge that it is the researcher whose questions guide the interview (Willig, 2009).

The questions selected to provide a structure for the interviews were based on a review of the literature presented in Chapter 3. The questions were clustered around themes considered relevant from previous qualitative studies examining children’s and parents’ experiences of ADHD. Themes identified in the literature review are detailed in Table 5.1, with example questions from the interviews:

Themes Identified	Study	Example Questions
Meaning and identity	Kruegar & Kendall (2001); Kendall <i>et al.</i> (2003); O’Leary (2007); Gallichan & Curle (2008); Davies (2009)	<ul style="list-style-type: none"> <li>• Has the diagnosis affected how you think about yourself?</li> <li>• Has ADHD ever got in the way of something you wanted to do?</li> </ul>
Beliefs about ADHD	Cooper & Shea (1998); Kendall <i>et al.</i> (2003); Travell (2005)	<ul style="list-style-type: none"> <li>• What do you think ADHD is?</li> <li>• Where does it come from?</li> </ul>
Problems associated with ADHD and their consequences	Cooper & Shea (1998); Travell (2005); O’Leary (2007); Gallichan & Curle (2008); Davies (2009)	<ul style="list-style-type: none"> <li>• Do you think ADHD gets in the way of you doing well at school?</li> <li>• Do you think ADHD gets in the way of you and your friends?</li> </ul>
Process of diagnosis (including participation and voice)	Kendall <i>et al.</i> (2003); Travell (2005); Gallichan & Curle (2008); Davies (2009)	<ul style="list-style-type: none"> <li>• Who noticed ADHD?</li> <li>• Did you think there was a problem?</li> </ul>
Interventions and support for ADHD	Cooper & Shea (1998); Travell (2005); Gallichan & Curle (2008); Davies (2009)	<ul style="list-style-type: none"> <li>• Have you found any ways to handle ADHD that you think might help others?</li> <li>• Do you get support from other people to handle ADHD?</li> </ul>
Unique skills/positive aspects	Davies (2009); Grant (2009)	<ul style="list-style-type: none"> <li>• Have you ever done anything that other people were surprised that you could do?</li> </ul>

Table 5.1: Themes identified in the literature review and example questions.

Although pharmacological treatment was alluded to within the discussion about the participants' experiences of diagnosis, and participants were of course able to talk freely about this aspect, I steered away from a range of questioning about medication, as this has been a dominant theme in research on ADHD (see Chapter 3, section 3.1.0).

A child interview was piloted to enable me to try out questions and change language terms and phrasing. Due to the difficulties recruiting participants (discussed in section 5.3), this interview formed part of the main study. The full interview structure used to guide the interviews is given in Appendix 8 and 9. There were no structural changes made to the interview schedule following the pilot interview; however, on reflection on the process, I believe the questions were delivered in a rigid way (one after another), rather than being used as a guide (as recommended by Smith *et al.*, 2009). This experience was 'held in mind' during subsequent interviews, to ensure the participants had the freedom to tell their stories.

Interview questions were constructed using terminology associated with a narrative therapy approach: 'externalising' language was employed to situate ADHD outside the person who has been given the diagnosis (e.g. how long has ADHD been in your life?). 'Externalising', or separating people from problems, is one of the most widely known constructs from narrative therapy and is considered helpful in creating distance between the person's identity and the problem, to make space for them to reflect on their experiences and consider who and how they would like to be (White and Epston, 1990). By

incorporating this language style, I was not intending to reject underlying structures associated with ADHD but rather, to ensure my questioning did not contribute to a belief that the problems the children were experiencing were 'characteristic of their identity' (Turns and Kimmes, 2014).

Willig (2008) suggests that interview schedules should include a relatively small number of open-ended questions and start with more general questions, to allow a rapport to be established. Smith *et al.* (2009) advise approximately 6–10 open questions, with prompts to elicit further information. The interview schedule for this study contained 5–6 key areas (five on the parents' and six on the children's schedules), with 1–2 key questions in each, and further questions as probes and prompts.

Heffron and Gil-Rodriguez (2011) argue that good quality IPA requires a more open-ended interview with 'a careful balance between guiding and being led' (p. 757). They recommend that interview schedules should be short, with broad general questions that set the parameters of the topic; they caution against interview schedules that are too long, overly extensive and detailed, which, they suggest, can be seen in research conducted by those less familiar with IPA (*ibid*, 2011). On reflection, it could be argued that the interview schedules used in this empirical study were long and detailed, and therefore risked leading rather than guiding the interviews, as described in my appraisal of the pilot study. However, I believe that this was not the case for the main study and detail my rationale below:

- a comfortable interaction with participants developed;

- participants talked at length and provided a detailed account of their experiences;
- questions were adapted to incorporate the language and terms used by the participants; and
- the schedule was delivered in a flexible way: not all questions were asked in all interviews, and questions were not asked in a set order.

### **5.2.3 Conducting the interview and collecting data**

Each interview was planned to last one hour, which is deemed to be an appropriate length of time for a semi-structured interview (Smith and Osborn, 2015). The mean length of the interviews which formed part of this study was 62 minutes for the parents' and 35 minutes for the children's interviews.

All participants chose the location for their interview. Three of the child participant interviews took place in a quiet room within their school and one took place at their home. Two of the parents' interviews took place at their home, one within the participant's workplace (a school) and the fourth took place at the researcher's place of work.

At the beginning of each interview, the Information Sheet (Appendix 4 and 5) was discussed and the Informed Consent Statement (Appendix 6 and 7) signed by all participants. Additional time was spent discussing these with the child participants to ensure they were fully informed about the study and the procedure for stopping the interview if they felt upset or uncomfortable

(including a short role play using the visual 'stop card'), and to provide time for them to ask any further questions.

The children's interviews began with the sharing of an 'all about me' poster (see Appendix 8), which the child participants had created about themselves as part of the preparation for the interview, to help to build rapport (Woolford *et al.*, 2015)

Following this, the children were invited to draw ADHD ('If you could see ADHD, what do you think it would look like?') to provide an alternative means of expression (Freeman *et al.*, 1997). Nylund (2000) suggests that the process of drawing can support children in 'seeing it [a problem] more clearly and pondering it more easily' (p. 82). For the purpose of this research these drawings were utilised as a means of supporting the children to focus on the subject matter (for this study, the phenomenon of ADHD) (Thomas and Jolley, 1998; Morgan, 2000) and a further method by which to build rapport (Thomas and Jolley, 1998; Bekhit *et al.*, 2005). For this research study the focus was on what the children had to say about their experiences of living with ADHD rather than interpretation of the drawings. Whilst drawings have been found to help children to talk about problems (Woolford *et al.*, 2015), empirical literature has questioned the reliability and validity in relation to interpretation (Malchiodi, 1998; Beaver, 2003; Bekhit *et al.*, 2005).

The parents' interviews commenced with the drawing of a family genogram, which prompted discussion about the family composition, interests and

experiences. These pre-interview activities were a means to develop rapport and put the participants at ease (Smith and Osborn, 2015). The research process should always be considered from the viewpoint of the participant (BPS, 2009), and I believed this to be particularly pertinent to my preparations for the children's interviews. To ensure the interview was accessible to the child participants and create a context that would support them to talk more openly, I stressed that there were no right or wrong answers, I phrased and rephrased questions, and used language meaningful to them, as well as visual images to support their understanding of more abstract concepts.

During the interviews, my purpose was to listen to the participants and engage in a position of 'naïve' listener, asking for clarification and not assuming I understood the terms used. Smith *et al.* (2009) caution that interviewers should not make assumptions that they already understand underlying meanings behind what is said without asking further questions to 'expose the obvious' (p. 69.). This way of engaging in conversations fits with the 'absent but implicit' (White, 2000) questioning used in narrative therapy. White (2000) suggested that there is a duality in all descriptions and in order to make sense of things, we need to contrast them to what they are not (Carey *et al.*, 2009). For example, pertaining to this research study, understanding 'naughty' (a term used by the child participants to describe their perceived difference) in the context of the children's beliefs about what they considered to be expected or the norm (influenced by wider social and cultural discourses).

The interviews were based on the interview schedules (Appendix 8 and 9) discussed in section 5.2.2. However, the sequence and content varied to ensure the interview remained participant- rather than interviewer-led, and so participants were positioned as experiential experts on the phenomenon of ADHD. In narrative therapy, this is known as using 'experience-near' language (White, 1995), which is used to ground the questions within the participants' own personal meaning and experience, and hopefully demonstrate that their views are being listened to – for example, metaphors and language used by the participants to describe their experience were noted and included in subsequent questions.

At the end of the interview each participant was thanked and prompted to choose a pseudonym to be used in the reporting of the research, to safeguard confidentiality.

#### **5.2.4 Data storage**

The interviews were digitally recorded with the permission of the participants. All research data have been stored in a secure and locked filing cabinet at my place of work (the local authority where this research study took place); data held on a computer were password-protected. The digital recordings of the interviews will be destroyed on conclusion of the examination of this research.

Notes taken (including the genograms completed with parent participants) during the interview process were stored following the guidelines provided by the Data Protection Act 2003.

### 5.3 Participants

IPA researchers aim to explore in detail how participants perceive and make sense of phenomena personal to them. For this reason, less is considered more (Reid *et al.*, 2005), and IPA studies are usually conducted on small sample sizes. For professional doctorates, between 4 and 10 interviews are recommended (Smith *et al.*, 2009).

IPA research undertakes purposive sampling, to identify a closely defined homogenous group for whom the research question will be meaningful (Smith and Osborn, 2015). In contrast to more positivist methods, participants are selected to serve an investigative purpose, rather than being statistically representative of a population (Ritchie *et al.*, 2003). In this study, homogeneity was defined in terms of all child participants having received a diagnosis of ADHD, and the children and their parents therefore sharing the experience of having ADHD in their lives. However, as discussed later, the final sample became particularly homogenous in that all child participants were male and all parents who took part were mothers.

The child participants were selected using the following criteria, they:

- had received a diagnosis of ADHD, according to the DSM-5 (APA, 2013) criteria, from either a consultant psychiatrist or consultant paediatrician;
- were aged between 8 and 11 years;
- were educated in the researcher's local authority area of work;
- had no history of being in the care of the local authority; and
- had no involvement with child protection services.

Parent participants were selected on the basis that their child met the criteria detailed above and that the child had given their initial consent to take part in the study. This latter criterion was to prevent, as far as reasonable, child participants feeling under pressure from their parents to take part in the study.

I decided to select children aged between 8 and 11 years for the following reasons:

- The views of children of primary school age or younger are under-represented in the available literature (Davies and Wright, 2008), leading to a gap in our understanding of the views and experiences of younger children.
- Singh *et al.* (2010) suggest that it is important to gain the views of young people through the period of middle childhood to the onset of adolescence as it is during this time that a diagnosis of ADHD is usually made. Furthermore, it is suggested that adolescence is a time of experimentation and identity conflict, which may impact on their experiences of ADHD (ibid, 2010).
- Children younger than 8 years may not have developed functional language skills to enable them to engage in an interview, or the cognitive skills, life experience and social capital to make a valid decision about whether to engage in an interview.

In addition to exploring children's lived experience of ADHD, this study sought the perceptions and experiences of their parents. In drawing on outcomes from relevant literature (e.g. Firmin and Phillips, 2009; Peters and Jackson,

2009; McIntyre and Hennessy, 2012), parents were included in order to understand more fully the experience of ADHD. I believed parents to be particularly important as it is often parents who first notice the difficulties their child may be experiencing, and consequently seek the involvement of education and health services (Stranger and Lewis, 1993). Parents, therefore, have their own personal experiences of the phenomenon under study. In addition, it has been suggested that parents and children view problems in very different ways (Yeh and Weisz, 2001), and I believed IPA's focus on convergence and divergence within the analysis may illuminate any differences.

It has been suggested that a research sample is, in part, defined by those who are prepared to be in it (Smith and Osborn, 2015), and this has certainly been true for this study. There were considerable difficulties in recruiting participants, and despite information sheets being sent to parents of boys and girls who had received a diagnosis of ADHD, only parents of boys provided their consent. In addition, it was mothers of these boys who agreed to take part in the study; as a consequence, and although not planned for, this study could be criticised for adding to research on ADHD that has been disproportionately skewed towards mothers and their 'problem boys' (Malacrida, 2002; Singh, 2004; Horton-Salway, 2013; Davies, 2014). In attempting to understand why this might be the case, Singh (2004) has suggested that an ADHD diagnosis may hold different meanings for fathers, due to their absence from a majority of diagnostic evaluations and greater scepticism about the reliability of the diagnosis. Research has indicated that

fathers are more sceptical of the diagnosis and less accepting of an interpretation of their child's behaviour through a medical lens (Davies, 2014). This may have contributed to the reluctance of fathers to take part in the research, as well as feasibility due to father's work commitments. Equally, it may be that a more active caring role by mothers led to a stronger desire for them to take part in the study, reflecting parents' different ascribed roles.

To ensure diagnostic validity, the child's diagnosis of ADHD was verified by requesting to view the letter of diagnosis that parents had received from a psychiatrist or paediatrician; all child participants who took part in this study had received their diagnosis from the same CAMHS team. To further increase confidence in the validity of the diagnosis, Lench *et al.* (2013) propose researchers also examine ADHD symptoms as reported by participants by asking them to complete a rating scale (e.g. Conners' Rating Scales; Conners, 1997). I decided against this additional level of scrutiny as I was familiar with the local CAMHS ADHD assessment process, and therefore knew that parents would have already completed a range of behaviour checklists (including the Conners' Rating Scales).

It has been suggested that the identification of a 'pure' ADHD group for research purposes is difficult, due to the high incidence of co-morbidity (Koelega, 1995). As discussed in Chapter 2, ADHD is characterised by a cluster of behavioural symptoms that are considered separate from, but highly correlated with, other conditions (Singh, 2008), with co-morbid diagnoses accounting for two-thirds of all diagnoses (Moncrieff and Timimi, 2013).

Horton-Salway (2007) has discussed the 'fuzziness' of contested and changeable illness labels, which make it difficult to establish a 'genuine' case. In relation to this study, two of the child participants had an additional diagnosis: one had received a diagnosis of dyspraxia and one had been given a diagnosis of oppositional defiance disorder (see Table 5.2 for a summary of participant demographics). Davies (2014) argues that in excluding those who do not fit within the exclusive ADHD category definition, one could be viewed as attempting to 'fix' the meaning of ADHD.

All of the child participants who took part in this study had been prescribed medication and were taking this at the time the interviews took place. This is consistent with previous qualitative research (including studies discussed in Chapter 3), which include samples of children prescribed medication for their ADHD. However, Hester (2007) has questioned whether children participating in studies should be 'off their medication' during the study in order to capture their 'true' beliefs. Furthermore, he suggests that children be given opportunities to share their narrative accounts both 'on' and 'off' medication. In response, Singh (2007) argues that there is no indication that pharmacological treatment for ADHD 'supports a shift in the moment in deeper levels of self-understanding' (p. 189); rather, the child's responses would be genuine for that child at that time (ibid, 2007). I concur with Singh's (2007) view, and also take the position that for those children who are prescribed medication, their treatment forms part of their lived experience of ADHD. In addition, there are ethical issues with regard to researchers interfering with children's compliance with pharmacological treatments.

The process for recruiting the participants was as follows:

- Contact, via letter (see Appendix 3), was made with special educational needs co-ordinators (SENCOs) of schools visited in my role as link psychologist (the local authority's educational psychologist assigned to the particular school). The letter outlined the nature of the study and asked for names of potential participants who met the research criteria detailed above.
- An information sheet was sent (via the SENCO) to potential participants (Appendix 4 and 5), outlining the nature of the study and asking them to return a stamped addressed postcard to the principal researcher or SENCO at their child's school, if they wished to participate.
- On receipt of the postcards, telephone contact was made with parents to provide further details and check their understanding about the study and what would be involved. The children were offered an opportunity to meet with me so that they could ask any further questions, which enabled me to check their understanding and reaffirm their consent.
- A consent form (Appendix 6 and 7) was sent to all potential participants. As the child participants were under 18 years of age, signed parental permission was also gained; however, as mentioned above, parents' signatures were not accepted on their own as indicating consent for the children.

Table 5.2: Demographic details of participants

<b>Participant</b>	<b>Mason</b>	<b>Michael</b>	<b>Robert</b>	<b>Sam</b>
<b>Age at Interview</b>	11 years	11 years	12 years	11 years
<b>Gender</b>	Male	Male	Male	Male
<b>Ethnicity</b>	White/Black Caribbean	White	White	White
<b>Age at Diagnosis</b>	10 years	7 years	7 years	10 years
<b>Stimulant Medication</b>	Yes	Yes	Yes	Yes
<b>Other Diagnosis</b>	None	None	Dyspraxia	ODD
<b>Type of School Attended</b>	Mainstream	Mainstream	Special (from Year 6) (A school for communication and interaction difficulties)	Mainstream
<b>SEN Support</b>	EHC	EHC	EHC	School Support
<b>Household Structure</b>	Birth mother 2 siblings	Birth mother and step-father 3 siblings	Both birth parents 3 siblings	Both birth parents 1 sibling
<b>Parent Interviewed</b>	Mother	Mother	Mother	Mother

#### **5.4 Ethical considerations**

Ethical protocols of both the university (*University of Birmingham Code of Practice for Research, 2012-13*) and local authority were adhered to in planning and carrying out this research. In addition, the British Psychological Society's (BPS) *Code of Human Research Ethics* (BPS, 2010) and British Educational Research Association's (BERA) *Revised Ethical Guidelines for Educational Research* (BERA, 2011) provided further guidance.

Ethical consent from the University of Birmingham was approved in September 2013. This required consideration of ethical principles relating to recruitment of participants, consent, withdrawal, confidentiality and psychological harm and distress. A copy of the submitted University of Birmingham ethical consent form (AER) is included within the appendices (Appendix 1), which provides details of the actions taken to demonstrate consideration of these principles.

#### **5.5 Research with children**

There has been a shift in thinking from deterministic theories, which have tended to view children as 'objects rather than subjects, as non-competent rather than competent, and as adults in miniature rather than citizens in their own right' (Mitchell, 2003, p. 284). It is argued that the (new) sociology of childhood has contributed to changes in our understanding of children's views and perspectives, and has led to an increase in childhood research (Tisdall, 2012; Quennerstedt and Quennerstedt, 2014; Parsons *et al.*, 2016). Drawing on these new ways of constructing childhood, ideas of children as social

agents in their own right, the concept of children's rights and concern to ensure that children's voices are heard, have all gained credence in national and international policy (Moran-Ellis, 2010); as, for example, in the United Nations (UN) *Convention on the Rights of the Child* (UN, 1989) and the Children and Families Act 2014.

Singh (2011), however, argues that much of the research on ADHD has silenced children, because their voices and experiences are ignored. Bringewatt (2013) suggests that the sociology of childhood provides a lens through which to explore and understand the perspectives of children, particularly those who have a mental health diagnosis. From this position, she argues that children can be seen as 'actively participating in a process of learning about and making sense of their diagnosis' (ibid, 2013, p. 1220). In carrying out my own research, I adopted the position described by Davis (2006): children are active and competent participants, capable of taking an active role in defining and responding to life problems and able to identify their own solutions.

Research directly recording children's perspectives contributes to a greater understanding of children's experiences and needs (Soderback *et al.*, 2011). A child's perspective is captured when their expressions, experiences, perceptions and understanding are explored (Sommer *et al.*, 2010). There has been criticism, however, that research has tended to be 'on' rather than 'by' children (Tisdall, 2012). To increase children's agency and to overcome power imbalances within research, researchers have included children as co-

researchers or collaborators (Spyrou, 2011). Given the longer time required for such an approach, however, this design was not adopted for this research study. This study still provided opportunities for children to have their say, which, as Byrne and Swords (2015) argue, is one way of equalise the power imbalances children face. In line with my view that children are active agents, rather than passive subjects (Tisdall, 2012), interview questions were presented in ways that positioned the children as 'knowledgeable' (O'Reilly *et al.*, 2015); whilst in my role of researcher, I positioned myself as an adult who 'lacks knowledge' and was interested in learning from them (Mayall, 2000, p. 122). Spyrou (2011) argues 'no single method can guarantee successful representation itself' (p. 162).

## **5.6 Summary**

Having outlined my research strategy and the factors influencing it, I now move on to describe the process that I followed to analyse the transcripts using IPA, how I arrived at a data set following that analysis and explore the ways in which I addressed the trustworthiness and validity of my research findings.

## **5.7 Analysis**

IPA involves the detailed examination of personal lived experience through the exploration of the meaning of this experience to participants, and how they make sense of it (Smith, 2011). In order to achieve this, the researcher is

required to enter a process of engagement and interpretation (Smith, 2011), influenced by the hermeneutic approach described in section 4.5.

Larkin *et al.* (2006) suggest that researchers approach their data with two aims: firstly, to understand their participants' world and describe it; and secondly, to provide a critical and conceptual commentary on participants' sense-making in order to position the initial descriptions within wider social and cultural contexts.

Analysis of the eight interview transcripts adhered to the process described and espoused by Smith *et al.* (2009), who suggest that a researcher using IPA for the first time follow their step-by-step process to facilitate the analysis.

The steps for analysing each case are:

- reading and rereading;
- initial noting;
- developing emergent themes;
- searching for connections across emergent themes; and
- looking for patterns across cases.

Table 5.3 presents each step and the process followed. Following the guidelines presented by Smith *et al.* (2009), and IPA's idiographic principle, I analysed one interview transcript at a time.

Steps	Description of the Process Followed
<p><b>Step 1:</b> Reading and rereading</p>	<p>Smith <i>et al.</i> (2009) describe this step as entering into a phase of 'active engagement with the data' (p. 82). There is repeated reading of the individual transcript at a careful pace (to avoid superficial reading) to enable a model of the individual structure to develop, identify more detailed sections and locate any contradictions.</p> <p>To increase my familiarity with each account, the interviews were read and reread three times. During the second reading I listened to the audio recording of the interview to enable me to 'hear' the participant's voice on subsequent readings. As suggested by Smith <i>et al.</i>, notes of my initial ideas (e.g. paraphrasing; connections between comments within the individual interview and across interviews; and tentative interpretations) were recorded on separate pieces of paper to set these aside (or bracket) whilst I continued to engage with the transcript.</p>
<p><b>Step 2:</b> Initial noting</p>	<p>Although documented under separate headings, as described by Smith <i>et al.</i> (2009), Steps 1 and 2 merge together as the researcher often makes notes and highlights aspects of the transcript whilst reading and rereading the interviews. During Step 2, however, the analysis moves towards a more interpretive level. Whilst there are no restrictions about what is commented on, the aim is to produce a detailed set of notes and comments (see Appendix 11).</p> <p>During this stage, I underlined certain sections of the text I believed to be of importance and, in the left-hand margin, made comments regarding my rationale. These notes incorporated the processes of exploratory commenting (descriptive, linguistic and conceptual) described by Smith <i>et al.</i> (2009). Descriptive comments have a phenomenological focus and remain close to the participant's meaning; they include the things that matter to the participant (e.g. key objects of concern, places, events, values) and the personal meaning of these (Smith <i>et al.</i>, 2009). Interpretive comments involve exploration of the language used by participants (e.g. pronoun use, pauses, laughter, repetition, tone) and the researcher's attempts to make sense of the 'patterns of meaning in their account' through the identification of more abstract concepts (ibid, p. 83). This involves moving away from the participant's explicit claims towards their 'overarching understanding of the matters they are discussing' (ibid, p. 88). These interpretations enter into 'reflexive engagement', whereby the researcher's experiential and professional knowledge is drawn upon in order to make sense of the participant. Smith <i>et al.</i> (2009) caution, however, that the</p>

	<p>interpretation must be inspired by and arise from the participant's words; to ensure this was the case I continually checked my comments on subsequent readings of the transcripts.</p>
<p><b>Step 3:</b> Developing emergent themes</p>	<p>During this stage of the analysis, the researcher identifies and labels themes that characterise sections of the text (Willig, 2008). The initial notes produced in the earlier stages evolve into more concise phrases, which aim to capture the participant's experiences. In doing so, the process becomes reductive in attempting to condense the larger data set that has been produced. Themes are conceptual, drawing on the 'interpretive' element in IPA, allowing theoretical connections to develop, which may include psychological terminology as the researcher attempts to produce 'concise and pithy' statements reflecting both the participant's lived experience (in their own words) and the researcher's interpretation (Smith <i>et al.</i>, 2009, p. 92): it is a process of description and interpretation (Smith and Osborn, 2015).</p> <p>Emergent themes were recorded in the right-hand margin of the interview transcript and then listed on a separate piece of paper in the order they appeared in the transcript (Smith and Osborn, 2015) (see Appendices 10 and 11).</p>
<p><b>Step 4:</b> Searching for connections</p>	<p>During this stage of the analysis, the researcher engages in a more analytical ordering of the themes by exploring connections between them. Some of the emergent themes will cluster together to produce a superordinate theme, whilst others may emerge as superordinate concepts, drawing together other themes (Smith <i>et al.</i>, 2009). Following a more traditional method, as described by Smith <i>et al.</i> (2009), emergent themes were typed and printed before being cut into individual themes. I then placed these on a large piece of paper and physically moved them around to identify patterns. Themes with commonalities were placed together and given a label to 'capture their essence' (Willig, 2008), in order to form a superordinate theme (Smith <i>et al.</i>, 2009).</p>
<p><b>Step 5:</b> Looking for patterns</p>	<p>The penultimate stage of the analysis involves looking for connections across the individual cases, to produce a 'master table of themes' for the group of participants (Smith and Osborn, 2015). Themes and superordinate themes for each participant were printed and cut out so that they could be displayed on a large piece of paper. These were then physically moved around the paper as connections were established, leading to a reconfiguring and relabelling of some of the themes (Smith and Osborn, 2015). Through continued re-engagement with the transcripts, these initial labels developed to include brief quotations used by the participants,</p>

	<p>ensuring the analysis remained grounded within the participants' personal accounts (Willig, 2008; Smith and Osborn, 2015). A table of themes for each group (the children and then their parents) was created displaying each superordinate theme and the themes incorporated within them. The 'table of master themes' for the children's and parents' interviews are shown in sections 6.1 and 7.1.</p> <p>The final stage of the analysis involves the researcher moving from the final table of themes to the translation of these into a narrative account (Smith and Osborn, 2015). A narrative account of the findings from this study is presented in Chapters 6 and 7.</p>
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Table 5.3: Summary of steps for the interpretative phenomenological analysis.

### **5.8 Demonstrating validity in data collection and analysis**

As with all research, qualitative researchers need to consider the scientific value of their work and their contribution to knowledge (Willig, 2008). However, it has been argued that the criteria adopted to evaluate quantitative research (e.g. objectivity, reliability and generalisability) are not appropriate for judging qualitative research (Elliott *et al.*, 1999; Yardley, 2000; Willig, 2008), since qualitative researchers are not seeking objectivity, predictable causal relationships and statistical generalisability.

In contrast, qualitative research is concerned with meaning in context and involves interpretation of data (Willig, 2008), which requires the researcher's active engagement with the data, and is therefore subjective. Qualitative researchers are integral to the research process and influence the knowledge produced through the development of their research questions, selection of methods and analysis, and through their interpretation of data (Yardley, 2015). Qualitative research is interested in the social context and the

complexities of individual experiences; therefore, small samples are selected based on participants' relationship to the phenomena under study.

To address these differences in research methodology, a number of guidelines have been produced for evaluating the quality and validity of qualitative research (Smith, 2011). These criteria aim to support the qualitative researcher in demonstrating that their study is 'trustworthy', 'legitimate' and 'useful' (Yardley, 2015). Yardley (2000) has presented a set of four broad principles that can be applied to judging the quality of a wide range of qualitative research. Table 5.4 shows the ways in which I have attempted to address Yardley's (2000) four principles and the weaknesses of this study in relation to these.

Table 5.4: Yardley’s (2000) four broad principles for evaluating the validity of qualitative research and the ways in which this study demonstrates these

Core principle	Ways the study demonstrates this principle	Weakness of this study
Sensitivity to context	<p>In order to give value to the perspectives of participants, interview questions were open-ended and the schedule flexible to enable participants to talk freely about their experiences (Yardley, 2015).</p> <p>Participants chose the location for the interview.</p> <p>Clear information was provided to participants in accordance with ethical procedures. This included a visual, ‘child-friendly’ information sheet to support the children’s understanding.</p> <p>In accordance with Smith et al. (2009), analysis focused on the particular (e.g. the uniqueness of each interview) before exploring the broader context of all the interviews. Interpretations included similarities and differences to ensure all experiences were illustrated to reflect the range of meaning and understanding.</p> <p>Verbatim extracts are provided in Chapters 6 and 7 to ensure the analysis remained grounded within the participants’ individual accounts</p>	<p>There may have been difficulties with children expressing themselves due to underdeveloped language skills (see section 5.2.1 for a more detailed discussion).</p> <p>Semi-structured interviews were the chosen data collection method. However it has been argued that in order to increase children’s agency and to overcome power imbalances within research, children should be included as co-researchers or collaborators (Spyrou, 2011). Given the time longer time frame required to establish the role of children as more equal research collaborators/partners, this design was not adopted for this research study. See section 5.5 for further discussion.</p> <p>The researcher’s status as a ‘psychologist’ may have had an impact on the views expressed. For example, parents’ previous experiences of interacting with psychologists within CAMHS and possible negative experiences around telling and re-telling their stories; and, children wanting to provide ‘socially acceptable’ answers to adults within school, may have influenced what and how they then communicated with me.</p>

	(Willig, 2008).	Boys with a diagnosis of ADHD and their mothers took part in the study. Unintentionally, this has reinforced stereotypes around ADHD (see section 5.3). The voices of girls and fathers remain silent.
Commitment and rigour	<p>Participants were purposively selected to obtain an homogenous group of children and their parents for whom the research question was meaningful (Smith &amp; Osborn, 2015).</p> <p>In addition to gaining the views of children the study sought the perspectives of one of their parents to understand more fully the phenomena being studied.</p> <p>Analysis of the interview transcripts adhered to the process described and espoused by Smith et al. (2009). Examples of this process have been presented in the appendices for review (see Appendices 10 and 11). Extracts from each participant are presented within each theme.</p> <p>To check the credibility of themes, participant feedback from one of the child-parent dyads was sought, to ensure themes were consistent with their views. However, as Osborn and Smith (1998) assert, the credibility check is not aimed at producing a single true account, but to ensure</p>	<p>The study did not seek feedback on the analysis from all those who took part in the study.</p> <p>In addition to ADHD two of the child participants were in receipt of another diagnosis (Dyspraxia and Oppositional Defiant Disorder) and their views may not solely reflect their experience of having ADHD. However, given the high rates of co-morbidity (see section 2.5) recruiting a sample of participants with an ADHD only diagnosis is difficult. Furthermore, as Davies (2014) has argued excluding those who do not fit within the exclusive ADHD category definition, one could be viewed as attempting to 'fix' the meaning of ADHD (see section 5.3 for further discussion).</p>

	the integrity of the final account.	
Coherence and transparency	<p>My epistemological and ontological position has been described (see section 4.2 and 4.5.3) and a clear rationale for the research design has been presented (see sections 4.3 and 4.4).</p> <p>Recruitment of participants using clear selection criteria, as described in section 5.3.</p> <p>The interview schedule was constructed following a thorough review of the literature, presented in Chapter 3 (see also Chapter 5, section 5.2.2).</p> <p>A detailed description of the analysis is presented in section 5.7. As stated above examples from the paper trail have been provided (Appendices 10 and 11). The study adhered to the underlying principles of IPA: 'phenomenology', 'idiography' and 'hermeneutics' (see results/discussion in Chapters 6 and 7).</p>	<p>IPA recognises that the researcher's interpretation of the participant's account is influenced by their own thoughts, understanding and conceptions (Willig, 2008). However, IPA has been criticised for not 'theorising' how the researcher's perspectives are incorporated within the research process (Brocki &amp; Weardon, 2006; Willig, 2008). As far as possible, ways in which my own perspectives may have influenced the interpretative process has been reflected upon (see section 4.5.2) and examples from the analysis provided to demonstrate what the interpretations were based on.</p>
Impact and importance	The impact and contribution of this research will be discussed in Chapter 8.	

## **5.9 Developing and presenting the data analysis**

Richardson (2000) suggests that writing and reporting in qualitative research are also part of the analytic process, in that the researcher's thinking and interpretation develops. In the following two chapters, I continue this analytic process by providing a narrative account of the superordinate and subordinate themes that emerged through the analysis of the interviews with the child and parent participants.

