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“It’s Not Just A Thing, It’s Everything”. A  
Longitudinal Narrative Study on The  
Parental Experience of The ADHD  
Diagnostic Journey

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PhD

2023

“It’s Not Just A Thing, It’s Everything”. A  
Longitudinal Narrative Study on The  
Parental Experience of The ADHD  
Diagnostic Journey

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# Abstract

Attention Deficit Hyperactivity Disorder [ADHD] is a common childhood diagnosis affecting an estimated 5-7% of school aged children. This thesis explores the needs and experiences of parents as their children traverse the often arduous and challenging process of referral, assessment, and diagnosis of ADHD otherwise characterised as the 'ADHD diagnostic journey'.

Narrative qualitative data was collected through 21 semi-structured longitudinal serial interviews over a two-year period with seven parents of children currently on the ADHD diagnostic journey.

The study employs a sociocultural narrative analytical framework and the concept of narrative 'plots' were developed to make sense of the construction and delivery of parental narratives. Within the findings, seven narrative plots emerged which encapsulate parental experiences on the ADHD diagnostic journey: "There Was a Problem", "The Diagnosis", "The System", "The Fight", "The Mother", "Narratives Regarding Medication", and "The Balancing Act Between Disability and Difference".

Additional findings emerged demonstrating how the parental ADHD diagnostic journey can be conceptualised as two significant forms of 'illness work'. The "Diagnostic Quest" details parental work recognising their children's needs, seeking diagnosis, engaging with the system of healthcare, and fighting for their children's needs and selfhood. Parents also engage in two distinct forms of biographical illness work. The personal and individual parental biographical response to the diagnostic journey ("Self-Biographical Illness Work"), and parental biographical adjustment and recontextualisation of their children ("Child Biographical Illness Work and Recontextualising the Child").

This project provides original contributions to ADHD parental research as the first qualitative study to explore the entirety of the ADHD diagnostic journey, including pre- and post-diagnostic periods additional to the experience of children's diagnosis. Original contributions are also made towards the field of illness sociology by utilising the theoretical concepts of illness work and biographical work to ADHD in a novel way.

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And finally, to my son Theo. You joined us midway through this journey and already fill my days with joy. I hope that one day you are proud of what these pages represent.

# Authors Declaration

I declare that the work contained in this thesis has not been submitted for any other award and that it is all my own work. I also confirm that this work fully acknowledges opinions, ideas, and contributions from the work of others.

I declare that ethical clearance for the research presented in this thesis has been approved. Approval has been sought and granted through the researcher's submission to Northumbria University's Ethics Online System and the Integrated Research Application System (IRAS).

I declare that the word count of this thesis is: 84,854.

Tom Nicholson

25.01.2023

# Abbreviations used

ADDISS: The National Attention Deficit Disorder Information and Support Service

ADHD: Attention Deficit Hyperactivity Disorder

APA: American Psychiatric Association

ASD: Autism Spectrum Disorder

CAMHS: Child and Adolescent Mental Health Service

CHADD: Children and Adults with Attention-Deficit/Hyperactivity Disorder

CYPS: Children and Young People's Service

DCD: Developmental Co-ordination Disorder

EHCP: Education and Health Care Plan

NICE: The National Institute for Health and Care Excellence

WHO: World Health Organisation

# 1. Introduction

## 1.1. Background and Rationale

Attention Deficit Hyperactivity Disorder [ADHD] is one of the most diagnosed childhood conditions (Barkley, 2015; Faraone et al, 2021), affecting an estimated 5-7% of school aged children (Polanczyk et al, 2007; Willcutt, 2012) and 2.5% of adults (Faraone et al, 2021). ADHD is currently classified as a heterogeneous neurodevelopmental disorder (Sonuga-Barke & Thapar, 2021), where children demonstrate increased inattention, hyperactivity, and impulsivity to levels negatively impactful on daily functioning (American Psychiatric Association [APA], 2015). To be diagnosed with ADHD, children must be assessed by mental health specialists with expertise in ADHD; often a psychiatrist, psychologist, or multidisciplinary team (NICE, 2019), in a process which has come under significant scrutiny in recent years (ADHD Foundation, 2018). The process of referral, assessment, and diagnosis within the UK is often protracted, fuelling a rising tide of criticism regarding the perceived failure of the ADHD diagnostic system in supporting parents and patients throughout the journey (Faraone et al, 2021; Young et al, 2020). Given that parents of children with potential ADHD are often the instigators of the diagnostic process (Honkasilta & Vehkakoski, 2019), understanding the experience of parents as their children traverse the ADHD diagnostic process is important. The parental experience of ADHD has seen much exploration, with findings describing the parental experience of living with a child with ADHD as exhausting (Cocoran et al, 2017a), challenging (Ghosh et al, 2016), and a battle for justification (Carr-Fanning & McGuckin, 2018). For many parents, the process of diagnosis is “arduous” (Mcintyre & Hennessy, 2012: 70), and experiences of distress, powerlessness, and invalidation are commonplace (Cocoran et al, 2017a; Carr-Fanning & McGuckin, 2018). However, evidence suggests that a diagnosis of ADHD is perceived by parents as essential in supporting their children. A diagnosis is experienced as legitimising and validating of the difficulties and challenges faced by parents (Carr-Fanning & McGuckin, 2018), whilst also granting an increased sense of parental control (Klasen, 2000) by reinterpreting the child’s behaviours and needs (Ringer et al, 2020). The shame and guilt reducing benefits of an ADHD diagnosis are also well documented (Cocoran et al, 2017a), as a medical diagnosis allows children’s difficulties to be reframed as a symptom of the condition and not parental failure (Singh, 2005; Gwernan-Jones et al, 2015; Ghosh et al, 2016).

Existing qualitative literature on the parental experience of ADHD is typically limited to studies in which parents are asked to reflect on their experience *after* their children have received a diagnosis (Cocoran et al, 2017a). These studies often explore the experience of *having* a child with ADHD (Mcintyre & Hennessy, 2012) or explore the parental experience of their children's ADHD diagnosis *after* the diagnosis has been given and integrated into their everyday experience (Harborne, Wolpert & Clare, 2004; Ghosh et al, 2016; Carr-Fanning & McGuckin, 2018). Furthermore, although many of these studies explored the parental experience of diagnosis, none have studied the overall parental experience of the diagnostic journey itself. The limited exploration of the parental experience pre-diagnosis, alongside a paucity of longitudinal projects on the parental experience of ADHD, provide a substantial theoretical gap within which this project is situated. This thesis develops understanding of the needs and experiences of parents whose children are travelling across the diagnostic journey of ADHD by exploring both pre- and post-diagnostic periods, in conjunction with the parental response to diagnosis.

## 1.2. The Research Study

The purpose of this study is to develop understanding of the needs and experiences of parents whose children are traversing the ADHD diagnostic journey. It will demonstrate how parental experiences change and adapt over time as the diagnostic journey transitions from referral and waiting list, to assessment and diagnosis, and living post-diagnostically. The project explores these parental experiences through the theoretical perspective of a sociology of illness and is heavily influenced by sociological discussion regarding the impact of illness and biography (Bury, 1982; Corbin & Strauss, 1985, Williams, 2000). Given the capacity for narratives to become a psycho-socio-cultural resource with which to develop understanding and context regarding others' lives and experiences (Phoenix, Smith & Sparkes, 2010), the thesis utilises a narrative methodological and analytical approach. Stories provide a rich medium to explore significant turning points within an individual's life (Creswell, 2013) and are a useful and relevant perspective from which to explore the significant 'turning point' experienced by parents as their children are assessed and diagnosed with ADHD (Jutel, 2009; Grbich, 2013). The research questions were informed by this methodological choice and were as follows:

- 1- What stories do parents tell regarding this journey?
- 2- What are the parental needs and experiences across the ADHD diagnostic journey?

- 3- Do these needs and experiences change across the journey and, if so, how?
- 4- How do parents make sense of the ADHD diagnostic journey?

Using longitudinal serial interviews, parental experiences at the temporally significant time periods of *pre-diagnosis*, *diagnosis*, and *post-diagnosis* were explored and I witnessed the meaningful changes that occur for parents as they traverse the journey. The thesis draws upon existing theory within illness sociology regarding the biographically impactful experience of parents of children diagnosed with long-term medical conditions (Rasmussen et al, 2020), whilst acknowledging the limited inclusion of ADHD within this field of study.

The project employs a sociocultural narrative analysis approach (Grbich, 2013; Jones & Mistry, 2019) with which the concept of the narrative 'plot' was developed to make sense of the construction and delivery of the parental narratives. In response to all four research questions, seven major narrative plots were developed from the data, evidencing how parents tell stories of their needs and experiences. The seven plots, explored in depth in Chapters 6-9, demonstrate the most prevalent and impactful of these experiences and assist us in understanding some of the difficulties and joys which parents face. It is argued in Chapter 11.2 [Development and structure of the Diagnostic Journey Narrative] that the construction of parental narratives engages with narrative plots in a loosely chronological structure, as four major plots were found to be associated with specific moments or experiences across all parental narratives, whilst three other plots were not found to exist within this structured framework.

From a wider sociological perspective, this thesis provides evidence on how parental experiences across the ADHD diagnostic journey can be conceptualised as significant illness work (Corbin & Strauss, 1988). The findings and conclusions are in keeping with similar studies investigating the experience of parents of autistic children (Singh, 2016), in which the illness work is divided into practical diagnostic work and biographical work. Parents must engage on a 'Diagnostic Quest [11.3.2], upon which they recognise their children's additional needs, seek diagnosis, engage with the complexities and failings of 'The System', fight for their children's needs and selfhood to be understood, and acquire educational and social resources. Parents were also found to engage in two distinct forms of biographical work: 'Self-Biographical Illness Work' [11.3.4] and 'Child Biographical Illness Work and Recontextualising the Child' [11.3.5]. The former work prioritises the personal and individual biographical response of the parent. A spectrum model of biographical cohesion and disruption (Rasmussen et al, 2020) is used to understand the biographical impact in response to the ADHD diagnosis, the "self-diagnostic" biographical response in parents with a diagnosis of ADHD themselves, and the biographical response to the diagnostic journey

itself. Parental biographical adjustment in the contextualisation of their children, alongside other child biographical work, is also evidenced. The arguments presented explore how the diagnosis of ADHD allows parents to recontextualise their children from a “*naughty typical child*” to a “*normal atypical one*” and explore their children’s identity and personhood within the remit of disability language and neurodiversity.

### 1.3. Chapter Overview

This section provides a brief overview of the thesis structure and each chapter:

**Chapter 2 [The Concept of Attention Deficit Hyperactivity Disorder [ADHD]]** explores the conceptualisation and construction of ADHD within academic, lay, and medical discourse. The chapter discusses inherent theoretical tensions between two competing dominant paradigms of ADHD; namely, a biomedical model versus a neurodiversity paradigm. Perspectives and criticisms of these paradigms are discussed, alongside a history of the diagnosis of ADHD and a discussion regarding epidemiology, prevalence, treatment, and terminology usage.

**Chapter 3 [Literature Review Part 1: Parents and ADHD]** presents the first of two literature reviews within this thesis. Chapter 3 reviews the wider literature in relation to parents and ADHD, exploring the parental experience of having a child with ADHD. The review also highlights the typical parental experience of childhood ADHD diagnosis.

**Chapter 4 [Literature Review Part 2: Illness Narratives]** reviews the sociological literature in relation to illness narratives. The review explores the history and development of the concept of biographical disruption and reconstruction (Williams, 1984), chronic illness and meaning (Bury, 1982), and the sociology of diagnosis (Jutel, 2009). This chapter also discusses Rammussen et al’s (2020) parent-biographical spectrum model of disruption and cohesion and provides justifications for its usefulness and applicability in exploring the parental experience of the ADHD diagnostic journey.

**Chapter 5 [Research Framework]** presents the theoretical and methodological considerations and framework utilised in this project, reflecting on the decision-making processes and practical application of research methods. The chapter also provides insights into decisions made throughout the analysis of the study findings and defines the concept of the narrative plot in detail.

**Chapter 6 [A Problem and a Solution: Plots 1 & 2]** is the first of four findings chapters. The four findings chapters [Ch. 6-9] define and critically discuss one or two of the narrative plots and link this discussion to the wider literature. Plot one [There was a problem] discusses how parents narrate a pre-diagnostic awareness of their children having a “problem” and the steps taken in pursuit of an answer to these concerns. Plot 2 [The Diagnosis] discusses the parental pursuit, conceptualisation, and the impact of ADHD diagnosis.

**Chapter 7 [The System and the Fight: Plots 3 & 4]** introduces the plot of “The System”, in which the systems of healthcare and education are merged into a major antagonist and source of dissatisfaction within parental narratives. Chapter 7 also introduces plot four [The Fight], in which the ADHD diagnostic journey is narrated as a constant source of conflict and battle.

**Chapter 8 [The Mother: Plot 5]** details the gendered experience of parents on the ADHD diagnostic journey and the impact of the journey on parental identity and self-concept. The plot of “The Mother” captures how the diagnostic journey requires mothers to consider and alter their mothering identity, recontextualising themselves within their narrative in response to the diagnostic journey. The chapter also explores the impact of the diagnostic journey on fathering identity, and the significant difference in self-identification experienced by the father participant.

**Chapter 9 [Medication, Disability, and Difference: Plots 6 & 7]** is the final findings chapter and discusses plot six [Narratives Regarding Medication] and plot seven [The Balancing Act Between Disability and Difference]. The plot of “Narratives Regarding Medication” explores the stories parents tell regarding ADHD medication, and the challenges faced in making medication decisions. The plot also demonstrates how parents wish to recontextualise ADHD medication, reframing its use as akin to medication for physical illness. Chapter 9 concludes by discussing the plot of the “Balancing Act Between Disability and Difference”. This plot personifies the theoretical challenge faced by parents who wish to reject the language of disability and the perception of their children as ‘disabled’, whilst also acknowledging the disabling experiences of their children and the enforcement of disability language when accessing support. This plot also demonstrates parental preference to social models of disability and a need for a nuanced parental language.

**Chapter 10 [Discussion]** presents a two-part discussion thesis findings. The chapter begins with an analytical discussion of the overall development and structure of the parental diagnostic journey narrative, examining the way in which parental narratives chronologically

and structurally engage with narrative plots. Part two of the chapter details the multiple forms of 'illness work' (Corbin & Strauss, 1985) parents are required to engage with across the diagnostic journey. The chapter describes three forms of unique illness work: The Diagnostic Quest [10.3.2], Self-Biographical Illness Work [10.3.4], and Child Biographical Illness Work and Recontextualising the Child [10.3.5]. The chapter concludes with an argument presenting the parental experience of ADHD as unique within the field of illness sociology and presents justifications for a distinct sub-discipline of ADHD within illness sociology, or a 'Social Science of ADHD' [10.4]. The elements of a nascent concept of a social science of ADHD is presented, laying the foundation for future development in a field proposed as fertile ground for further sociological discussion.

**Chapter 11 [Conclusion]** concludes the thesis by summarising the overall findings of the project and presents the original contributions to knowledge in research regarding ADHD and parents, and research regarding illness sociology and ADHD. Finally, the limitations of the project are considered, alongside recommendations for future research and the potential impact on practice and policy.

## 1.4. My Story and Authorship

This thesis explores the stories of parents of children as they traverse the ADHD diagnostic journey. I wish first to tell a little of *my* story, reflexively exploring my own ADHD story and the concept of authorship. Although reflexive accounts within qualitative research have become commonplace, the process itself is "perilous, full of muddy ambiguity and multiple trails" (Finlay, 2002: 212). Nonetheless, my relationship with ADHD is unusual within the field of ADHD academia and may prove insightful to a reader in understanding the unique perspectives granted by my experiences.

Prior to my career as a researcher, I was employed as a mental health nurse within the neurodevelopmental assessment service for a local children's mental health team. Within that team, I was responsible for the assessment and diagnosis of children with neurodevelopmental disorders such as ADHD and autism, alongside being the primary contact for parents as they traversed the diagnostic journey. As a clinician, I witnessed the failures within the system and the damaging effect of these failures on the experience of parents and patients. I left the NHS, an organisation which I believe in and am proud of, feeling disappointed at the inability to deliver the truly patient-centred service which most nurses endeavour to give. Although other clinicians and I were able to support families and

do some amazing work, bureaucratic barriers, unrealistic expectations, and other issues created an environment in which parental stories of dissatisfaction became commonplace in appointments.

I was also diagnosed with ADHD at 6 years old. I have spent my life living with the symptoms of ADHD, identifying with the label as an intrinsic part of my personal identity. Like many others, I describe myself as *being* ADHD and not *having* ADHD, distancing myself from narratives of medical disorder in preference of conceptualisations of ADHD as neurological difference, not deficit. However, in undertaking this project and exploring the concepts of ADHD, medication, disability, and difference, I must acknowledge that the way in which I see my own ADHD has changed. As I witnessed parents battling with the decisions of whether to medicate their children [Ch.9], I was forced to reflect on my own position. For years I had refused to commence medication treatment out of fear of stigma and a belief that medication was an admission of my own deficit and failure. I found that the experience of parents mirrored my own in unexpected and often uncomfortable ways, as they battled with similar concerns in relation to their children. Unbeknownst to the parental participants, their own explorations of the meaning behind ADHD medication allowed me to adjust my own perspective and recommence stimulant medication for the first time in 25 years during the writing of this thesis.

The findings discussed in section 9.2 [The Balancing Act Between Disability and Difference] echo my personal experience as, like the parental participants, I had previously refused to conceptualise myself as *disabled*. The writing of that chapter required significant introspection, as my own concept of what it means to *be* or *have* disability shifted in tandem with that of the parents. This process exemplifies how reflexivity in sociological research can be a process of “mutual collaboration” (Finlay, 2002: 218). In what was an unexpected result of this project, my personal story and that of parents on the ADHD diagnostic journey had more in common than I had anticipated. When discussing the findings of this thesis with my own mother, she was struck by how perfectly aligned the findings reflected her own experiences as a mother of an ADHD child 25 years ago. Although the stories explored within this thesis are unique and individual, they are in some way an exploration of my own.

# 2. The Concept of Attention Deficit Hyperactivity Disorder [ADHD]

## 2.1. Introduction

The background chapter of this thesis explores the concept and construction of ADHD within academic, medical, and lay discourse. It begins by exploring the inherent theoretical tension between the dominant paradigms and conceptualisations of ADHD, and the impact of this tension on ADHD research and on those whose lives are impacted by ADHD. To bolster research transparency and reflexivity this section includes a summary of the paradigm utilised within this thesis. This is followed by a presenting of the primary arguments for, and the typical criticisms of, the two most prominent and opposing conceptualisations of ADHD: 'The Biomedical Model' [2.3] and a social model personified within 'The Neurodiversity Paradigm' [2.4]. Section 2.3 explores how biomedical constructions of ADHD, within which ADHD is presented as a neurodevelopmental disorder or neurological deficit, utilise the language of disease and disorder whilst prioritising effective diagnosis, aetiological causation, classification, prevalence data, and treatment (Gray, 2008). It presents a history of the label ADHD within psychiatry and outline the current evidence of ADHD's prevalence as a medical condition within the UK and globally. Section 2.4 [The Neurodiversity Paradigm] focuses on non-medical or social conceptualisations of ADHD, with emphasis on the growing paradigm of neurodiversity (Singer, 2016). The section explores how a neurodiversity model prioritises strength-based approaches in the framing of ADHD, opting to conceptualise the condition as neurological difference or a failure of environments and/or society to enable and not disable those with ADHD. The final three sections of this background chapter outline the typical assessment process for childhood ADHD within the UK [2.5: Assessment], common treatments and interventions [2.6: Treatment] and a discussion on the use of illness related terminology [2.7: A Note on Terminology].

## 2.2. The Theoretical Tension Between Paradigms of ADHD

The dominant and most pervasive conceptualisation of ADHD in western society defines ADHD as a heterogeneous neurodevelopmental disorder where an individual exhibits deficit within the areas of impulsivity, inattention, and hyperactivity. These three core symptom areas form the basis for the categorisation of ADHD under the umbrella of neurodevelopmental disorder within the American Psychiatric Association's [APA] Diagnostic and Statistical Manual of Mental Disorders Fifth Edition [DSM-V] (APA, 2013) and the World Health Organisation's (WHO) International Classification of Diseases (ICD-10/11) (WHO, 1991; 2018). These two diagnostic manuals form the 'rulebook' from which medical authorities present scientific evidence of what can be identified and considered as medical disorder and disease, granting practitioners a categorised list of clinical understandings, potential diagnoses, and evidence-based treatment options. However, prior to an exploration and implicit acceptance of a biological construction of ADHD, it is important to illustrate the significant theoretical tension between two opposing paradigms in ADHD's conceptualisation. This theoretical tension exists between the dominant neurobiological medical conceptualisation of ADHD and non-medical and/or social paradigms of ADHD utilised by the neurodiversity movement and disability scholars.