## CHAPTER 6: RESULTS AND DISCUSSION OF INTERVIEWS WITH CHILDREN

### 6.1 Introduction

The following two chapters provide a narrative account of the superordinate and subordinate themes that emerged through the Interpretive Phenomenological Analysis (IPA) of individual interviews with the child and parent participants (see Chapter 5, section 5.3 for information on the participants). To explore their personal meaning and lived experience of ADHD, a general research question was selected for this study (see section 5.1). In keeping with the 'broad and exploratory' nature of IPA (Smith and Osborn, 2015), this question simply asked: what is it like to live with ADHD?

Findings from the child interviews are discussed in this chapter and results from the parent interviews will be presented in Chapter 7.

When using IPA there are two main aims in the analysis and presentation of the research data. At the very core of these are the 'phenomenological' and 'interpretative' elements underpinning IPA's approach: firstly, to attempt to understand the participant's world and their experience of a particular phenomenon; and secondly, to develop an interpretative account which positions the initial descriptions within social, cultural and theoretical contexts (Larkin *et al.*, 2006). The analysis involves a double hermeneutic in which the researcher has a crucial role in interpreting and making sense of the participants' attempts at making sense of their experience (Smith *et al.*, 2009). This interpretative activity (Smith and Osborn, 2015) continues at a third

hermeneutic level as readers of this research attempt to make sense of the researcher making sense of the participants' lived experience. In the context of this study, the participants' sense-making is in relation to the phenomenon of ADHD.

Superordinate themes, and their corresponding subordinate themes, are presented individually. In keeping with the 'phenomenological' element of IPA, themes will be explained and illustrated with verbatim extracts from the interview transcripts (in italics) alongside summarisation of key points and interpretative commentary. Connections between themes and the different ways in which participants manifest the same superordinate and subordinate themes (Smith *et al.*, 2009) will also be discussed. To ensure anonymity, extracts from participants are labelled with their chosen pseudonym. All other means of identifying participants (e.g. through names of family members, educational institutions and professionals involved) have been removed. Alongside verbatim extracts the abbreviations 'Int' (interviewer) and 'Resp' (participant respondent) are used to aid identification of the speaker.

In this chapter I present findings from the individual semi-structured interviews with the four child participants. Two superordinate themes were constructed through the analysis. These superordinate themes and their corresponding subordinate themes are illustrated in Table 6.1:

Superordinate Theme	Subordinate Theme
1. 'I think they just knew something was up': stories of suspicion, silence and exclusion	1.1 Identifying the problem: 'she just thought I got something wrong with me; I didn't really know what was going on'  1.2 Naming the problem: 'basically you are listening to what they say'  1.3 'They're to make you good': stories of compliance and control
2. 'It's like a serious mystery': how ADHD is perceived, experienced and managed	2.1 Understanding ADHD: 'an extra factor in your brain that makes it go quicker'  2.2 'I'm not very much like other kids': experiences of stigma and difference  2.3 ADHD is in charge: 'I can't make it go'

Table 6.1: Two superordinate themes and their corresponding subordinate themes emerging from the analysis of the four individual interviews with the child participants.

Each superordinate theme and corresponding sub-theme is presented individually under their selected headings.

## **6.2 'I think they just knew something was up': stories of suspicion, silence and exclusion**

From the children's accounts, ADHD appeared to be understood within the context of their behaviour. They recalled being observed and monitored by parents and teachers, and of being 'taken' to various professionals in order to identify a cause. There were stories of being silenced and subservient during consultations with health services and of little opportunity for the expression of their views within an adult-orientated process. On being 'told' they had

ADHD, a prescription for medication soon followed. This appeared to be understood as a means to modify and control their behaviour.

### **6.2.1 Identifying the problem: ‘she just thought I got something wrong with me; I didn’t really know what was going on’**

The children described ‘the problem’ in terms of their ‘naughty’ behaviour and, in their view, this had led to parents and/or teachers becoming concerned about ADHD. Their narratives appeared to reflect common stereotypes of ADHD, such as those portrayed within the media (Horton-Salway, 2011).

Robert (18p3): *Um being naughty.*

Michael (26/27p4): *Me be... behaviour... I was naughty.*

Sam (2p1): *I was always getting in trouble and I was just a bit silly...*

Mason (31p8): *...I think when I was in Year 1 I sort of like sort of took to bombing around the houses, up and down, up and down everywhere.*

Behavioural descriptions varied between actions likely to be considered extreme, such as fighting and throwing objects, and behaviour likely to be understood as commonly observed in children, such as being ‘a bit silly’.

In describing the problems associated with ADHD, Robert and Michael spoke of feeling ‘angry’ and of regularly ‘fighting’ with peers. Similarly, Mason described the effect on his emotions, which he believed caused him to be ‘a bit more sensitive’. In addition, he spoke of being ‘hyper’ and ‘bouncy’,

resulting in the inability to 'sit still'. Sam, on the other hand, linked ADHD to being reprimanded by his parents and teachers, and as he reflected on his early years, he concluded that ADHD must have always been in his life because he could recall times when he had been chastised. There appeared to be little differentiation between his behaviour and the behaviour of many children his age and yet, for Sam, these actions had resulted in a diagnosis of ADHD.

The hyperactive and emotional elements of their experiences of ADHD are exemplified in their own name for the problem:

Mason (49p11): *I think I'd call it OSHS... Oversensitive Hyperactiveness Syndrome.*

Sam (45p8): *I'd probably call it um, Hyperactive.*

Robert (215p26): *Energy Fun.*

Michael (71p10) *...I call it Bonkers.*

According to NICE guidelines (2013), ADHD is understood to be present when the core symptoms of hyperactivity/impulsivity and/or inattention are observed in multiple settings. In the case of 'severe ADHD', all three of the core symptoms are observed to be present in multiple settings. From the children's accounts, hyperactivity and aggression were the behaviours most often experienced, although the specific actions related to 'naughtiness' were not fully expanded upon and therefore may have included aspects of inattention or impulsivity.

Interestingly, anger and aggression are not listed within the diagnostic criteria and therefore, following NICE (2013) and SIGN (2009) guidance, would not be considered as evidencing core symptoms. However, their presence within the experience of ADHD has been documented by previous qualitative studies (Travell, 2005; Davies, 2009; Singh, 2011). For example, in exploring differences of how ADHD is understood between countries, Singh (2011) found that within the UK, ADHD is often viewed as a disorder of anger and aggression. The children's accounts of their experiences appeared to support this trend.

Once their behaviour had become an object of concern, the children's accounts indicated awareness of being watched, monitored and chronicled. This surveillance included: observations by teachers and health professionals; sharing of information between professionals and parents; and, in some instances, written records being compiled and presented as evidence.

Sam (24p5): *...I think they (teachers) mentioned it to my mum but I don't get told any of them things because my mum keeps it secret and then, well not secret, but like keeps it away from me and then she goes and tries to...*

The secrecy of which Sam spoke pointed to the children's absence at the very earliest stage within the investigative process, and this was further illustrated by Robert's account of 'her daily diary' to monitor his behaviour:

Robert (34/35/36/37p5):

Resp: *...she just, she just rang me mum.*

Int: *What did she tell your mum?*

Resp: *I don't know because she wouldn't let me listen.*

Int: *Oh, what do you think she told your mum then?*

Resp: *It goes on her daily diary.*

Int: *Oh. How come you were on a daily diary?*

Resp: *For being naughty and always fighting.*

It was as if from the outset a dominant story had been created of the problem being located within the child, and from this position, the action to be taken was examination of the child and their behaviour.

Following this examination, a narrative of 'something wrong' began to emerge within the adult discourse. Whilst information about parental and teacher concerns appears to have been withheld, Mason and Sam were clearly aware of the stories circulating around them:

Mason (46p10): *I don't think they would have known what it was. I think they just know that something's up.*

Sam (19p4): *Like um, she didn't know about ADHD then, she just thought that I'd got something wrong with me...*

From the children's descriptions, these 'something wrong' concerns culminated in their parents seeking assistance from other professionals to identify what may be causing the problem.

Sam (4p1): *So, um, my mum thought, uh, read about ADHD and she thought well I guess it's worth a try seeing if [child] got it...*

This resulted in further scrutiny of the child and their behaviour, as discussed in the next subordinate theme.

### **6.2.2 Naming the problem: 'basically you are listening to what they say'**

Throughout the children's accounts were stories of passivity and compliance in relation to assessment and receipt of their ADHD diagnosis. Where they had been given a role this tended to be a 'physical' one, in which their bodies were presented for observation and measurement. From the children's accounts, there was little evidence to suggest they had been listened to, informed or consulted. This is illustrated in the extract from Sam (124p22):

Int: *Did they ask for your views at the time about what you thought about it?*

Resp: *No, they just actually, they don't, um, probably they... basically you're listening to what they say and then you take that in and you put that in to... you use that information to help you.*

Similarly, Robert's recollections of his visits to CAMHS suggested an adult-orientated process.

Robert (76p10)

Int: *Did they ask you questions?*

Resp: *No, they asked me mum.*

Robert's descriptions indicated that the doctor had asked his mother questions and that he was unable to recall the details, as he 'wasn't listening to them'. Robert's appraisal was that the process had been 'boring':

Robert (83p10): *Mm-mm just talked more and then height and weight.*

Robert's contribution appeared to be a 'physical' one, as described above, which perhaps took place at the end of the appointment when medication had been discussed or agreed. Conversely, on subsequent visits Robert recalled that his views had been sought; however, when explored further, this appeared to be limited to reviewing the efficacy of his medication ('Uh, how's school been?'). In addition, interactions with the psychiatrist illustrated further stories of compliance and control, as Robert recalled being instructed to 'be good at school, see you next time'. As Blood (2015) has described, Robert's utterances seemed to represent vocalisations rather than voice.

Robert and Sam spoke of strategies of distraction and incentive that were used to 'entertain' them during the 'adult-focused' consultation. Rather than attempting to facilitate their contribution, these strategies further minimised their position and rendered them invisible.

Robert (57p8): *There was pictures and they were just talking and I was on my PSP [PlayStation Portable].*

Sam (126p22): *Usually I'm doing something that entertains me, something like Lego or something like that...*

Michael and Mason had little recollection regarding their visits to CAMHS; however, like Sam and Robert, both recalled being 'told' they had ADHD.

Michael (12p2): *Me doctor told me.*

Mason (10p5): *I got diagnosed...*

Robert (12p2): *Someone tells them, I got told.*

Sam (120p21): *Um Dr A. telling me that I've actually got it...*

For Michael, there appeared some confusion about ADHD and 'tablets', and both terms were used when talking about the disorder as if they were one and the same. Viewing ADHD and drug treatment synonymously is a trend found in previous research (Travell, 2005; O'Leary, 2007; Gallichan and Curle, 2008). Like Sam and Robert, there was little evidence in his account to suggest attempts had been made to seek his feelings and views, or that 'relevant, age-appropriate information' had been shared (NICE, 2013, p. 12).

In contrast, Mason stated that he knew what he needed to know about ADHD and that he had been given the opportunity to ask questions. However, like Michael, his accounts indicated concern and confusion about his 'condition':

Mason (53p11): *Well, it's a bit of uh, it's a bit weird thinking that you, you, you've got like a condition and, um, and it's thinking, 'Oh my god, people are going to be looking at me like what's wrong with him' and all that.*

According to NICE (2013) 'all people with ADHD, including children, should have an opportunity to be involved in decisions about their care' (p. 7). The guidance advises that health professionals 'allow' the child or young person to give their account and to record this in their notes. The language used is striking and, as Davies (2014) notes, it could be argued it positions the child in a passive and powerless role in requiring 'permission' to contribute. Such advice appears to do little in motivating services to actively involve children and young people in their care, however.

Drawing on interviews with young adults who had been diagnosed with ADHD in childhood, Bringewatt (2013) found that when information was absent or limited, the participants tended to fill the void with concern about the diagnosis. This absence of information and engagement is likely to have contributed to uncertainty in how the children in this study could influence the problem and its effects, exacerbating a sense of not being in control. Instead of active collaboration in exploring possible solutions, the story of them as being the problem continued to thicken.

Despite initial concern and confusion, having a name for the problem seemed to provide some reassurance:

Robert (219p27): *When you want to sit down and do something you can't because you have something wrong.*

Mason (52p11): *I think they [staff in school] might have paid a little more attention to me just to see if I'm okay and stuff cos I've got ADHD, it's not my fault really.*

Michael (20p3): *Your brain...it goes weird, makes you go bonkers.*

These descriptions appeared to reposition the child from being naughty or badly behaved to a child with a medical condition. As Kildea *et al.* (2011) and Kendall (2016) have found, this name can provide an explanation of their difference and exonerate the child.

Sam (43p8): *ADHD, I prefer a name with it because if there wasn't a name then it would get a bit confusing because, and also I feel, I feel like if it was mischievous, because there's no name, it wouldn't feel right, I feel like a name kind of makes me feel a bit better as well.*

Perhaps for Sam and the other participants this name alleviated feelings of guilt and shame generated by the deficit view created around them and their behaviour. However, whilst this may have had a positive impact in the short term, Carrey (2006) has argued that a 'disease metaphor' can unintentionally produce narratives of helplessness and hopelessness. These narratives

appeared to be present in the children's accounts of their experiences and sense-making in relation to their treatment. These experiences comprise the next subordinate theme.

### **6.2.3 'They're to make you good': stories of compliance and control**

All participants reported that they had been prescribed medication for their ADHD, as advised by their psychiatrist. This treatment had been decided upon at the time of diagnosis or shortly afterwards. Three of the participants spoke at length about their medication and indicated their views about why they were taking it. In contrast, one of the participants, Mason, spoke only when asked directly, to establish whether he had been prescribed any pharmacological treatment.

Stories of conformity and compliance peppered the children's accounts when recalling their experiences of receiving medication.

Michael (43p6): *No, every day [to take medication], doctor said.*

Mason (169p28): *A person at [the child and adolescent mental health service clinic] said to take it.*

Robert (97p12): *He didn't tell me, he told me mum.*

Sam (26p5): *I had to have tablets and stuff like that...*

As in the previous sub-themes, there appeared little evidence in their descriptions that they had been listened to or consulted.

When considering drug treatment, NICE (2013) advises that children should be involved, but does not state how or to what extent. From their accounts, the children's involvement appeared to be at the level of being 'told' about the medication and given a persuasive argument for their need to take it. This latter information seemed to relate to the medication offering to improve their behaviour by 'making' them 'good', reflecting dominant 'before-and-after' stories about drug treatment (Horton-Salway, 2011). Given the narratives of 'naughty' present within the previous sub-themes, this influential rationale would be difficult to ignore, as it offered a way for the children to please their parents and teachers, thus reducing the negative responses that had become a familiar experience.

Alarming, for Robert, the decision had been further incentivised by the risk of loss of privileges if he did not comply; the possibility of informed consent had been silenced:

Robert (97-102p12):

*Int: ...so what did he say he was giving you those tablets for?*

*Resp: He didn't tell me, he told me mum.*

*Int: He told your mum about the tablets. So, what did you think about having the tablets, were you okay about it?*

*Resp: Mm-mm no, not at the beginning.*

*Int: Not at the beginning, so what...? Why were you not okay about it at the beginning?*

*Resp: I didn't know what they were.*

*Int: Ah, so who told you what they were?*

*Resp: My mum when she got home.*

*Int: So, what did your mum say?*

*Resp: They're to make you good.*

*Int: Right. And what did you think about that?*

*Resp: Okay, I wasn't going to argue because I'd lose me PSP.*

A striking theme within the children's collective experience was the 'power' and 'control' ascribed to their medication, and this appeared to leave little opportunity for their own personal agency and position as actors in their own lives. In effect, they appeared passive subjects of their medication (Nylund, 2000).

Reproducing the persuasive argument they had been given, Michael, Sam and Robert related medication to improving their behaviour by 'making' them 'good'; this included helping them to 'keep calm' and preventing them doing 'silly things'. The medication was positioned as a means by which to support them in complying with the expectations of school, a trend seen in previous research (Kendall *et al.*, 2003; Travell, 2005; Prosser, 2006; O'Leary, 2007; Gallichan and Curle, 2008; Davies, 2009; Grant, 2009).

In the extract below, Michael (40-42p6) explains the effect of his medication and consequence of not taking it:

*Int: ...so, can you tell me about these tablets then? So, what, what are they for?*

*Resp: Keeping calm.*

*Int: Okay. What would happen if you didn't take the tablets?*

*Resp: I'd go more nuts.*

Change in their behaviour appeared to provide the evidence that they needed to take their medication: so as to avoid the 'naughty' behaviour and negative responses associated with it.

Sam explained that his medication had a dual function in treating both his ADHD and co-morbid ODD. This included relief from angry feelings, prevention of engaging in 'silly things' and prompting him to think before acting. The outcomes Sam described appeared to go beyond accepted effects of stimulant medication, such as improving focused attention and calming hyperactive behaviour (Moncrieff, 2009).

*Sam (37p7): It uh, it helps more on the ODD that I've got which is basically a little bit like anger but um, it also helps the ADHD side um, with stop doing the silly things, thinking before I do stuff.*

The recurrent theme appeared to be that medication led to the participants feeling more in control, or rather, controlled, as found in previous research

(Kendall *et al.*, 2003; Travell, 2005; O’Leary, 2007; Gallichan and Curle, 2008; Davies, 2009; Grant, 2009). This is exemplified in Robert’s account of a storyline from a television drama. Like Michael and Sam, his perception of the storyline spoke of the power of ADHD medication and the implications, although somewhat exaggerated, of not taking it. The view appeared to be that he would be dangerous without it, and therefore the medication was required for both his own and others’ safety.

Robert (116-119p14):

*Resp: Kyle Stack off Waterloo Road.*

*Int: Ah, so what happens to him?*

*Resp: In the end he didn’t take his medicine, he brought, he brought a weapon to school, he shot somebody and then he got arrested ‘cos he didn’t have his medicine.*

*Int: Oh no. And then what happened at the end?*

*Resp: He, they went to him, ‘have you had your medicine today?’ He’s gone, ‘no’. And he was only ten.*

Whilst the medication seemed to offer behavioural control, there were contradictions in the children’s accounts. For example, Sam spoke of times when he had been sent out of class despite taking his ‘tablets’, and Robert and Michael included ‘sometimes’ when providing specific examples of the positive effects the medication had on their behaviour. From their descriptions, there appeared to be an element of confusion as to why they

were doing these things given that they had taken their medication, as if they had become separated from their own influence within their lives.

The theme of compliance and control was repeated within the children's daily routines, as teachers and parents provided regular prompts to ensure they had taken their medication, as Michael described.

Michael (122-125p16):

*Int: Okay. So, it sounds like the tablets are quite important in your life, sort of when you take them, is that right?*

*Resp: Yeah.*

*Int: Okay. Who, who reminds you to take them or do you know to take them?*

*Resp: Me mum.*

*Int: Your mum reminds you. What about at school?*

*Resp: Teachers.*

*Int: Your teacher reminds you.*

*Resp: I, I used to have an alarm clock go. I used to have an alarm clock and it, it rings and it's tablet time.*

For Michael, medication had a prominent role within his daily routine, and despite his difficulties recalling some events within the interview, his clarity around 'tablet time' was striking. This 'adult monitoring' was present in the

accounts of Sam, Mason and Robert, who also spoke of regular reminders by their teachers and parents.

Within the accounts there was an absence of the ambivalence described in previous research (Cooper and Shea, 1998; Travell, 2005; O'Leary, 2007; Gallichan and Curle, 2008; Davies, 2009) regarding views about medication. However, despite the lure of the medication's physiological outcomes, some of the children briefly mentioned less appealing social and relational effects. Michael identified an additional advantage in being able to 'get out of class' when it was 'tablet time'. However, as a consequence, he missed parts of lessons and needed to ask peers for help to catch up. Although not described within his account, this appeared to place him at risk of further reprimands about his behaviour.

For Sam, the medication appeared to be an external sign of difference that set him apart from his peers, and which had had negative effects on his social relationships:

Sam (26-29p6):

*Int: ...have people treated you differently since the ADHD?*

*Resp: I do think actually 'cos like people had... because I had to have tablets and stuff like that everybody was like why have you got to have tablets, why have you...? They were being a bit nasty, you know, but um, [hesitates] I just ignored them and try and carry on with my life and then everybody stops. Everybody stopped being, being nasty after I tried to be me.*

*Int: So, what might, when you say people were nasty, what sort of things might they have done?*

*Resp: [sing-song voice] Oh, [child] got to have tablets, [child] got to have tablets, picking on me for having tablets and stuff like that.*

*Int: Are they people in your class?*

*Resp: Yeah.*

*Int: Oh gosh.*

*Resp: Yes, and my best friend as well, so I had no friends.*

In handling this difficult situation Sam adopted a strategy of trying to be 'me'. He does not describe the meaning of this, but it suggests his attempts at concealing his apparent 'difference' by presenting himself as being 'normal' like his peers. Themes of normality and difference are discussed within the subsequent superordinate theme.

Sam's experience, however, raises questions about how children's medication is handled, particularly within schools. Current advice appears to offer little guidance in this respect, apart from suggesting medical information is treated confidentially and there should be involvement from parents and children in decisions about who should have access to records (DES/DH, 2005).

### **6.3 'It's like a serious mystery': how ADHD is perceived, experienced and managed**

The children attributed ADHD to neurological and genetic factors, and there were references to its longevity and control over their lives. There appeared to be dissonance in accepting they were and, in some instances, seeking to be different, whilst, on the other hand, constructing themselves as 'normal' and being like their peers. As described within the previous superordinate theme, a deficit view appeared to have been constructed around the children and their behaviour, to which they also seemed to subscribe. This positioned them as being at the mercy of the disorder and as 'passive recipients of care' (LeFrancois, 2008).

#### **6.3.1 Understanding ADHD: 'an extra factor in your brain that makes it go quicker'**

The predominant view was that ADHD is caused by biological factors; manifesting in differences within the brain and likely to be genetic. These views appeared to reflect information they had been given by their parents and professionals from CAMHS, and which replicated dominant discourse around ADHD (Timimi, 2013).

Sam believed the ADHD made his brain function more quickly, which he likened to a 'nuclear power station':

Sam (1/5p1):

*Int: So, can you tell me about ADHD? What is it?*

*Resp: ADHD is um, something that people can get from birth and can sometimes affect how they're thinking.*

*Int: So, where do you think it comes from?*

*Resp: ...it's just something that a little teeny bit of your brain is um, took over by ADHD that just makes, it's like an extra factor in your brain that makes things quicker.*

*Int: Right. So, do you...? Is ADHD then sort of to do with the brain then do you think?*

*Resp: Yeah, I've got... I've been told by somebody who um, [CAMHS practitioner]. And he told me that um, it's basically something that, a little bit of your brain is being sped up so I thought like it's a little bit like a nuclear power station making it go quicker and quicker.*

Michael provided less information, but similar to Sam, he believed the cause of ADHD to be located in the brain, causing it to be 'weird' and 'bonkers'.

Michael (19p3): *Your brain it goes weird, it goes bonkers.*

Mason's view centred firmly on his 'genetics', and he supported his claims by presenting 'genetic evidence' related to his family:

Mason (23p7/35p9):

*Int: Okay. So, where did... where does ADHD come from, do you know?*

*Resp: Genetics.*

*Int: ...when you said about the cause of this ADHD is genetics, how do you know that? What... how have you found out about those things?*

*Resp: Well, I think he... 'Cos me cousin's got it as well... me mum says it like runs in the family, isn't it. So, I think it's just like skipped me older brother and come to me, the genetics.*

These views appeared to influence stories of their identity and shape understanding of their experiences, as described in previous research (Cooper and Shea, 1998; Krueger and Kendall, 2001; Travell, 2005; O'Leary, 2007; Grant, 2009). From the biological perspective, there was something intrinsically wrong and therefore little they could do to bring about change.

In contrast to the neurological and genetic factors described by the other child participants, Robert believed the cause of ADHD was 'being naughty' and 'when you are angry'. However, despite describing causes that could be considered within his control, his account (described in the previous sub-theme) spoke of a lack of control and personal agency, as if the 'naughtiness' had been assimilated into his core being. Like the other participants, his views seemed to shape the narrative of his identity and thus his experiences.

Although ADHD was described as a problem within the brain, Sam's account suggested that there remained some confusion and uncertainty in his understanding:

Sam (112p20): *...it's like a serious mystery, so you don't really know, you only know a couple of things but you, you... you do know more things but there's no um, right or wrong answers, if you know what I mean.*

Sam's use of the phrase 'serious mystery' to describe ADHD is interesting, as his description of the neurological difference (presented earlier in this sub-theme) suggested doubt about the extent to which ADHD controlled his 'thinking' (and perhaps his behaviour). It was as if he was grappling with the degree to which the ADHD defined him. Recognition of his own autonomy provided acts of resistance against ADHD and gave him some control; however, in doing so, he risked placing himself in a position of blame in being responsible for his actions.

### **6.3.2 'I'm not very much like other kids': experiences of stigma and difference**

A theme across the accounts was of negotiating normality and abnormality in relation to the self and others, with frequent references to feeling 'normal' and being 'different'. These feelings have been documented in previous research exploring children's views (Kendall *et al.*, 2003; Gallichan and Curle, 2008; Grant, 2009; Meaux *et al.*, 2009; Jones and Hesse, 2014). Narratives of difference appeared to relate to their experiences of standing out due to their

behaviour, and of social exclusion as a consequence of a dominant story that there was 'something wrong'. However, within these stories there appeared some conflict between accepting this perceived 'difference' and 'normality', with frequent contradictory comments. On one hand, there was a sense of wanting to fit in and not stand out, similar to the experiences described by O'Leary (2007) and Gallichan and Curle (2008); however, on the other hand, there was a view that being different was positive (in relation to the positive attributes they associated with ADHD) and, perhaps, desirable, similar to findings in previous research (O'Leary, 2007; Davies, 2009; Grant, 2009).

Mason (56p12):

*Resp: I think it's quite fun that not, that not all people know it, because if they saw me now and they didn't know, they wouldn't, they wouldn't, they wouldn't think anything of me; they'd just think, 'Hmm, normal kid' and walk on.*

*Int: ...and do you like that? Is that very important, do you think, to be seen as a normal kid?*

*Resp: I don't think... I like to be different.*

In this extract, Mason's reference to being a 'normal kid' appears to relate to his ability to fit in by functioning in an acceptable manner. As described in previous sub-themes, 'difference' had been defined through the children's interactions with the social world and in comparison with others (e.g. their siblings and peers); a trend in previous research (O'Leary, 2007; Gallichan

and Curle, 2008). School in particular presented them with situations that provided proof of their difference.

Similarly, Sam swung between narratives of difference and normality as if struggling to reconcile which he preferred or, perhaps, which was a more socially acceptable position.

In referencing normality, Sam comments:

Sam (41p8): *I, I even when people are talking I've got ADHD, I still feel normal.*

Sam (48p9): *It feels normal, you don't really know what other people... You... I, I've found that you wonder that if they have ADHD is there any, the other people, is there any differences and if, if um, [hesitates] if... what other people would be thinking and if I was thinking what they would be thinking normally if you know what I mean.*

The ADHD seems to set Sam apart from others; however, there is confusion regarding the extent to which the label defines him. Sam also comments about his 'difference' positively, with particular reference to the skills he has, which he perceives to be as a result of the ADHD:

Sam (50p9): *...you have more energy and you use that little bit more energy to um, accomplish more things and if you can contain that extra thoughts that you have you can actually make something really good out of it.*

For Robert, 'difference' was experienced through others' reactions to him and the resulting social exclusion, which he believed to manifest from a belief that there was 'something wrong' with him:

Robert (122-127p15):

*Int: Does it make you feel different than other people?*

*Resp: Mm-mm sometimes.*

*Int: Sometimes. So, how does it make you feel different?*

*Resp: When you want to be someone's friend they say no.*

*Int: Ah. Why do you think they might say no?*

*Resp: Mm-mm for some people it's if someone has something wrong with them they don't want to be friends with them.*

*Int: Ah. So, do you think having ADHD is like that you've got something wrong with you?*

*Resp: No.*

*Int: No. But do you think that's what other people might think?*

*Resp: Yeah.*

*Int: Yeah. Why do you think other people might think that?*

*Resp: 'Cos sometimes when you're outside playing people say, 'I don't want to play with you, you've got something wrong with you.'*

Robert spoke about how these stigmatising views were held by not only his peers but also their parents:

Robert (141p17): *And sometimes their parents say that 'cos when I was in, when I was in the other school this boy's dad came up and went, 'I don't want you playing with my son, you've got problems.' I went 'I'm not bothered.'*

Robert's dismissive 'I'm not bothered' response appeared to hide a more deeply felt emotional reaction, as illustrated:

Robert (128p16): *Mm-mm they make you upset.*

Michael's difference was narrated through his emphasis on being 'bonkers' and 'nuts', and his need for 'tablets', both of which seemed to originate from his interactions with adults at home and school.

Michael (21p3): *It [brain] goes bonkers.*

Michael (3p1): *Going nuts, going nuts, I go nuts.*

The terms 'bonkers' and 'nuts' were used throughout to describe his brain, thoughts and actions, and appeared to set him apart from others. For Michael, these terms seemed to have become totalising descriptors of his identity.

Whilst the children experienced narratives of normality and difference in various ways, early dominant stories presented by those in authority appeared to influence the ways in which ADHD had come to define them. Kinderman *et*

*al.* (2013) argue that in coming to understand ADHD as a within-person deficit has the potential to exclude other possible meanings in people's different responses and experiences, thus preventing people from understanding how they might use their own resources to address their difficulties. These experiences are discussed within the next sub-theme as the children negotiated narratives of passivity and control.

### **6.3.3 ADHD is in charge: 'I can't make it go'**

Consistent across the children's accounts was a dominant story that ADHD had considerable control over their actions, and their experiences seemed to be filtered through the lens of ADHD. The theme of control has been identified in previous research in relation to the controlling effect of medication (Cooper and Shea, 1998; Kendall *et al.*, 2003; Travell, 2005, O'Leary, 2007; Gallichan and Curle, 2008; Grant, 2009); however, in this study, the children also spoke of the controlling effect of the ADHD. In a sense, ADHD was perceived as determining their behaviour, echoing the early concerns that had emerged from adults around them (including their parents) during identification of 'the problem'.

Sam (9p2): *I can't make it, I can't make it go but yeah that's all I can really say about that.*

Mason (6p5): *It [ADHD] makes you a bit more sensitive...(3p4) well, I think it's [ADHD] a condition that like sort of messes with your emotions and makes you a bit, a bit more hyper than other kids.*

Michael (202p25): *It [ADHD] makes people crazy.*

However, like the stories of normality and difference described in the previous sub-theme, these were peppered with contradictions as the children attempted to make sense of a self as defined by ADHD and self as separate from the dominant ADHD story. This uncertainty is illustrated by Sam in the following transcript:

*Sam (56p10): The thing is I don't... myself I don't know about, this is just my opinion, I don't think ADHD does that, I think that um, it's just... It does do that but it's not, it's not as... It just doesn't do it as much if you know what I mean, I can't really explain that one.*

The children appeared to take a determinist stance when explaining the difficulties they experienced; for example, 'can't', 'incapable' and 'never' appeared frequently in their descriptions. As described by Tait (2003), behaviour was perceived to be a function of the disorder and therefore not under their control. They appeared to have become passive subjects of their medication and the ADHD, rendering invisible their competence and personal agency.

*Mason (61p13): Cos I know that I'll, I'll never be able to just relax...(5p4) I can never sit still... incapable of it.*

*Sam (58p11): Um, my sister can't be in the same room 'cos that will be just in case then if I do anything. Because when we were young me and my sister used to always fight. I guess that's what brother and sister do, but you know. My sister, my mum doesn't want me to do that when I've got a bit angry just in case I hurt her.*

Robert (219p27): *When you want to sit down and do something you can't because you have too much energy.*

Michael (149p20): *Yeah, if I don't have 'em [medication]. Sometimes I do it and sometimes I can't.*

Their accounts also spoke of what they believed they needed to do rather than what others could do, particularly in the context of the difficulties faced in fitting in with the expectations of school.

Sam (11p2): *And now I think it's getting worse but because I'm doing stuff that [hesitates] I shouldn't be in year 6 but, 'cos, because it's very restrictive and I'm not rest... I'm not going with that.*

Mason (17p6): *Well, I do... I can sit moderately still like I'm doing now. But I just can't keep completely still.*

This appeared to reflect the construct of the problem where interventions, or rather medical (drug) intervention, seemed to focus on changing the child rather than altering the environment.

As referred to in the previous sub-theme, the experiences provided proof of their difference and of the control of the ADHD.

There had been painful memories triggered for Mason as he recalled a recent school trip during which he had been sent home early. Due to his distress we did not discuss this further, but I wondered about the adjustments, if any, that

may have been made to support him, or whether the onus was on Mason to adapt. An aspect of the experience he could recall was his teacher's anticipation and subsequent relief at his response to falling in water:

Mason (143p24): *...I jumped, grabbed onto the side, but me legs, all me legs... I got out. Me teacher expected me to just explode and bolt off. Well, I was like, I was like, I was like I, I just went, 'I'm okay' and I just went back to the activity with me boot still filled up with water. We did, we did the last one, and, and then after the last one me teacher... we got... me, me teacher was dead happy with me like that I didn't kick off.*

This problem-determined expectation (that he would 'kick off') highlighted Mason's difference and set him apart from his peers. Yet, feeling somewhat disgruntled and upset might be a typical response to falling in cold water; however, for Mason, I wondered whether these events and expectations were being interpreted through the lens of the problem story.

The children also spoke of their skills and abilities, particularly their 'extra energy', which were viewed collectively as an enviable trait. Mason believed it had developed his sporting prowess to become 'the fastest kid in school'; Robert indicated that he was never out of breath; Sam believed it had helped his martial arts because 'you have to be moving 24/7'; and Michael related the extra energy to being able to run quickly ('like a nut'). However, loitering underneath these skills and qualities remained the powerful influence of ADHD. It seemed ADHD had become intertwined with their identity.

Sam (70/74p13/14): *I think I'm creative because of ADHD... I think I've got the extra energy because I've got ADHD...*

Glimmers of alternative stories were present in the children's accounts as they described aspects of themselves that did not fit with the dominant discourses surrounding their behaviour. Sam and Michael spoke of their flare creating Lego constructions; Sam spoke of his interest in creating origami designs; Mason described his sporting abilities, including his success learning kick-boxing; and Robert spoke of his 'daring' abilities when riding his scooter. Although perhaps overlooked, there was evidence that ADHD's effects fluctuated according to the situation and context. Sadly, for Mason, Sam, Michael and Robert, rather than being used to mount resistance against the effects of the ADHD, and to create alternative stories of their identity, these appeared thin identity descriptions overshadowed by a thickened narrative of a disordered child.

#### **6.4 Summary**

Through analysis of the children's experience of having ADHD in their lives, two superordinate themes were constructed. These themes described the ways in which ADHD came to be present in the children's lives and how it was perceived, experienced and managed. As described in previous research, including the studies presented in Chapter 3 (Kruegar and Kendall, 2001; Kendall *et al.*, 2003; O'Leary, 2007; Davies, 2009; Grant, 2009; Kildea *et al.*, 2011; Byrne and Swords, 2015), the children's personal experience tended towards 'being', rather than 'having' ADHD.

From the children's accounts, and similar to studies presented in chapter 3, ADHD was understood in the context of their behaviour, which had been positioned by their parents and teachers as an object of concern. There had been close examination of the child and their behaviour, in which they had been watched, monitored and chronicled. As described by Kendall *et al.* (2003), it was adults in authority who seemed to construct the reality of the ADHD.

A child-centred approach was described, but not in a positive way of being included in decisions or of being listened to, but rather, as Travell (2005) and Davies (2009) found, a process in which they were presented as being at the centre of the problem and therefore the focus of investigation. Similar to O'Leary's (2007) research, these experiences appeared to influence the ways in which ADHD came to define them and seemed to render invisible other factors that may have been contributing to the problem. In responding to their own similar findings, Cooper and Shea (1998) and Travell (2005) argued for a more 'balanced view' of ADHD, one that acknowledges the range of causal factors associated with it (e.g. those presented in Chapter 2, section 2.6), and application of a 'broad theoretical perspective' when interpreting behaviour (e.g. biological, social, cultural and relational factors).

Akin to studies presented in Chapter 3, the children's accounts spoke of what they needed to do rather than what others could do, with interventions focused on changing the child (e.g. through medication) rather than altering

the environment. Byrne and Swords (2015) have cautioned that investing in repertoires of 'something is wrong' may allow avoidance of more difficult conversations of 'something wrong with our situation' (p. 74). Drawing on their findings, Gallichan and Curle (2008) assert that children and young people can experience difficulties 'fitting in' when they feel forced to change without the environment adapting to their needs. Such experiences are likely to have contributed to the ways in which ADHD came to define the participants.

A recurring theme was of negotiating normality and abnormality in relation to the self and others, with frequent references to feeling 'normal' and being 'different'. These contradictory feelings were also documented in studies presented in Chapter 3 (Kendall *et al.*, 2003; Gallichan and Curle, 2008; Grant, 2009) and more recently, by Jones and Hesse (2014). On the one hand, there was a sense of wanting to fit in and not stand out (similar to findings by O'Leary (2007) and Gallichan and Curle (2008)); however, on the other hand, there was a view that being different was positive (in relation to the positive attributes they associated with ADHD) and, perhaps, desirable (as found by O'Leary (2007), Davies (2009) and Grant (2009)). As described by O'Leary (2007) and Gallichan and Curle (2008) the 'difference' the participants' described appeared to be defined through their interactions with the social world and in comparisons with others.

Stories of being silenced weaved through many of the themes as the children described processes and procedures that rendered invisible their voice and

participation, from initial identification of the problem to diagnosis and treatment. An adult-orientated system appeared to operate in which the adult's needs, views and experiences were heard and responded to. As stated previously, it was the adults in authority who constructed the reality of ADHD (Kendall *et al.*, 2003). In contrast, the children were positioned as passive and subservient, and expected to conform and comply with being assessed, monitored and treated, similar to findings described by Kendall *et al.* (2003), Travell (2005) and Davies (2009). The accounts spoke of being 'told' about their problem behaviour, being 'told' there was 'something wrong', being 'told' they had ADHD and being 'told' to take their medication. Despite increasing recognition of children's rights and right to participate both in mental health services (e.g. *National Service Framework for Children, Young People and Maternity Services* (2004)) and in education (e.g. *Children and Family Act 2014* and associated *Special Educational Needs and Disability Code of Practice: 0 to 25 Years*), there seemed little evidence of their being listened to, informed or consulted.

Wrapped within the discourse of their problem behaviour, medication appeared to be offered as first-line treatment (similar to findings from studies discussed in Chapter 3), and presented as a means by which to modify and control them in order to 'make them good'. Such experiences have prompted some (e.g. Travell, 2005, Traxson, 2010, Brady, 2014) to question adherence to clinical guidelines (e.g. NICE, 2013) which recommend the prescription of medication as first-line treatment only in severe cases whilst still forming part of a multi-modal approach. As Breggin (2014) has commented, the

experiences the child participants described appeared to further relinquish personal agency and control, leading to uncertainty about how they could influence the problem and its effects. The children spoke of the controlling effects of not only their medication, as described in the research presented in Chapter 3 (Cooper and Shea, 1998; Kendall *et al.*, 2003; Travell, 2005; O’Leary, 2007; Gallichan and Curle, 2008; Grant, 2009), but also the ADHD. ADHD was perceived as determining their behaviour, which appeared to echo early concerns that had emerged from the adults around them during the identification of ‘the problem’.

Similar to the studies described in Chapter 3 (Kendall *et al.*, 2003; Travell, 2005; Davies, 2009) medication had a prominent role in the children’s daily routine and ‘adult monitoring’ was used to ensure the prescribed medication was taken at the correct intervals. In contrast however, there was an absence of the ambivalent attitude towards medication described in previous research (Travell, 2005); O’Leary, 2007; Gallichan and Curle, 2008). Participants in this study, as discussed in Chapter 6, spoke overwhelmingly of the positive offerings of their medication (e.g. ‘making them good’), which appeared to reflect the persuasive arguments given by their parents, teachers and health professionals.

Having a name for the difficulties experienced produced positive and negative effects. It provided some relief from blame (similar to findings from a recent study by Kendall (2016) but an experience not described in the research presented in Chapter 3) and triggered access to additional support within

school (as described by Travell, 2003, and Davies, 2009); however, it set them apart from others by confirming their 'difference' (akin to findings by Gallichan and Curle (2008), Davies (2009) and Grant, (2009)) and appeared to locate the problem within their neurobiological make-up, a trend in previous research. These views appeared to influence stories of their identity and shape understanding of their experiences, similar to the research presented in Chapter 3 (Cooper and Shea, 1998; Krueger and Kendall, 2001; Travell, 2005; O'Leary, 2007; Grant, 2009).

Despite negative descriptions and deterministic accounts, there were exceptions to the dominant story. Similar to findings by O'Leary (2007) and Davies (2009), the children spoke of positive attributes, which they linked to the ADHD (e.g. 'extra energy'), and described skills and qualities, which would not have been predicted by the dominant discourse that surrounded them. Whilst these experiences provided the starting point to alternative stories about their relationship with ADHD (as a narrative approach developed by Nylund (2000) has described), they remained thin descriptions within a thickened child-centred plot. As Byrne and Swords (2015) have described, the label (and discourse surrounding it) brought forth 'assumed truths' which appeared difficult to negotiate and separate from.

In order to enrich understanding of the phenomenon of ADHD, this study also sought the views of parents (see Chapter 5, section 5.3 on participants). The following chapter presents findings from the individual interviews with the four parent participants. The three superordinate themes constructed through the

analysis are discussed alongside discussion of similarities and differences in the child and parent accounts. Specific links between the parent and their child are not made directly, as child participants were informed that their accounts would not be shared with their parents. This decision was made to enable, as far as possible, the children to talk 'freely' about their experiences. Following a review of studies investigating ways to encourage children's involvement and participation in their own healthcare, Day (2008) reported that children voiced dilemmas of privacy and worries about parental reactions. Whilst there was a focus on enabling the children to talk 'freely' local authority protocols were adhered to in relation to safeguarding guidelines (see p. 280 *University of Birmingham Application for Ethical Review*).

## CHAPTER 7: RESULTS AND DISCUSSION OF INTERVIEWS WITH PARENTS

### 7.1 Introduction

In this chapter I present the findings from the interpretative phenomenological analysis of individual interviews with the four parent participants. As discussed in Chapter 5, they were parents, all mothers, of the child participants who also took part in this study (see Chapter 5, section 5.3, for information on the participants).

Three superordinate themes were constructed through the analysis of transcripts from the semi-structured interviews. These themes, and their corresponding subordinate themes, are illustrated in Table 7.1:

Superordinate Theme	Subordinate Theme
1. Seeking help: a journey of pleading, proving and compliance	1.1 'Just help me': pleading and proving that there is something wrong 1.2 The hoops and hurdles: 'Everything they threw at me, I did' 1.3 'Diagnosis then off you go': the absence of support and consultation 1.4 'He must have the condition because the medication works': the medication conundrum
2. 'Through all them four letters, changes everything': stories of acceptance and validation	2.1 'You can't have an unlabelled child; it doesn't work': proof and acceptance 2.2 'It's not just him playing up; there is a problem there': an ADHD self and identity

<p>3. 'Stress, stress, pure stress': ADHD is hard to live with</p>	<p>3.1 'ADHD is hard, it's hard to live with': the fights and sacrifices</p> <p>3.2 'You're the one person that's got their back': watching, protecting and restricting</p> <p>3.3 'You get used to it, you learn how to cope': determination and developing expertise</p> <p>3.4 'You're nothing like us': separated, excluded and stigmatised</p>
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Table 7.1: Three superordinate themes, and their corresponding subordinate themes, emerging from the analysis of the four individual interviews with the parent participants.

Each superordinate theme, and their corresponding subordinate themes, is presented individually under their selected headings. Themes will be explained and illustrated with verbatim extracts from the interview transcripts (in italics) alongside summarisation of key points and interpretative commentary. To ensure anonymity, extracts from participants are labelled with their chosen pseudonym; all other means of identifying participants (e.g. through names of family members, educational institutions and professionals involved) have been removed.

## **7.2 Seeking help: a journey of pleading, proving and compliance**

The parents spoke of feeling concerned about their child from the earliest years, having noticed differences in their behaviour. Frequent visits to educational and health professionals followed, and parents recounted stories of pleading, proving (through their engagement in a variety of assessments), and waiting for acknowledgement and confirmation of their own explanatory

hypothesis. For some, a crisis appeared to accelerate the final stages of what had already been a lengthy process. In contrast to their long wait for assessment, parents spoke of a diagnosis being given quickly following a visit to a psychiatrist. Medication followed and parents spoke of its positive impact in controlling their child's behaviour. However, pharmaceutical treatment was not considered the panacea and there remained disappointment at the lack of post-diagnostic support.

### **7.2.1 'Just help me': pleading and proving that there is something wrong**

This sub-theme comprises the parents' attempts to understand and make sense of concerns regarding their child. A narrative of 'difference' ran through their accounts, with some of the parents 'knowing' from their child's earliest years (and even pre-birth) that something was wrong (or different).

Their initial concerns appeared to be confirmed as comparisons were drawn with their child's siblings. Such observed differences, despite experiencing a similar familial environment, seemed to set the problem on a biological explanatory path.

*Netty (15p3): Just generally completely different. We've got a huge family so you're looking at all different kids in the family and things like that. I was just thinking... I just put it down to he's diff... and I still say it, he's just different.*

For Dionne, Clare and Marie, concerns about their children appeared to relate to increased activeness and inability to sit still. Confirmation of this difference

by others (e.g. health visitor) seemed to validate the extreme and abnormal nature of the behaviours they had come to observe, and appeared to confirm they were not 'normal' child behaviours.

Dionne (18p7): *Seriously when he was 3 years old he was um, well I can't say when he was 3 actually, it was like when he was a baby... 2 months old he was bouncing in a door bouncer, you know, the health visitor would say oh my god, you know, he shouldn't be doing that yet and he was very forward in that way and he was very active.*

Clare (22p4): *Oh yeah, from very, very young. The minute he's moved, he's never ever sat still...*

Marie (65p14): *He never sat down.*

Netty (23p4): *The age of about 2. Even from a baby, but, you know, you just think they haven't, they haven't really got a personality at that stage.*

For Netty, these concerns related to a range of unusual behaviours that appeared to be related to sensory sensitivities and differences in social interaction:

Netty (15/16p3): *Completely different, doesn't like being touched, liked being on his own, rocking mode, just completely different, didn't like people touching his food... things that aren't normal, like eating clothes. You're just like why are you eating clothes and, you know, licking lamp posts?*

Her description emphasised the extreme and unusual nature of the behaviour, reinforcing the narrative that there was 'something wrong'. This narrative of

difference and of 'something being wrong' had not gone unnoticed by the child participants, who were aware that their behaviour was an object of concern and that as a result, they were subject to surveillance from their parents, teachers and other professionals (see Chapter 6, section 6.2.1).

Despite the parents' early concerns, it was often within the school context where proof of their child's difference became most apparent, and where the case for ADHD began to develop:

Marie (73/74p15): *From his behaviour when he was in nursery, nursery reception. Every day I used to get a phone call from school.*

Dionne (18p7): *I was trying to work it so I got a job in a cake shop which was just opposite where I lived, and I was having phone calls, oh [child] absconded out of the class, he's walking around, you know.*

Clare: *... you get cheeky little boys sometimes don't you and loveable cheeky rogues when they're younger but as they grow up the expectation then changes, so your expectations more, but he wasn't coming up with the expectation. So, that's when we kept noticing and it was getting more wider, the gap, um, because I mean like in nursery and stuff he'd never sit still, you know, wherever he's been he won't sit.*

As Clare describes, the 'typical boy' behaviour she had initially observed appeared to take on new meaning in the context of school and changing expectations. As the child participants described, the school presented situations that highlighted their difference (Chapter 6, section 6.3.2). However, despite the influence of these contextual factors, the focus appeared to

remain on Clare's son and his presenting problems. A narrative that 'something must be done' began to gather pace.

In their quest for answers, parents spoke of their pleas for help from educational and/or health services. A lengthy and arduous process began in which many battles would be fought on behalf of their child.

Dionne (19p8): *... so from 3 years I was taking him to the doctor, I was taking him to the GP and asking for support, asking for that, they can't diagnose it until a certain age, because obviously he was only 3 and kids can be like that.*

Netty (16p3): *And I went to me doctors and he transferred me to CAMHS [Child & Adolescent Mental Health Service] and then nothing. I don't know whether the letter didn't get there or nothing. I struggled through just thinking well maybe they don't think it's anything.*

Clare (23p5): *... so we went to the doctors and he didn't keep still for the 10 minutes we were there. So, he then referred us to CAMHS who then said no because it had only been referred by the doctor.*

For Marie, help had initially been requested through educational and social services. She described the process as 'horrendous' and, like Netty, Dionne and Clare, she had 'muddled through' without support.

Marie (97/100p18): *I went to a failed CAF [Common Assessment Framework]. I did CAF and failed that... Um social care wouldn't accept us because [local authority] social services don't see ADHD as a disability.*

Marie's use of the term 'failed' in her description appeared to emphasise the extreme nature of the difficulties being experienced, in which universal support systems were unable to provide the specialist assistance required.

Progression to specialist services such as the Child and Adolescent Mental Health Service (CAMHS) appeared to require further evidence from schools, to provide additional validation of parental concerns. Once again, stories of pleading, proving and persisting weaved through their accounts as parents 'battled' to secure this support.

For Dionne and Clare, this had been a simple process. Their child's school already had concerns and were eager to support the referral to CAMHS:

*Clare (24p5): I'd asked... I spoke to school and asked them if he would refer him and they said yes...*

Dionne expressed her relief that someone was 'listening' – legitimising her early fears that there was 'something wrong' with her child. The referral to CAMHS appeared the all-important element through which to provide an expert perspective to substantiate her hypothesis, and gain access to support:

*Dionne (21p9): And then Mr A. said I think we need to refer him because there is a problem and I said well, you know, whoopy-do, thank god somebody's listening because I've tried before but they wouldn't listen because of his age; so Mr A. actually put him in for CAMHS.*

In contrast, for Marie and Netty, the process had been lengthy and difficult, as they described a lack of 'willingness' to support them. This stance was interesting given the exclusions and constant telephone calls home, and perhaps reflected a view of the problem within the discourse of poor parenting.

Netty (17p3): *... the school were noticing in the school, although they were noticing, weren't willing to do anything about it. So, this went on for years.*

Marie (42/43p11): *So, when you've got a child who's at their wits... and unfortunately schools are only interested when it starts hitting their targets. So, if a child with ADHD is still conforming but isn't reaching their own potential they're not really concerned.*

Crucially, for both these parents, a crisis had then taken place which appeared to trigger assessment and subsequent diagnosis:

Netty (18/19p3/4): *And in the end I went back to me doctors, 'Just help me. Something's not right. Something's going to go seriously wrong'. I said, 'Please'. Because before that I... [child] wouldn't have been here because he tried to kill himself, tried to hang himself and things like that, so the help come when it needed to, but it come too late.*

As Netty describes, in negotiating the many hurdles to CAMHS, help came (nearly) too late and as a consequence, the initial presenting problems had evolved into a more complex set of difficulties.

Marie (108p20): *I had a 2-year wait then for CAMHS... Dr A., me appointment was for Christmas Eve with Dr A. at the health centre, because he was standing in, and Dr A., Dr A. cancelled on me. And I rang him back and I said I wasn't accepting it and if my son hurt anybody over Christmas then I would hold him personally responsible... [he telephoned] 20 minutes later saying he wanted to see [child].*

In these extreme descriptions, and in those presented by the child participants (see Chapter 6), it appeared the severity of the behaviour problems prompted referral rather than whether or not the difficulties could be demonstrated as resulting from core ADHD symptoms (see Chapter 2, section 2.2).

As parents entered the assessment process, there was a belief that their views were of less value and that 'professionals' were required to visit them in order to quality assure concerns. Dionne reported that following an observation of her child (within the home and school context) by a CAMHS practitioner, she was informed: '... oh I don't think he's got ADHD, he's just very boisterous'. Dionne believed that this conclusion was reached after her son was observed watching a favourite programme:

Dionne (23p11): *So, she saw that side of him just sitting there watching it but she didn't see, like I said, the other side of [child].*

This alternative view was not welcomed by Dionne and led to conflict between herself and the professional. From Dionne's perspective, this lack of experiential knowledge rendered invisible the obviousness of her child's difficulties and risked placing her within the discourse of poor parenting.

In Marie's case, she believed her child had been prejudiced after another of her children had already been assessed by CAMHS with no diagnosis given.

At an initial appointment, she recalled the CAMHS practitioner stating:

Marie (106p20): *'You do know your other son never met our criteria for a diagnosis'. And I knew then [child] would never get the support or help.*

This perceived denial of help placed Marie back on the path of pleading, proving and waiting; risking further crisis for her child and her family, as Netty described:

Netty (answer 55p13): *you see a mum that's asked for help for years and years and years and then snaps; that should never happen.*

### **7.2.2 The hoops and hurdles: 'Everything they threw at me, I did'**

When the CAMHS system was finally accessed, the lengthy and arduous process continued, with many 'hoops and hurdles' to be negotiated. For example, the parents described being asked to complete checklists about their child's behaviour (e.g. Conners' Rating Scale, 1997) and early development, obtain reports from their child's school, present themselves for interview with a CAMHS practitioner and complete a parenting course. The various aspects of assessment appeared to progress at a slow and disrupted pace, and parents reiterated their 'long wait' during which they were left to 'muddle' through and find their own way (discussed in more detail in section 7.4.3).

Clare (115/116p25):

*Resp: ... nothing happens from like when you get that appointment for like 12 months later or 2 years later, nothing's happening in-between.*

*Int: So, if you could make key changes that would have changed your experiences what things would you have liked?*

*Resp: ... something in there, that middle bit, some input. No, we haven't been diagnosed but they've acknowledged that there's something, whether they know what it is or not I would have liked more.*

*Netty (42p8): ... it has constant knock-on effects if it's not picked up soon enough. If you're waiting 5, 6 years before you even get a diagnosis, but you've waited 6, 7 months before you even get an appointment, it's too long.*

The process had been particularly slow for Marie. She explained that her child had already been referred to a specialist autism assessment team within CAMHS and had not received a diagnosis; however, she had been informed her child may have ADHD and been re-referred into the CAMHS system. The quote below illustrates her frustration at what she perceives to be complicated and fractured systems within her local CAMHS:

*Marie (107p20): And I went back and he... they sat there and she says, 'We don't think it's autism... ASD, but we think he may be ADHD'. Well, what I didn't know at that time is they shared the same office with the ADHD department, so they sent it all the way back through CAMHS!*

Reflecting on the assessment process, Netty reported her frustration at having to tell and retell her 'life story', which not only probed for details about her pregnancy and child's early history but also details of her personal

relationships and her own mental health. Gaining a developmental history is considered good practice (NICE, 2013) in diagnosing ADHD; however, the rationale did not appear to have been explained to Netty, who had begun to suspect this as a means by which to apportion blame.

Netty (110p29): *You've got to... they go... they do the whole... And you get used to it, it's so many times they're telling your story... just telling your life story basically.*

Not only had she felt this an intrusion into her own 'life history', she had a sense that it was an attempt to 'find an excuse not to give [a diagnosis] or to help':

Netty (180/p50): *... so in the end when they realised she couldn't find blame that's when you get it. It shouldn't take that long, that's the only thing.*

As discussed within the previous sub-theme, there appeared to be a belief from the parents that their views and experiences were of less value (or perhaps less objective) than those of school staff and other professionals. This prompted feelings of frustration and despair, as the parents had already formulated their explanatory hypothesis, as Marie described:

Marie (235p53): *... most of the parents who have got to diagnosis stage already know their child has got ADHD.*

This was further evidenced by Netty's account of the 'near match' of her own and school's copy of the Conners' Rating Scale (1997). As she explained, 'never has that scale been so similar'; there appeared some relief at the

validity this provided for her long-standing concerns. Whilst the guidance states that diagnosis should not be made solely on the basis of rating scales (NICE, 2013), Netty's recollection was that this had been a turning point in the assessment process: firstly, that professionals within CAMHS had 'started to notice', as if the matching scales provided the 'gold standard' evidence required; and secondly, that she was not to blame as a result of poor parenting practices.

Whilst the parents stated that they understood the need for certainty, they expressed their frustration at the long wait with little meaningful support offered in the interim, a trend in previous research (Dennis *et al.*, 2008; Peters and Jackson, 2009; McIntyre and Hennessy, 2012).

In accordance with NICE guidelines (2013), the parents were invited to attend group parent training as part of the assessment process; however, rather than being optional, this seemed obligatory in order to advance their referral. Given their stories of pleading and proving (described in the previous sub-theme) during their long wait, and, in some cases, deterioration of their children's presenting problems to crisis point, I wondered about the parents' motivation and commitment to engage at this point in the assessment. This is worth consideration, as potential outcomes may be used to determine severity of the ADHD and steer thinking around further treatment options.

Dionne spoke positively about the parenting course she had been required to attend ('we learned a lot through that') and understood that time was needed to implement and review the strategies she and her partner had learned. Likewise, Clare believed some of the strategies had been helpful; however, she commented on the lack of advice offered after completion, particularly the availability of 'someone there to talk'.

In contrast, Marie and Netty expressed frustration at the many hoops and hurdles they had to navigate as they sought help and answers for their children's difficulties. Staggeringly, Marie reported that she had already completed five parenting courses, having requested help for several of her children. Like Netty, she questioned 'the system' and its practices that, in their view, implied, and aimed to prove, they were 'bad' parents. Marie expressed concern that the process risked parents becoming reluctant to 'come forward', and of impacting hugely on parents' confidence in their parenting skills. As Harborne *et al.* (2004) found, when parents feel blamed, they are less likely to engage in the therapeutic process.

Netty appeared to accept this as a 'fait accompli': 'everything they threw at me I did' in order to be viewed favourably; 'I gave it 100% because that way I'm doing my part'. She believed her 'honesty' and commitment in engaging with the hoops and hurdles presented, ensured the assessment progressed:

Netty (112p31): *And then eventually she was like, 'Right, we're going to put you up to Dr A.' and that's when he see the child psychologist or child psychiatrist, whatever they're called.*

Experiences of meeting a psychiatrist are discussed in the next sub-theme.

### **7.2.3 ‘Diagnosis then off you go’: the absence of support and consultation**

In contrast to the lengthy assessment process described in the previous sub-themes (sections 7.2.1 and 7.2.2), a final diagnosis was given quickly on the first or second appointment with a child and adolescent psychiatrist:

Netty (116p32): *She, obviously they have files and files and files, so she’s already looking at all this anyway before your child goes in. And on the first appointment [clicks fingers] [child] was diagnosed like that.*

Clare (45p9): *... we just went to see the doctor and then she just said, doing different things, and then she started saying things about ADHD and I said, ‘oh well, it’s definitely that then?’ And then she put it on this letter it was ODD as well.*

Marie (109p21): *We went to see [the doctor], [child] um, he gave the diagnosis there and then...*

The descriptions of the speed at which the diagnosis was given appeared to construct the diagnosis as obvious and reinforce the severity of their child’s problem. However, whilst the parents expressed initial relief (discussed more fully in the following sub-theme) at the confirmation of their explanatory hypothesis, there was dissatisfaction with the post-diagnostic care:

Marie (228p52): *There is no... you get your diagnosis and then off you go.*

Netty: ... *in all honesty they [CAMHS] don't do a great deal for me. They're there to dive into your past and to try and find an, an easier solution than seeing a solution, you know; to find blame rather than... And, and that, that's just my opinion; it might not be true.*

The parents reported that they wanted more information about ADHD and its various presentations: in particular, as Netty described, 'the other side of it; the anger, the aggression, you know...'.

In attempting to fill the void, Clare spoke of using Internet searches, but was concerned that this was not 'official' and therefore may provide conflicting information. For all the parents, they simply wanted information regarding strategies to support their child, including ways to respond to crisis points; an issue highlighted by parents in a previous study (Smith *et al.*, 2014).

As a result, they were once again left to find their own solutions, as Netty describes:

Netty (12p2): *You're pretty much on your own and you sort of figure it out, what works and what doesn't...*

From their accounts, the parents appeared to be seeking a more holistic service that provided opportunities to discuss the multitude of difficulties experienced and where a range of interventions could be customised to their unique needs. What they experienced seemed to be a linear process in which a particular diagnostic pathway (e.g. ADHD) was followed from the outset, therefore steering the context of discussions, data gathering and subsequent

treatment. For the child participants, this process reinforced narratives of behaviour as a function of disorder (see Chapter 6, section 6.3.3).

#### **7.2.4 ‘He must have the condition because the medication works’: the medication conundrum**

On receipt of a diagnosis of ADHD, the parents reported being offered medication soon afterwards. For some this was during the appointment when the diagnosis was confirmed; for others it was some weeks later:

Marie (109p21): *We went back a week later and he started his medication.*

Netty (21p4): *He got his diagnosis, um – he’s not been on medication that long...*

Dionne (22p9): *So, when we did actually go to the doctor’s and he said he’s got ADHD he offered the medication.*

Whilst all the parents consented to their child receiving stimulant medication, Dionne spoke of the conundrum she experienced in considering ‘the pros and cons’. In positioning her choice as considered and responsible, she described that her final decision ‘to give it a go’ had been driven by her motivation ‘to help’ her child so that he could ‘try to settle down’. The parents’ accounts seemed to support descriptions by the child participants of the absence of them being listened to and consulted (see Chapter 6, section 6.2.3).

Initial apprehensions regarding the accuracy of the ADHD label (discussed within the next superordinate theme) and the decision to give their child medication appeared to dissipate as the parents observed the medication's effectiveness:

Netty (119p32): *Give him the medication it works. So, therefore he must have that condition because this medication works.*

These observed effects provided the persuasive argument described by the child participants of their need to take their medication. In addition, it appeared to legitimise the diagnosis, as the medication was understood as helping to reverse abnormal processes by moving the child towards a more normal biological state (Moncrieff, 2009). However, the effects for the child appeared to be reduced personal agency and helplessness, as the medication was deemed to 'control' them:

Marie (290p47): *He didn't have a very good junior school... uh, infants I'd say, because there was no medication. No medication, a child with no medication is horrendous; I'll be very honest with you. A child with medication is a delight; he's a delight. But without medication no, no; it stops, it stops you doing anything.*

Dionne (29p14): *Even with his medication that controls him and helps him to calm down he still struggles.*

For Dionne, however, the medication had not been the panacea as indicated in the latter part of her account. She explained that her child had questioned the efficacy of the medication, as he believed it had had little impact on

academic success; in response, Dionne had explained to her son, 'it's not a magic pill'. This resulted in confusion for the child participants (as described in Chapter 6, section 6.2.3) in trying to negotiate the extent to which they or the disorder had control over their behaviour.

Clare and Netty also expressed some disappointment about the medication: for Netty, this had been the limited effect within the home context:

*Netty (128/129p34): Because I get no benefits of these medications apart from weekends. So, by the time [child] comes in [from school] I have, everything that's been pent up all day I have leashed out on me.*

For Clare, it had been an increase in aggressive behaviour that had led to several changes in medication and dosage. However, in contrast, Marie believed her child to be aggressive without the medication, and that this had implications socially, in terms of maintaining relationships with peers. These conflicting experiences illustrate the complexities of both ADHD and pharmacological treatment. The consensus appeared to be that it controlled the disorder but was not a cure.

Interestingly, like the child participants, none of the parents raised significant concerns about side effects of the medication. This may have been due to the interview questions, which did not specifically focus on these, or maybe that whilst these may have been experienced, the benefits were seen to outweigh any negative effects.

Apart from the obligatory parent training described previously, there were little indications in the parents' accounts to suggest a comprehensive (including psychological, behavioural and educational interventions) treatment plan (as recommended by the NICE guidelines) had been offered, or that a multi-professional response had been co-ordinated.

According to NICE guidelines (2013) group-based parent training and education programmes are recommended as first-line treatment for children (and young people) with ADHD and moderate impairment. For children with severe ADHD, it is advised that medication is prescribed as first-line treatment, although parents should also be offered parent training. Whilst the experiences of parents suggested that this advice was followed, it had been offered at a time of immense stress, and for some, a period of crisis. Such experiences are likely to have impacted upon the parents' commitment and motivation to engage. This requires consideration, as these interventions take longer to demonstrate desired outcomes and require high levels of investment from parents before effects are experienced. As Smith *et al.* (2014) found, parents are likely to disengage from programmes if the improvements they expected did not happen quickly enough. This is concerning in the context of Foreman's (2010) research, which found that clinics took a failure of behavioural interventions in primary care as sufficient indication to prescribe medication.