Despite its categorisation within psychiatric diagnostic manuals, some have argued that there exists "no absolute consensus historically or currently on ADHD's status as a health condition" (Horton-Salway & Davies, 2018: 1). Although Pajo and Cohen's (2013) systematic review found 27 of the 30 studies analysed defined or asserted ADHD as a valid disorder, the language used by researchers to describe ADHD varied significantly across the studies, with definitions ranging from: "psychiatric disorder", "developmental disorder", "behavioural disorder", "childhood disorder", "neurobiological and neurodevelopmental condition", "neurodevelopmental disorder", "hyperactivity disorder", "invisible disability", "psychiatric illness" and most commonly "attention deficit hyperactivity disorder". The variable terminology used to frame ADHD within these studies demonstrates a potential controversy within ADHD research; how does one conceptualise ADHD?

There is a growing interest and popularity in the use of social models of disability and strength-based paradigms of ADHD, in which the medical perspective is disregarded or even directly challenged. The most popular non-medical framework is that of neurodiversity (Singer, 2016), in which the language of disease, deficit, and disorder are exchanged for the terms different, neurodiverse, and neuroatypical. The neurodiversity movement frames ADHD and other neurodevelopmental disorders within a social model of disability, where

lived reality of disability is brought to attention devoid of medical ‘obfuscation’ (Swain et al, 2003). For proponents of a social or neurodiversity model, the priority is not to develop a deeper awareness of disease aetiology and treatment, but to highlight and combat the “social barriers, discrimination and exclusion, societal stigma, lack of access to resources, and poor perception of the disabled person” (Swain et al, 2003: 24). Sonuga-Barke and Thapar (2021) argue that positive interaction and collaboration across the paradigms would allow for better understanding in the lives and experiences of neuroatypical individuals by acknowledging and transforming discriminatory and impairing environments and social structures, whilst also forging a ‘shared’ narrative of what ADHD means. However, individuals positioned at the furthest wings of each paradigm may find little shared ground between the biological position of ADHD as neurological deficit (Barkley, 2015), and the social position that neurodiversity is a beneficial strength and “wonderful variation of humanity” (Singh, 2015: 1111).

These contrary positions present an interesting challenge for research on ADHD, as the position taken by the researcher is likely to have a direct impact on the form of the research project, and the subsequent discussion of findings. Pajo and Cohen (2013: 23) argue that researchers who acknowledge the controversies with ADHD as a concept are more likely to “explore the difficulties of mothers to comply with the myths of motherhood” and to question the medicalization of childhood behaviours. They also argue that the construction of ADHD utilised by parents will directly influence the parental decision-making process of whether to medicate a child, as a biological construction more readily accepts a medical response when compared with a social construction. The following sections of this chapter will present two conceptualisations of ADHD: As Biomedical construction [2.3] and The Neurodiversity Paradigm [2.4]. This chapter does not aim to give a conclusive or exhaustive critique on each argument within the various approaches, but to present the primary arguments of each position alongside common criticisms.

### 2.2.1. The Project’s Paradigm

It is unavoidable that the theoretical paradigm of ADHD taken by the researcher will have an impact on the project and present with certain biases. Therefore, this section plants the theoretical flag of this thesis by describing the paradigm taken as conciliatory to both paradigms and as biologically and socially agnostic. Given my position as a sociologist, a neurodiversity advocate and activist, mental health nurse, and person diagnosed with and

medicated for ADHD, I acknowledge that both biological and social constructions offer significant, situation specific, benefits.

The potential benefits of a biological repertoire are difficult to deny, as ADHD related behaviour described as disruptive and problematic can be reconceptualised as symptoms of neurocognitive disability. My personal choice to utilise stimulant medication, alongside the vast amount of evidence of its effectiveness at improving the lives of those with ADHD I witnessed as a nurse, indicates at least a partial acceptance of biological conceptualisations. However, purely biological paradigms are often reductionist, prioritising the biological 'failure' inherent within the ADHD individual whilst ignoring and disregarding the monumental impact of environment. On the contrary, purely social or psychological paradigms may classify ADHD behaviour as 'socially deviant' behaviour of otherwise 'typical' individuals due to social, environmental, or cultural factors. This position places the onus of responsibility on wider society to make accessible and inclusive environments, undoubtedly an important step forward. However, this paradigm can discount or minimise the lived experience of impairment brought on by the neurological challenges of ADHD.

This position may be criticised by others, as it has been argued that a sociological account of ADHD must be directly and distinctly oppositional to the biological, as there is little "space" for disagreement in explanation between the two (Bowden, 2014). However, it has also been argued that there exists a more conciliatory position, in which one can recognise the biological account of ADHD without holding a definitive position on the matter, whilst also utilising an autonomous sociological understanding of ADHD (Bowden, 2014). Within this study, it is not the goal to add evidence to either side of the argument of whether ADHD 'exists' as a disorder in the truest sense, nor to discuss its legitimacy within psychiatry. Like Singh (2002), this thesis will simultaneously treat ADHD as both a 'real' and a 'constructed diagnosis', regardless of my self-conceptualisation. The definitive neurological explanation of ADHD as a disorder is not important to the aims and exploration of this study, but what is important is the way in which the parental participants incorporate and utilise the various ADHD constructs. As Conrad and Barker (2010) argued, it is not the role of sociology to adjudicate between what is real illness and what is socially constructed but instead to explore the changing cultural meanings of illness whilst remaining 'agnostic' to the biological aspects of the condition. It is the *idea* of ADHD that is of primary interest. This interpretive research study does not attempt to fully formulate a definition of ADHD, nor is it concerned with the 'Truth' of the matter in relation to aetiology or legitimacy. This study is concerned with the ways in which parents own constructions of ADHD impact their experience and needs across the diagnostic journey.

## 2.3. The Biomedical Construction of ADHD

The biomedical construction of ADHD presents ADHD as a discrete, categorical neurodevelopmental disorder originating in early development (Sonuga-Barke & Thapar, 2021). This heterogenous diagnosis is one of the most commonly diagnosed childhood psychiatric disorders and individuals with childhood ADHD continue to present with problematic symptoms into adulthood (Faraone et al, 2006). A medical diagnosis of ADHD requires the individual to present with developmentally inappropriate levels of inattention, impulsivity, and hyperactivity, and for these symptoms to have been present for at least six months (APA, 2013; WHO, 2018; Young et al, 2021). Symptoms must be pervasive in nature by presenting within multiple settings, and must cause impairment in daily functioning, typically in the areas of educational, social, emotional, and professional settings (APA, 2013; WHO, 2018). Finally, these symptoms must be present within early to mid-childhood and should not be better explained through other disorder or disease. Since there is no objective biometric test for ADHD, as is available in other medical conditions such as diabetes, the diagnosis is made through clinical observations of behaviour, neuropsychological testing, and rating scales (Young et al, 2021). Although there are criticisms of the supposed objectivity of this method of diagnosis, discussed later in this chapter, proponents of a medical model of ADHD claim that this method meets the reliability and validity criteria for the diagnosis of mental disorders generally (Faraone, 2005). The biomedical model of ADHD promotes a “brain-based discourse” (Singh, 2002: 598) in which ADHD is represented as a neurological matter requiring medical intervention and treatment (Lasky et al, 2016). The findings from a large fMRI study including over 3,000 participants (Hoogman et al, 2017, 317) concluded with the authors stating that those with ADHD have “truly altered brains” after presenting clear evidence of altered brain structure within ADHD when compared with controls. They go on to state that ADHD should be labelled as a brain disorder given the robustness of their findings. Barkley (2011: 42) uses more negative terminology when he stated that ADHD is a “very profound disturbance in one’s brain’s capacity”.

Regarding an aetiological cause for ADHD, there exists a complex and extensive body of research in which there is no fully encompassing and accepted answer (Young et al, 2021). The biomedical position ADHD’s cause is multidimensional, as genetic, biological, and environmental risks coalesce into a complex picture of causation (Faraone et al, 2015; Young et al, 2021). There is evidence to suggest a genetic component to ADHD in which single genetic abnormality has been implicated (Faraone & Larsson, 2018), alongside

specific risk allele interaction (Morris-Rosendahl & Crocq, 2022). The increased incidence of ADHD in identical twins when compared with non-identical twins (Barkley, 2015; Larsson et al, 2015) presents further justification for genetic based arguments of ADHD, with genetic explanations being prevalent in UK media (Horton-Salway, 2012). Evidence of increased heritability is also important to biological arguments of ADHD (Faraone et al, 2005), as children of parents diagnosed with ADHD have a “risk” of around 57% of being diagnosed, leading some to declare ADHD to be the most “genetically influenced psychiatric disorder” (Barkley, 2015: 357). Finally, additional environmental risk factors which impact on biology have been implicated, with low birth weight, nutritional deficiency, exposure to toxicants, smoking during pregnancy, and infection all presenting some evidence of increased ADHD risk (Young et al, 2021).

Biomedical constructions of ADHD place the diagnosis within the remit of disease and disorder, requiring effective intervention and treatment to remove the presence of abnormality (Rowlands, 2017). Consequently, central nervous system stimulant medications are presented as an effective treatment of the problems and deficits associated with ADHD due to argued neurochemical imbalance. The use of these medications is typically justified due to their capacity to “increase the availability of norepinephrine and dopamine” (Connor, 2015, 666) within targeted areas of the brain to ameliorate the reduced presence of these chemicals in those with ADHD (Volkow et al, 2002). Proponents of a biological repertoire point towards the plethora of benefits associated with stimulant medication use as further evidence of its biological objectivity (Faraone et al, 2021). Recent meta-analyses (Boland et al, 2020) demonstrate many benefits of ADHD medication, with significantly reduced risk of mood disorders, substance abuse and traumatic brain injury, alongside significant improved academic outcomes.