Given the effectiveness of medication, parents may not have needed to supplement this with other approaches, particularly in a climate and culture of

the 'quick fix' (Baggini, 2005, Schmidt Neven, 2008). However, akin to previous research (Dennis *et al.*, 2008; McIntyre and Hennessy, 2012), the parents in this study seemed to indicate they were seeking further intervention, with which, having had their initial concerns (finally) listened to, understood and validated, they were perhaps in a position to engage.

### **7.3. 'Through all them four letters, changes everything': stories of acceptance and validation**

Having a name for the difficulties the parent and their child were experiencing appeared to legitimise and validate their concerns and galvanised support, empathy and acceptance. The parents, however, reported some surprise at the ADHD diagnosis, having held their own, or been informed of others' (e.g. teachers, mental health practitioner), alternative hypothesis of an autistic spectrum condition. The causality of ADHD was attributed to neurological and genetic factors, and parents described many of the difficulties their children experienced as being a result of their ADHD.

#### **7.3.1 'You can't have an unlabelled child; it doesn't work': proof and acceptance**

Throughout the interviews, the parents spoke of the pros and cons of having a 'label' for their child's difficulties. The consensus was that the 'label' was valuable because it provided a reason for their child's difficulties: an explanation as to the continued challenges they faced (despite trying various strategies); an answer to the differences they had observed between their

child and their siblings; and acceptance from friends, other parents and professionals. In effect, it legitimised and validated their concerns:

*Dionne (57p 27): ... some people think oh my god, I don't like being labelled, well it's not such the fact of being labelled, it's the fact that knowing... I was happy to know what was wrong with him...*

*Marie (259p42): Yeah, because anybody can say, 'We think he's got this and this and this, and this is a need and that's a need', but the minute you've got a diagnosis that's proof that they've got it.*

*Netty (149p41): I think it makes it easier having a reasoning behind the behaviour than not having a reasoning behind the behaviour.*

*Clare (36p7): Yes, I think it has, because he's like, he's been diagnosed so I think they know now where to go, do you know what I mean, they know what to put in where and stuff.*

Although a trend in previous research (Rafalovich, 2004; Singh, 2004; McIntyre and Hennessy, 2012), feelings of relief and happiness on receipt of a diagnosis seems an unexpected human response. However, as Marie described, the diagnosis (and 'label') provided 'proof' that there was 'something wrong' with her child: as she explained, 'it turns the question of, "Is it this? Is it this? Is it this?"' (151p27). The relief the parents felt on gaining this 'proof' appeared wrapped in much wider social and cultural connotations around behavioural difficulties and parenting: in particular, increased scrutiny, negative judgements and blame in relation to their parenting. The positioning of blame appeared important in both child (see Chapter 6, section 6.2.2) and parent stories.

As Dionne describes:

Dionne (16p6): *... they need to understand that it's not you that's causing the problem, you're not the bad parent, you know, the child has got some problems...*

The change in narrative from naughty child/bad parent to disordered child/vigilant parent appeared to prompt acceptance from within their wider social networks, as Marie explained:

Marie (256p42): *Um, I think it learned them to accept a bit more that he wasn't naughty all the time.*

Similarly for the child participants, the change in narrative from naughty child to disordered child provided explanation of their difference and, within their wider social networks, could exonerate their behaviour.

In some instances, this change in narrative had profound effects, as Marie and Dionne describe:

Dionne (16p6): *He never got invited to parties because he was always the bad child, you know, but after all this came across I was bombarded by invitations...*

Marie (55p12/13): *One parent said to my friend, 'Why do you let your child play with that horrible child?' and she said, 'You know he's got special needs, don't you?', and it never occurred to her.*

Following a review of research exploring experiences of stigma, Hinshaw (2005) found that the predominant coping mechanism of parents, after receipt of a mental health diagnosis for their child, was secrecy and concealment. In

contrast, the parents in this study actively informed professionals, friends and other parents as a means of validating and legitimising their child's difficulties, and, in their view, reducing stigma. These views were similar to findings from a study by Neely-Barnes *et al.* (2011), who interviewed parents of children diagnosed with autism.

Within the school context, once the label had been shared, the parents spoke about the power of the diagnosis in triggering additional support and school staff appearing more willing to accept that their child required more specialist strategies and increase their knowledge about it. The 'problem' had been legitimised and validated.

Having a name or label for their child's difficulties was not overwhelmingly positive, as Netty described:

Netty (39p7): *So, I was determined I'd not have [child] labelled with anything, because no parent wants that.*

When pressed further, this appeared to be related to the controversy surrounding ADHD; as she explains:

Netty (3p1): *Just because it's been on the news and things, like you see all kids that are naughty being diagnosed with it, and it's not true. I know that's not true now them things.*

Similarly, Marie commented:

Marie (136/7p25): ... *okay he's got ADHD, but actually he's just a naughty boy.*

The diagnosis confirmed the parents' view of the biological nature of their children's condition, but others were not always in agreement as to the nature and causes of the difficulties, similar to the 'ignorance and discrimination' described by participants in McIntyre and Hennessy's (2012) study. As Singh (2004) has described, the brain-blame binary appears to provide only short-term relief.

There were also differences in the parents' understanding of the effects of ADHD on their children as they negotiated accountability (e.g. whether their child's behaviour was related to the disorder or part of 'normal' troubling behaviour). Marie appeared to take a more determinist stance, as illustrated below:

Marie (151p27): *Well, actually I can't do it because I've got this...*

However, for Netty, there was some uncertainty as she attempted to understand which difficulties she believed could be attributed to the ADHD and which were her child 'just being a little bugger':

Netty (150p41): ... *Sometimes you have to make a point of no, this isn't because of the condition; this is just [child] being [child], just being a little bugger like any other child.*

Themes of control and accountability were evident in both the children's (Chapter 5, section 6.3.3) and parents' accounts; the latter influencing the degree to which ADHD was deemed to determine the presenting behaviour. The more control ADHD appeared to have, the more ADHD was perceived entwined with their identity.

Whilst the label had implications for the parent and child participants, the parents believed it was they who experienced the most significant effects, as illustrated by Marie:

Marie (248p40): *I think because I, I, [sighs] I don't think the diagnosis means anything to, probably, to a child, if I'm honest with you; it's more to the parent. I think what matters to the child is they probably don't get told off as much.*

The children's accounts indicated otherwise, however; whilst change for the parents had been overt, change for the child had been covert, as ADHD weaved silently into the child's construct of their identity.

As Netty describes: *'through all them four letters, changes everything'*.

Whilst there had been positive outcomes from the diagnosis, there were concerns raised that ADHD may have been the incorrect label, or that their child should have received a dual diagnosis of both ADHD and autism. For three of the parents (Clare, Dionne and Marie), doubts had been triggered by others (e.g. friends, family members) and/or from their own Internet research. However, once in the CAMHS system, and having been referred for an ADHD

assessment, these additional concerns were either not followed up – as explained by Clare:

Clare (31p6):

*Resp: Uh no, I think [CAMHS practitioner] said it was ADHD with autistic tendencies but he didn't know whether it would be enough to diagnose with autism and it was something that maybe should be looked into. So, he did say that from the beginning.*

*Int: Okay, but that wasn't looked into in a sense at that time?*

*Resp: No.*

or involved a further period of waiting as their child re-entered the CAMHS system:

Netty (121p32): *... that's basically, that took another 12 months...*

or was not satisfactorily explored because their child had travelled through the ADHD diagnostic pathway and already received an ADHD diagnosis:

Netty (107p29): *As a main diagnosis. They all said Asperger's. The only downside to Asperger's is once any diagnosis you get for ADHD it is so hard to get any other diagnosis for Asperger's and things like that because of the similarities and things like that... she said although he's got loads and loads of characteristics he fits into too many boxes.*

Whatever their thoughts regarding the extent to which the ADHD label encompassed all the difficulties they experienced, the consensus was that there was 'something wrong' with their child which could not be explained by

narratives of poor parenting or naughty behaviour, as the theme below describes.

### **7.3.2 'It's not just him playing up; there is a problem there': an ADHD self and identity**

The parents' understanding of the problem was firmly rooted in brain-based aetiology. The consensus was that ADHD is caused by a neurological abnormality and likely to be genetic; this information had been gained through their own research using the Internet and by asking their child's psychiatrist.

Differences within the brain were attributed to increased speed and atypical chemical structure:

Marie (2p5): *It literally just charges forward faster than anybody else.*

Dionne (1p1): *Um, obviously, you know, it's a chemical imbalance in the brain and, you know...*

Netty (43/44p9): *It's just their brain goes too fast, you know. Instead of connecting it sort of by... bypasses each other really, really quickly.*

Within the parents' accounts, the child's brain became the main and isolated actor (Singh, 2004). This narrative was reproduced within the children's accounts (see Chapter 6, section 6.3.1).

The most informed of the participants appeared to be Marie, who ran a local ADHD support group. She spoke of acquiring knowledge about certain modes of thinking from research in America and used medical terminology (e.g. 'neurological condition') in explaining her beliefs about causality. In addition to her biological explanation, Marie provided a metaphorical description, as if to support my understanding of her brain-based explanatory model, further emphasising this as the primary cause.

*Marie (2p5): Um, it's where, um, your brain doesn't carry all the information; it's like a little train missing... and gaps are missing.*

In contrast, Clare appeared less clear in her understanding; however, her reference to the problem existing pre-birth seemed to suggest she too ascribed to a biological cause:

*Clare (2p5): Well no I'm just, I just think when you have a baby, you know, I suppose it can come out, you know, they can come out all different things can't they, so I just assumed that, you know, I was just one that had one that, you know.*

The vagueness in her account may also be a strategy to deflect challenge (Davies, 2014), given the controversy surrounding ADHD.

Two of the parents (Netty and Dionne) described how ADHD ran 'rapidly' through their family, thus confirming the genetic explanation. For Dionne, this had led to worry and panic following the birth of subsequent children, particularly her son, as she describes:

Dionne (36p20): ... *oh my god, it's a bloody boy, what happens if he's going to have the same?*

From their early childhood, Dionne's view was that her sons were likely to have ADHD, and she remained attentive to 'the signals' that may indicate the disorder:

Dionne (23p11): ... *you do pick up the signals and the behaviour. The girls, no problem, but the boys, it was the same.*

This determinist stance risked reducing autonomy for both Dionne and her sons in relation to any behavioural difficulties experienced, and rendered invisible other contributory factors. However, Dionne believed she had developed expertise through her experience of parenting children with ADHD and, it could be argued, was applying this knowledge in her role as a vigilant mother; a theme discussed within the following superordinate theme.

The parents described the effects of ADHD as constant and persistent, reinforcing the narrative that their child's behaviour was abnormal and different. It was the severity of these behaviours that appeared to be the basis on which a diagnosis had been formulated; examples given included: an 'impossibility to sit down' (Netty 151p41); being unable to focus and concentrate (Marie 171p30); increased susceptibility to being coerced by 'the wrong crowd' (Marie 173p30); engagement in dangerous acts as the child didn't 'think before they act or do' (Netty 98p25); and that the ADHD 'stopped' the development of friendships (Marie 290p46).

Within these accounts, their child was promoted as the focus of the problem and viewed through a lens of symptoms, disorder and limitations (Singh, 2005). From this position, the dominant story of the controlling influence of ADHD continued to thicken (for the parents and their child: see Chapter 6, section 6.3.3).

Netty (145 p40): *It's always there. It'll all... no matter what decision [child] will make the ADHD will determine which way it goes, you know.*

Marie (266p43): *... ADHD pushes him forward, but then the ASD pulls him back.*

However, as discussed in the previous sub-theme and within the children's stories (see Chapter 6, section 6.3.3), refrains of control and accountability weaved through the themes as the parents (and their child) negotiated the extent to which the child was responsible for their behaviour:

Marie (228p30): *But I don't know if that's the ASD... or the AD... or it's a mixture of both.*

Clare (99p21): *I don't know whether this is ADHD as a whole or whether this is just [child].*

Netty (150p41): *But then there are some things he'll do, people will look at him and go, 'Why that? Why would he do that?' A normal child... because he's not.*

It could be argued that the dominant story of ADHD as a controlling force influences the approach taken in finding solutions, and may have influenced the parents' readiness to accept medication, particularly in the absence of a more comprehensive treatment plan. As Jenkins and Carpenter-Song (2005) argue, 'a biological aetiology has the secondary consequence of removing personal agency' (p. 405). From this position, contradictions to the problem story and the influence of context can be rendered invisible; for the child participants, this was understood as a need to change them rather than altering their environment (see Chapter 6, section 6.3.3).

As Clare and Dionne's accounts suggested, the presenting problems appeared to fluctuate according to the situation and context; however, these contradictions to the dominant story were not elaborated on further.

Clare (60p12): *Well literacy again it does, but I don't know if that's his understanding or whether that's to do with ADHD, I don't know if it's the same or if it's a separate thing. Maths, quick, sharp answers he can do, it's not a problem. So, I suppose it does in a way but then in other ways not because like with art and stuff, do you know, he's very good at anything like that.*

Dionne (42p21): *If you give him some Lego he'll play with the Lego for hours and you'll think there's nothing wrong with him because he was so engrossed.*

Diagnosis provided a reason for the problem and medication appeared successful in controlling the symptoms, thus confirming the disorder. Within this narrative, what could they or their child do? Alternative perspectives (e.g. psychosocial) perhaps risked the unfavourable position they had already experienced of being judged, stigmatised and labelled bad parents.

#### **7.4 ‘Stress, stress, pure stress’: ADHD is hard to live with**

For the parents in this study, ADHD appeared to have a huge impact on their family. Their accounts spoke of the demanding nature of their child and the impact on siblings, personal relationships and general family life. In addition, parents described feeling stigmatised, isolated and excluded, and under constant pressure to prove themselves and their parenting. Having lived experience appeared crucial in understanding their struggles, and parents reported having to find their own way of supporting their child, due to a lack of post-diagnostic support. Stories of determination developed from these experiences, and parents spoke of their growing knowledge of ADHD and of their pseudo-expert role.

##### **7.4.1 ‘ADHD is hard, it’s hard to live with’: the fights and sacrifices**

The consensus from parents was that family life was highly stressful. They described the demanding nature of their child, which resulted in that child becoming the centre of their family system, impacting upon all aspects of family life.

Marie (180p31): *It can be horrendous; it can be absolutely... Um, it’s he’s argumentative; it’s his aggression; his bouncing around, jumping on the settees, smashing the doors and climbing up the cooker and cupboards.*

In particular, the parents spoke of the more rigorous parenting required (discussed in the following theme), the emotional impact on family members (e.g. fathers, siblings) and the restrictions on social events. Within the stories

came a strong sense of their critical role in maintaining the family system; perhaps partly reflected by the more 'traditional' mother role in which they were engaged.

Dionne (33p16): *I'm chilled because I'm used to... And I'll say get a grip, because I'm used to it now because he is working all the time so I'm used to it; so I'm like sitting and he'll [partner] say how can you sit there being chilled? You get used to it and you learn how to cope and you calm down.*

At times this demanding role left them overwhelmed, exhausted and emotionally drained:

Netty (141p38): *Anything that I know will have an impact on [child] I will try and do before I fetch me kids... But there is times when it needs to be done and it's hard, it's... by the time you come in you feel emotionally and physically drained.*

For Netty, there had been times when the stress had been particularly overwhelming, and she described feeling 'so far down' that she had contemplated that 'death was peaceful'. Her additional responsibility as a sole carer for her children, the lack of support from professionals and feeling a 'burden' on wider family and friends appeared to have contributed to her emotional despair:

Netty (12p54): ... you've got a younger sibling then as well, uh, they need all your attention because they just think they deserve the whole attention because they're the younger one. And then you can't find, when you're single you can't find a balance. This is where the support of ad... not so much else sometimes, your family – although they're fantastic and they're there, they don't understand. Sometimes you don't want to keep going on to them about it I think. And that's where the outside agencies come in. But everything's a waiting game. And like I said, it got to the stage where, with [child] being the way he was, [younger sibling] was an ill baby anyway, [older sibling] went from being a really good child to going in high school and completely changing – I thought death was peaceful.

Negotiating attention between siblings and their child with ADHD was viewed as a 'balancing act', and triggered feelings of guilt about the lack of attention their other children received:

Netty (53p12): *I think it's just... you forget to pull out your time for them.*

Clare (70p14): ... because it's always about [child], everything has always been about [child], it's always... We can't go here because [child] won't do that, we can't go here because [child] won't eat that, do you know what I mean, it's always been [child]. And as much as we try not to, and we do things with [sibling], and do things for [sibling].

Parents reported that siblings were often on the receiving end of aggressive behaviour, had their belongings 'smashed', had to comply with their sibling's (the child with ADHD) demands and adjust to the restrictions placed on family outings. In addition, older siblings were recruited to assist in watching and protecting the child with ADHD, as Netty and Dionne describe:

Netty (53p12): *Um, as much as you try not to do it, you constantly have them watch this child.*

Dionne (36p18): *[child with ADHD] will be looking at something and his brother will say here, 'I know what you're thinking about, forget it'. He clicks on straight away that he's going to get into mischief or, you know, and he pulls him up straight away... because they understand, they've had to, they've had to learn from to understand.*

Despite the challenges these siblings faced, there was a sense from Clare that her older child had benefitted from her caring role and from the experience of having a sibling with additional needs:

Clare (73p15): *... she's very um, she's grown up and she's very, very good with him now. And if she sees that he's going, like going in one or anything like that she can bring him round...*

As described in Clare's account, the parents spoke of family routines and outings being restricted or influenced by the needs of their child with ADHD. In some cases, outings as a family ceased and certain places were avoided, minimising the risk of problems occurring:

Marie (201p34): *We don't go out as a family for trips out.*

Clare (67p14): *... we couldn't go out for a meal or, and I'd be very, like if we went like a school thing and it was sitting in a hall you couldn't do that with [child] because he wouldn't sit. So, yes, we don't go far or you know, we're careful where we do go.*

Netty (142p39): *You, you, you're on edge because you don't know what's going to happen when you're out.*

Dionne (56p26): *Well it's stopped quite a few. Like obviously, I don't know, like taking him certain places, you know.*

Although there had been difficult times, Clare and Dionne believed that there had been improvements over time as they developed their knowledge and practised and modified strategies:

Clare (71p15): *... it's much easier now, but yes we've had all that.*

Dionne (56p26): *It's not so bad now but before we could never take him out to certain places like restaurants or whatever because of his behaviour...*

Parents spoke of the impact ADHD had on relationships, particularly with their partner. Dionne described that it had been a 'battle' to ensure her relationship survived, and stated that she was aware that many parents of children with ADHD separate due to the stress on family life. The parents described disagreements on parenting style and sanctions, and of increased stress for their partner who was often absent from the family home due to work commitments, and therefore not 'used to it'. In addition, they described the impact of increased tiredness due to their rigorous parenting role and as a result of their child's poor sleep patterns.

Dionne (38p19): *... [step-dad] was like a nervous wreck for the first couple of years [laughs] do you know what I mean, he was like how do you cope with this?*

Marie (197p34): *It's awful, it's awful, it's awful. My husband goes to a safe house once every 3 months because he can't cope.*

Clare (68p14): *Yeah, we bicker, we don't argue, argue, but we bicker. I'm probably softer and he's more strict, stricter than I am, do you know what I mean, so sometimes we do.*

The parents' accounts resonate with existing literature that has suggested a tendency by mothers to position themselves as the partner who has better understanding of their child's needs (Doucet, 2006). It could be argued, however, that this position tended to be placed onto the mothers rather than solely their choice.

The ADHD also had an impact on relationships with wider family members, and connections with them were often disrupted due to their child's difficult behaviour, as Marie explains:

Marie (182p31): *Well, me mother... don't speak to, me... mother-in-law... I mean, [husband's], [husband's] mum and dad a lot. They can't accept it, full stop. Uh, and my sister says it's like being like in a whirlwind; she can't... she says, 'A couple of hours with him I can do it. But after that it's hard'.*

The consensus was that parenting a child with ADHD is complex, requiring high levels of investment in time and energy, and of sacrifice, a trend in previous research (Dennis *et al.*, 2008; Firmin and Phillips, 2009; Peters and Jackson, 2009; McIntyre and Hennessy, 2012). The effects ricocheted across all aspects of family life and placed emotional, social and physical demands on all family members, particularly the mothers, who appeared to have the primary role in caring for their child.

#### **7.4.2 ‘You’re the one person that’s got their back’: watching, protecting and restricting**

The parents positioned themselves as protective, proactive and vigilant – a trend seen in the research (Singh, 2004; Blum, 2007; Firmin and Phillips, 2009; Peters and Jackson, 2009; Davies, 2014). This involved watching and monitoring their child’s actions, protecting them from the consequences of difficult behaviour and imposing additional restrictions to keep them safe. The parents spoke of the need to be prepared for difficult situations and, where possible, to plan in advance to reduce issues occurring.

Netty (142p39): *... without the extra care I give [child] now with things like that he would not be able to be the way he is.*

Clare (76p16): *So, you’d be thinking, if it wasn’t happening you’d be thinking god, it could happen, so you’ve got to be aware just in case.*

Dionne (26p12): *... you’ve got to keep on track all the time because they’re so hyperactive they can put themselves... it’s not just that but they can put themselves in danger, they don’t think, you know, so it is hard, yeah.*

As part of the ‘extra care’ required, Dionne and Marie described the importance of being prepared for incidents at school, including being available during the school day and, when required, collecting their child early:

Marie (74p15): *Every day I used to get a phone call from school.*

Dionne (17p8): *I was having phone calls... And he couldn’t, when he started nursery they couldn’t take him where they do a term of like, you know, half*

*days and then you introduce full days, he never went to the full days until he was 5 because they couldn't cope with him.*

Their accounts spoke of the experience of exclusion from their child's earliest years and the absence of typical schooling experiences. This had implications for parent's work and social life, as they were required to be readily available to attend to their child's complex needs, further contributing to a feeling of being overwhelmed, exhausted and emotionally drained.

There was an overwhelming sense of responsibility for their child's well-being, as found in previous research (Bull and Wheelan, 2006; Firmin and Phillips, 2009), including the need to ensure their safety by pre-empting and planning for difficulties. This involved placing limits and restrictions on the types of activities their child engaged in, and on their social time with friends:

*Netty (133p35): ... you can't just to [child], 'Oh go out and play', you cannot physically do that... You have to, you have to think before you say yes to make sure he gets there safe...*

The consensus was that their child required constant surveillance and it was their responsibility to provide this. For Netty, this intense monitoring had led to her following her child (whilst remaining out of sight) as he made his way home from school with friends; her rationale appeared to be that she must ensure his safety.

Clare's strategy was to allow her child out for short intervals and to be vigilant to 'gauge his mood' before permitting further social time with friends:

Clare (53p11): *... if I do let him out I let him out for small bursts, so I might let him out for half an hour and then I'll have him in and then I'll let him go out again um, because he can't cope if it's a long time so it's better just being a short time... And I always gauge what mood he's in too to see whether, you know, if I let him go.*

As Firmin and Phillips (2009), Peters and Jackson (2009), Davies (2014) and Brunton (2014) found, the parents appeared to take the view that their child required a different type of parenting, exceeding that of typically developing children. This required them to be vigilant and act in proactive and protective ways; according to Singh (2004), the biological explanatory model can change the emphasis of the mother's role from causing their child's behavioural problems to preventing further difficulties.

Some of the parents spoke of a special bond that they and their child had developed through their more vigilant parenting role:

Dionne (34p17): *I'm very close to [child] and always will be, and people say to me, 'Oh god, he wants to try and get off the apron strings a bit', do you know what I mean, because he won't go out or anything, he's got to be with mum all the time. And I don't think it's because of the apron strings, I think it's because we've got that bond where I've said to him, you know, you talk to me if you need to talk to me, and we are close.*

Clare (77p16): *I can see what's up with him so that's why I'm normally quite mellow with him and I let him ride it out.*

Concerns about dependency appeared to be dismissed by Dionne: the dominant narrative, as discussed above, was that this is what her child required. Clare and Netty were aware that their child felt restricted, although they offered no further thoughts about the impact this had on them.

From their accounts, the parents appeared caught in a cycle of relentless action (Blum, 2007) in order to meet the complex needs of their children. In effect, this appeared to be a very different parenting experience as participants in Peters and Jackson's (2009) study described.

#### **7.4.3 'You get used to it, you learn how to cope': determination and developing expertise**

Parents spoke of the lack of advice and support available at all points on the journey towards their child receiving a diagnosis of ADHD; this included contact with education and health services when initial concerns about their child's difference were raised, the period of referral to CAMHS and the assessment process, and following their child's diagnosis. As Marie described, they were left to 'muddle through' in finding strategies to cope with their child's behaviour:

Marie (101p19): *Um, and I think yeah, I think that was it. We just muddled through and muddled through and muddled through.*

Dionne (59p28): *How to cope with it, how to actually cope with it, try to learn to cope with it and also get them to cope with it... You've got to keep reassuring things that everything's going to be... you've got to make sure you understand certain things, and I'm still learning now, do you know what I*

*mean and you're still learning, you still pick up things about how to have a child with ADHD or a teen, you know, I've got to learn now again with a teenager with ADHD.*

*Clare (103p22): ... I don't think there is enough [support]. Because I mean, I still didn't know. Now, I mean what we do now, I don't know if it's to do with ADHD, we know what's good for [child] and what's not, you know, we know how to be with [child], whereas then I didn't know.*

*Netty (100p27): We problem-solved ourselves because we know what we're talking about.*

In navigating their way through the difficulties of parenting a child with ADHD, the parents spoke of the value of the support they received from other parents who had similar experiences. Many had developed these supportive relationships through attending a parenting course as part of the assessment of their child's ADHD. Whilst their appraisal of the course delivery and content tended to be negative, the course had provided a turning point at a very stressful time in their lives:

*Netty (182p51/175p49): But like I said, the biggest support for me come from finding that mutual understanding with somebody who knows what you're going through... get that group, get that circle around you of people who know what you're going through and, you know what, bounce off each other.*

*Dionne (61p29): Yeah, so I think to start off with I had nobody, but then you get used to all these groups and you get used to people in the same predicament as you... you know, you're listening to other people's stories but you pick on, yeah.*

Having opportunities to listen to shared experiences, being able to discuss problems and solutions with people experiencing similar predicaments, building relationships and feeling valued has been identified by parents as positive aspects of attending parent training (Smith *et al.*, 2014). For the parents in this study, these relational effects had been crucial.

Negative aspects of the parent training appeared to relate to being 'told' rather than consulted. This resulted in generic strategies being prescribed rather than specific advice offered to suit the unique needs of their child and their circumstances. The perceived unhelpfulness of programmes has been found to be a barrier to parental engagement (Koerting *et al.*, 2013).

Netty (37p7): *And I said, 'You know what you are making me read a book', you know, I says, 'What works for one kid does not work for every, for everyone'... So, all these parenting groups that tell you to do this, this and this, it doesn't work for all kids.*

Netty (172p46): *I aren't in the medical profession, I haven't studied it, I haven't this – they're wrong. And I'll quite happily sit there and I'll, I'll tell them they're wrong as well because you're basing it on... No different than your parenting books: biggest load of crap I have ever read, seen, heard, whatever; they need to change their views on it. It's not about a printed letter; it's not a book.*

As Netty concludes:

Netty (37p7): *You have to find your way around it.*

Like their children, the experience of not being listened to or valued as a partner within the process ran through all superordinate themes. However, there appeared contradictions in how parents were perceived and consulted;

for example, despite their passivity within the assessment process, on occasions there had been an expectation from school staff that they provide advice and direct action in a type of pseudo-expert role (e.g. being called into school to calm their child). These roles appeared to reinforce narratives of mothers' duty and responsibility, repositioning them at the centre of their child's problem.

The parents legitimised their knowledge through their experience of parenting a child with ADHD, and demonstrated this in their talk of their acquired strategies and skills in learning how to cope with their child's behaviour. In her role as a pseudo-expert, Dionne spoke of being consulted by her friends:

*Dionne (17p7): Two of them [friends] have actually come to me because their child was having problems with behavioural problems and they've actually been diagnosed as ADHD, and they've actually come to me to support because they didn't know how to handle the child or how to cope with certain things, so they've asked me for advice...*

and of being called into school to rescue difficult situations when staff appeared to have run out of ideas:

*Dionne (64p31): [teaching assistant] was ringing me up, I can't cope with [child], come down to the school... I had to go and sit with [teaching assistant] with him for 25 minutes because he wouldn't sit still and do his exam... I mean when I went to the exam and I sat there and [teaching assistant] says 'Come on now', timid voice, 'Come on [child] now, I'm getting a bit annoyed now, can you do your work?' And I looked at her, I thought, 'Oh my god,*

*[child], will you please just sit down now, get your pencil, sit down and do your work'. I didn't say it nasty and he was like, he did his work.*

In her account, Dionne appears to construct and evidence her 'superior' knowledge about strategies that do and do not work. The parents were evolving from 'muddling through' to becoming experts and 'strategists' (Firmin and Phillips, 2009) on ADHD.

In their role as advocates, the parents were often caught in 'battles' with the school to ensure their child received the appropriate support and provision, and felt obliged to take on a CAMHS/school liaison role to ensure information was shared between services:

*Marie (267p58): ... [the psychiatrist] sits on my CiN [Child in Need] every 3 months. And every 3 months I say to her, 'Send one to school'. And every 3 months I have to take it into the school, photocopy it.*

*Dionne (10p4): So, over the years with experience with teachers you know what, I mean as you know I've had battles with some of the teachers at [child's school] where they didn't get the drift of the ADHD...*

*Clare (111p24): I mean CAMHS, we got to chase them up, do you know what I mean...*

Despite the unrelenting cycle of vigilance and protection, the narrative of poor parenting seemed to be never too far away, as discussed in the next sub-theme.

#### 7.4.4 'You're nothing like us': separated, excluded and stigmatised

Consistent with previous research (Dennis *et al.*, 2008; Peters and Jackson, 2009; McIntyre and Hennessy, 2012), parents spoke of their experiences of stigma as a result of their child's difficult behaviour. This culminated in separation, exclusion and alienation, as they came to be viewed as 'the bad mum with the bad child':

Dionne (15p6): *Yeah, it is yeah, because, because the fact that it doesn't just affect the child, it also affects the parents, because when [child] started going to [school]... I got parents that wouldn't speak to me. For 2 years they would not speak to me. I was known as the bad mum with the bad child.*

Although not confined to school, it was often within the school setting where the stigma appeared to be most potent: other parents avoided them and prevented friendships developing between their children (as described by Robert, see Chapter 6, section 6.3.2); there were descriptions of physical attacks, and isolation during the beginning and end of the school day. Whilst stigmatised as a result of the association with their child, known as courtesy stigma (Goffman, 1963), they also experienced personal or self-stigma, in being viewed as the 'cause' of their child's difficulties:

Marie (56/58p13): *I used to get loads of abuse off parents; I used to get called a fat cow, a fat b\*\*\*\*, everything. I was reported to social care once because [child] was, was charging around and hitting one of their children, and she thought it would be good to bring social care in because I was a rubbish mother.*

Netty (88-91p22): ... *unless they've heard of it or researched it or work in that, you dragged them up – and that's it, that's how people see it. You're the crap parent, you know.*

The parents appeared to be constantly caught in a cycle of being judged and trying to prove themselves; resulting in further stress and isolation, and continual questioning of themselves and their ability to be good parents:

Netty (47p9): ... *you're constantly trying to prove yourself. And sometimes even me when I'm out with [child], before we go I'm, '[child], always remember whatever actions you do comes back on me as well. It doesn't just make you look bad, it makes me look bad'.*

Like the child participants' responses to being viewed through the lens of ADHD, the parents' reaction to the experience of stigma was resignation that this is the way it is and that there was little they could do to prevent it:

Netty (158p43): *The people who see beyond it see a fantastic child. The people who see the diagnosis see a naughty, rude child – even if he hasn't been – because that's just the way it is. You've got that so that's the way it is.*

Parents spoke of a lack of understanding surrounding ADHD, which they believed to be linked to misconceptions about the condition. There was a belief that ADHD was less accepted than other conditions and that they and their child were stigmatised as a result:

Dionne (12p5): *Because like I said, you know, I mean if there's a child in the school with Down's Syndrome or whatever, you know, they know, so with ADHD they should be told, you know.*

Clare (44p9): *... you know, people, like autism people, yeah that's valid, do you know what I mean? ADHD, I don't think people...*

The perceived legitimacy and validation following receipt of the diagnosis had not provided the removal of blame that they had been seeking.