### 2.3.1. A History of ADHD and Psychiatry

Although ADHD as a specific neurological issue has been described as “unimportant as a medical, educational or cultural entity until the more recent past” (Smith, 2015: 25), modern psychiatry argues that the ‘syndrome of ADHD’ has been present in the medical literature since 1775 (Faraone et al, 2021). Hoffmann’s (1845) characters ‘fidgety Phil’ and ‘Johnny Head-in-air’ in the nursery rhyme “Struwwelpeter” have been claimed by Taylor (2011) to demonstrate societal awareness of classic ADHD symptoms prior to more typical medical constructions of ADHD presented by Still (1902) over half a century later. Within Still’s (1902) lectures, children with ADHD type symptoms were described as having “poor moral

control” and a “defect in cognitive relation” to their environments, alongside a proneness to accidental injuries. These behaviours have been declared by Barkley (2015) as evidence of both ADHD related cognitive deficits as well as typical ADHD difficulties such as increased injury. Since 1902, psychiatry has conceptualised ADHD as post-encephalitic behaviour disorder (Barkley, 2015), brain damage in the diagnosis of Minimal Brain Damage [MBD] (Smith, 2015), hyperkinetic impulse disorder (Laufer & Denhoff, 1957) and behavioural dysfunction (Lange et al, 2010). Previous editions of the DSM demonstrate this conceptual change in psychiatry towards ADHD from brain injury to psychiatric abnormality to neurocognitive deficit. Within its second edition [DSM-II] (APA, 1968) the diagnosis of ‘hyperkinetic reaction to childhood’ was introduced, which was subsequently radically altered to Attention Deficit Disorder [ADD] in the DSM’s third edition (APA, 1980). With each edition of the DSM, criticisms were presented within psychiatry, as a lack of empirical evidence of the subtypes present in the DSM-III led to a further renaming of the diagnosis to ‘Attention Deficit Hyperactivity Disorder’ in the 1987 revision (APA, 1987). The introduction of robust and validated symptom rating scales presented the diagnosis as increasingly empirically legitimate, paving the way for increased specificity within the DSM-IV (APA, 1994). The DSM-IV stated that symptoms must be pervasive and reintroduced the subtypes, ‘ADHD without hyperactivity’ and ‘inattentive type ADHD’ as distinct disorders (Lange et al, 2010). The DSM-IV (APA, 1994) also provided a significant conceptual change within ADHD pathology by introducing adult ADHD. No longer was ADHD exclusively a childhood disorder, but could now be considered a chronic, persistent, and potentially lifelong diagnosis (Lange et al, 2010; Barkley, 2015). The current iteration of the DSM-V (APA, 2013) granted minor but important alterations by increasing the threshold for the onset of symptoms to ‘prior to age 12’ up from age 7 within the DSM-IV, and by adjusting the language from requiring symptoms to be “clinically significant” (DSM-IV wording) to “reducing the quality of social, academic, or occupational functioning” (DSM-V). Alongside removing autism as an exclusionary diagnosis, the widening of diagnostic potential in the most recent diagnostic manuals gives some indication to why rates of diagnosis continue to rise (Epstein & Loren, 2013).

The World Health Organisation’s [WHO] ICD (WHO, 1992; 2018) is a second diagnostic manual that presents some important differences when compared to the DSM worth citing. Doernberg and Hollander (2016) argue that where the DSM focusses on psychiatry and diagnosis, the ICD prioritises classification. As such, the absence of ADHD from the ICD-10 provided a strong point of contention for those challenging the diagnosis, even though the diagnosis of ‘Hyperkinetic Disorder’ was almost identical to that of ADHD but with a more restrictive onset of symptoms as prior to age 6 (WHO, 1991). Hyperkinetic Disorder was also

classified as a “behavioural and emotional disorder with onset usually occurring in childhood and adolescence”, eschewing the neurological or brain-based classification present within the DSM. However, in its most recent iteration the ICD-11 (WHO, 2019) not only includes the diagnosis of ADHD, but also recategorises the diagnosis as a neurodevelopmental disorder and widens the onset of symptoms to “during the developmental period, typically early to mid- childhood”. Therefore, both diagnostic manuals’ conception and classification of ADHD are consistent for the first time since their inception.

### 2.3.2. Prevalence and Epidemiology

Although ADHD is one of the most common childhood psychiatric diagnoses, diagnostic rates have been found to be significantly variable (Polanczyk et al, 2014). Worldwide prevalence rates of ADHD appear to be around 5.29%-7.1% (Polanczyk et al, 2007) or 7.2% (Thomas et al, 2015) in children and adolescents and 1.2-7.3% in adults (Fayyad et al, 2007). Although there is no evidence that ADHD is becoming more common over the last three decades (Polanczyk et al, 2014), increases in diagnostic rates have been linked to improved clinician recognition and more robust referral processes (Faraone et al, 2021). Meta-analyses have found no significant differences in the prevalence of children fulfilling the diagnostic criteria between the continents (Polanczyk et al, 2014), however, diagnostic rates do differ widely from 4% in Asia to 12% in South America (Polanczyk et al, 2007). Within the UK, ADHD diagnosis has typically fallen short of worldwide prevalence data as Russell et al’s (2014) millennial cohort study indicated a rate of 1.4% parent reported ADHD in a sample of 14,000 children. More recently, the 2018 NHS survey series (Forbes et al, 2018) reported a prevalence rate of 1.6% for all hyperactivity disorders in children within the UK. The statistic of 1.6% is relatively in keeping with Russell et al’s finding of 1.4% in 2014; however, when considering Forbes’ study, one must be mindful of the diagnostic criteria used. Forbes et al (2018) used the ICD-10 criteria for a diagnosis of a hyperactivity disorder and not the DSM-V diagnostic criteria for ADHD nor the most recent ICD-11 criteria. As the ICD-10 diagnostic criteria can be seen as ‘more restrictive’ than the DSM, especially with the age of required symptoms being 7 years old instead of 12, one could argue that the overall rates of ADHD within the UK may be under-represented by the survey (Lahey et al, 2006). Noteworthy differences also occur across socioeconomic status within UK diagnoses. Children whose parents were claiming income-related benefits or benefits related to disabilities were more likely to have a hyperactive disorder (2.6% and 5.8% respectively) than children living with parents who were not receiving these benefits (1.2%) (Forbes et al,

2018). This variation in ADHD diagnosis across socioeconomic status is echoed by Hire et al (2015), who found statistically significant increases of ADHD diagnosis within lower socioeconomic areas.

Further considerations regarding lower diagnostic rates of ADHD within the UK are given by Taylor (2017, 377), who states that “apparent underdiagnoses of the UK is paralleled by underproviding of specialist services”. Taylor also argues that teaching staff often lack the requisite skills and knowledge in recognition and assessment of ADHD. Studies exploring teachers’ knowledge and confidence regarding ADHD have indicated significant knowledge gaps in teacher awareness (Bekle, 2004), with many UK teachers feeling ill-equipped to meet the needs of ADHD children (Ward, Kovshoff, & Kreppner, 2021), and 19% of teachers feeling uninformed about ADHD (ComRes, 2017). Taylor (2017) also argues that parents may be less likely to pursue assessment due to associated stigma, blame, and perceived excessive use of diagnosis and medication. Where proponents of a biological model point to lower UK diagnostic rates of ADHD as evidence of a failing system, Tait (2008) declares this as fallacious reasoning. Tait argues against the ‘golden mean fallacy’, claiming that to assume the correct diagnostic rate is between the lowest (1.4% in UK) and highest (15.6% in North Carolina) estimates is a logical fallacy and should not be considered truth. Tait (2008, 12) declares that the “tidal wave of modern behaviour disorders is more related to the pathologisation of conduct, than with ontological validity.”

### 2.3.3. Criticisms of the Biological Construction of ADHD

When discussing criticisms of a biological model of ADHD one must acknowledge that any challenge to medical classification or biological conceptualisations can be perceived as a challenge to the ‘reality’ of ADHD. The intention of this section is not to challenge the lived experience of those with ADHD, but to explore potential limitations of a solely biological position.

Gray (2008) demonstrates how the inherent scientific and positivist epistemology of biomedical understandings of ADHD focuses exclusively on improving precision in classification, diagnosis, and treatment. She goes on to argue how the biological reductionism in this position limits exploration and study of ADHD to that of the simple biological components within the individual, avoiding potentially significant factors important to the experience of those with ADHD. This static “disembodied brain-based discourse is devoid of contextual data” (Lasky et al, 2016: 161) as it completely negates the impact and

influence of environments *on* the individual. These biological models of psychopathology are argued not to consider the potential that deficits may be due to difficulties in adaptation to environmental context, rather than inherent psychopathological abnormality (Jensen & Hoagwood, 1997: 232). Davies (2014) echoes this approach, describing an exclusively biomedical model to be overly simplistic in understanding the complex and nuanced discussion regarding ADHD. Lasky et al (2016: 161) describe ADHD as contextually fluid, as the experience of those with ADHD is often dramatically altered dependent on environment. They go on to question whether it is even necessary to conceptualise the disorder as ‘within the person’ or ‘mental’ at all, bracketing ADHD outside of solely neurological spheres.

Further criticisms are directed at the subjective nature of the diagnostic process, as there is often limited acknowledgement by proponents of biomedical models of the highly subjective clinician interpretations required in assessment (Gray, 2008). Critics question how one is to quantify the boundaries and remit of what is to be considered an ‘impact on functioning’ as outlined within the DSM (APA, 2015), alongside assertions that what is considered ‘impactful’ to one clinician may be minimised by another. Furthermore, the DSM (APA, 2015) requires children to “*often* fail to give close attention”, leading Whitely (2015) and Davies (2018) to question ‘how often is often enough?’. ADHD assessment is perceived not as a “value-free scientific endeavour” (Davies, 2018: 45), but a subjective clinical judgement founded on cultural understandings of abnormality and deviancy (Conrad, 1975; Conrad & Potter, 2000). The lack of clear-cut boundaries between diagnosis and non-diagnosis, and the woolly and imprecise language of psychiatry (Wakefield, 2013) provides further fuel to this position, as empirical uncertainty invalidates the certainty with which ADHD is often discussed (Stevens et al, 2018; Sonuga-Barke & Thapar, 2021). Sociological discussions of the medicalisation of social ‘problems’ will be explored further in Chapter 4.

Critics of a biomedical construction of ADHD challenge the negative laden language inherent within the paradigm, in which emphasis is placed on *dysfunction, deficit, disorder, and disability*. The diagnosis of ADHD alone utilises two of these negative attributes, displaying a prioritisation of failings with no acknowledgement of potential benefits. This concept of *disorder* assumes an agreed recognition of normality (Nesse & Stein, 2012), though it is noteworthy that the WHO (1992; 2018) declare disorder as an inexact term. When one reads Barkley’s (2011, 42) claim that ADHD is a “very profound disturbance in one’s brain’s capacity that makes us uniquely human compared to other primates”, it is difficult not to feel discomfort at the implication that those of us with ADHD have a “less human quality” when compared to those without (Steward, 2017: 92). Some have argued that as the rate and pace of cultural and societal change increases, we may see increased numbers of individual fulfilling the criteria for ‘disorder’ (Aragona, 2009).

It is reasonable to question why this chapter has discussed a solely biological paradigm of ADHD, given that biopsychosocial models are often utilised with UK contexts and include biological, psychological, and social factors as contributing factors. Although a biopsychosocial model does acknowledge the impact of other factors, it leaves the construction of ADHD as a biological condition “largely unchallenged” (Gray, 2008: 16). This ‘awkward alliance’ (Davies, 2018) between the psychological, social, and biological discourses does not remove responsibility for pathological symptoms from individuals or question the validity of ADHD as a medical construct but accepts a biomedical conceptualisation of ADHD whilst leaving criticisms of biological reductionism (Gray, 2008) unanswered.