The parents believed that the continued debate about the existence of ADHD had an impact on the willingness of schools in making adaptations to their child's environment and curriculum, and prompted the initial reluctance to acknowledge and support the concerns that their child had ADHD:

Clare (39p8): *there's a lot of there, it doesn't exist, so people that don't know don't... So, it can be negative in that way where, you know, people say 'Oh there's no such thing'.*

Dionne (9p3): *... there's still some teachers that don't want to know, it's just bad behaviour, an excuse.*

Netty (75/76p18): *For most schools, a child like [child] is odd and, you know, teachers have to deal with kids, and that I can respect. But don't overlook a child because of certain issues, because they're doing certain things, because you don't know the reason why.*

Marie (21/22p7): *Because when, um, I remember sitting round a CAF [Common Assessment Framework]... we all sat there and this head teacher was there, SENCo [Special Educational Needs co-ordinator] was there, and [clinical psychologist] says, 'I think you need to remember [child] got severe*

*ADHD', and they went, 'Severe?', and she went, 'Yes, I'm telling you now [child] got severe...', and the shock on their faces said everything.*

Alongside their own experiences of separation and isolation, most (Netty, Dionne and Marie) had experienced their child being excluded from educational and social situations, from the very earliest years:

*Netty (24/25p5): [child] must have been the only child that got kicked out of playgroup because he would, like, as soon as you put his toys on the table he'd take them all off, just so nobody else touched it and things like that... They just said, 'We don't think it's wise you bring him'.*

*Marie (84p17): We got barred from playgroup, we weren't allowed to go.*

*Dionne (18p8): ...he never went to the full days until he was 5 because they couldn't cope with him.*

*Dionne (16p6): He never got invited to parties because he was always the bad child...*

*Netty (86p21) So, kids, like I said, there's no racist kids, there's racist parents. No different than biased children: you don't get biased children; there's biased parents... say, 'Oh, you can't play with them because they've got their...'; I see it at that school. Not one friend did [child] get invited to, not one party, not one parent would allow the kid to come here because obviously they thought it was me there.*

Netty believed this 'bias' was present within the school context, and, as a consequence, influenced peer acceptance of her child, as illustrated below in her comparison of the two primary schools her child attended:

Netty (97p25) ... *every single one of them kids [at her child's new school] was accepting. And [child] was running out of school, breaking things, snatching things, hitting, lashing out – not one of them walked away from him. Because you haven't got a teacher going, '[child] do this, [child] do that'. The old school the kids wouldn't go near him because you've got an adult saying that [child's] dangerous and this and that.*

Lack of understanding by family members, friends, schools, services, other parents and the general public resulted in various experiences of prejudice and discrimination. For some, this was further exacerbated by the portrayal of ADHD in newspapers and television programmes, which produced and reproduced dominant narratives linked to the controversy surrounding ADHD. As Clarke (2011) describes, the media can reflect uncertainty, scepticism, doubt and confusion.

Marie (16p7): *There is no, there is no courses for teachers. So, unfortunately they have to go off media, which is ADHD kids bouncing off the walls and... So, they just go off that. But that is not ADHD.*

For Clare, this doubt and confusion had been reproduced through the storyline of a popular television drama:

Clare (42p8): *...but [in a television soap] they had somebody with ADHD in for about a week and then it's not really mentioned and I just think it doesn't help does it? Yes, he was fine, this child was fine and then it was a naughty child and then he was ADHD and then, you know, you hear nothing of it. And I just think it doesn't go...*

In Clare's view, the ADHD had been minimised and biological explanations dismissed, reflecting popular misunderstandings. This placed the parents at further risk of being judged and blamed.

Despite the stigmatising experiences, there were positive stories of acceptance within the parents' accounts, similar to the 'life lines' described by Hibbitts (2010, cited in Gwernan-Jones *et al.*, 2015), in which people were described as seeing the person rather than the problem:

Netty (160/161): *Seeing your child smile and it being real, not a forced like awkward; it's a laughing and joking and feeling accepted – completely different feeling, when you've had a child that's been pushed aside for so long. So, there's a million and one things you can say, but that for me is top of anything.*

Marie (257p57): *I had [charity support group worker]... it was the very first person I never had to prove I wasn't a bad parent.*

Although a rarity, these experiences had been profound: their child had been accepted within their peer group and also by their teachers, and they, as parents, had been accepted like any other, just trying their best.

## **7.5 Summary**

Through analysis of the parents' experiences of having ADHD in their lives, three superordinate themes were constructed. Similar to findings from the studies reviewed in Chapter 3 (Dennis *et al.*, 2008; Firmin and Phillips, 2009; Peters and Jackson, 2009; McIntyre and Hennessy, 2012), these themes

described the parents' attempts to make sense of concerns about their child's 'difference', the 'battles' with schools and health services in order to have these concerns listened to and acknowledged, and the impact on family systems and the more intense parenting required. Woven within these themes were stories of the parents' constant action to meet the complex needs of their children, as described in research by Firmin and Phillips (2009), Peters and Jackson (2009) and McIntyre and Hennessy (2012), and to defend them against stigmatising forces that sought to position the parent and their child within a naughty child/bad parent dyad.

Parents' attempts to understand and make sense of their concerns placed their child within a narrative of 'difference'. Similar to the experiences described by McIntyre and Hennessy (2012), extreme examples of their child's behaviour and comparisons with siblings and peers appeared to evidence the abnormal and unusual nature of these behaviours and confirm that it was not a result of their poor parenting. Whilst concerns had existed from their child's earliest years, it was within the school context where proof of difference became more apparent (similar to findings from studies by Travell (2005) and Gallichan and Curle (2008), presented in Chapter 3, and more recently, in a systematic review of parents' experience of ADHD by Gwernan-Jones *et al.* (2015)) and where a narrative of 'something must be done' began to gather pace. This appeared to reflect the different schooling experience they and their child encountered, as Peters and Jackson's (2009) research had found, including reduced school hours, parents being called into school as a result of their child's behaviour, their child being sent home and, in some

cases (similar to findings by Doubet and Ostrovsky (2015) and King *et al.* (2016)), permanent exclusion.

Consistent with previous research (Dennis *et al.*, 2008; McIntyre and Hennessy, 2012), the parents spoke of pleading for help and battles with professionals in health and education as they sought to prove that universal services were unable to meet the specialist needs of their child. A lengthy and arduous process was described, and parents expressed their frustration at the lack of recognition of their opinions as an expert on their child. These themes not only reflected findings from studies described in Chapter 3, but are also consistent with findings from studies exploring the views of parents who have children with a range of complex needs, such as Novak *et al.* (2011), Woodgate *et al.* (2013) and Parker *et al.* (2016). As a consequence of the lengthy wait and battle for services, the parents in this study described how they were often left to ‘muddle through’ without support, contributing to increased stress and deterioration in the presenting concerns, which, for two of the parents, had led to a more complex set of difficulties. These crisis points, however, as participants in the study by Dennis *et al.* (2008) described, appeared to expedite referral and involvement from CAMHS. This acceleration proved only temporary, however, as once within this system, the long and arduous process appeared to continue, and parents described the many ‘hoops and hurdles’ to be negotiated as they sought acknowledgement and validation for the child’s difficulties. Their accounts echoed findings from a study by Kildea *et al.* (2011) who described experiences of ‘struggling and getting nowhere’. Descriptions of the speed with which diagnosis was given

seemed to construct the problem as obvious and severe, and this severity appeared to contribute to medication being prescribed at diagnosis or shortly afterwards, as Travell's (2005) study had found.

Akin to studies presented in Chapter 3 (Dennis *et al.*, 2008; McIntyre and Hennessy, 2012), parents expressed relief following their child's diagnosis, as the 'label' appeared to legitimise and validate their initial concerns and, as was the case for their children, provided a reason for the behaviours. The efficacy of medication provided 'evidence' of a biological explanatory hypothesis and alleviated the conundrum faced in consenting to this treatment. In some instances, receipt of a diagnosis had profound implications for the parents, and there was a view that it was they who experienced the most significant effects. However, whilst change for parents had been overt, change for the child had been covert, as ADHD had been woven silently into their identity. In referencing causality, the brain became the main and isolated actor (Singh, 2004), and the consensus was that ADHD was caused by a neurobiological abnormality. These views reflect findings from research exploring children's views, presented in Chapter 3, and also studies by Firmin and Phillips (2009) McIntyre and Hennessy (2012), however, they conflict with the views of parent participants in Dennis *et al.*'s study who suggested biological and social causes, and that the condition is not life-long.

The focus of the problem was viewed through the lens of symptoms, disorder and limitations (Singh, 2005). Within this narrative, the children were positioned as passive and subservient, and expected to conform and comply

with being assessed, monitored and treated, as reflected in their own accounts, and in previous studies exploring children's views (Travell, 2005; Davies, 2009), presented in Chapter 3. A thickened story of the controlling effects of ADHD and medication developed, which appeared to influence the approach taken in finding alternative solutions (as indicated in previous studies, such as Cooper and Shea, 1998; Travell, 2005; Kildea *et al.*, 2011). Contradictions to the problem story and contextual factors were rendered invisible, as the focus appeared to be on changing the child rather than altering their environment; this was further evidenced in the accounts of the child participants who spoke of what they needed to do, rather than what others could do. Themes of control and accountability permeated through both the parents' and children's accounts, with some variation in the extent to which ADHD was deemed to determine behaviour. The more control ADHD was perceived to have, the more it became entwined with their child's identity.

Consistent with a wealth of literature (including the studies reviewed in Chapter 3), the positioning of blame was apparent in both child and parent stories, and their accounts spoke of exposure to increased scrutiny and negative judgements. The parents described being stigmatised as a result of their child's difficult behaviour (similar to Peters and Jackson (2009) and McIntyre and Hennessy (2012)) and being positioned as the 'cause', leading to a cycle of being judged and trying to prove themselves (similar to Dennis *et al.* (2008), Peters and Jackson (2009) and McIntyre and Hennessy (2012)). Parental experiences of 'courtesy' and 'self'-stigma were reported in a systematic review carried out by Gwernan-Jones *et al.* (2015), whilst findings

from previous studies (Broomhead, 2013; Nurullah, 2013 Lee *et al.*, 2015) suggest that parents of children with emotional and social difficulties are viewed differently than parents of children with more 'visible' conditions, with the difficulties being linked to ineffective parenting. In effect, there appears to be differing parental experiences, based on the nature of their child's needs.

A change in narrative from naughty child/bad parent to disordered child/vigilant parent following diagnosis, provided acceptance from others and removal of blame (similar to Dennis *et al.* (2008) and McIntyre and Hennessy (2012)). Sadly, as Singh (2005), Peters and Jackson (2009), Kildea *et al.* (2011), McIntyre and Hennessy (2012) and Broomhead (2013) have described, perceived legitimacy and validation on receipt of diagnosis did not provide the removal of blame they had been seeking. The controversy surrounding ADHD, including representations in the media, were viewed as contributing to this, although Kildea *et al.* (2011) have suggested the lack of long-term solutions is likely to contribute to this relief from blame proving only temporary.

In reflecting on their journey through CAMHS, the parents spoke of complicated and fractured systems, similar to the 'disconnected encounters' described in Dennis *et al.*'s (2008) study. Akin to Dennis *et al.* (2008), Peters and Jackson (2009) and McIntyre and Hennessy (2012), there appeared to be little early intervention offered to provide space for discussing and making sense of the difficulties they were experiencing, and where interventions could be customised to their unique needs. Instead, the participants in this study

described a linear process where a particular diagnostic pathway was followed, steering the context for discussions, data gathering and, at the end of the process, treatment. These systems appeared to reinforce the view of the behaviour as a function of disorder, silencing other contributing factors. Similar to the findings of Dennis *et al.* (2008), Peters and Jackson (2009), Kildea *et al.* (2011) and McIntyre and Hennessy (2012), there remained dissatisfaction with the post-diagnostic care, and a sense that a more comprehensive and holistic approach would be helpful. Kildea *et al.* (2011) argue that these difficulties arise from dominant models of practice within CAMHS, which, in their view, restrict discussion about the range of factors at different levels of analysis. Furthermore, they caution that 'a culture on guideline and prescription rather than psychological formulation will continue to reinforce pressure for professionals to have an answer long before they have had chance to think one through' (Kildea *et al.*, 2011, p. 615). Based on findings from this study, I would concur with Kildea *et al.* (2011), whilst also proposing that increased severity and complexity of problems as a result of a long and arduous wait for help, and in the absence of early interventions, are also likely to contribute to the later pressure to find quick answers and speedy solutions.

Consistent with studies described in Chapter 3 (Dennis *et al.*, 2008; Firmin and Phillips, 2009; Peters and Jackson, 2009; McIntyre and Hennessy, 2012), living with ADHD was described as stressful, as it impacted upon the whole family microsystem. Parents spoke of how their child (with ADHD) became the centre of the family, which affected all aspects of family life and placed

emotional, social and physical demands on family members. The consensus was that parenting a child with ADHD is complex, requiring high levels of investment of time and energy, and sacrifice. This is consistent with a wealth of literature, including the studies presented in Chapter 3 and previous research exploring the experiences of parents who have children with a range of complex needs (e.g. Neeley-Barnes *et al.*, 2011; Novak *et al.*, 2011; Koch and Mayes, 2012; Nurullah, 2013; Doubet and Ostrovsky, 2015; Woodgate *et al.*, 2015; Stapley *et al.*, 2016). In particular, the mothers described the rigorous parenting required, and their critical role in keeping their child safe and maintaining the family system. At times this left them overwhelmed, exhausted and emotionally drained, as they appeared caught in a cycle of constant action. Similar to previous studies (Dennis *et al.*, 2008; Firmin and Phillips, 2009; Peters and Jackson, 2009; Novak *et al.*, 2011; McIntyre and Hennessy, 2012; Nurullah, 2013; Davies, 2014), the view appeared to be that their child required a more rigorous and different style of parenting. However, the experience of parenting a child with ADHD contributed to the development of specialist knowledge, similar to findings of previous studies (Dennis *et al.*, 2008; Firmin and Phillips, 2009; Peters and Jackson, 2009; Novak *et al.*, 2011; Gwernan-Jones *et al.*, 2015; Lee *et al.*, 2015; Woodgate *et al.*, 2015), and as a result, the parents spoke of being consulted by schools and other parents as pseudo-experts on ADHD. Whilst this appeared to recognise (finally) the parent as an expert on their child, it reinforced narratives of mothers' duty and responsibility, repositioning them at the centre of their child's problem.

In talking about their experiences, the parents rarely spoke of the 'joy and happiness' and rewarding nature of parenting a child with complex needs, as described in studies by McIntyre and Hennessy (2012) and Nurullah (2013). Whilst this is likely to reflect the nature of the questions asked during the interview, I have also considered whether this also reflects the lack of long-term solutions (described by Kildea *et al.*, 2011) and the controversial nature of ADHD (and emotional and social needs more generally), which place the parent and their child within a presumed naughty child/bad parent reciprocal interaction.

The following chapter will identify the implications of these findings in relation to the broad research question and superordinate themes from the individual interviews with the child and parent participants. Evaluation of the research design, and the degree to which the theoretical framework and methods supported this study, will also be discussed, and limitations of the study will be outlined.

In addition, implications of the overall findings will be discussed, including new questions that have arisen from this study.

## CHAPTER 8: CONCLUSIONS

### 8.1 Introduction

Elliot *et al.* (1999) argue that the value of a research study 'must be evaluated in its ability to provide meaningful and useful answers to the questions that motivated the research in the first place' (p. 216). With this in mind, as the story of this research study draws to a close, this final chapter presents a summary of the findings, discusses its contribution to existing understanding, considers its limitations, and discusses the implication for future practice.

As discussed in Chapters 2 and 3, there has been increasing concern that an abundance of quantitative research and medicalised discourse has dominated the meaning and understanding of the phenomenon of ADHD (Brady, 2004; Timimi and Radcliffe, 2004; Singh *et al.*, 2010; Dunne and Moore, 2011). Furthermore, by focusing on the physical basis of ADHD, voices of those whose lives have been touched by it have remained silent – particularly so, for the children and young people to which the label has been ascribed. This study sought to shift the 'lens of understanding' (Gergen *et al.*, 2004, p. 390) by inviting children, and parents, into the discussion on ADHD and giving voice to, and learning from, their personal experiences and perspectives.

Seeking and listening to children's views is not a new concept. In education, health and social care, in particular, the rights of children and young people to be consulted meaningfully in decisions made about them has been documented:

- in education (e.g. from the Children Act 1989, through to its most recent iteration, the Children and Family Act 2014 and subsequent *Special Educational Needs and Disability Code of Practice: 0 to 25 Years* (DfE/DH, 2014);
- and in health (the Department of Health White Paper, *Valuing People* (DoH, 2001) and Department of Health guidance, *Person-Centred Planning: advice for using person-centred thinking, planning and reviews in school and transition* (DoH, 2010)) policy.

In the context of current education policy, the new *Special Educational Needs and Disability Code of Practice: 0 to 25 Years* (DfE/DH, 2014) places great emphasis on the participation of children, young people and parents (Norwich and Eaton, 2015; Tellis-James and Fox, 2016).

In remaining true to IPA, the aim of this study was for the participants (children and parents) to tell their personal story in their own way, in order to support understanding of what it means for them to have ADHD in their lives. To achieve this endeavour, this small-scale 'phenomenological' research study used individual semi-structured interviews to illuminate ways in which parents and children make sense of their lived experience of ADHD by listening to their personal accounts – to reveal experiences unique to them as well as shared experiences across the sample (Smith *et al.*, 2009). Through

use of interpretative phenomenological analysis, description moved to interpretation as I attempted to understand the children's and parents' sense-making in relation to their personal experiences of ADHD; thus remaining true to the very core of IPA studies: 'phenomenology', 'idiography' and 'hermeneutics'. Through self-reflexivity in my role as researcher (see Chapter 4, section 4.5.3 and Appendix 12), including awareness of my contribution to the construction of meanings, and the transparency with which interpretations can be traced back to children's and parents' verbatim accounts (see Appendices 10, 11 and 12), the interpretations offered can be considered valid in telling us something about what it is like to live with ADHD. Wider applicability of the findings can be claimed cautiously through theoretical generalisability (Smith and Osborn, 2015) (see also section 8.4.1). This allows for comparisons to be made with findings and theoretical arguments derived from other 'well-described', situated studies, so that convergence of argument and/or data trends is accepted as strengthening indications that the findings of any particular study do reflect wider trends characteristic of the target population (in the present case, primary-aged children who experience ADHD, and their mothers). As discussed (see Chapter 6, 7 and 8 and Appendix 13) findings from this research study reflect themes presented within the existing literature, which Ware and Raval (2007) suggest lend credence to the validity of the research.

The main research question was 'broad and exploratory' (Smith *et al.*, 2015), simply asking: what is it like to live with ADHD? Within this 'broad and exploratory' research question, however, interview questions were informed

by themes derived from previous qualitative research, including: meaning and identity, beliefs about ADHD, effects of ADHD, the process by which ADHD came into their lives, support and interventions, and positive aspects. The aim has been to understand the phenomenon within a local context; therefore, generalisations to the wider context of ADHD are offered cautiously.

Superordinate themes and their corresponding subordinate themes, constructed through analysis of the interviews, are presented in Table 6.1 (child participants) and 7.1 (parent participants).

## **8.2. Contribution of this research to existing understanding**

From the children's accounts, a child-centred approach to the problem was described in which the children were presented as being at the centre of the problem and the focus of investigation and subsequent change. These experiences appeared to influence the ways ADHD came to define them, and their personal experiences, so that, as reported in previous studies (Kruegar and Kendall, 2001; Kendall *et al.*, 2003; O'Leary, 2007; Davies, 2009; Grant, 2009; Kildea *et al.*, 2011; Byrne and Swords, 2015), the children tended towards 'being' rather than 'having' ADHD.

The children were positioned as passive and subservient in an adult-orientated system that valued and responded to adult's needs, views and experiences. The children's accounts spoke of the controlling effects not only of their medication, as described in previous research (Cooper and Shea, 1998; Kendall *et al.*, 2003; Travell, 2005; O'Leary, 2007; Gallichan and Curle,

2008; Grant, 2009), but also the ADHD, leading to uncertainty in how they could influence the problem and its effects. Despite increasing recognition of children's rights and participation regarding education and health (see Chapter 1 section 1.2, Chapter 6 section 6.4 and Chapter 8 section 8.1), there seemed little evidence of them being listened to, informed and consulted.

Notwithstanding the negative descriptions, the children also spoke of positive attributes, and described skills and qualities which would not have been predicted by the dominant discourse surrounding them. However, whilst these experiences provided a starting point to alternative stories, they remained thin descriptions in a thickened narrative of a disordered child.

In seeking an explanation for their child's 'difference', parents spoke of 'pleading' and 'battling' with health and/or education services, and of a long and arduous process: firstly, to gain recognition that there was a problem; and secondly, in negotiating the 'hoops and hurdles' of the various stages of assessment and subsequent outcomes. Similar to findings from previous research (Dennis *et al.*, 2008; Firmin and Phillips, 2009; Peters and Jackson, 2009; McIntyre and Hennessy, 2012), mental health services were described as complicated and fractured, and at many stages during the journey towards diagnosis, parents spoke of having to 'muddle through' without support. There appeared to be a paradox, however, for whilst diagnosis was at the end of the journey, it also formed the beginning in terms of support, intervention and solutions. In the absence of early intervention, this process appeared to contribute to increasing complexity and severity of the problem.

Consequently, desperation for help triggered an increased impetus to find quick answers, whilst the severity of the problem provided confirmation of the validity of the diagnosis and medication as first-line treatment. Furthermore, the linear diagnostic pathway described, appeared to steer the context for discussion, data gathering and treatment, in which information and experiences falling outside this remit (of diagnosing ADHD) appeared to be overlooked.

Receipt of a diagnosis had been profound for the child and parent participants, although these experiences presented differently in their consequences. For the parents, similar to previous research (Dennis *et al.*, 2008; McIntyre and Hennessy, 2012), the 'label' triggered feelings of relief, as it appeared to legitimise and validate their concerns and provided a reason for their child's behaviour. A change in narrative from naughty child/bad parent to disordered child/vigilant parent provided acceptance from others and removal of blame. Similarly, for the child participants, the repositioning of their behaviour from badly behaved to being the result of a medical condition provided some reassurance in explaining their 'difference'. However, in being located within their neurobiological make-up, ADHD became woven into their identity.

Consistent with a wealth of literature (Dennis *et al.*, 2008; Firmin and Phillips, 2009; Peters and Jackson, 2009; McIntyre and Hennessy, 2012), family life was described as stressful, as the ADHD impacted upon the whole family microsystem. The consensus was that their child with ADHD required a

different style of parenting, demanding high levels of investment in time and energy, and sacrifice. A more rigorous method of parenting was described and parents appeared caught in a cycle of constant action in order to keep their child safe, maintain the family system and ensure their child received the appropriate care and intervention. The experience of parenting a child with ADHD contributed to the development of specialist knowledge, and a role of pseudo-expert ensued.

Whilst by no means universal, from the children's accounts, a trio of facets appeared to influence the controlling effects of the ADHD and the extent to which the label came to define them: these seemed to be the ways in which the problem was constructed, the adult-orientated systems and use of medication in the absence of a more comprehensive approach. Similarly, these facets, albeit in a slightly different guise, appeared to contribute to parent's experiences of stigma and blame, their cycle of constant action and their dissatisfaction with post-diagnostic care, including lack of long-term solutions. For the parents, these presented as a (partial) construction of the problem, rigid and linear support and diagnostic systems, and absence of a more comprehensive and holistic approach.

The purpose of this research study has been to contribute to knowledge about children's and parents' unique understanding and experience of the phenomenon of ADHD, and of shared meanings. Findings are consistent with previous studies (as discussed in the concluding syntheses accompanying the analysis presented in Chapters 6 and 7) and add to a growing body of

knowledge about the lived experience of ADHD (see concluding syntheses accompanying the analysis presented in Chapters 6 and 7, Chapter 8 section 8.2 and Appendix 13, which provides further comparison of findings with those of the research studies presented in Chapter 3). These findings address one of this study's stated aims (see Chapter 1, section 1.2), which, until recently, has been lacking in evidence.

This study's particular contribution, however, has been to explore similarities and differences in how children and parents understand and experience the 'disorder'. As Firmin and Phillips (2009) argue, in order to better understand ADHD, it is helpful to explore common problems, patterns and solutions experienced by the children and parents who have ADHD in their lives. Similarly, Bracken (2014) asserts, 'any experience can only be grasped through an understanding of context in which the person lives and through which that particular experience has significance' (p. 242). Firmin and Phillips' (2009) study, conducted in the USA, offered an insight into these aspects, but in replicating a previous study, was somewhat constrained in its design.

### **8.3 Implications for practice**

The findings from this small-scale 'phenomenological' study suggest that there remains much to do in supporting children, young people and families who have ADHD in their lives. The following recommendations, informed by the research findings, address, but are not confined to a key aim of this research study: *to help to inform local policy decisions regarding ADHD interventions and the future training needs of teachers and other professionals*

*working with children and to help to improve services and support for children and their families.*

### **8.3.1 Child voice and participation**

Although not a new concept, as discussed in section 8.1, eliciting children's and young peoples views has taken on particular significance in light of the *Special Educational Needs and Disability Code of Practice: 0 to 25 Years* (DfE/DH, 2014), which places greater emphasis on children and young people's voice and participation (Tellis-James and Fox, 2016). The Code of Practice states that there 'must' be regard to children, young people's and parents' views and participation (DfE/DH, 2014, p. 19), and refers to a 'person-centred' approach being used to ensure that they are involved in all aspects of planning and decision-making. This is significant for educational psychology practice as there has been longstanding interest in ascertaining the voice of the child (Aston, 2005; Aston and Lambert, 2010; Ingram, 2013). It also has significance for children and young people who experience social, emotional and/or mental health difficulties, such as those with a diagnosis of ADHD, who have been described by Cooper (2006) as the 'least empowered and liked group of all' (p. 39).

Despite their potential valuable contribution, findings have consistently shown that children remain on the periphery during assessment, diagnosis and treatment, and are rarely consulted directly (Kendall *et al.*, 2003; Travell, 2005; Davies, 2009; Stafford *et al.*, 2016). In relation to this research study, the children were positioned as passive and subservient within an adult-

orientated system that valued and responded to adults' needs, views and experiences. There seemed little evidence of them being listened to, informed and consulted. As Gallichan and Curle (2008) have argued, such a position is likely to result in children feeling powerless and unable to escape the problem. If provided the opportunity however, children are able to provide balanced and useful contributions that prove helpful in decision-making (Dogra, 2004; Davis and Wright, 2008; Day, 2008). Furthermore, listening to children and young people may 'hold the key to our understanding of the problem and its resolution' (Davie *et al.*, 1996 p. 7). Ross and Egan (2004) concur, suggesting that eliciting children's views gives them a sense of worth and involvement, produces unique perspectives that are distinct from others and informs service providers in understanding the impact of service involvement on children.

In moving beyond the rhetoric of children's rights and participation, children should be part of discussions about their presenting problems and consulted as a partner in any subsequent assessment, diagnosis and intervention. A change in the language of NICE (2013) guidance, and also at a local policy level, would be helpful in setting the agenda for this, by recommending services should 'encourage' rather than 'allow' children's participation and voice, and providing examples of how to foster their participation. As Day (2008) has described, children would benefit from access to developmentally appropriate, personally relevant and accurate information presented in useable forms, to assist involvement in their own healthcare. Educational psychologists could be involved in developing 'child/young person-friendly'

information to enable them to learn about and understand their diagnosis, to support their contribution to assessment and foster their engagement in plans for intervention.

Drawing on the current trend within special educational needs legislation, person-centred approaches, previously recognised within education, health and social care policy (White and Rae, 2016), could be utilised to support the contributions of children, young people and their parents, and to empower them to participate in planning and decision-making. Many educational psychologists are familiar with these approaches and their psychological underpinnings (White and Rae, 2016), and are suitably skilled and well placed to support and promote children's and young people's engagement (Hill and Turner (2016). Research by Corrigan (2014) found that stakeholders (parents, teaching and support staff in schools, health professionals and educational psychologists questioned about the implementation and long-term outcomes) reported that person-centred planning meetings had a positive impact upon children and young people's motivation and achievement across social, emotional and academic domains.

Person-centred approaches share principles similar to those of narrative therapy in recognising children as 'experts on their own lives' (Sanderson, 2000) and like narrative therapy, they encourage talk about all aspects of the child/young person's life, leading to new stories or narratives about them (Taylor-Brown, 2012). These alternative stories can be helpful in recognising strengths and skills, raising aspirations and promoting a positive sense of

identity that can counter thin identity conclusions associated with ‘within child’ symptoms and mental health labels. When asked the right questions, and provided with the opportunity to have their voices heard, children and young people are able to identify a range of strengths and resources in themselves (reflecting the nature of their individual experiences), their schools, their family and their community (Tellis-James and Fox, 2016). Such an approach encourages an ‘interactionist’ perspective, where possibilities for change within the child’s context are also considered and where children’s agency is recognised, leading to a more holistic understanding of their lives (Roffey *et al.*, 2016). This is particularly pertinent to children and young people with social and emotional difficulties (such as those with a diagnosis of ADHD) as it is suggested that they are likely to have poor educational outcomes (Barbaresi *et al.*, 2007) (see Chapter 2, section 2.7) and that transitions from educational settings to adult life can be more problematic (Daniels *et al.*, 2003; Pritchard and Cox, 1998).

### **8.3.2 Comprehensive and holistic assessment and intervention**

Clinical pathways have been described as tools to improve the quality of care, by ensuring it remains evidence-based (de Luc *et al.*, 2000); however, as Jones (2004) cautions, these systems can lead to over-reliance on diagnosis in determining care delivery, as found in this study. Referral guidelines are important, but basing them on categories of presenting symptoms may not be enough to ensure a person receives the most appropriate assessment and intervention (Howarth and Gallagher, 2015). As discussed in section 8.2 there appeared to be a paradox in the delivery of mental health care, for whilst

diagnosis was at the end of the journey, it also formed the beginning in terms of support, intervention and solutions. Furthermore, in the absence of early intervention, this process appeared to contribute to increasing complexity and severity of the problem. The linear diagnostic pathway described, steered the context for discussion, data gathering and treatment, in which information and experiences falling outside this remit (of diagnosing ADHD) appeared to be overlooked.

These experiences suggest the need for multi-perspective case formulation, where consideration is given to all levels of the ecological system. As found in this research, the difficulties described by the parents could not all be understood through the lens of ADHD symptoms, and medication did not appear to alleviate all of their concerns.

A multidisciplinary approach that goes beyond the completion of checklists by teachers and parents is required to ensure a deeper, more comprehensive understanding of the difficulties and their contexts (Harborne *et al.*, 2004; Hill and Turner, 2016). Such an approach would move towards systems that are more helpfully needs-, rather than diagnosis-, led, improving services and support for children and their families. This approach is consistent with the key principles of recent education legislation (e.g. Children and Families Act 2014) and health policy (e.g. *No health without mental health* (DoH, 2011) and *Future in Mind: promoting, protecting and improving our children and young people's mental health and wellbeing* (DoH, 2015)) all of which aspire to the early identification of children's and young people's needs, early intervention

to support them, and greater collaboration between education, health and social care services.

EPs are in a position to contribute greatly to a process that is more needs-, rather than diagnosis-, led, as they have a wealth of knowledge about the child, family and school, and are already skilled in the use of multi-perspective formulations (Woods *et al.*, 2006; Woods and Farrell, 2006). As Greig *et al.* (2016) assert, EPs' 'systemic knowledge of education services, schools and families, their community access and models of service delivery, offer an economically viable service' to address children's and young people's mental health needs (p. 7). Furthermore, EPs can play a key role in facilitating multi-agency collaboration between schools and external mental health services, support the integration of mental health provision and the translation of research into practice (Wolpert *et al.*, 2015). This role appears particularly pertinent, given that most child mental health-related contacts with services occur within the education sector and, similar proportions of children who have diagnosed psychiatric disorders access specialist education professionals as attend child and adolescent mental health services (Ford *et al.* 2007). This is supported by recent findings from Department of Education research into mental health provision in schools and colleges (National Centre for Social Research & the National Children's Bureau Research and Policy Team, 2017). The research found that 'the most common types of support offered for pupils with identified mental health needs were educational psychological support (61%) and counselling services (61%)', and that more

clinical forms of support (e.g. cognitive behaviour therapy (18%) and clinical psychological support (14%)) 'were much less commonplace' (ibid, p. 8).

In their survey of EPs' perspectives on the medicalisation of childhood behaviour, Hill and Tuner (2016) found a correlation between EP involvement in the assessment process for ADHD and increased use of psychological interventions. A more formalised role within health guidance, at both a national and local level, would be helpful in increasing the participation of EPs in assessment, intervention and follow-up care.

### **8.3.3 Multifactorial construction of the problem**

It is important to understand that families come to services having been exposed to dominant medicalised discourse about ADHD, and mental health more generally, and that their views and experiences need to be validated whilst also encouraging exploration of a range of factors that are not purely based on a medical model (Lewis-Morton *et al.*, 2014). Labels such as ADHD may provide an initial rationale, but, as described in this research, they often do not explain the full complexity of the difficulties being experienced. In addition, the dominant, often within-person, construction of the problem tends to influence how the problem is perceived, experienced and managed. As Wheeler *et al.* (2008) suggests, in the management of ADHD there is a definite need for a multi-modal approach to a multi-faceted problem.

An holistic biopsychosocial formulation (e.g. BPS, 2011 – *Good Practice Guidelines on the Use of Psychological Formulation*) of the problem offers a more balanced and comprehensive approach to address the breadth of the presenting difficulties. In drawing on this approach, EPs can further contribute to assessment and intervention of children with ADHD in the following ways:

- providing training for school staff and parents to increase their knowledge and understanding of the complexities of the condition. Training for schools could also include awareness of the curricular contexts and approaches, which have been found to produce fewer ADHD symptoms and increase on-task behaviour (Wheeler, 2007).
- supporting the development and implementation of multi-modal interventions that are tailored to the individual needs of the child and the contexts in which they find themselves. As Norwich and Eaton (2015) suggest, not all children identified as having ADHD will have the same educational needs, and other personal and contextual factors are also important in order to understand individual cases.
- delivering therapeutic intervention. EPs have been described as key therapeutic resources for children (MacKay, 2007) and are increasingly using a range of psychotherapeutic approaches when working in school settings (Al-khatib and Norris, 2015), including involvement in government-funded projects such as TaMHS (Targeted Mental Health Services) and CYP-IAPT (Children and Young People-Increasing Access to Psychological Therapies) which have focused on increasing children's access to psychological therapies within local contexts.

As complexity and co-morbidity of presenting problems increase, multimodal interventions – involving multiple systems – are crucial in order to produce effective and lasting change (Havighurst and Downey, 2009).

## **8.4 Evaluation of the study**

### **8.4.1 Limitations of the research**

In contrast to quantitative research approaches, qualitative research is concerned with meaning in context and involves interpretation of data (Willig, 2008), which requires the researcher's active engagement with the data (see Chapter 4), and is therefore subjective. To address these differences in research methodology, a set of four broad principles has been developed (Yardley, 2000) to judge the quality and validity of qualitative research. These principles aim to support the qualitative researcher in demonstrating that their study is 'trustworthy', 'legitimate' and 'useful' (Yardley, 2015). In Chapter 5 section 5.8 and Table 5.4, I discussed the criteria developed by Yardley (2000, 2015) and the ways in which I attempted to address the four principles, and the weaknesses of this study in relation to these. In addition to the potential weaknesses identified in Table 5.4, further evaluation of the research design is presented in Table 8.1.

Limitation	Evaluation of the Limitation
More than one meaning	<p>Qualitative researchers are integral to the research process and influence the knowledge produced through the development of their research questions, selection of methods and analysis, and through their interpretation of data (Yardley, 2015). Through my engagement with the data there was a risk of accounts being privileged that particularly resonated with me. Furthermore, my direction of questioning and non-verbal communication may have encouraged and/or discouraged certain responses. As discussed (see Chapter 4, Chapter 8 and Appendices 10, 11 and 12) I aimed for trustworthiness and transparency throughout the analysis and interpretation, but acknowledge that the findings are based on my interpretations and offer one of many possible explanations of the data (Yardley, 2000; Finlay, 2002; Smith <i>et al.</i>, 2009). Other researchers may have constructed different themes and/or included other themes, and organised and presented similar themes in different ways. However, as advocated by Yardley (2000), Elliott <i>et al.</i> (1999) and Smith <i>et al.</i> (2009), all themes have been grounded within the data, and furthermore, as recommended by Smith (2010), themes were supported by extracts from each participant to present 'breadth and depth' of the theme and to enhance rigour (p. 24).</p> <p>Through individual semi-structured interviews, participants were invited to share a rich and detailed first-person account of their experiences of ADHD. These findings, however, only reveal something about the participants' 'current positioning' (Larkin <i>et al.</i>, 2006, p. 109), thus offering a brief time-limited illustration of their perceptions within certain specific contexts on a particular day.</p> <p>At the interpretative level of the analysis, IPA has been criticised for the meaning placed on the participants' account by the researcher, which has been perceived as potentially denying their voice (Willig, 2008, p. 63). As described, my interpretation remained grounded within the participants' accounts, and participant validation was sought from one of the parent/child dyads to ensure themes represented their experiences. Osborn and Smith (1998) suggest that in the context of IPA, the aim of validity checking is not to prescribe a 'singular true account' but rather, to ensure credibility of the final account (p. 69).</p>

<p>Idiographic rather than nomothetic</p>	<p>IPA focuses on the ‘idiographic’ rather than ‘nomothetic’, and the aim of this small-scale exploratory study has been to further idiographic understanding of children and parents who have ADHD in their lives. IPA studies involve small samples to enable greater depth (Heffron and Gil-Rodriguez, 2011), making generalisation to the wider population problematic, which could be viewed as limiting; however, as Smith <i>et al.</i> (2009) assert, generalisation should not be an issue because IPA studies are not claiming to create general or grand theories.</p> <p>In addressing generalisability, Smith and Osborn (2015) discuss ‘theoretical’ as opposed to ‘empirical’ generalisability (p. 28): in the case of ‘theoretical’ generalisability, the reader of the study makes links between the findings and their own personal and professional experiences, as well as claims in the existing literature. Generalisations can be made cautiously with support from findings within the existing literature, although these would be specific to the particular group studied – findings from this study reflect themes presented within the existing literature. Ware and Raval (2007) suggest that internal consistency of the data and their coherence with other research findings lend credence to the validity of the research.</p> <p>Findings from this study are offered tentatively, given such a small sample, and are in no way suggested as being typical of all children and parents who have ADHD in their lives; for example, all of the child participants were taking medication, male and predominantly White British, whilst parent participants were all mothers and drawn from the same area. However, the insights gained from the participants’ accounts may be of relevance to others experiencing the phenomenon of ADHD. IPA studies should be judged first and foremost on how illuminating they have been to the particular cases studied (Smith, 1999).</p>
<p>Power imbalances</p>	<p>As discussed in Table 5.4, my status as a ‘psychologist’ and ‘researcher’ may have had an impact on the views expressed. However, my experience was that participants spoke in detail about their experiences, and in one of the child interviews, the participant (Mason) chose to share an emotional experience and, despite becoming upset, stated that he wanted to continue because he wanted me and others reading the research to know about it. From the parent interviews, my perception was that they too were eager to ‘tell their story’ and help others in similar situations; having their voice (finally) heard, appeared important to them.</p>

A reliance on language	The use of semi-structured interviews with children could be seen as limiting, as children may have had difficulties expressing themselves due to poorly developed language skills (see Table 5.4 and section 5.2.1 for a more detailed discussion). In the context of this study, I was able to recruit a group of children who were able to articulate their experiences; however, consideration should be given to the potential value of other data collection methods, for example: drawings (Humphrey and Lewis, 2008; Woolford <i>et al.</i> , 2015), discussion of vignettes (O’Driscoll <i>et al.</i> , 2012) or use of (participant-generated) photographs (Wagstaff, 2009).
Situating the sample (Elliott <i>et al.</i> , 1999)	IPA studies sample purposively in order to illuminate a particular research question (Brocki and Weardon, 2006); therefore, studies are not aiming to achieve a representative sample in terms of population or probability. This study’s sample of participants is not presented as being representative of the population of children with ADHD, particularly given the heterogeneity of the disorder and the gender bias, due to only boys and their mother’s taking part. However, as Smith and Osborn (2015) suggest, over time, subsequent studies with other groups will further illuminate experiences of the particular phenomenon under study and enable more general claims to be made.

Table 8.1: Further Evaluation of the research design.

#### 8.4.2 Implications for future research

Whilst qualitative studies exploring the experiences of ADHD have increased in number, I believe there is still much to be gained from involving those who have direct experience of the disorder in research. Although by no means exhaustive, there are a number of areas where future research could focus attention:

- Age of participants

As discussed in Chapter 2, the majority of qualitative studies have focused on young people of secondary-school age, and I therefore decided to

concentrate on the upper (Key Stage 2) primary-school age range (8–11 years). However, the mean age of the sample for this study was 11 years, as these were the children who (with parental permission) consented to take part. Future research could focus on the experiences of children aged 8–10 years to explore any differences in the experiences of this age group.

- The experiences of girls who have a diagnosis of ADHD

There has been limited research involving girls with ADHD. Findings by Krueger and Kendall (2001) and Gallichan and Curle (2008), whilst offered tentatively due to their small samples, suggest there may be differences in how ADHD is experienced. Furthermore, recent neuropsychological research suggests ADHD is differently mediated and experienced in girls and boys (e.g. differences in brain structure possibly underlying gender-related differences in externalising and internalising symptomology) (Villemonteix *et al*, 2015).

- The experiences of fathers

The extent to which findings from existing literature can be said to ‘speak for’ fathers of children with ADHD is limited; however, studies whose samples have included fathers, suggest differences in how ADHD is conceptualised (Harborne *et al.*, 2004; Koro-Ljunberg and Bussing, 2009; Keown, 2012; Brunton *et al.*, 2014). Exploring the perceptions and experiences of fathers will be helpful in furthering the understanding of the lived experience of ADHD.

## **8.5 Conclusion - impact and importance**

Referring back to the outset of this study, no system of universal categories (Freedman and Combs, 2012) and, equally, no qualitative research method are able to capture people's lives in all their complexity. Whilst privileging individual views and experiences of children and their parents, this small-scale qualitative study does not claim to present these experiences, or the phenomenon of ADHD, in all its complexity. However, in keeping with the aims of IPA, by presenting a 'deep and textured' account (Ware and Raval, 2007, p. 563) of children's and parents' experiences, I believe this research study has contributed something interesting, important and useful (Smith *et al.*, 2009) both to the children, young people and families to which the label is ascribed and to those working with and supporting them.

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**Appendix 1: University of Birmingham Application for Ethical Review  
(AER)**



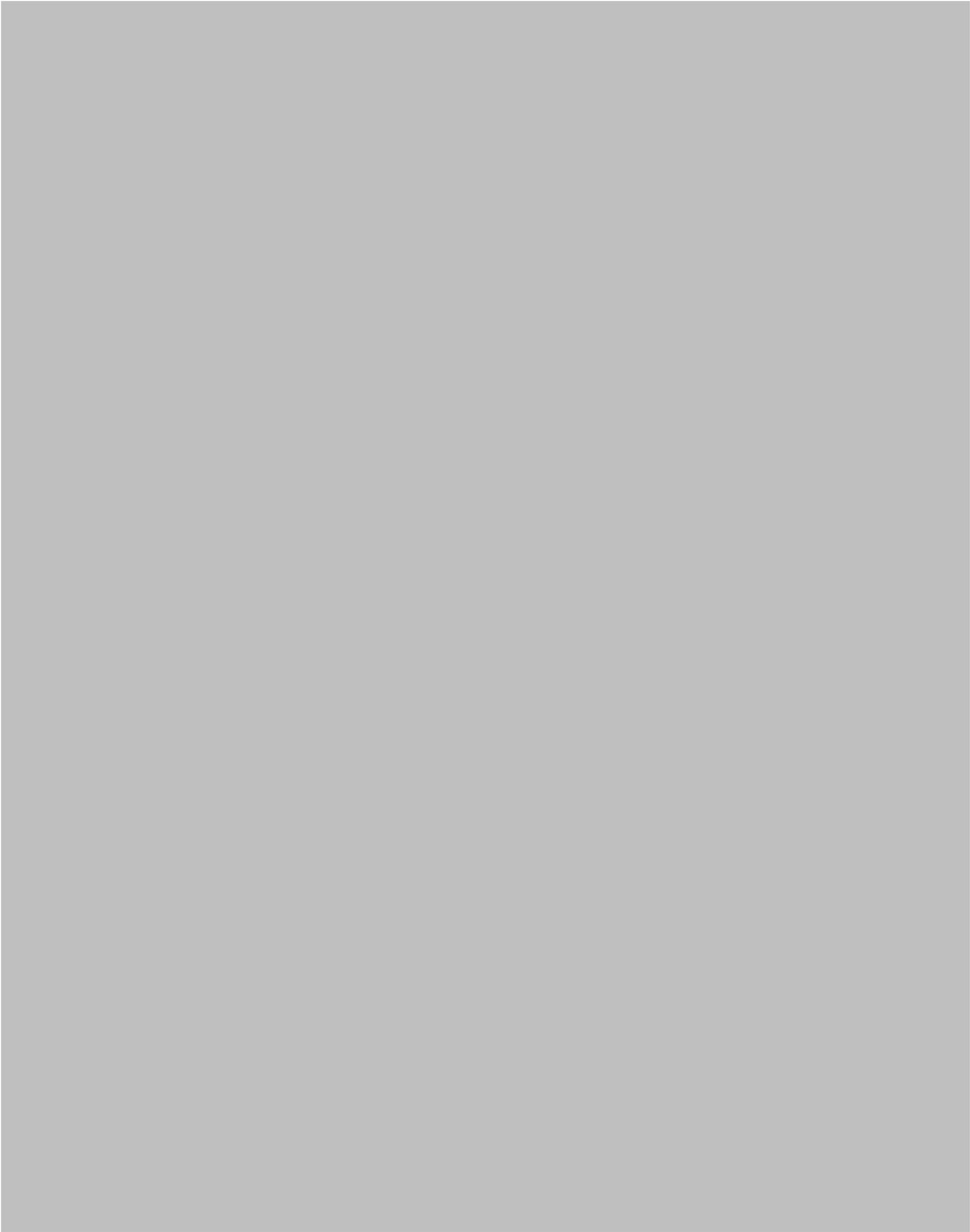




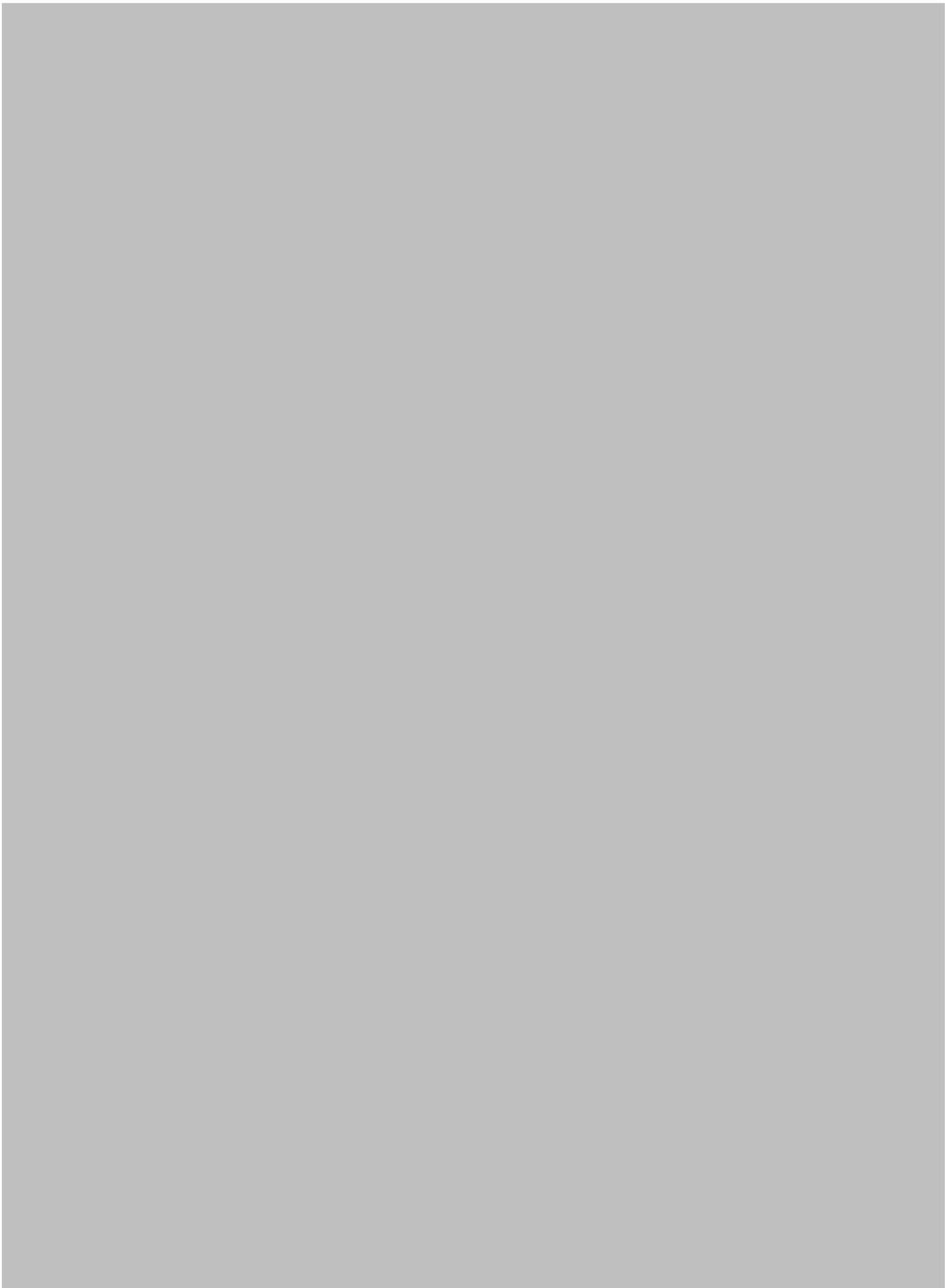




















## **Appendix 2: Examples of Behaviours for the Three Core Symptoms of ADHD**

## **DSM-5 Diagnostic Criteria for ADHD**

### **Inattention**

- Fails to pay close attention to details
- Has trouble sustaining attention
- Doesn't seem to listen when spoken to directly
- Fails to follow through on instructions and fails to finish schoolwork or chores
- Has trouble getting organised
- Avoids or dislikes doing things that require sustaining focus/thinking
- Loses things frequently
- Easily distracted by other things
- Forgets things

### **Hyperactivity and Impulsivity**

- Fidgets with hands/feet or squirms in chair
- Frequently leaves their chair when seating is expected
- Runs or climbs excessively
- Trouble playing/engaging in activities quietly
- Acts "on the go" and as if "driven by a motor"
- Talks excessively
- Blurts out answers before questions are completed
- Has trouble waiting or taking turns
- Interrupts or intrudes on what others are doing

(Ref: American Psychiatric Association (2013) Diagnostic and Statistical Manual of Mental Disorders (DSM-5))

**Appendix 3: Letter to Special Educational Needs Co-ordinators  
(SENCOs)**

Dear SENCo

**Proposed title of research:**

***When ADHD came into our lives: an exploration of the lived experiences of young people, with a diagnosis of ADHD, and their parents.***

As you know I am currently completing a post qualification doctorate in educational psychology at the University of Birmingham, and as part of the course I am required to conduct a research study. Given my growing interest in understanding the needs of children with ADHD I have decided to conduct a research study into the experiences of children, who have a diagnosis of Attention Deficit hyperactivity Disorder (ADHD), and their parents.

Research with children and young people with ADHD is limited and I hope that this proposed research, by focusing upon the lived experiences of children, and their parents, who have direct experience with it, will:

- add to a body of knowledge still in its infancy, on what it is like to live with ADHD;
- help to inform local policy decisions regarding ADHD interventions; allocation of resources; future training needs for teachers and professionals working with children with ADHD;
- help to improve services and support, for children, their families and professionals; and,
- offer other children and young people, with ADHD in their lives, an opportunity to learn about other children's stories about what is like to live with ADHD.

I would like to interview up to four children and their parents (these will be separate interviews) using a semi-structured interview. The interviews will be conducted either at their home, school, or at a 'neutral' venue at the participant's request. Interviews will be recorded on audiotape and transcribed. Please be assured that no school or participants will be named in the study.

The criteria for selecting child participants will be that the child:

- has a diagnosis of ADHD from either a consultant psychiatrist (CAMHS) or consultant paediatrician;
- will be aged 8-11 years;
- has no history of living in the care of the local authority; and,
- has no involvement with child protection (e.g. has a Child in Need (CIN) or Child Protection (CP) plan).

The criteria for selecting adult participants will be:

- a parent/carer of a child who meets the criteria detailed above.

If you have any pupils in your school who meet the above criteria for inclusion in the study and who you believe would be interested in taking part, I would be grateful if you could provide the child and parent/carer with an information

sheet and request that, if interested, they return the 'opt in' postcard to you or to me (via post – post cards will be stamped and addressed). Alternatively, parents can contact me by telephone to discuss the research study prior to returning their 'opt in' post card and I would be happy to meet with any pupils in school to answer any queries they may have.

If you have any further questions about the study please do not hesitate to contact me.

Yours sincerely

Lucie Rowlands  
Educational Psychologist

## **Appendix 4: Information Letter to Parents and Parent Information Sheet**

Dear Parent

My name is Lucie Rowlands and I am a psychologist working for X Educational Psychology Service (at X Council). You may have seen me around as I regularly visit schools in your area to work with children, parents and teachers.

I am currently completing further studies in educational psychology (called a Doctorate in Educational Psychology) at the University of Birmingham and as part of my course I am required to carry out a research study.

I am very interested in understanding the needs of children who have a diagnosis of ADHD and I have decided to carry out a study to look at the experiences of children and their parents.

I hope that this study will:

- add to the small number of studies that have looked at what it is like to live with ADHD;
- help to inform local decisions regarding ADHD interventions e.g. resources, training needs for teachers;
- help to improve services and support; and,
- offer other children and young people, with ADHD, an chance to learn about other children's stories about what is like to live with ADHD.

You and your son/daughter are being invited to take part in this research project. Before you decide I would like to tell you about what it will involve for you and your child. Included with this letter is an information sheet to help to answer questions you may have. However I would be happy to answer any further questions.

You can contact me on [REDACTED] or complete and return the postcard below to Mr/s \_\_\_\_\_, the Special Educational Needs Co-ordinator (SENCo), at your son/daughter's school and I will contact you.

Yours sincerely

Lucie Rowlands  
Educational Psychologist

## **Parent/Carer Information Sheet**

### ***Do I have to take part?***

No. This study is totally voluntary. Please be assured that saying “no” will not affect your child’s access to any future services.

### ***How can I withdraw if I change my mind?***

If you give your consent to take part you will be given a postcard to inform me of your decision to withdraw should you change your mind.

The postcard can be posted to me or given to a member of staff (e.g. SENCo) at your child’s school. You do not have to give a reason for withdrawal and I will not contact you to ask you to change your mind.

Your son/daughter will also be provided with a postcard to use if they decide to withdraw.

### ***Will I need to sign a consent form?***

Yes, if you agree to take part you will be asked to sign a consent form.

Your son/daughter will also be asked for their signed consent but they will not be able to take part unless you also give signed consent for them.

All forms will be kept in a locked filing cabinet and will be destroyed once the study has finished. If you would prefer, I can give you your signed consent form when the study is finished.

### ***How will my son/daughter be informed about the study?***

Your son/daughter will be given an information sheet with pictures to help them to learn about the study. A member of staff at their school will be asked to read this with them.

If your child is interested to take part I will arrange to meet them in school to tell them more about the study; to check they understand what will happen; and, to gain their signed consent.

### ***What will happen next if I give my consent?***

You and your son/daughter will be asked to participate in separate interviews.

The parent interview can be carried out at your home or child’s school. Please tick where you would prefer on your consent form.

### ***How long will it take?***

The interview may last up to an hour. However, the interview can be completed in two sessions if one hour is too long for you.

### ***How will you record what I have told you?***

The interviews will be recorded using a digital audio recorder. After the interview I will type our conversation into a written version and the digital recordings will be destroyed.

The digital audio recorder will be switched off if you feel upset or need to stop for any reason. We will not continue until you give your consent. You may decide to re-arrange the interview for another time.

Your son/daughter will be given a 'stop' card to place on the recorder if they want to stop the interview. The recorder will be switched off.

If you decide to withdraw from the study the digital audio recording and any written version of the interview will be destroyed.

### ***Will my views be kept confidential?***

Our discussion will not be shared with other participants, including your child, and my discussions with child participants will not be shared with other people taking part in the study, including their parents.

However, where information is given from you or your son/daughter that suggests a threat of serious harm to you, your son/daughter, or others, I am duty bound to disclose this to a relevant professional. This will be discussed with you in the first instance.

Parts of your interview may be used in the research findings. Only you and I will know what you have said and no one else will be able to identify you from reading the finished report. At the end of the interview we will choose a different name (a pseudonym) for me to use instead of your own name and references to places and any other personal details will be changed to maintain anonymity.

The findings will be written up as a report (called a doctoral thesis) for the University of Birmingham. The findings may also be used in conference papers and journal articles, which the public will be able to read.

### ***Will I be informed about the results of the study?***

You and your son/daughter will be given copies of our conversation in typewritten form. We can discuss this together and I will take out any parts you would prefer to be withdrawn from the study.

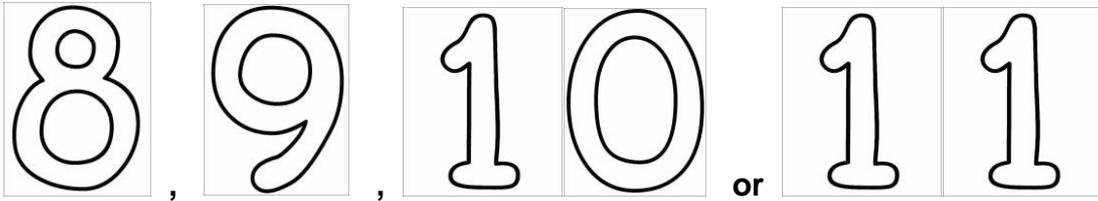
Once the study is fully completed I can provide a brief version of the findings if you would like a copy. The report will contain parts of the interviews from all participants who took part in the study but these will be recorded under their 'chosen name' so that they can't be identified.

**Please do not hesitate to contact me if you have any further questions before you decide to take part.**

## **Appendix 5: Information Letter to Children**

Dear ....

Are you



years old?

Is ADHD in your life?

INSERT IMAGE

Could you help me to learn about ADHD?

IMAGE TO BE INSERTED

**I am running a project to find out what it is like to live with ADHD.**

**IMAGE TO BE INSERTED**

**I would like to chat to you about how you feel about living with ADHD.**

**IMAGE TO BE INSERTED**

**I hope that what you tell me may be able to help other children who also have ADHD in their life.**

**IMAGE TO BE INSERTED**

**Here are answers to some questions you may have...**

<b>Questions</b>	<b>Answers</b>
<p><b>Who are you?</b></p> <p><b>INSERT IMAGE</b></p>	<p>Here I am!</p> <p><b>PHOTO OF MYSELF INSERTED HERE</b></p> <p>My name is Lucie Rowlands. I am an educational psychologist.</p> <p>I come to your school to work with children, parents and teachers. You may have already seen me around school.</p> <p>I am doing a study to find out about what it is like to have ADHD.</p>
<p><b>Why me?</b></p>	<p>You have been given this sheet because you are aged between 8 and 11 years old and, you know about ADHD.</p>
<p><b>What will happen if I agree and say 'yes' to taking part?</b></p> <p><b>INSERT IMAGE</b></p>	<p><b>First,</b> you will let me know where you would like us to meet e.g. at school or home</p> <p><b>Then,</b> we will talk about the study and what to do if you change your mind about it</p> <p><b>Then,</b> we will meet to have a chat about you, your friends and family, and about ADHD</p>
<p><b>How long will it take?</b></p> <p><b>INSERT IMAGE</b></p>	<p>Our chat will last about 1 hour but we can have a break or meet again another time if 1 hour is too long for you.</p>

<p><b>How will you remember what I have said?</b></p> <p><b>INSERT IMAGE</b></p>	<p>I will tape our chat using a recorder.</p> <p>Our chat will be typed so I can read it again. I may include some of our chats in my study.</p> <p>Do let me know if you don't want me to do this.</p>
<p><b>Will anything bad happen?</b></p> <p><b>INSERT IMAGE</b></p>	<p>Some of the things you want to tell me about might be upsetting.</p> <p>If you feel upset we will stop.</p> <p>You can stop at any time. I will give you a stop card to place on the recorder.</p> <p>If you choose to tell me about things that are harmful (e.g. someone bullying you or hurting you) then I will need to share this information with another adult.</p>
<p><b>How can I help?</b></p> <p><b>INSERT IMAGE</b></p>	<p>I hope the study will help me to understand the feelings of children with ADHD, about what it is like to have ADHD.</p> <p>It might also help teachers to understand what it is like to have ADHD.</p>
<p><b>Will people know what I have said?</b></p> <p><b>INSERT IMAGE</b></p>	<p>Only you and I will know what you have said.</p> <p>If I include some of our chats in my study I will use another name so that no one will know it is you. This is called being <i>anonymous</i>.</p> <p>We can talk about names you would like me to use.</p> <p>The chats I have with you, other children, and parents will be written up as a report for the University of Birmingham. They may also be used in conference papers and journal articles, which other people can read.</p>
<p><b>What if I change my mind?</b></p>	<p>You can change your mind and say 'no' at any time and there is no need to give a reason.</p>

<b>What happens after our chat?</b>	We can meet up again when I have typed up our chat so that you can make a change or take things out.
<b>What If I have more questions?</b>  <b>INSERT IMAGE</b>	I would be happy to answer your questions before we get started.  Fill in the postcard and give it to Mr/s _____.  If you would like to know more I will come to school to meet with you.

**Thank you for your time.**

**I look forward to meeting with you!**



Please tick if you agree

Yes! I want to take part in the study.	
Yes! Please come and see me so I can find out more.	
No! I am not interested.	

Name: \_\_\_\_\_

## **Appendix 6: Parent Consent Form**

**Title of Research:** *When ADHD came into our lives: an exploration of the lived experiences of young people, with a diagnosis of ADHD, and their parents.*

**Name of Researcher:** *Lucie Rowlands*

	Tick to Agree
I confirm that I have read and understand the information sheet for the above study, and have had the opportunity to ask questions.	
I understand that my participation is voluntary and that I am free to withdraw at any time and without giving a reason.	
I understand that my responses will be anonymised. Names and other identifying information will be changed.	
I agree to take part in the above research project.	
I agree for my son/daughter _____ (insert their name) to take part in the above research project.	
I understand that my child's participation is voluntary and that he/she is free to withdraw at any time without giving a reason.	

Home

I would like to be interviewed at...  
(please tick)

My child's school

Name of participant: \_\_\_\_\_

Signed: \_\_\_\_\_

Date: \_\_\_\_\_

## **Appendix 7: Child Consent Form**



**Please tick if you agree**

INSERT IMAGE	I want to take part in this study and to share my views on ADHD.	
INSERT IMAGE	I know I can say “NO” to any questions that I don’t want to answer.	
INSERT IMAGE	I know our chat will be recorded using a digital recorder. I know I can say “NO” if I don’t want our chat taped.	
INSERT IMAGE	I know that I can show a ‘STOP’ card if I want to stop. I know the digital recorder will be turned off.	
INSERT IMAGE	I know that my name will not be used in the study report. A ‘made-up’ name will be used instead.	

INSERT IMAGE	I know who to talk to if I want help or information.	
INSERT IMAGE	<p>I understand.</p> <p>I agree to all of these things.</p> <p>I want to join in.</p>	

Name: \_\_\_\_\_

Signature: \_\_\_\_\_

Date: \_\_\_\_\_

\_\_\_\_\_ (name) read this form with me.