## 2.4. The Neurodiversity Paradigm

In recent years, the neurodiversity movement has rejected dominant biological constructions of deficit and disability in relation to ADHD and other neurodevelopmental disorders. Coined by Judy Singer (2016), neurodiversity refers to the variability and diversity in our neuro-cognitive experience and aims to frame those with neurodevelopmental disorders/conditions as neurologically *different* as opposed to neurologically *disordered* or *deficient* (O’dell et al, 2016). Those with a neurodevelopmental diagnosis or atypical neurological development are often referred to as neurodivergent, neurodiverse, or neuro-atypical; terms felt by many to be more positive and inclusive than the medical use of *disability* and *disorder* (Smith & Kirby, 2021). This reframing allows the neurodevelopmental disorders to be conceptualised as human variance in which the language of sickness and disease is inappropriate (Tan, 2018). Proponents use historic examples of inappropriate medicalisation to further this claim, such as the American Psychiatric Association’s (1994) classification of homosexuality as medical disorder until 1973 and subsequent reclassification to social difference (Runswick-Cole, 2014). Often pioneered and championed by neurodiverse individuals, the neurodiversity movement promotes a strength-based approach to neurological differences whilst acknowledging the daily challenges faced by neuroatypical individuals (Houting, 2018). The neurodiversity paradigm is heavily influenced by the social model of disability (Swain et al, 2003) and typically acknowledges the lived experience of *impairment* whilst denying the framing of the individual as disabled or disordered. Medical models of disability and disorder are argued to ignore the role played by society in excluding those labelled as ‘disabled’ and the contribution of the non-disabled majority in creating social environments where the disabling aspect of impairment is magnified (Barnes, 1991; Anastasiou & Kauffman, 2013).

The neurodiversity paradigm defines the experience of *impairment* as the “functional limitation within the individual caused by physical, mental, or sensory impairment” (Barnes, 1991: 2) and places the onus on environments to minimise the impact of impairment and not the individual to treat or ‘cure’ impairment. Consequently, the majority of disadvantages faced by neurodiverse individuals are argued to be due to prejudice, stigma, and other systemic, social and environmental barriers rather than inherent biological disability (Shields & Beversdorf, 2019). This perspective positions the neurodiverse as a societally oppressed minority group instead of a medically sick one and has paved the way for the introduction of the term ‘neurominorities’ to communicate this (Doyle, 2020; Smith & Kirby, 2021).

A primary tenet within the neurodiversity paradigm is that all neurological diversity is valuable within the right context and environments (Houting, 2018). Although there have been few empirical studies focussing specifically on the strengths of ADHD, a variety of ADHD related benefits have emerged across the literature. These positives include increased creativity (Leroux & Levit-Perlan, 2000; Brod et al, 2012), improved creativity in problem solving (Zentall et al, 2001; Schreuera & Dorot, 2017), higher levels of passion, enthusiasm, and performance in areas of specific interest (Laskey et al, 2016), increased energy and speed (Rosenfield et al, 2008) and increased entrepreneurship (Wiklun et al, 2017). The neurodiversity paradigm claims that biomedical conceptualisations of ADHD not only minimise or ignore these ADHD-related strengths, but risk the eradication of these strengths through medicalisation, ‘treatment’ of difference, and deficit driven narratives. Unlike biomedical and biopsychosocial approaches, the neurodiversity paradigm may be used to directly oppose the core assumptions of a biological model of disability for ADHD, as the reduction of the ‘unwanted symptoms’ of inattention and hyperactivity through the altering of brain chemistry via medication is seen as a masking of the ‘real’ issue. Proponents of neurodiversity may argue that if a child with ADHD is struggling to engage with schoolwork, then responsibility is on the school environment to adapt and alter to fit the needs of the child, and not for the child to be chemically altered to fit in with an ineffective environment.

Strength-based approaches may also include even more positive conceptualisations of ADHD, in which it is narrated as a superpower. This growing trend is proving increasingly popular outside of academia, and is often utilised in children’s books (Larson, 2020; Lazarus, 2021) and UK news articles (Brown, 2019). On the more radical end of the neurodiversity movement, some argue that **any** impairment faced by a neurodiverse individual occurs due to the mismatch of individual and society, and that further research and exploration into improving diagnosis and treatment of ADHD theoretically inappropriate (Sonuga-Barke & Thapar, 2021). This wholly positive conceptualisation of ADHD, within which ADHD children

may be labelled 'indigo' or the next stage of human evolution has been argued to stretch beyond the boundaries of the neurodiversity movement and has become a movement in its own right (Carroll & Tober, 1999; Lench, Levine, & Whalen, 2013; Singler, 2015, 2017). I briefly mention this more radical theoretical perspective of ADHD as one parent in this thesis, Jane, presented a similar argument (Numbers represent line numbers of the overall transcript of all three interviews):

**Jane 555-559**

*I think they are like the superheroes of society. People in the world label it as a 'disability', but I completely disagree with that. It's wrong. It's completely wrong. It's like one day, neurodiversity is going to take over. That's my inside, honest opinion. I love it. I think it's amazing*

#### 2.4.1. Criticisms of Neurodiversity

As with the biological paradigm of ADHD, noteworthy criticisms have been directed towards a solely social or neurodiversity conceptualisation. Naturally, proponents of a biological perspective utilise the arguments brought forward within Chapter 2.3 [The Biomedical Construction of ADHD] to challenge the neurodiversity perspective; however, these arguments do not typically challenge the theoretical perspective of neurodiversity. The framing of ADHD and other neurodevelopmental conditions as 'cultural identity' or individual difference is argued to disregard the experience of those who feel disabled and impaired by their ADHD experience (Houting, 2018). Singer, neurodiversity's progenitor, acknowledges how the paradigm can lead some to a "Pollyanna" version of the movement, in which excessively optimistic portrayals of neurodevelopmental difference ignore the real-life experience of challenge and impairment. Although a social model of disability would prioritise disability arising from ableist prejudice and gaps in accessibility within social structures (Shields & Beversdorf, 2019), critics of a solely neurodiversity perspective and many with neurodevelopmental conditions point towards the individual experience of impairment outside of these structures.

A second criticism relates to how the neurodiversity movement is felt to be primarily appropriate for those with minimal support needs, often described as 'higher functioning' individuals (Houting, 2018). Those outside of this 'higher functioning' group are argued to be

less able to utilise the movements rhetoric due to a more pronounced experience of disability. However, Houting (2018) disagrees, declaring that the dichotomisation of people into high- and low-functioning categories erases the variation in ability across multiple skills and ability inherent to the movement's perspective. The denial of autonomy and agency for those classed as 'low functioning', alongside restriction of access to support for 'high functioning' individuals, exemplifies the ableist prejudice the paradigm aims to abolish. However, the homogenisation of 'disabled' people and their experiences has also been criticised (Davis, 1998; Runswick-Cole, 2014), and the binary grouping of individuals into neurodiverse/neurotypical may further marginalise and exclude those with differing needs within the group. The restriction of access to support is of particular interest, as the positive framing of neurodiverse conditions may imply a reduced need for social support due to it being a 'natural variation'. This does present a challenge for neurodiversity campaigners and advocates who aim to extol the strengths and benefits of neurological variation and cultivate respect and acceptance, whilst also fighting for the support and interventions necessary to meet these differing needs. Runswick-Cole (2014: 1124) points towards the "inherent contradiction" of arguing for neuroatypical rights and recognition for their 'differences' whilst also wishing to claim natural variation. The simultaneous claim that neurodiverse and neurotypical people are both the same and different presents a theoretical challenge.

A final criticism of note is Neumeier's (2018) concept of 'neurodiversity lite'. Neumeier argues that the paradigm may be adopted by 'neurotypical newcomers' to neurodiversity who wish to utilise the feel-good positive language of the movement and give lip service to neuroatypical individuals' inherent worth with minimal changes in effective accommodation or inclusivity. Those who employ the rhetoric of neurodiversity without fully understanding the foundational assumptions of the movement are likely to cause harm to its aims and credibility and may end up infantilising or placing neurodiverse individuals on a pedestal due to misunderstandings. Neumeier (2018) defines this process as 'neurodiversity lite', arguing that at best it unintentionally undermines the movement by using language which overlooks or contradicts the core concepts of neurodiversity, but at worst "disguises ableist stereotypes and harmful practices" by allowing service providers to sound like they are supporting neuroatypical individuals whilst doing nothing to change practice.

In conclusion, the biological and neurodiversity paradigms of ADHD pose an interesting and contentious area for debate. As previously explored [2.2.1: The Project's Paradigm], this thesis is influenced by a position which eschews both a radical biological and radical neurodiversity perspective of ADHD and aims for a nuanced theoretical position in which the benefits granted by both interpretations are utilised and criticisms are minimised. However, the thesis does not attempt to convince readers of which paradigm is the 'right' model of

ADHD, but instead aims to understand how the interplay between these dominant paradigms influence the parental diagnostic journey and sensemaking of their children's ADHD.

## 2.5. Assessment of ADHD

This section will briefly outline the typical process for assessment and diagnosis of ADHD within the UK undertaken by participants within this study. The exhaustive process of identification, referral, assessment, and diagnosis is outlined in NICE guidelines [NG87] (2019) which are included in full in appendix C.

### 2.5.1. Step 1: Interaction with General Practitioner [GP]

Although GPs are not qualified to formally diagnose ADHD, they are typically the first medical point of contact for parents and families and often the primary referrer for specialist ADHD assessment (NHS, 2021). NG87 1.2.7 outlines how GPs may consider a period of “watchful waiting of up to 10 weeks” or offer referral to a group-based ADHD-focussed support prior to referral. It is noteworthy that no such ADHD focussed support exists within the geographical area in which this project recruited participants. If, however, impairment is felt by the GP to be “moderate” or higher, immediate referral to a specialist is the recommended next step. However, UK survey data indicates that only 27% of adults and children eventually diagnosed with ADHD were referred straight to a specialist following their initial GP appointment, whilst a further 38% visited their GP three times before referral (ADHD Foundation, 2017). One potential reason for this failure to follow NICE guidelines is likely unhelpful attitudes and uncertainty expressed by some GP's regarding the legitimacy of ADHD as a diagnosis (Hall et al, 2013; Young et al, 2021). Young et al's (2021) expert consensus statement highlights the cultural and structural barriers at all levels of the ADHD diagnostic process, with gatekeepers such as GP's, teachers, and CAHMS workers being integral in determining the effectiveness of the process. Nonetheless, following interaction with a primary care practitioner, the child is typically referred for specialist assessment within CAHMS or to a private healthcare provider.

### 2.5.2. Step 2: Specialist Assessment

Following referral to CAHMS, many parents find themselves on a prolonged waiting list, upon which they may have their primary meeting with a mental health specialist anything from 2- to 55- weeks after referral (ADHD Foundation, 2017). At the time of this study, the typical waiting list for all parental participants was between one and two years from referral to first contact with CAHMS in the form of initial assessment. At this stage, around 24% of referrals to CAHMS are rejected in what has been described as an “erratic” usage of exclusionary criteria, where some children are only accepted for assessment if there are comorbid difficulties such as self-harm (Young et al, 2021: 5).