Signed: \_\_\_\_\_ (person who read this form with the child)

## **Appendix 8: Semi-Structured Interview for Children**

## Children's Interview

### **Reminders at start of interview**

- **Remind the child about the purpose of the interview using a copy of the children's information sheet**
- **Remind the child about the use of the tape recorder (and check that this is still ok)**
- **Remind the child about the use of the 'stop card' and practice using this**
- **Remind the child there are no 'right' or 'wrong' answers**
- **Ask if the child has any questions before starting the interview**

### **Warm up**

Ask the child to share their 'all about me' poster  
(poster will show child's favourite activities, favourite things, interests, pets, people in their life, favourite places)

### **Drawing ADHD**

Child asked to draw what ADHD looks like (if you could see ADHD what do you think it would look like?)

### **About ADHD**

Can you tell me about ADHD? What it is?  
How do you know ADHD is in your life?  
How long has ADHD been in your life? (use timeline)  
Where does it come from?  
Is it always in your life or in your life some of the time? (use shape)

### **Diagnosis**

Who noticed the ADHD?  
What did you/they notice?  
Did you think there was a problem?  
Did you have any ideas about what may be causing the problem?  
What did others think was causing it?  
Have people treated you differently since you have had a name for it?  
Is it better to have a name for it? How?  
Do you have your own name for it? What would you call it?

### **Mapping the effects**

What is it like having ADHD in your life?  
Does it make you feel different from other people your own age? How? (picture)  
Does ADHD get in the way of you doing well at school? How? (show 'school')  
Does ADHD get in the way of you and your friends? How? (show 'friends')  
Does ADHD get in the way of your relationships with your mum/dad/brother/sister? How?

Are there any good things about having ADHD?  
(Has ADHD ever helped you to do something?)  
Are there not so good things about having ADHD?  
(Can you remember a time when ADHD got in the way of something you really wanted to do?)

### **Separating the person and the problem**

Have you ever done anything that other people were surprised that you could do?

Is there something you have done that was really hard to do but you really wanted to do it?

Do you have other skills and qualities?

Are these sometimes hidden by ADHD?

Do other people know about these skills and qualities? Who?

### **Coping with ADHD**

What would you have liked to know about ADHD that you think would help other children who have ADHD in their lives?

What is/are the most important things to know about ADHD?

How do you handle the ADHD?

Have you found any ways to handle ADHD that you think might help other children?

Do you get support from other people to handle the ADHD? Who?

What support has helped most?

### **Closure**

- **Provide debriefing at the end**
- **Mention some main points from the interview**
- **Ask the child if they have any questions**
- **Ask: Is there anything we haven't talked about that is important for me to know?**
- **Explain what will happen next**
- **Ask the child to choose a pseudonym**

## **Appendix 9: Semi-Structured Interview for Parents**

## Parent Interview

### **Reminders at start of interview**

- **Remind the parent about the purpose of the interview using a copy of the parent information sheet**
- **Remind the parent about the use of the tape recorder (and check that this is still ok)**
- **Ask if the parent has any questions before starting the interview**

### **Genogram**

Where x fits into the family

Family composition

Family members with similar difficulties/ADHD

### **About ADHD (show prompt cards for each area)**

What do you understand by the term ADHD?

Where does it come from? What causes ADHD?

What do you think x understands by the term ADHD?

What do you think x's teachers understand ADHD to be?

What do you think x's friends think ADHD is?

What do you think other parents/your friends think ADHD is?

### **Diagnosis**

Tell me about when you first noticed that ADHD was around?

Did anyone else notice?

Did you receive any help from other people e.g. services, friends, family?

What happened next? And?

What do you think other people thought may be causing the problem?

Have people treated you differently since you have had a name for it?

Is it better to have a name for it? How?

Do you have your own name for it? What would you call it?

### **Mapping the effects**

What affect does ADHD have on x's life?

Does ADHD get in the way of x doing well at school? How?

Does ADHD get in the way of x having friends? How?

What affect does ADHD have on family life?

Does ADHD get in the way of your/others relationship with x? How?

Is ADHD always around or only some of the time?

Do other people notice that ADHD is not around? What do they notice?

Do you think the diagnosis has affected how x thinks about him/herself?

Do you think the diagnosis has affected how you/other family members see x?  
Do you think the diagnosis has affected how other people think about x?

### **Separating the person and the problem**

What skills and qualities does x have?

Do other people know about these skills and qualities? Who?

Has x done anything that you were surprised that he could do?

Has ADHD ever helped x to do something?

Has ADHD ever stopped x from doing something?

### **Coping with ADHD**

How do you explain ADHD to other people?

What would you have liked to know about ADHD that you think would help other parents who have ADHD in their lives?

What is/are the most important things to know about ADHD?

How do you handle the ADHD?

Have you found any ways to handle ADHD that you think might help other parents?

What kinds of support have you had that has been most helpful?

What support have you had that has been least helpful?

Is there any other support you feel would be helpful?

### **Closure**

- **Provide debriefing at the end**
- **Mention some main points from the interview**
- **Ask the parent if they have any questions**
- **Ask: Is there anything we haven't talked about that is important for me to know?**
- **Explain what will happen next**
- **Ask the parent to choose a pseudonym**

**Appendix 10: Table of Emergent Themes from One Child and One Parent Interview**

## Parent Themes: Netty

Always been different: 'My child isn't like my other child'

- Knew from early on
- What is ADHD/what is the child
- Brain problem
- Can't help it/lack of control

Long wait: 'things have to get really bad'

- Pleading for help/proving something is wrong
- Hoops and hurdles in order to navigate the system
- Crisis oriented approach
- Diagnosis changes everything

Excluded and stigmatised: 'constantly trying to prove yourself'

- Excluded from normal school experience
- 'seeing the problem not the child'
- Mother-blame - under the gaze/judged

Hard work: 'constantly have to watch this child'

- Watching, protecting, restricting
- Finding your own way
- Stress – 'unless you've lived it you can never understand'
- Fights and sacrifices

## Child Themes: Sam

Problem in the brain: 'an extra factor'

- Brain works differently
- ADHD is about behaviour
- 'It's here to stay'

A name for it: 'makes me feel better'

- Worry – not knowing what it was
- Relief – a reason: 'not mischievous'
- Medication

Normal versus different: 'I feel normal'

- Label/medication – sets apart from others
- Feeling normal but surrounded by narratives of difference
- Positives – more energy to accomplish things

Control versus no control: medication 'stops me doing silly things'

- Silence and passivity – adult-oriented systems
- We/I – lack of autonomy
- ADHD/medication in control - 'Can't stop' - carry on doing things

**Appendix 11: Sample of an Analysed Transcript from One Parent and One Child Interview**

## Sample Interview: Netty

<p>Reluctance – stigma? Impact?</p>	<p>Int: So, what do you understand by the term ADHD?</p> <p>Resp: <u>I don't, if I'm honest.</u></p> <p>Int: Okay.</p> <p>Resp: <u>I don't really know a great deal about it. It was one thing I didn't want to have him labelled with, I know that much.</u></p> <p>Int: Right.</p>	
<p>Media portrayal Powerful narrative – ADH a term for naughty, stigma</p>	<p>Resp: Just because <u>it's been on the news and things</u>, like you see all <u>kids that are naughty being diagnosed with it</u>, and it's not true. <u>I know that's not true now them things.</u></p> <p>Int: Yeah.</p>	<p>Controversial Stigma</p>
<p>Something wrong but unsure ASD/ADHD</p>	<p>Resp: <u>But I always thought more on the autistic side rather than the ADHD side.</u></p> <p>Int: Right.</p>	<p>Wrong label</p>
<p>Researching causality Absence of help – got to be something</p>	<p>Resp: <u>Because you, you do your own research and you read things.</u></p> <p>Int: Yeah.</p> <p>Resp: And when I was reading up on ADHD <u>it didn't sound like my child.</u></p> <p>Int: Right.</p>	
<p>Behaviours appeared to support a different</p>	<p>Resp: When <u>I've read up on Asperger's</u> it was</p>	

<p>hypothesis</p> <p>Complexity of behaviours – different hypothesis</p> <p>Brain problem – ‘I know’ – something within</p> <p>Medical terminology to support</p> <p>Research – brain is faster</p> <p>Things not fully answered Complexity reduced to a piece of paper – ‘confused’</p> <p>Piece of paper but lack of support – need to find own solutions to cope</p>	<p>like <u>they were talking about me child.</u></p> <p>Int: Right.</p> <p>Resp: Because it’s got... there's <u>so much similarities in them</u> and things like that. <u>But to be honest</u> I don’t understand a great deal, you know. <u>I know it affects them mentally.</u></p> <p>Int: Yeah.</p> <p>Resp: And, you know, it’s their <u>brain works a hell of a lot faster</u>, and it’s like a <u>chemical imbalance</u> and things like that and, you know. But apart from that I don’t... <u>you can only go by what you read.</u></p> <p>Int: Yeah.</p> <p>Resp: And sometimes it’s <u>conflicting on what you read.</u> So, <u>they give you a piece of paper when they get diagnosed</u> and it’s like: so he moves around a lot, doesn’t concentrate, you know. <u>But it doesn’t go into the other side of it: the anger, the aggression,</u> you know – it does say the impulsivity.</p> <p>Int: Yeah.</p> <p>Resp: But it doesn’t give you a guideline on...</p> <p>Int: Yeah.</p> <p>Resp: ... what could happen, what’s going to happen. <u>You’re pretty much on your own</u></p>	<p>Brain-based difference</p> <p>Parenting is hard –finding your own way</p>
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<p>ADHD – view of CAMHS</p> <p>Comparison with siblings – evidence of difference</p> <p>Emphasis on difference repeated Not familial causality Stigma?</p> <p>Normal/different – evidence of Referral –wait for help</p>	<p>and <u>you sort of figure it out, what works and what doesn't</u>, so.</p> <p>Int: So, who, um, who was the person that sort of come up with the idea that it might be ADHD or...?</p> <p>Resp: <u>CAMHS</u>.</p> <p>Int: Oh right, okay.</p> <p>Resp: So. Because I went to the doctor and just said, you know, for years before he even, you know, got diagnosis, <u>“My child isn't like my other child”</u>.</p> <p>Int: Right.</p> <p>Resp: <u>Completely different</u>, doesn't like being touched, liked being on his own, rocking mode, <u>just completely different</u>, didn't like people touching his food. Just generally <u>completely different</u>. We've got a huge family so you're looking at all different kids in the family and things like that. I was just thinking... I just put it down to <u>he's diff...</u> and I still say it, <u>he's just different</u>.</p> <p>Int: Yeah.</p> <p>Resp: But you just know. And then they start <u>doing things that aren't normal</u>, like eating clothes. You're just like why are you eating clothes and, you know, licking lampposts? ((Laughs)) Random, you know. So, you just know. And <u>I went to</u></p>	<p>Something wrong/different</p> <p>Normal versus different</p>
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<p>Fighting for help from school – lack of willingness adds to problem</p>	<p><u>me doctors and he transferred me to CAMHS and then nothing.</u> I don't know whether the letter didn't get there or nothing. <u>I struggled through just thinking well maybe they don't think it's anything.</u></p> <p>Int: Yeah.</p> <p>Resp: And then from school the school were <u>noticing in the school</u>, although they were noticing, <u>weren't willing to do anything about it.</u> So, this went on for years.</p> <p>Int: Right.</p>	<p>Pleading for help</p>
<p>Pleading for help – crisis – difficult systems</p>	<p>Resp: And in the end I went back to me doctors, <u>“Just help me. Something's not right. Something's going to go seriously wrong”.</u> I said, “Please”. And in the end they got me through to CAMS and I met a lovely lady [CAMHS practitioner], and <u>got the ball rolling.</u> But like I said, it's only been this past seven or eight months when it's really started to actually... you, <u>you're noticing that</u>, you know, <u>everything that's been put in place is helping</u> and things like that.</p> <p>Int: Great.</p>	<p>Long wait</p>
<p>Long wait – for things to be put into place Support?</p> <p>Crisis before help given –problem becomes more complex</p> <p>Long wait</p>	<p>Resp: Because before that I... [child] <u>wouldn't have been here</u> because he <u>tried to kill himself</u>, tried to hang himself and things like that, so the <u>help come when it needed to, but it come too late.</u></p>	<p>Crisis</p>

<p>Crisis initiated care Lack of value of parental reports?</p>	<p>Int: Yes.</p> <p>Resp: The progress for children like [child] is <u>far too long</u>. And it took him hanging himself, you know, wrapping a cord around his neck – he was only, he was nine when he did that – before you, you know, you actually go this needs pulling up a bit quicker. <u>It shouldn't have to get to that stage</u>. That's the only thing: <u>it takes too long</u>. You can just go off the kids' school records, from what the parents are saying to know where they should be, because there are other kids that aren't socialising that are ahead of them. And I'm not saying that your child just because... but they should be categ... categorised to where... how quick.</p>	<p>Long wait</p>
<p>Diagnosis – medication</p>	<p>Int: How old was he then when he got his diagnosis?</p> <p>Resp: <u>He got his diagnosis</u>, um – <u>he's not been on medication that long</u> – I think it was ((hesitates)) the middle of last year he got it.</p> <p>Int: Right. So, he'd be about ten then?</p> <p>Resp: Yeah.</p> <p>Int: Right, gosh. And yet you'd been worried from?</p>	<p>Diagnosis/ Medication</p>
<p>Concerns since baby</p>	<p>Resp: <u>The age of about two</u>. <u>Even from a baby</u>, but, you know, you just think they haven't,</p>	<p>Always been different</p>

<p>Playgroup – kicked out – different</p>	<p>they haven't really got a personality at that stage.</p> <p>Int: Yeah.</p> <p>Resp: But when he went to playgroup [child] must have been the only child that <u>got kicked out of playgroup</u> because he would, like, as soon as you put his toys on the table he'd take them all off, just so nobody else touched it and things like that.</p>	<p>Excluded</p>
<p>Problem within school - understood as naughty?</p>	<p>Int: Yeah.</p> <p>Resp: He wouldn't let anybody, once he was playing with something nobody else could go near it, even if you moved it or something he changed. They just said, "<u>We don't think it's wise you bring him</u>". And I thought well, <u>he weren't being naughty; he was just set in certain ways</u> that he just didn't like things. So, I think that set bells ringing. And then as he was going through school it <u>progressively got worse</u>. But I think when he left <u>we had a file about that big, not exaggerating...</u></p>	<p>Excluded</p>
<p>File – evidence of difference</p>	<p>Int: Right.</p>	
<p>Finally – a supportive school</p>	<p>Resp: ... on all the things we were doing, the school were doing. And at [school], <u>you know, they've been a godsend really</u>. Without them [child]...</p> <p>Int: So, had he changed schools then?</p>	

<p>Excluded again</p>	<p>Resp: He got expelled.</p> <p>Int: Oh right, gosh.</p> <p>Resp: He <u>got expelled</u>.</p> <p>Int: Where was he then?</p> <p>Resp: He was at [school].</p> <p>Int: Right.</p>	<p>Excluded</p>
<p>Seeking help Parent is the driver</p>	<p>Resp: And they... <u>I asked for a statement to be done, educational psychologist and things like that,</u> and yeah, yeah, yeah, yeah. And <u>that went on from Reception.</u></p> <p>Int: Right.</p>	<p>Pleading</p>
<p>Lack of support and understanding</p>	<p>Resp: <u>All the way till he got kicked out.</u> Um, he got kicked out in Year 4. So, they just, they didn't do anything. And I, <u>I've not got anything to thank that school for.</u></p> <p>Int: Ah.</p> <p>Resp: In any way, shape or form. If anything <u>they let him down, and they let him down big time.</u> And I'll have no qualms about telling that either because there was a lot more they could have done.</p> <p>Int: Right.</p>	
<p>Out of school – further contributing to the problem Impact on parent</p>	<p>Resp: Then <u>he was out of school for a good six, six months,</u> if not longer, with [a teaching service].</p>	<p>Excluded</p> <p>Things have to get really bad for help</p>



<p>Parenting programmes – ‘tell’, ‘generic’ not specialist</p>	<p>you’re not just saying it once; you’re saying it three, four, five times. After the second time they’ve probably forgot what you’re saying, or they’re bored and their, their ‘ead’s gone somewhere else.</p> <p>Int: Yeah.</p> <p>Resp: <u>So, all these parenting groups that tell you to do this, this and this, it doesn’t work for all kids.</u> And you don’t find a group that tells you any different. <u>So, the only people that can learn and things is yourself.</u></p>	<p>Hoops to negotiate</p>
<p>Conundrum – wanting an answer/ help, not label</p>	<p>Int: Yeah.</p> <p>Resp: So, <u>I was determined I’d not have [child] labelled with anything, because no parent wants that.</u></p>	
<p>Impact of lack of early help –crisis</p>	<p>Int: Of course.</p> <p>Resp: You know, my child’s got a label of ADHD. ODD as well because that’s another thing that’s been picked up. But the... because the school – this is it, they’ve got a lot to answer for – because they didn’t put the, the places in for the help straightaway and get the statement in and get all these teams involved and things like that, I had to do it myself. <u>That brought on ODD.</u></p>	<p>Long wait - impact</p>
<p>Further complexity due to long wait</p>	<p>Int: Right.</p> <p>Resp: <u>Without that [child] wouldn’t have the</u></p>	

<p>Mother's understanding of her child – knowledge</p> <p>Impact of lack of early support Long and arduous wait before support</p> <p>Brain-based, speed</p> <p>Brain-based, cause – not in control Brain to blame</p>	<p><u>disrespect for the adults</u> that he's got. <u>He's not rude</u> – you'll, you'll know, you'll know that by speaking to him.</p> <p>Int: He's lovely.</p> <p>Resp: He just finds that you should treat him with the same amount of respect you get. If you talk down to me I'm going to talk down to you – and that's how [child] sees it. But they... if they put this part of it wouldn't have come into it. But because it got left, that's what I'm saying, <u>it has constant knock-on effects</u> if it's not picked up soon enough. <u>If you're waiting five, six years before you even get a diagnosis, but you've waited six, seven months before you even get an appointment; it's too long.</u></p> <p>Int: It is. I was going to ask you about what the causes are, and I know that you've talked about there's a chemical imbalance. Is that something you've found out or is that what they told you happens?</p> <p>Resp: That's what they told, <u>that's what they told you</u>, and you read up about it. It's just their <u>brain goes too fast</u>, you know.</p> <p>Int: Yeah.</p> <p>Resp: <u>Instead of connecting it sort of by... bypasses each other really, really quickly. And that's why they get so frustrated and</u></p>	<p>Long wait</p> <p>Problem in the brain</p>
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<p>Changing expectations – highlighted behaviour problems</p> <p>Child not environment has to change</p> <p>Pressure on schools for grades – lack of understanding</p>	<p><u>angry</u>, you know. And as for sitting down, it's because they constantly need to be doing something because they can't. When you tell a child to sit down and don't move, sort of thing, most kids will... for kids like [child] it is an impossibility. [child], <u>they'll say to [child], "Sit down" and he'll say, "It's like asking me not to breathe"</u>. It can't be done. And, and you can see, you can see the pure frustration, the concentration of trying. And they can't do it. It's, it's a physical imp..impossibility. So, when you've got adults saying, 'Sit down! Stop moving!' They're trying and that's bringing their anxiety levels up and everything else. <u>The kids have meltdowns then because they're not actually doing anything wrong;</u> they're just not sitting in an acceptable way to an adult. Well.</p> <p>Int: So, do you think that's part of the problem sometimes that there's these expectations that they have to sit.</p> <p>Resp: Yes, <u>adults have a lot to answer for</u>, especially adults in authority. I'm not like, you know, disrespecting them and things like that. I think they <u>expect far too much from children anyway these days</u>. They're not kids no more, the little...<u>we need grades coming in and we need it now</u>, you've got four year olds reading books. <u>We learned through play; didn't do us any harm</u>. They expect too much. <u>So, when</u></p>	<p>Different – lack of control</p> <p>Excluded – lack of</p>
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<p>Difference needs to be accepted – rigid systems</p> <p>Judged/under the gaze Stigmatised Single parent/problem child</p> <p>Constantly under the gaze –cycle of trying to prove self</p>	<p><u>you've got expectations on a normal child, and to put a child, put the same expectations onto a child with any condition, you know, from autism and whatever, you're asking too much.</u> And these kids, you know, I've, I've seen a lot... I've got... I made a cracking bunch of friends, two of them especially that I'll keep with me for a lifetime, whose kids are like [child] ones or autistic ones, ADHD. All of them completely different.</p> <p>Int: Yeah.</p> <p>Resp: Each and <u>every one of them completely different.</u> And these kids try so, so hard because they thrive on praise, it's the one thing they... you know. Because nobody gives it to 'em.</p> <p>Int: No.</p> <p>Resp: Because most people you know, you're out and about, and you've got a kid running asking questions, can't stop moving, and they get, '<u>Put the stares in</u> because you can't look after your kids'. <u>Single parents especially have got a stigma around: you're dragging your kids up,</u> you're doing this, you're doing that. Hold on, I never asked to be a single parent. When I had love I thought it was life the person I was going to have kids with; we live in the real world, things don't always happen. But you're <u>constantly</u></p>	<p>acceptance</p> <p>Stigma Excluded</p>
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<p>Parent – lots of pressure</p> <p>Courtesy and self-stigma</p> <p>Cultural/societal expectations</p>	<p><u>trying to prove yourself</u>. And sometimes even me when I'm out with [child], before we go I'm, "[child], always remember <u>whatever actions you do comes back on me as well. It doesn't just make you look bad, it makes me look bad</u>". And I try and say that because [child] doesn't want me to look bad; [child] only wants the best for me and things like that, so. But the other two, "Behave, hey? Let's go". And I'm... but with [child] <u>I'm constantly reminding from the minute we leave to the minute we get somewhere, you know. It can be embarrassing</u>, but.</p> <p>Int: Do you think there is a stigma, um, for parents who have got a child with ADHD then?</p> <p>Resp: <u>Yeah I do, yeah, definitely.</u></p> <p>Int: What?</p>	<p>Excluded – stigma</p>
<p>Stigma/ Controversial – adds to the difficulties</p> <p>Mother-blame – has an emotional impact</p> <p>Lack of acceptance – parent? Child?</p>	<p>Resp: I think along the lines is because <u>ADHD is such a controversial subject</u>, you know, old school parents are like there was no such thing in our day, it's <u>just naughty kids, you've dragged them up</u> and things like that. And, and <u>you do question yourself as a parent</u>. I've questioned myself not for just a few months, for years <u>I blamed myself for [child] being the way he did</u>. And that <u>emotionally impacts on you</u>.</p>	<p>Stigma Blame</p>

## Sample Interview: Sam

<p>From birth/innate</p>	<p>Int: So, can you tell me about ADHD? What is it?</p> <p>Resp: ADHD is um, <u>something that people can get from birth and can sometimes affect how they're thinking.</u></p>	<p>Biological understanding</p>
<p>We/I ADHD is trouble Minimising it – just a bit silly?</p> <p>Part child/part ADHD</p>	<p>Int: Okay, yeah. How do you know that ADHD is in your life? How, how do you know...?</p> <p>Resp: Mm-mm <u>we got diag... I got diagnosed</u> um, my mum sort of gave it away because I was <u>always getting in trouble</u> and <u>I was just a bit silly</u> but that, but that, some of it um, is <u>partly because I have ADHD.</u></p>	<p>About behaviour</p> <p>Trouble</p>
<p>Not a big deal – trivialising/minimising Less concern for Sam, more for mum?</p>	<p>Int: Right. So, how do you know that you have this ADHD then? Does it...? Do you do different things to other people or how do you know?</p> <p>Resp: It's just that um, <u>I used to do these little, little things which made into a big thing.</u></p>	
<p>Adult concerns</p>	<p>Int: Right.</p> <p>Resp: So, um, <u>my mum thought, uh, read about ADHD</u> and she thought well <u>I guess it's worth a try seeing if [child] got it, so um,, whoops.</u> So, uh, that's why.</p> <p>Int: Yeah, it's okay because we can take your names out after so don't worry. So, where do you think it comes from?</p>	<p>A reason – for trouble</p>

<p>Causality – neurological, fast, part of brain taken over</p>	<p>Resp: Um, I think it's just something that was discovered and it comes from the person who discovered it and named it and um, it's just something that <u>a little teeny bit of your brain is um, took over by ADHD that just makes, it's like an extra factor in your brain that makes things quicker.</u></p> <p>Int: Right. So, do you...? Is ADHD then sort of to do with the brain then do you think?</p> <p>Resp: Yeah, I've got... I've been told by somebody who um, [CAMHS practitioner].</p> <p>Int: Right okay.</p>	<p>Brain-based problem</p>
<p>Adult knowledge – innate positioning</p>	<p>Resp: And he told me that um, it's basically something that, a little bit of your brain is being sped up so I thought <u>like it's a little bit like a nuclear power station making it go quicker and quicker.</u></p> <p>Int: Ah what a good idea, I like that. Yeah, I can see that that works. So, how long do you think ADHD has been in your life? Has it always been in your life from when you were very little or is it something that came along when you were perhaps in year one or year two or...?</p>	<p>Brain-based problem</p> <p>Adult-oriented knowledge</p>
<p>ADHD = getting told off</p> <p>Changing expectations – contributing to difficulty</p>	<p>Resp: Thinking about it 'cos when I was younger <u>I used to do things a bit like then I'd get told off, well I reckon that I've had it since birth but it's got, it's getting a little bit worse each day</u> because of um,</p>	<p>Different</p>

<p>ADHD in control – innate, lack of autonomy</p>	<p>((hesitates)) <u>because it's getting stricter and I'm not um, ((hesitates)) going with it.</u></p> <p>Int: I see.</p> <p>Resp: <u>I can't make it, I can't make it go</u> ((slight laugh)) but yeah that's all I can really say about that.</p>	<p>Rigid systems – exclusion</p> <p>Control versus no control</p>
<p>Example of being angry – is he relating this to ADHD?</p>	<p>Int: Yeah. So, when you say it's got worse then what is, what have you noticed about ADHD?</p> <p>Resp: Well, when I was three, I remember this because my dad, I had a big bedroom and I had this toy train and I loved it to pieces but it was dead noisy. One day my dad went in the bath and I was playing with my toy train, um, it was quite big but then... and then that noise so I got it and smashed it up.</p>	
<p>Description of difficult behaviour and adult expectation/ responses</p>	<p>Int: Right.</p> <p>Resp: And now <u>I think it's getting worse but because I'm doing stuff that ((hesitates)) I shouldn't be in year six but, 'cos, because it's very restrictive and I'm not rest...</u> I'm not going with that.</p> <p>Int: Oh. So, what is it when you say 'I'm not going with that'? So, what is it that you're not going with or what is it that you're doing that...?</p>	<p>Rigid systems – child to change</p>
<p>Changing expectations – child to change,</p>	<p>Resp: Like... ((hesitates)) You know my teacher's the strictest person in the</p>	<p>Control versus no control</p>

<p>not environment</p> <p>ADHD holding Sam back?</p> <p>Rigid expectations</p> <p>Diagnosis – instigated by mother</p> <p>Long wait</p> <p>We/I – who owns this?</p> <p>Behaviour different – control/lack of</p>	<p>school and um, she'll even admit that and I, like if <u>I do something that I did in year five I wouldn't be able to do it in year six but I still do it.</u></p> <p>Int: Ah.</p> <p>Resp: As in I'm not, <u>I'm not moving on.</u></p> <p>Int: Right, so what sort of things are you doing then? What would, could you give me some examples?</p> <p>Resp: Um, maybe doing what I said I was doing, like this, <u>not looking at the teacher</u> when she's um, talking, when she's talking <u>but I'm still listening to her.</u></p> <p>Int: Right, I see, okay. So, who noticed the ADHD first? Who noticed that you had it?</p> <p>Resp: I think, I'm not quite sure about that one, I think it's <u>my mum because</u> um, like I said <u>she read it</u> and then she was, then she went, when we started I mean <u>we had to wait 12 months on a waiting list</u> and we went to see somebody and she was like, <u>I think uh, well then I got diagnosed with ADHD but we didn't</u> get told that until this year sometime.</p> <p>Int: Right. So, what did your mum notice? What do you think your mum noticed that made her think, oh I wonder if...?</p> <p>Resp: Just um, when I was in like year three, two, one, whatever, I was doing little</p>	<p>Different</p> <p>Silence/passivity</p> <p>Control versus no control</p>
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control	<p>things like... Well, <u>when, when somebody's doing something they'd stop but then I don't stop and I carry on doing it.</u></p> <p>Int: Okay.</p> <p>Resp: And um, little things like that.</p> <p>Int: Okay. Did you notice things at home or was it around school?</p>	
Adult concerns	<p>Resp: It was around... Like she got told <u>at school</u> sometimes and <u>at home</u> as well.</p> <p>Int: Oh. So, what sort of things might she have seen at home that made her think, oh I wonder if this is ADHD?</p>	
<p>Something wrong – within child versus normal child behaviour</p> <p>Might there be other reasons?</p>	<p>Resp: Like um, she didn't know about ADHD then, <u>she just thought that I'd got something wrong with me,</u> but then um, I said something, what was it? Oh yeah, I was doing this sort of silly little... I was doing ((hesitates)) little like doing stuff that I shouldn't be doing um, and she thought, because I was doing the things that I shouldn't be doing I would have grown up <u>but I, well stopped doing them things after a while so that's why she didn't go straight away, but then she realised that I hadn't so she just wanted to get on the waiting list just in case.</u></p> <p>Int: I see. So, when your mum was a bit worried about some of the things that</p>	<p>A name for it</p> <p>Something wrong</p>

<p>Feeling normal – told different</p>	<p>she'd noticed and she was perhaps thinking I wonder if I need to refer on did you think there was a problem at that time?</p> <p>Resp: <u>I feel completely normal</u> that I've got ADHD except from you just know that... <u>You don't know what you've done until you've done it.</u> So, it's just...</p>	<p>Normal versus different</p>
<p>9 years at the time Adult-oriented problems, decisions and knowledge</p>	<p>Int: Oh I see. So, even though your mum was a bit worried about you and wanted perhaps to go to CAMHS or to see [CAMHS practitioner] you didn't particularly know that there was anything? No?</p> <p>Resp: I didn't know... because at that time <u>I was quite young so I didn't really know what was going on.</u></p>	<p>Silenced/passivity</p>
<p>Adult driven Child role?</p>	<p>Int: I see.</p> <p>Resp: But I think <u>my mum wanted to know while I was younger</u>, not while I was older.</p>	<p>Silenced</p>
<p>Worry – what is wrong –ill? Never going away, life-long, autonomy?</p>	<p>Int: Yeah. When your mum started to talk to you about um, that she was a bit worried about you did you think anything, did you have any ideas of what it could be or...?</p> <p>Resp: I just thought that um, <u>I might have an ill... like an illness, it'll just go like...</u> I never, 'cos I, I always... I never bothered with it because I was like oh so what, I've just got a little something and then it'll be</p>	<p>Within-child Control versus no control</p>