Once the assessment process begins there will typically be an in-depth assessment of the young person’s needs, coexisting conditions, social, familial, and educational circumstances, and the child’s physical health. At either this a or in a separate appointment a developmental and family history will be taken in which parents will be questioned regarding their child’s development thus far. Concerns have been raised regarding the inconsistency in approach to developmental histories across practitioners and the lack of a structured and validated tool in gaining said histories (Waltereit et al, 2020). Although not in common usage at the time of writing, Waltereit et al’s (2020) tool appears to be both a valid and sensitive interview routine available to practitioners wishing to complete developmental histories.

Although not always undertaken during private assessments, CAHMS based assessments often include a school observation in which a mental health professional covertly observes the child within a school-based context (McConaughy et al, 2009). School observations are typically conducted utilising a validated assessment tool such as the original ADHD School Observation Code (Gadow, Sprafkin, & Nolan, 1996) or Behaviour Observation of Students in Schools (Shapiro, 2004). However, observations may be invalidated in their effectiveness if the child becomes aware of the observation, the observation is undertaken by an individual unskilled in assessment of ADHD, or if the school context is atypical at the time of observation (such as a school sports day).

### 2.5.3. Step 3: Diagnostic Appointment

Once a clinical assessment, developmental history, and observatory reports on mental state have been completed, NICE Guidelines [NG87] 1.3.1 dictates that a “specialist psychiatrist, paediatrician, or other appropriately qualified healthcare professional with expertise in the diagnosis of ADHD” is able to confirm a diagnosis of ADHD (NICE, 2019). This decision requires that either the ICD-10 or 11 (WHO, 1991; 2018) or DSM-V (APA, 2013) diagnostic

criteria for ADHD have been sufficiently evidenced. Within private assessment, this decision is typically made by the primary diagnostician (often a psychiatrist or psychologist with expertise in ADHD). However, within the Northeast local CAHMS teams in which many study participants were assessed, the final diagnostic decision is typically made within a multidisciplinary team meeting in which multiple professionals contribute. Once a diagnosis of ADHD is confirmed, a diagnostic meeting is arranged with parents in which a structured discussion should be had detailing why a diagnosis has been made and the potential positive and negative impacts of diagnosis. This meeting will typically include a discussion regarding whether the family wishes to pursue interventions such as pharmacological treatment.

## 2.6. Treatment of ADHD

Within the UK the most common treatment option used to reduce the symptoms of ADHD are psychostimulant medications such as methylphenidate and dexamphetamine, or non-stimulant medications such as atomoxetine, clonidine, and guanfacine (Barkley, 2015; NICE, 2019). The efficacy of both stimulant and non-stimulant medications in improving ADHD symptoms is well documented in multiple meta-analyses (Cheng et al, 2007; Castells et al, 2011; Cortese et al, 2018) and its use is recommended within both current ADHD expert consensus statements (Young et al, 2020; Faraone et al, 2021) and NICE guidelines (NICE, 2019). Stimulant medications have been shown to be effective for both males and females across the lifespan (Young et al, 2020), and evidence suggests they are more efficacious than many medications used for non-psychiatric disorders (Leucht et al, 2012). However, there are many unpleasant side effects associated with ADHD medications including reduced appetite and reduced bodyweight, sleep difficulties, and increased anxiety (Barkley, 2015; Faraone et al, 2021). Additional concerns have been raised regarding stimulant medication use and delayed growth in children (Faraone et al, 2021), although evidence remains mixed and inconclusive (McCarthy et al, 2018). For many, adverse side effects and uncomfortable experiences commonly lead parents of children taking stimulants to cease treatment even with the highest level of educational improvement (Khan et al, 2022). Evidence suggests that around 40% of adults using atomoxetine discontinued usage due to side effects (Cunill et al, 2013) and 20% of children discontinue stimulant medication, typically within the first year of use, due to psychological side effects (Toomey et al, 2012). Interestingly, recent meta-analysis found small but statistically significant evidence that discontinuing ADHD medication leads to reductions in quality of life amongst children and adolescents but not adults (Tsuji et al, 2020), indicating that perceived quality of life and

experience of adverse side effects are important aspects in the medication experience. Whilst medication for conditions such as diabetes are typically clinician led, patient preference in ADHD medication decisions is an integral part of individualised treatment regimens (Young et al, 2020).

The prioritisation of patient choice within ADHD medication presents some salient issues in the context of ongoing controversies in societal discourse. As parents are often the arbiters of medication decisions for their children (Davis, 2014), they can become the target of negative portrayals in which they are painted as abusively “drugging” their children (Horton-Salway, 2011: 542). These issues will be explored in greater detail within Chapter 9.1 [Narratives Regarding Medication], within which the parental decision-making process regarding ADHD medication is discussed.

Although there are many non-pharmacological treatment options available to those diagnosed with ADHD, evidence suggests that these are significantly less effective at reducing the impact of core ADHD symptomology when compared with medication (Faraone et al, 2021). Within the context of the current study, no parental participants were offered healthcare interventions other than pharmacological treatment for their children even though there is evidence to suggest positive effects on parental stress (Daley et al, 2014) and academic functioning (Bikic et al, 2017) for interventions such as cognitive behavioural therapy [CBT] and other behavioural interventions (Faraone et al, 2021). Although supplement, dietary, and exercise-based treatments have been proposed, there remains minimal evidence of the effectiveness of any of these interventions (Faraone et al, 2012) outside of small improvements in symptoms following Omega-3 fatty acid supplementation (Chang et al, 2018).

## 2.7. A Note On Terminology: “Illness” and “Disability”.

Given the differing conceptualisations of ADHD as medical versus non-medical entity, and the significant array of terms in which ADHD may be described, it is important to clarify the language utilised throughout this thesis and the intended meaning of specific terminology. Inconsistencies in terminology are apparent across the corpus of neurodevelopmental disorder related research, in part due to a lack of universality in language but also influenced by medically dominant discourse where neurodevelopmental disorders are “characterised as a list of impairments” (Scavarda & Cascio, 2022: 2). For instance, the language used to identify and describe ADHD includes: as a disorder or neurodevelopmental disorder (APA,

2015; WHO, 2018), an impairment, disease, disability, illness or injury (Ortega, 2009), a psychiatric/medical problem (Conrad, 2007), a cognitive disability or learning difficulty (Lassinantti & Almqvist, 2021), a neurobiological disorder, injury, or personality trait (Scavarda & Cascio, 2022), and as a superpower (Lench, Levine, & Whalen, 2013) or simply a difference (Kirby & Smith, 2021). This smorgasbord of alternative descriptors across the literature illuminates the terminology considerations necessary within ADHD research. Consequently, when referring to other literature throughout the thesis, the terminology utilised within the cited research will be used to ensure a consistent and accurate portrayal of the intentions of the original author. Outside of these instances, the term neurodevelopmental disorder will be the preferred term to identify ADHD throughout this thesis as this is most common expression within UK health-based research.

This thesis does not intend to make a claim regarding the correct or most appropriate linguistic conceptualisation of ADHD but will adhere to common terms recognised within the field of illness sociology. Therefore, throughout this thesis the words 'illness' and 'long-term/chronic illness' will be referred to and utilised in relation to ADHD. The use of the term illness does not intend to confirm a biological or disease construction of ADHD or to claim ADHD should be identified as a mental illness but is instead used as a sociologically recognised word in which to articulate the experience of non-typical health related experiences. Illness is often used as a meaningful word to denote unwellness in general but may also be defined as any somatic anomaly that can "manifest to bother or make sick the affected person" (Flegel, 2010: 486). The notions of disease, illness and disorder are medical in nature, and are often missing from educational or professional discussions of ADHD outside of the medical sphere (Rogalin & Necini, 2015). However, given that this project explores the parental diagnostic journey of ADHD, the framing of ADHD is intrinsically medical given that the journey is predicated on ADHD being considered medical in nature due to the required engagement with healthcare and the pursuit of diagnosis. Although neurodiversity activists may challenge the use of illness language in relation to ADHD, denying the use of these terms is not sufficient in avoiding the potentially stigmatising effect of labelling a child as 'ill' or the illness related narratives of parents on the diagnostic journey. Fundamentally, the reality of illness is invariably evoked by the diagnostic label of a medically recognised disorder and the labelling of a child to be in some way impaired or as having additional difficulties when compared to non- 'ill' children (Rogalin & Necini, 2015)

A further term requiring consideration prior to inclusion within the thesis is 'disability'. Throughout, the term disability will be referred to when describing the experience of parents of children with ADHD. The word disability is complicated by the ongoing scholarly debate regarding both definition and applicability. When utilising the term disability from a legal

perspective, the thesis will adhere to the legislative definition outlined within the Equality Act (2010) and Disability Discrimination Act (1995) in which disability is defined as:

*“A physical or mental impairment which has a substantial and long-term adverse effect on your ability to carry out normal day to day activities”*

However, in agreement with disability scholars such as Goodley (2011), Barnes (1991), and Anastasiou and Kauffman (2013) the position of the author is that prevailing medical definitions of disability ignore the societal role in excluding and disabling an individual with ADHD associated impairment. Medical and legislative disability perspectives individualise the experience of disability, presenting disability as something that someone can ‘have’, as opposed to a social model in which disability is the result of a process in which one is ‘done to’ due to their having ‘impairments’ (Turowetz, 2015). Therefore, unless the above legal definition is explicitly referred to within the text, the definition of disability utilised by this thesis will be as follows:

*Impairment: The functional limitation within the individual caused by physical, mental, or sensory impairment.*

*Disability: The loss or limitation of opportunities to take part in society on an equal level with others due to social and environmental barriers*

(Barnes, 1991: 2).

A detailed analytical discussion on the concept of disability and ADHD, alongside the theoretical and linguistic challenges associated with disability language for parents, will be presented within Chapter 9.2 [The Balancing Act Between Disability and Difference].

There is a final consideration regarding terminology present within ADHD scholarship absent from other neurodevelopmental conditions. Within autism research there exists a prolonged debate regarding whether to describe the individual as ‘*being* autistic’ or ‘*having* autism’ (Ortega, 2009). The contemporary UK position is that the term ‘person with autism’ has negative connotations by presenting autism as a potentially undesirable thing to possess whilst denying the integral role in which autism plays regarding identity (Silverman, 2008). Consequently, the leading UK autism charity (National Autistic Society, 2022), states in their “dos and don’ts” to refer to individuals with a diagnosis of autism as “autistic” and to avoid stating that they “have autism/are a person with autism”. Similarly, individuals with a diagnosis of dyslexia or dyspraxia have the opportunity be referred to or self-identify as ‘dyspraxic’ or ‘dyslexic’. However, there is currently no equivalent linguistic identifier to

describe an individual diagnosed with ADHD. Additionally, ADHD specific charities do not give specific advice on terminology (Green, 2022; ADHD Foundation, 2022). This presents a problem in how one is to refer to an individual with a diagnosis of ADHD, and whether to describe them as an 'ADHD child', 'ADHD'er', 'child with ADHD' or other similar term. The language of ADHD is cumbersome, ultimately leading this thesis to use the terms "ADHD child" and "child with ADHD" throughout, despite the name utilising two negative and potentially pejorative words (*deficit* and *disorder*) to identify a child. Although words such as 'neurodiverse' child are potential terminology options, they are non-specific to ADHD and therefore do not present a satisfactory alternative. These issues and their impact on the parents of children on the diagnostic journey of ADHD will be explored further within Chapter 10 [Discussion].

# 3. Literature Review Part 1:

## Parents and ADHD

### 3.1. Introduction

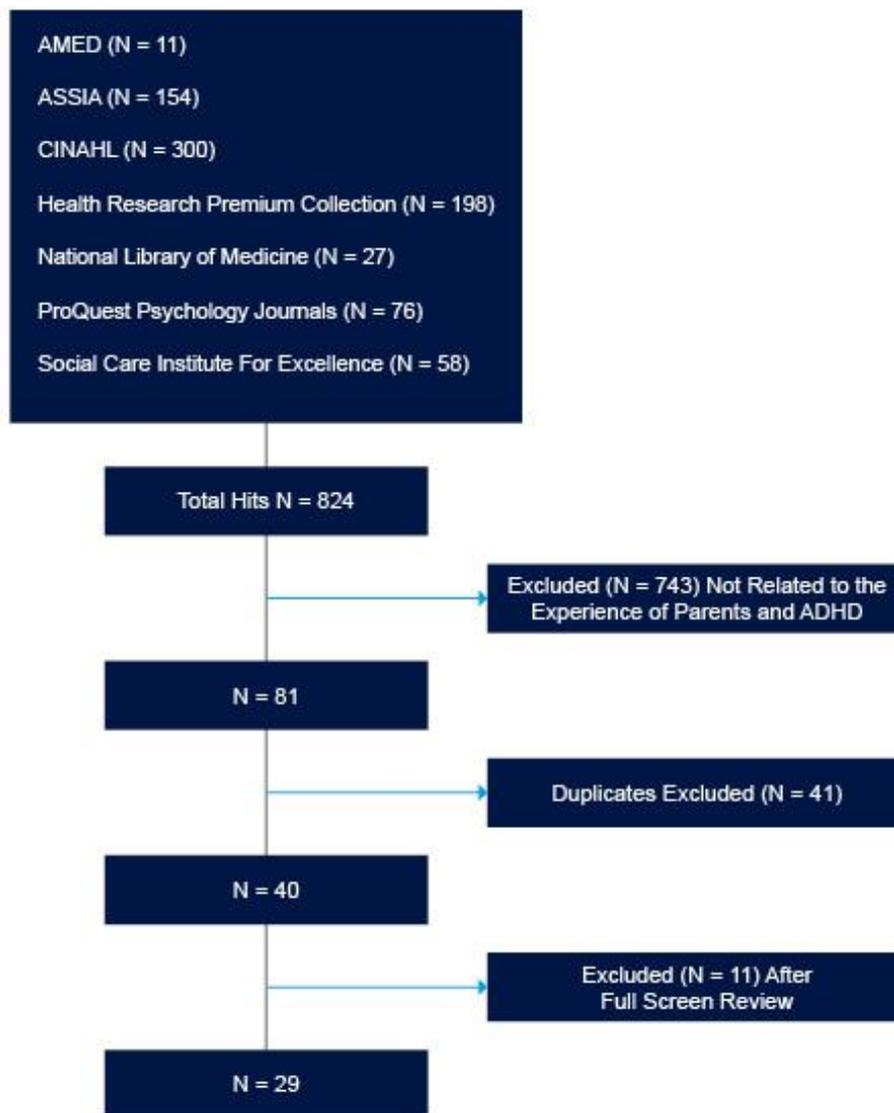
Part one of this two-part literature review critically examines literature regarding parenting a child with ADHD and the parental experience of the diagnostic process. The chapter explores how having a child with ADHD presents complex emotional, physical, and social challenges (Cocoran et al, 2017a) which lead to significant stress (Rowland, 2016), tiredness and fatigue (McIntyre & Hennessey, 2012) and increased psychiatric difficulties such as anxiety and depression (Chuang & Theule, 2016; Durukan et al, 2017; Yan et al, 2018). Evidence suggests that parents of children with ADHD experience significant burdens such as negatively impacted relationships (Cocoran et al, 2017a) and a need to constantly fight 'battles' for their children (Wolpert & Clare, 2004). The challenges associated with ADHD often leads to parents seeking assessment and diagnosis both to find meaning and relief from parental guilt and shame (Klasen, 2000; Jutel, 2009) but also as an "essential" tool to receiving support and empowerment (Carr-Fanning & McGuckin, 2018: 207). Unfortunately, the parental experience of having a child assessed for ADHD is not always simple, with long wait times (ADHD Foundation, 2017; Thevathasan et al, 2022), "wait to fail" approaches (only accepting referrals once the child begins to fail or struggle), and watchful waiting guidelines exacerbating parental anxiety and stress (Carr-Fanning & McGuckin, 2018). Parents describe interactions with CAMHS as disempowering, describing feelings of powerlessness and dismissal before, during, and after assessment and diagnosis (Laugesen et al, 2017). When a diagnosis is made, stigma and blame is commonly experienced from schools (Watson, 2011), the general population (McIntyre & Hennessey, 2012) and from within the family, especially mothers-in-law (Horborne, Wolpert & Clare, 2004). Finally, ADHD medication also represents a significant area of parental consternation and decision making within the wider literature (Charach et al, 2006, 2014; Hansen & Hansen, 2006; Leslie et al, 2007; DosReis et al, 2009; Clarke & Lang, 2012; Coletti et al, 2012; Cormier, 2012).

The process of identifying key literature regarding ADHD and parenting influenced by Cocoran et al's two-part meta-synthesis of parents of children with ADHD (2017a, 2017b).

Their systematic reviews explore the lived experience of having a child with ADHD (Cocoran et al, 2017a) and the parental experience of diagnosis and medication use (Cocoran et al, 2017b). The 80 publications cited in their review were originally screened for appropriateness within the current chapter. A subsequent literature search was undertaken utilising similar inclusion and exclusion criteria to Cocoran et al (2017a) between the dates April 2015 to October 2022 to efficiently capture recent relevant literature. Within this literature review the search terms used included (reflection OR experience OR qualitative OR narrative OR story) AND (mother\* OR father\* OR caregiver\* OR parent\* OR family\*) AND (attention deficit hyperactivity disorder OR attention deficit disorder OR ADHD). The Databases searched included: AMED, CINAHL, Health Research Premium Collection, ProQuest Psychology Journals, National Library of Medicine (Pubmed), ASSIA, and Social Care Online.

The results of that literature search are represented below, followed by a review of the emotional impact of ADHD on parents:

Figure 1: Literature Review Results



**Included Papers**

Ching et al (2022)  
 Davoody et al (2022)  
 Emmanuel et al (2022)  
 Thevathasan et al (2022)  
 Khan et al (2022)  
 Paidipati et al (2022)  
 Patkar (2022)  
 Lu et al (2022)  
 Gordon et al (2021)  
 Özaslan & Yildirim (2021)

Rasmussen et al (2021)  
 Schiltz et al (2021)  
 Spencer et al (2021)  
 Taylor & Antshel (2021)  
 Lundin (2020)  
 Paidipati et al (2020)  
 Ringer et al (2020)  
 Wong & Wong (2020)  
 Flood et al (2019)  
 Honkasilta & Vehkakoski (2019)

Leitch et al (2019)  
 Ruuskanen et al (2019)  
 Gladiola et al (2018)  
 Wong et al (2018)  
 Bringewatt (2017)  
 Ghosh et al (2016)  
 Mofokeng & Van der Wath (2016)  
 Laugesen & Groenkjae (2015)  
 Sikirica et al (2015)

## 3.2. The Emotional Impact on Parents

The first major theme evident within the literature regarding parenting a child with ADHD was the significantly emotional impact of the experience. The typical parental experience has been personified by: “exhaustion, isolation, anxiety, irritation and frustration, anger and resentment, despair and desperation, powerlessness and helplessness, grief, guilt, pressure and stress, and suicidality” (Cocoran et al, 2017: 328). This assortment of negatively charged terms is repeated across the literature, where the parental experience has been described as “difficult to manage, challenging, exhausting, and not normal” (Ghosh et al, 2016: 145), a rollercoaster between hope and hopelessness (Laugesen & Groenkjae, 2015), significant effort (Paidipati et al, 2020), and a battleground of justification (Carr-Fanning & McGuckin, 2018). Family life with ADHD children is often “chaotic, conflictual, and exhausting” (Kendall, 2017: 842). The resulting stress from these negative emotional experiences leads to adverse parental outcomes emotionally, socially, and physically (Ching’Oma et al, 2022).

The physically exhausting nature of parenting the ADHD child has been likened to the literal ‘sapping of parental energy’ (Mcintyre and Hennessey, 2012), with some parents becoming physically unwell due to the unrelenting nature of the experience (Cocoran et al, 2017a). When considering mental health needs, parents of children with ADHD have reported higher levels of psychological difficulties when compared with parents of typically developing children, including increased depression and anxiety (Chueng & Theule, 2016; Durukan et al, 2017; Yan et al, 2018) and a myriad of psychological problems (Chin’Oma et al, 2022). A participant in Rowlands (2016, 175) doctoral project described ADHD parenting as “stress, stress, pure stress”, supporting her findings that “ADHD is hard to live with”. These difficulties are often exacerbated by a sense of parental duty and responsibility for their children, which inflicts greater distress and demands (Paidipati et al, 2020). Often it is not only the effort required in managing the ADHD behaviours but also the ineffectiveness of the strategies used by parents, as typical parenting strategies are often inappropriate for the ADHD child, (Brinkman et al, 2009) leading parents to feel uncertainty in their parental capacity (Wong & Wong, 2020). Firmin and Phillips (2009), mirroring Segal’s (1998) study, explored the ways in which parents attempt to effectively support a child with ADHD. Parents stated that they were involved to a higher degree with their ADHD diagnosed child, devoting additional resources and time to increase the chances of success. They described adapting their own routines to better support their child, whilst utilising a myriad of supportive

strategies such as “chore lists, instructions, sticker reward charts, rewards, dry erase boards to display instructions, and post it notes” (Firmin & Phillips, 2009: 1168). These strategies and supports required constant monitoring and attention from parents, leading to fatigue and tiredness. It is worth noting however, that participants in Firmin and Phillips’ study were all members of the Children and Adults with Attention-Deficit/Hyperactivity disorder [CHADD] support group. Therefore, their awareness of potential effective strategies and additional psychological and emotional support delivered by the group may influence their willingness to utilising a multitude of different strategies.