<p>Lack of child role – silenced. Adult concerns and decisions Secrecy due to stigma?</p> <p>Confusion – wants to know more/doesn't want to know Passivity</p> <p>Have to have these tablets – choice?</p>	<p>going in like a month or two and then I <u>realised after a month or two that it's not going, it's here and it's staying for life.</u> And then I got a bit like... and then I started trying to notice.</p> <p>Int: I see, okay. So, did other people have any ideas about what might be causing some of these things? Can you remember anybody else saying oh I wonder if it's, or...?</p> <p>Resp: I think teachers because like when I was in class I was doing them silly things. I think they <u>mentioned it to my mum</u> but I <u>don't get told any of them things because my mum keeps it secret</u> and then, well not secret, but like keeps it away from me and then she goes and tries to...</p> <p>Int: Oh. Would you like to know more or do you like being...?</p> <p>Resp: <u>I'd like, I'd like to know more but I don't,</u> I don't want to, I want to know more but um, not many people do know what more is.</p> <p>Int: Okay, yeah. So, have people treated you differently since that you've had this name called ADHD? So, since you've been given this diagnosis do you think people have treated you differently or...?</p> <p>Resp: I do think actually 'cos like people had... <u>because I had to have tablets and stuff</u></p>	<p>Silence/passivity</p> <p>Adult-oriented</p> <p>Silence</p> <p>Difference</p>
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<p>Trying to be normal, not different?</p> <p>Medication – external sign of difference</p> <p>Stigma – ways medicines are managed in the classroom</p> <p>Different – stigma – no friends</p> <p>Lack of confidentiality – child rights</p> <p>Something wrong – class needed to be told Normal – not something wrong?</p>	<p><u>like that everybody was like why have you got to have tablets, why have you...?</u></p> <p>They were being a bit nasty, you know, but um, ((hesitates)) I just ignored them and try and carry on with my life and then everybody stops. Everybody stopped being, <u>being nasty after I tried to be me.</u></p> <p>Int: So, what might, when you say people were nasty, what sort of things might they have done?</p> <p>Resp: ((singsong voice)) <u>Oh, [child's] got to have tablets, [child's] got to have tablets, picking on me for having tablets and stuff like that.</u></p> <p>Int: Are they people in your class?</p> <p>Resp: Yeah.</p> <p>Int: Oh gosh.</p> <p>Resp: Yes, and my best friend as well <u>so I had no friends.</u></p> <p>Int: How do you think they found out about it?</p> <p>Resp: Um, <u>'cos the teachers talk about it in the classroom</u> so I think that was what, that was why.</p> <p>Int: And how did that feel when people say things like that?</p> <p>Resp: <u>It didn't feel nice because</u> I was like, 'cos I felt like at that point I was going to get</p>	<p>Medication – a sign of difference</p> <p>Stigma – alienation</p> <p>Stigma</p>
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<p>We – lack of child role</p> <p>Side effects</p>	<p>bullied but then I tried to stand up for myself and luckily it worked and I got um,, I got Miss... <u>I got Miss... well Miss asked the class if... that there's nothing wrong with me and stuff like that.</u></p> <p>Int: Right, and was that quite helpful do you think?</p> <p>Resp: Yeah, because everyone then was like, "are you all right, [child]? Are you all right?"</p> <p>Int: So, what are the tablets for? Do you still take tablets?</p> <p>Resp: Uh, I used to take about three a day.</p> <p>Int: Gosh.</p> <p>Resp: Three a day, yeah.</p> <p>Int: At the same time or at different times in the day?</p> <p>Resp: Different times a day, one at night, one in the morning and one at dinner. And now I only take one long lasting ADHD tablet which is um, <u>we found is a bit more, works better</u> but the thing I don't like about it is it is, <u>when I take it you can taste all the stuff and then it gets stuck in your throat so you feel like you're going to be sick.</u></p> <p>Int: Right, so is it quite a big tablet then?</p>	<p>Tablets</p>
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<p>Medication – controls the ADHD Complex role</p>	<p>Resp: It's that basically, it's a big capsule.</p> <p>Int: Oh right, so yeah it's not very pleasant is it to swallow. And so what does the tablet do?</p> <p>Resp: It uh, <u>it helps more on the ADD</u> that I've got which is basically a little bit like anger but um, <u>it also helps the ADHD</u> side um, with <u>stop doing the silly things, thinking before I do stuff.</u></p> <p>Int: Right, so it sort of helps you to think before you do things.</p> <p>Resp: Yeah.</p> <p>Int: And have you noticed that that does work?</p>	<p>Tablets –to control ('stops you')</p>
<p>More normal – able to fit in?</p>	<p>Resp: When I, <u>when I have my tablets I don't, I feel more me.</u></p> <p>Int: Right.</p> <p>Resp: I don't, <u>I don't feel any other thing than me.</u></p>	<p>Negotiating normal/different</p>
<p>Negotiating normal and different</p> <p>Positioned by others as being different</p> <p>Acceptance, not naughty</p>	<p>Int: Right.</p> <p>Resp: I, <u>I even when people are talking I've got ADHD I still feel normal.</u></p> <p>Int: So, when you take your tablets and it helps you to think a bit more does anybody ever say, oh I notice you thought a bit more about it, or do they, do other</p>	<p>Normal versus different</p>

<p>Positive feedback – encourages tablet taking – better than negative feedback described earlier</p>	<p>people notice that it's made a difference?</p> <p>Resp: Yeah, 'cos people, well the teachers know that I have tablets so they are like <u>I know you really struggle with your life and tablets and all that and you're really dealing with it well</u>, stuff like that. If you handle it right.</p>	
<p>Name – provides a reason for difference – not naughty, exonerated</p>	<p>Int: Do you think it's better to have a name for it? Do you think it's better to have a name such as ADHD for the, for the um, difficulties or...?</p> <p>Resp: <u>ADHD, I prefer a name</u> with it because if there wasn't a name then it would get a bit confusing because, and also I feel, <u>I feel like if it was mischievous</u> because there's no name it wouldn't feel right, I feel like a name kind of <u>makes me feel a bit better as well</u>.</p>	<p>A name for it – relief</p>
<p>Child's view of the problem?</p>	<p>Int: Do you think it's helpful for the teachers as well to know there's a name for it?</p> <p>Resp: I don't... I've never actually thought about that question, I don't... No, I don't think, no.</p> <p>Int: If you could have your own name for it what would you call it?</p> <p>Resp: I'd probably call it um, ((hesitates)) <u>hyperactive</u>. ((slight laugh))</p> <p>Int: Right, so do you think that, that's the bit that you notice a bit more, that you've</p>	

<p>Energy</p> <p>Taming energy – strengths</p> <p>Negotiating normality/difference Comparison with others</p>	<p>perhaps got a bit more, is it energy or...?</p> <p>Resp: I, I know... The thing with me, I don't know if this is about every ADHD person who's got it, but <u>I have never in my life got out of energy.</u></p> <p>Int: Right okay, so for you it is a lot of energy.</p> <p>Resp: But what I found is um, what helps try and calm the energy down is I go um, and it helps, everything that I do it helps anger issues, it helps everything, <u>I do martial-arts, so that really helps.</u></p> <p>Int: Super. So, what's it like having ADHD or hyper, I'm going to use your word, hyperactive, in your life? What's it actually like?</p> <p>Resp: <u>It feels normal</u>, you don't really know what other people... You... I, I've found that you wonder that if they have ADHD is there any, the other people, <u>is there any differences and if, if um, ((hesitates)) if... what other people would be thinking and if I was thinking what they would be thinking normally if you know what I mean.</u></p> <p>Int: Yeah, yeah. So, what do you think they might be thinking? Do you think there are any differences? Do you think that it makes you different?</p> <p>Resp: I don't know, it just, I wonder. It makes</p>	<p>Different – energy</p> <p>Normal versus different</p>
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<p>Positive side of difference – having extra energy</p>	<p>me think.</p> <p>Int: Do you feel different from other people your age or...?</p> <p>Resp: Mm-mm no, because like I feel just the same and I feel a bit better about myself a little bit because <u>you have more energy and you use that little bit more energy to um, accomplish more things and</u> if you can contain that extra thoughts that you have you can actually make something really good out of it.</p> <p>Int: Yeah, right. Does ADHD ever get in the way of you doing well at school do you think or...?</p> <p>Resp: Not necessarily no, because I think, like I said at the beginning like as in I think it's just that little small but a bit and I think it only appears when you are doing something else but not concentrating like doing stuff with your friends. <u>I've found that that is, it's more, it's worse when I'm with my friends.</u></p> <p>Int: Right, so...</p> <p>Resp: Because you're trying to be like, you know, get along with them.</p> <p>Int: Ah, so that was my next question, I was going to say does ADHD get in the way of you and your friends. So, is that where you would say it does cause problems?</p>	
<p>Impact on friendships</p>		
<p>Energy, faster – better than others Positive side of difference</p>		

<p>Stigma-judged Need to know the person</p> <p>Conflicting views of impact of ADHD and control over behaviour</p>	<p>Resp: It ((hesitates)) it does but, but like I say it makes me feel a bit better because <u>you have more energy so you can, so you can win bets.</u> Well if you're having a race you'd probably win so it makes you actually feel a bit better about yourself when you think about it in them terms.</p> <p>Int: Okay, so what things are more difficult then with your friends would you say?</p> <p>Resp: The fact that say if I took a tablet one day um, and they saw me they'd be like ((singsong voice)) [child's] got a tablet, you know, stuff like that. <u>That just gets, that's all until they get to know you, but now...</u></p> <p>Int: What about playing with friends or making friends, does it get in the way of those things?</p> <p>Resp: No, that's um, luckily it doesn't, no.</p> <p>Int: Okay. And you were talking about when you've got to do a task where you've really got to concentrate and you were talking about sometimes you might get into trouble because you're perhaps looking down or... So, would that be a time do you think when ADHD would get in the way of school work?</p> <p>Resp: The thing is I don't... myself I don't know about, this is just my opinion, <u>I don't think ADHD does that,</u> I think that um, it's</p>	<p>Control versus no control</p>
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	<p>just... <u>It does do that but it's not, it's not</u> <u>as... It just doesn't do it as much if you</u> know what I mean, I can't really explain that one.</p>	
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**Appendix 12: Examples of the interpretive analytic process for some of the child participant quotations**

Examples of the interpretive analytic process for some of the child participant quotations (descriptive comments) related to the first superordinate theme ('I think they just knew something was up': stories of suspicion, silence and exclusion)

Descriptive comments (What the participants say/do)	Interpretive Comments (Researcher's interpretative comments)	Personal Reflective Comments (Researcher's thoughts and feelings)	Reflective Comments (Reflective engagement with the literature review)
Sam			
<p><i>...I think they (teachers) mentioned it to my mum but I don't get told any of them things [concerns] because my mum keeps it secret and then, well not secret, but like keeps it away from me and then she goes and tries to...(24p5)</i></p> <p><i>Like um, she didn't know about ADHD then, she just thought that I'd got something wrong with me...(19p4)</i></p> <p><i>So, um, my mum thought, uh, read about ADHD and she thought well I guess it's worth a try seeing if [child] got</i></p>	<p>Sharing information about the problem Child the object of concern – watched and monitored 'keeps it away from me' - child's voice and views – silenced and excluded/means of protection?</p> <p>Child the object of concern – something wrong with the child Parent protection? Trying to find answers to the problem and to get help for the child</p>	<p>Sam positioned early on as focus of the concern and yet rendered invisible – what could Sam have offered in the problem solving process? Sam seems very aware of the conversations surrounding him despite the 'secrecy' of which he spoke.</p> <p>'Something wrong' – could this be construed by Sam as something broken and that needs to be fixed. On the other hand, is it natural for a parent to seek professional advice when they are concerned about their child?</p>	<p>Understanding ADHD in the context of behaviour found in previous studies, including those presented in Chapter 3 (Cooper and Shea,1998; Kendall <i>et al.</i>, 2003; Travell, 2005; O'Leary, 2007; Gallichan and Curle, 2008; Davies, 2009), and positioned the child as the focus of the problem.</p> <p>A lack of child voice and passive role within the process of diagnosis and treatment was highlighted in the studies conducted by Kendall <i>et al.</i> (2003), Travell (2005) and Davies (2009). In these studies the children were presented as being at the centre of the</p>

<p><i>it...(4p1)</i></p> <p><i>I was quite young [9 years old] so I didn't really know what was going on [visit to CAMHS] (21p4)</i></p> <p><i>No, they just actually, they don't, um, probably they... basically you're listening to what they say and then you take that in and you put that in to... you use that information to help you. (124p22)</i></p> <p><i>Usually I'm doing something that entertains me, something like Lego or something like that... Sam (126p22)</i></p> <p><i>Um Dr A. telling me that I've actually got it...(120p21)</i></p> <p><i>I had to have tablets and stuff</i></p>	<p>Other possible factors considered?</p> <p>Silenced and excluded Adult-oriented –problem, decisions, knowledge</p> <p>Silenced and excluded 'listening to what they say' - a lack of voice/inclusion/agency</p> <p>Adult-oriented systems that appear to silence and exclude the child Distraction (by Lego) – further minimised his position and rendered him invisible Listened to, informed, consulted?</p> <p>Passivity and compliance Child's role? A physical one – to comply with process and to take prescribed tablets Child as object of concern - medication – locates as the child's problem, child needs to</p>	<p>Were any attempts made to engage with Sam and his views? <i>'I didn't really know what was going on'</i> suggests he wasn't part of the process. I feel sadness on reading Sam's comments. There are many ways in which Sam could have been included.</p> <p>Sam appears to only be 'heard' in relation to the diagnosis assigned.</p> <p>The silencing of Sam is so overt – providing Lego. Why could he not have been included? Was Lego used because Sam was distracted during the lengthy consultation? Were there ways to make the process more inclusive?</p>	<p>problem and therefore the focus of the investigation. As described by Kendall <i>et al.</i> (2003), it was the adults in authority who seemed to construct the reality of the ADHD.</p> <p>O'Leary (2007) found that the experience of diagnosis and treatment influenced the ways in which ADHD came to define the participants. Silencing the 'balanced view' Cooper and Shea (1998) suggested was required in order to acknowledge the range of causal factors, associated with ADHD.</p> <p>The prescription of medication as first-line treatment was described in the studies presented in Chapter 3. Furthermore, studies by Kendall <i>et al.</i> (2003), Travell (2005) and Davies (2009) described the prominent role of the medication within the participants' daily routine and its controlling effects</p>
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<i>like that... (26p5)</i>	change		(Cooper and Shea, 1998; Kendall <i>et al.</i> , 2003; Travell, 2005; O’Leary, 2007; Gallichan and Curle, 2008; Grant, 2009).
Robert			
<p><i>...she [teacher] just, she just rang me mum.</i></p> <p>(Int: <i>What did she tell your mum?</i>)</p> <p><i>I don’t know because she wouldn’t let me listen...it goes on her daily diary.</i></p> <p>(Int: <i>Oh. How come you were on a daily diary?</i>)</p> <p><i>For being naughty and always fighting. (34/35/36/37p5)</i></p> <p>(Int: <i>Did they [CAMHS] ask you questions?</i>)</p> <p><i>No, they asked me mum. (76p10)</i></p> <p><i>They (mum and psychiatrist) were talking (67p9)</i></p>	<p>Sharing information about the problem ‘<i>she wouldn’t let me listen</i>’ - child’s voice and views – silenced and excluded/means of protection?</p> <p>Child as object of concern – watched, monitored and chronicled (records of behaviour to evidence of the problem) Under surveillance by adults (mum/teacher)</p> <p>Adult-oriented – lots of adults talking/adult construction of problem/meeting adult needs</p> <p>Passivity and compliance – appears not to have been</p>	<p>Is there a pattern emerging or am I being drawn to these comments in light of recollections from the previous participant?</p> <p>I am struck, and saddened by the secrecy and silence Robert describes. There seems to be a problem-saturated discourse surrounding him. Does this impact on how Robert and others narrate and respond to the problem? Are there factors considered that Robert is perhaps not aware of?</p> <p>I value children’s views and believe they should be consulted and included. Were attempts made to engage with Robert? Did they use a child-friendly approach? Robert’s</p>	

<p><i>...it was boring (74p9)</i></p> <p><i>...just talked more and then height and weight. (83p10)</i></p> <p><i>There was pictures and they were just talking and I was on my PSP [PlayStation Portable]. (57p8)</i></p> <p><i>Someone tells them [about the ADHD diagnosis], I got told. (12p2)</i></p> <p><i>He didn't tell me, he told me mum. (97p12)</i></p> <p><i>They're [medication for ADHD] to make you good.</i></p> <p><i>(Int: Right. And what did you think about that?)</i></p> <p><i>Okay, I wasn't going to argue because I'd lose me PSP. (97-102p12)</i></p>	<p>listened to, informed, consulted</p> <p>Child's role? A physical one – his body presented for observation and measurement</p> <p>Adult-oriented systems that appear to silence and exclude the child Distraction (by PSP) – further minimised his position and rendered him invisible</p> <p>Conformity and compliance Child 'told' – about diagnosis/tablets</p> <p>Passivity and compliance The child is centre of problem and solution Lack of autonomy/coercion (would lose PSP if didn't take it), persuasive argument ('make you good') Lack of informed consent</p>	<p>recollections of adults talking and it being 'boring' suggests otherwise.</p> <p>The conversations taking place are likely to have a profound impact on Robert and yet he is not part of the process. How is he to understand the diagnosis and the treatments offered?</p> <p>Is Robert told that the medication will 'make him good' because it is believed this is more meaningful, something he will understand? On the other hand does this suggest to Robert that he is 'not good' and therefore bad? How can he give informed consent when he risks losing something of value to him by refusing? I feel shocked.</p>	
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Mason			
<p><i>I don't think they would have known what it was. I think they just know that something's up. (46p10)</i></p> <p><i>... 'cos it, it's just I acted differently (24p7)</i></p> <p><i>Well, I got diagnosed...(10p5)</i></p> <p><i>Well, it's a bit of uh, it's a bit weird thinking that you, you, you've got like a condition and, um, and it's thinking, 'Oh my god, people are going to be looking at me like what's wrong with him' and all that. (53p11)</i></p> <p><i>A person at [the child and adolescent mental health service clinic] said to take it [medication], for me hyper-activeness and me emotions</i></p>	<p>Child the object of concern – something wrong with the child</p> <p>Other possible factors considered? Child aware there is a problem with his behaviour - adult's constructed the nature of the problem?</p> <p>Child the object of concern Lack of inclusion/information about the problem – leading to worry about what it is and the consequences</p> <p>Passivity and compliance Child's role? A physical one – to comply with process and to take prescribed tablets</p>	<p>I'm struck by the pattern emerging of the child as the focus of the concern.</p> <p>Mason's comment about acting differently suggests he too was under surveillance and measured to a particular norm</p> <p>Mason appears to be trying to make sense of the diagnosis and of there being something 'wrong' with him. There seems to be some worry and confusion. Again I feel touched by sadness and exasperation that Mason is rendered invisible in this process despite the richness of his account during the interview. Clearly he has/had much to offer. Was Mason given an accurate story about the medication?</p>	

<p>(169p28)</p> <p><i>(Int Did they [CAMHS] ever ask for your thoughts about the problem or the medication?</i></p> <p><i>They just made sure it was safe for me to take the tablets</i> (173p29)</p>	<p>Child as object of concern - medication – locates as the child’s problem, child needs to change No mention of other possible factors</p>	<p>This seems to go beyond the effects noted by researchers. Is this silencing other factors associated with ADHD?</p>	
<p>Michael</p>			
<p><i>(Int So, who noticed that you had ADHD?)</i></p> <p><i>My doctor...me mum</i> (23/24p4)</p> <p><i>(Int So, what did they notice?)</i></p> <p><i>Me be...behaviour...I was naughty</i> (26/27p4)</p> <p><i>(Int ...so was it mum’s idea to see the doctor?)</i> <i>Yeah</i> (33p5)</p> <p><i>No, every day [to take</i></p>	<p>Child’s behaviour the object of concern</p> <p>Under surveillance by doctors/parent</p> <p>Passivity and silence – child’s view of the problem not sought Adult-oriented –problem, decisions, knowledge</p> <p>For the child? Conformity and compliance</p> <p>‘Told’ to take tablets/about</p>	<p>Others have noticed differences in Michael’s behaviour. I wondered about how was this was communicated? Michael seems to narrate this as ‘naughty’. Does seeing the doctor position this within Michael? Am I being unfair here having experienced the other accounts? Is the parent seeking help for genuine concerns? Wouldn’t any caring parent? Is this a skewed view e.g. parts specific to Michael that resonated with him? How did his mother experience this?</p>	

<p><i>medication], doctor said. (43p6):</i></p> <p><i>(Int ...what's been helpful to you having ADHD?)</i></p> <p><i>Tablets...keeping me calm (40/42p5)</i></p> <p><i>(Int: Okay. What would happen if you didn't take the tablets?)</i></p> <p><i>I'd go more nuts. (40-42p6)</i></p> <p><i>(Int: Okay. Who, who reminds you to take them or do you know to take them?)</i></p> <p><i>Me mum...teachers...I, I used to have an alarm clock go. I used to have an alarm clock and it, it rings and it's tablet time. Michael (122-125p16)</i></p>	<p>diagnosis/focus of the problem</p> <p>Control versus lack of autonomy – controlled by tablets, persuasive argument Child's understanding -age-appropriate information shared to counteract the narrative of 'nuts' and 'bonkers'</p> <p>Conformity and compliance Child's role? A physical one – to comply with taking the prescribed tablets</p>	<p>I am struck by the importance ascribed to the medication. Is this further reinforced by the 'policing' actions described, to ensure Michael takes this?</p>	
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**Appendix 13: Comparison of findings with those of the research studies  
presented in Chapter 3**

**A brief summary of the two superordinate themes from the child interviews and comparison with studies discussed in Chapter 3.**

Superordinate Theme	Brief Summary of the Superordinate Theme	Compare/Contrast with Studies Presented in Chapter 3
<p>'I think they just knew something was up': stories of suspicion, silence and exclusion</p>	<p>ADHD was understood in terms of behaviour, which had been positioned by parents and teachers as an object of concern. A child-centred approach was described, but not in a positive way of their being included or of being listened to, but rather, a process in which the children were presented as being the focus of the problem and therefore the focus of the investigation.</p> <p>Throughout the process of diagnosis and treatment this child-centred approach continued within an adult-oriented system that seemed to focus on the adult's (parents and teachers) needs, views and experiences. In contrast, the children were positioned as passive and subservient, and expected to conform and comply with being assessed, monitored and treated. There seemed little evidence of their being listened to, informed or consulted. These experiences appeared to influence ways in which ADHD came to define the child participants and seemed to render invisible other factors that may have been contributing to the problem.</p>	<p>Understanding ADHD in the context of behaviour is a trend in previous studies, including those presented in Chapter 3 (Cooper and Shea, 1998; Kendall <i>et al.</i>, 2003; Travell, 2005; O'Leary, 2007; Gallichan and Curle, 2008; Davies, 2009). A lack of child voice and passive role within the process of diagnosis and treatment was highlighted in the studies conducted by Travell (2005) and Davies (2009).</p> <p>The experiences of how ADHD came to define the child participants is similar to those described by participants in the studies by Cooper and Shea (1998), Travell (2005) and O'Leary (2007). Relief from blame in response to diagnosis was not described in research presented in Chapter 3.</p> <p>Access to additional support, following diagnosis of ADHD, is described in studies by Travell (2005) and Davies (2009), however, as Gallichan and Curle (2008), Davies (2009) and Grant (2009) found this appeared to confirm their difference by setting them apart from their peers.</p> <p>The prescription of medication as first-line treatment</p>

	<p>Having a name for the difficulties experienced produced positive and negative effects. It provided some relief from blame and triggered access to additional support within school; however, it set them apart from others by confirming their 'difference'.</p> <p>Medication was offered as first-line treatment and presented as a means by which to modify and control the child's behaviour in order to 'make them good'. Child participants spoke of the positive effects of their medication, which appeared to reflect the persuasive arguments they had been given. The medication had a prominent role in the children's daily routine and 'adult monitoring' was used to ensure it was taken at the correct intervals.</p>	<p>was described in the studies presented in Chapter 3. Furthermore, studies by Kendall <i>et al.</i> (2003), Travell (2005) and Davies (2009) described the prominent role of the medication within the participants' daily routine.</p>
<p>'It's like a serious mystery': how ADHD is perceived, experienced and managed</p>	<p>ADHD was attributed to neurological and genetic factors, and there were references to its longevity and control over the children's lives.</p> <p>A recurring theme within the children's accounts was of negotiating normality and abnormality in relation to the self and others. There appeared to be dissonance in accepting they were and, in some instances, seeking to be different, whilst, on the other hand, constructing themselves as 'normal' and being like their peers.</p>	<p>Neurobiological factors were the most commonly stated cause of ADHD in the studies presented in Chapter 3, with the exception of Kendall <i>et al.</i> (2003) whose participants stated a range of factors (including neurological, pre-natal and psychosocial adversity).</p> <p>Contradictory feelings about normality and abnormality were documented in the studies reviewed (Kendall <i>et al.</i>, 2003; O'Leary, 2007; Gallichan and Curle, 2008; Davies, 2009; Grant, 2009).</p> <p>Descriptions of positive attributes in relation to the</p>

	<p>Despite negative descriptions and deterministic accounts the children also spoke of positive attributes, which they associated with ADHD.</p> <p>The children's personal experience tended towards 'being', rather than 'having' ADHD and ADHD was deemed to have considerable control over their actions. In this study the children spoke of the controlling effects of not only their medication, but also the ADHD.</p>	<p>ADHD are documented in research conducted by O'Leary (2007) and Davies (2009).</p> <p>Research presented in Chapter 3 described how ADHD became intertwined with identity (Kruegar and Kendall, 2001; Kendall <i>et al.</i>, 2003; O'Leary, 2007, Davies, 2009; Grant, 2009). For example, Kruegar and Kendall (2001) described an 'ADHD defined self'.</p> <p>The experiences of the controlling effects of medication have been documented in the studies reviewed (Cooper and Shea, 1998; Kendall <i>et al.</i>, 2003, Travell, 2005; O'Leary, 2007; Gallichan and Curle, 2008; Grant, 2009).</p>
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**A brief summary of the three superordinate themes from the parent interviews and comparison with studies discussed in Chapter 3.**

Superordinate Theme	Brief Summary of the Findings	Compare/Contrast with Studies Presented in Chapter 3
<p>Seeking help: a journey of pleading, proving and compliance</p>	<p>The parents spoke of feeling concerned about their child from the earliest years, having noticed differences in their behaviour. Their attempts to understand and make sense of these concerns seemed to place their child within a narrative of 'difference'. Extreme examples of their child's behaviour and comparisons with siblings and peers appeared to evidence the abnormal and unusual nature of these behaviours and confirm that it was not a result of their poor parenting.</p> <p>Frequent visits to educational and health professionals followed, and parents recounted stories of pleading, proving (through their engagement in a variety of assessments) and waiting. For some, a crisis appeared to accelerate the final stages of what had already been a lengthy process. This acceleration proved only temporary, however, as once within this system, the long and arduous process appeared to continue, and parents described the many 'hoops and hurdles' to be negotiated as they sought acknowledgement and validation for the child's difficulties. Furthermore, the parents described being left to 'muddle through'</p>	<p>Similar to the experiences described in this research study parent participants in McIntyre and Hennessy's study (2012) described their struggle to make sense of their child's behaviour and that comparisons with siblings and peers appeared to evidence the abnormal and unusual nature of these behaviours. These comparisons were a means by which to understand the relationship between their role and their child's behaviour.</p> <p>Dissatisfaction with the quality of care and support was reported by participants in Dennis <i>et al.</i>'s (2008), Peters and Jackson's (2009) and McIntyre and Hennessy's (2012) research. In these studies the parents spoke of an absence of early intervention, lengthy waiting times for assessment and diagnosis, a lack of alternative treatment to medication, battles for basic care and of feeling blamed by professionals. Furthermore, Dennis <i>at al.</i> (2008) described a 'crisis-oriented' approach whereby help and support was offered in response to a crisis rather than recognising problems earlier.</p> <p>Similar to the experiences described in this study</p>

	<p>without support, contributing to increased stress and deterioration in the presenting concerns.</p> <p>In contrast to their long wait for assessment, parents spoke of receiving a diagnosis quickly following a meeting with a psychiatrist. Descriptions of the speed with which diagnosis was given seemed to construct the problem as obvious and severe, and this severity appeared to contribute to medication being prescribed at diagnosis or shortly afterwards.</p> <p>Parents spoke of the positive impact of their child's medication, which appeared to provide 'evidence' of a biological explanatory hypothesis and alleviated the initial conundrum they described in consenting to this treatment. However, parents described the limited effect within the home context due to the effects of the medication wore off over time and of the lack of impact on academic success. The consensus appeared to be that it controlled the disorder but was not a cure.</p> <p>In reflecting on their journey through CAMHS, the parents spoke of complicated and fractured systems, and their disappointment at the lack of post-diagnostic support. There appeared to be little early intervention offered to provide space for discussing and making sense of the difficulties they were experiencing, and where interventions could be customised to their unique needs.</p>	<p>findings from the research presented in Chapter 3 indicated that medication was the primary treatment. Prescription of medication as first-line treatment was also identified in Travell's (2005) research. A lack of treatment choice and limited effects of the medication over time were highlighted by Dennis <i>et al.</i> (2008) and McIntyre and Hennessy (2012).</p> <p>The descriptions of complicated and fractured systems are similar to the 'disconnected encounters' described in Dennis <i>et al.</i>'s (2008) study. Similar to the findings of Dennis <i>et al.</i> (2008), Peters and Jackson (2009) and McIntyre and Hennessy (2012), there remained dissatisfaction with the post-diagnostic care, and a sense that a more comprehensive and holistic approach would be helpful.</p>
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<p>'Through all them four letters, changes everything': stories of acceptance and validation</p>	<p>The parents expressed relief following their child's diagnosis. A name for the difficulties the parent and their child were experiencing appeared to legitimise and validate their concerns. It provided acceptance from others, removal of blame, and ensured additional support within school. The parents, however, described some surprise at the ADHD diagnosis, having held their own, or been informed of others' (e.g. teachers, mental health practitioner), alternative hypothesis of an autistic spectrum condition.</p> <p>In referencing causality, the brain became the main and isolated actor (Singh, 2004), and the consensus was that ADHD was caused by neurobiological and genetic factors. The focus of the problem was viewed through the lens of symptoms, disorder and limitations (Singh, 2005) and the parents described many of the difficulties their children experienced as being a result of the ADHD.</p> <p>A thickened story of the controlling effects of ADHD and medication developed, which appeared to influence the approach taken in finding alternative solutions.</p>	<p>Similar to this research study, Dennis <i>et al.</i>'s (2008) and McIntyre and Hennessy's, (2012) participants spoke of the removal from blame and label of 'bad parent' following diagnosis. However, findings from research presented in Chapter 3 did not indicate confusion with the diagnostic label or of their own or other's differing hypotheses.</p> <p>Beliefs about causality reflect findings from research presented in Chapter 3. The findings of this research study conflict with the views of participants in Dennis <i>et al.</i>'s study who suggested biological and social causes, and that the condition is not life-long.</p> <p>The influence of medication on treatment trajectories and limited availability of other interventions were highlighted in previous research by Cooper and Shea (1998) and Travell (2005).</p>
<p>'Stress, stress, pure stress': ADHD is hard to</p>	<p>Living with ADHD was described as stressful, as it impacted upon the whole family microsystem. Parents spoke of how their child (with ADHD)</p>	<p>Akin to the findings of this research, participants in studies presented in Chapter 3 spoke of a different parenting experience, which required a high degree of</p>

<p>live with</p>	<p>became the centre of the family, which affected all aspects of family life and placed emotional, social and physical demands on family members. The consensus was that parenting a child with ADHD is complex, requiring high levels of investment of time and energy, and sacrifice.</p> <p>Having a lived experience appeared crucial in understanding their struggles, and parents reported having to find their own way of supporting their child. They described the rigorous parenting required, and their critical role in keeping their child safe and maintaining the family system. At times this cycle of constant action left them feeling overwhelmed, exhausted and emotionally drained. The view appeared to be that their child required a more rigorous and different style of parenting.</p> <p>The experience of parenting a child with ADHD contributed to the development of specialist knowledge and the parents spoke of being consulted by schools and other parents as pseudo-experts on ADHD. Whilst this appeared to recognise (finally) the parent as an expert on their child, it reinforced narratives of mothers' duty and responsibility, repositioning them at the centre of their child's problem.</p> <p>The parents described feeling stigmatised, isolated and excluded, and under pressure to prove</p>	<p>involvement in all aspects of their child's life. As described in research by Firmin and Phillips (2009), Peters and Jackson (2009) and McIntyre and Hennessy (2012) parent's were in a cycle of vigilance and attention to meet the complex needs of their children.</p> <p>Similar to research findings discussed in Chapter 3, the experience of parenting a child with ADHD contributed to the development of specialist knowledge. Strategies were tested and adapted to fit the needs of the child and family and this developing knowledge was drawn upon in their role as advocate for their child.</p> <p>Consistent with a wealth of literature (including the studies reviewed in Chapter 3), the positioning of stigma and blame was apparent in the parent's stories. Parents described being stigmatised as a result of their child's difficult behaviour (similar to Peters and Jackson (2009) and McIntyre and Hennessy (2012)) and being positioned as the 'cause', leading to a cycle of being judged and trying to prove themselves (similar to Dennis <i>et al.</i> (2008), Peters and Jackson (2009) and McIntyre and Hennessy (2012)).</p> <p>In contrast to McIntyre and Hennessy's (2012) findings the parents in this study rarely spoke of the rewarding nature of parenting a child with complex needs.</p>
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	<p>themselves and their parenting. They described being stigmatised as a result of their child's difficult behaviour and of being positioned as the 'cause', leading to a cycle of being judged and trying to prove themselves. The parent participants rarely spoke of the 'joy and happiness' and rewarding nature of parenting a child with complex needs.</p>	
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