Precipitating factors to this negative parental experience were discussed by Ghosh et al (2016), who found that although parents did struggle with their children’s lack of concentration and poor behaviour, the most significant concerns were worries regarding their child’s poor achievement at school and their lack of friendships. These worries are appropriately placed, as it is well documented that being a child with ADHD negatively impacts on academic, occupational, and educational outcomes across the lifespan (Klein et al, 2012; Barkley, 2015; Ramos-Olazagasti et al, 2018; Faraone et al, 2021). In a US sample, adult males with ADHD have on average two and a half years less formalised schooling than their non-diagnosed counterparts (Klein et al, 2012) and have an average of 33% reduced earning potential (Fletcher, 2013). Although no longitudinal study within the UK has mimicked the expansiveness of Ramas-Olazagast et al’s (2018) 33-year long project, the negative impact on schooling for children with ADHD is evident globally. A common belief held by parents is that academic achievement is one of the requirements for higher likelihood of later life success, therefore pushing the child to academically achieve and function adequately at school is of great importance (Ghosh et al, 2016). This issue is present across the literature, as parents are often concerned with their child not reaching their full potential (Charach et al, 2014), or having more practical academic difficulties such as repeated failure in exams (McIntyre & Hennessy, 2012). A child’s difficulties at school often leads to stress and external pressure at home, as concerns permeate into wider family life (Brinkman et al, 2009). The National Attention Deficit Disorder Information and Support Service [ADDISS] published “The School Report”, a ‘research informed report of the impact of ADHD on the school day’ (ADDISS, 2005). The report surveyed 90 parents and 50 children regarding the impact of ADHD at school, alongside undertaking focus groups with both parents and children. Of those surveyed, 70% of parents rated the impact of ADHD on their child’s education as “huge”, and 90% of parents were “concerned about the impact of the condition on their child’s future” (ADDISS, 2005: 8). Consequently, parents of children with ADHD spend a significant amount of mental energy, and experience a heightened level of stress, regarding their children’s academic and educational experience.

However, for some parents the primary concern within school environments is not academic attainment, but social experience. The ADDISS report (2005) showed that almost a quarter (23%) of parents were more worried about the difficulties their children had making friends than with poor academic performance. Poor social relationships were apparent within Cocoran et al's meta-synthesis (2017a), where the difficulties associated with forming and maintaining friendships were linked to the uninhibited behaviour of children with ADHD. Parents in one study explicitly expressed concerns around their child's ability to form meaningful social relationships (Moen, Hall-Lord, & Hedelin, 2014). Although some parents become actively involved in promoting the socialisation of their children, these attempts are often ineffective, resulting in additional withdrawal from social activities (Walerius, Fogleman, & Rosen, 2016; Fossati et al, 2020). The resulting social isolation and peer rejection leads to parental concern about childhood low self-esteem and loneliness, an issue only exacerbated by school policies and behaviour management techniques which actively isolate the child with ADHD such as time in 'isolation' rooms (DosReis et al, 2010). These worries are appropriate, as poorer self-esteem within children and adolescents experiencing ADHD is well documented (Edbom et al, 2008; Mazzone et al, 2013; Fossati et al, 2020). Relationship difficulties are not only experienced by children diagnosed with ADHD but are also an issue for their parents.

### 3.3. Relationships

Parenting a child with ADHD is often described as challenging and burdensome due to the difficulties associated with the core ADHD symptoms of inattention, hyperactivity, and impulsivity. However, major complexities are also associated with both core symptomology and the societal or familial response towards the child's behaviour (Cocoran et al, 2017a). The constant management of the child's ADHD behaviours, alongside the resource cost required to maintain discipline, have been found to lead to parental fatigue and strained marital relationships (Whalen & Henker, 1999). Whalen and Henker's findings have since been replicated multiple times. Impact on spousal relationships was discussed in 13 of the papers explored by Cocoran et al (2017a), with many citing the requirement for constant parental supervision of the ADHD child leading to reduced time spent together. Outside of papers included within the meta-synthesis, it has been documented that parents face difficulties finding a compromised middle ground between the responsibilities of family and work (Sellmaier et al, 2016). The experience of caregiving "24 hours a day" is one shared by many parents of ADHD children (Hallberg et al, 2008), and has been likened to a constant struggle (Cocoran et al, 2017a). Difficulties in romantic relationships are not exclusive to pre-

existing relationships, as single parents describe having to prioritise the care of their child over the nurturing of new and potentially supportive relationships (McIntyre & Hennessy, 2012). Harborne, Wolpert and Clare's (2004: 333) work exploring UK parental understanding of the causes of ADHD found that many mothers believe that their concerns about the wellbeing of their sons were "unsupported or dismissed" by partners, likely influencing relational disharmony. Harborne and her team speculated on whether the increased difficulty of parenting the ADHD child exacerbated previous relationship difficulties, or whether ADHD parenting created new ones. At the nadir of this continuum some couples have turned to marital counselling or divorce to manage these difficulties (Ho., Chien., & Wang, 2011). The result of these additional stressors on marital relationships is an increased rate of divorce, and shorter latency to divorce for parents of children with ADHD when compared to parents of children without ADHD (Wymbbs et al, 2008). A participant in Leitch et al's (2019: 6) study succinctly, albeit pessimistically, stated "relationships don't survive". The idea that having a child with ADHD creates conflict within intermarital relationships represents one of the many 'battles' that parents of children with ADHD must fight.

### 3.4. Battles

The experience of 'battles' features heavily within the ADHD literature (Harborne, Wolpert and Clare, 2004; Lundin, 2020), as parents describe a need to constantly ensure their children are appropriately supported. Saulsberry et al (2017: 4) explored the strategies that African American parents utilised for managing ADHD, finding that parents were required to be their child's advocate, "standing up" and pushing back against the system. Comparably, parental 'Fights' and 'The System' represent two of the seven primary findings within this thesis and are explored at length in Chapter 7 [The System and the Fight: Plots 3 & 4]. ADHD literature presents clashes with teachers as one of the parental battlegrounds, as battles are fought over the validity ADHD diagnosis, the level of classroom support given to the child, and the expectation that parents come to school to remove their child from the classroom (Harborne, Wolpert, & Clare, 2004). This finding is echoed by Honkasilta et al (2014), who found that mothers need to fight for the child's wellbeing at school, and by Peters and Jackson (2009), who portray a lack of mother support from partners and school. Parents describe the degrading and offensive experience of being blamed by teachers for their children's ADHD behaviour (Moen, Hall-Lord, & Hedelin, 2014), as behaviour is seen as evidence of familial deviance (Gwernan-Jones et al, 2015) and not medical symptomology (Malacrida, 2001). Gwernan-Jones et al's (2015) systematic review also indicated that

parent-teacher communication is typically problem focussed, with limited communication of positive child behaviour and teachers 'giving advice' in an unequal discussion. Parents describe teachers as "critics" who discount parental knowledge and expertise (Gwernan-Jones et al, 2015: 290). A further challenge which exacerbates conflict within school-based interactions occurs when parental conceptualisations of ADHD differ from that of teachers. Due to the multitude of models and understanding of ADHD aetiology, conflict arises when schools and teaching staff remain ambivalent to the diagnosis of ADHD (Carpenter & Austin, 2008), or when they hold a deficit driven model of ADHD which discounts the child's strengths (Gwernan-Jones et al, 2015). Parents are often required to utilise professional medical advice and opinion in their battles with teachers, drawing upon ADHD "truths" as the ultimate act of resistance (Malacrida, 2001) in a battle for 'superior knowledge' claims (Davies, 2014). These "truths" often include biomedical conceptualisations of ADHD, with reference made to brain development and chemical imbalance based on books and articles on ADHD. Some may query the necessity for parents to fight so vehemently for their children at school, however, O'Regan (2009) highlights that 39% of all UK children with ADHD have experienced some form of fixed term exclusion, and of those students, 11% have been excluded permanently. The increased rate of educational exclusion and expulsion for ADHD children presents a significant concern for parents, especially given that the diagnosis of ADHD may become a "justifiable reason to exclude in and of itself" (Rose, 2010: 20). Outside of the school environment, parental battles continue to rage.

Parents engage in 'intense battles' to obtain diagnosis (Lundin, 2020). Rowland's (2017: 175) PhD project presented the theme of "seeking help, the journey of pleading, providing and compliance" as an example of the continued battles that parents face with medical professionals. Parents in Rowland's work felt a need to prove to medical professionals that something was 'wrong', jumping through hoops and tests to rule out non-ADHD explanations of their children's difficulties. The requirement of parents to "convince" medical professionals of their children's ADHD is well documented (Harborne, Wolpert, & Clare, 2004), as difficulties are often attributed to a perceived failure in "parenting ability" if left uncontested (Carr-Fanning & McGuckin, 2018: 206). Parents describe a fight to have their concerns legitimised, even when these concerns have been present from an "early age" (Carr-Fanning & McGuckin, 2018: 206). The "agonising and prolonged experiences" of "structural hostilities" within institutions such as healthcare are argued by Thomas (2020: 454) as indicative of the typical treatment of parents of children with disabilities. Young et al's (2021) ADHD consensus statement declares the cultural and structural barriers of healthcare as instrumental in the negative experience of ADHD. The parental experience of ADHD assessment will be explored further later in this Chapter [3.7].

The final battleground to be discussed is within the family unit. Although parental conflict with romantic partners has already been discussed, having a child with ADHD may also cause difficulties in relationships with non-ADHD children and extended family. For multiple child households, siblings of a child with ADHD report that the non-ADHD child's needs are more likely to be ignored as the ADHD child's increased supportive needs are given "more attention" (King, Alexander & Seabi, 2016: 915). Although non-ADHD siblings experience an unequal amount of caregiver attention, it is worth bearing in mind that mother-child relationships with the child with ADHD are often more impaired than those with non-ADHD children (Lifford, Harold & Thapar, 2009). Parents are also required to become peacekeepers between inter-sibling conflict, as increased sibling rivalry and family conflict have been linked with childhood ADHD (Mikami & Pfiffner, 2008). Within a large UK study, reduced perceived happiness, sleep, and quality of life were present for both the child with ADHD and their siblings (Peasgood et al, 2016), an outcome which would naturally impact on parental experience. This 'war at home' (Leitch et al, 2019) culminates in there being no safe refuge from inter-family conflict for parents of children with ADHD. However, Laugesen and Groenkjae's (2015: 231) systematic literature review found that it was primary mothers who were advocates for their children within the battlefield of the system and family. A final point of note is that evidence suggests some parents faced significantly higher parental burden during the Covid pandemic lockdown (Patkar, 2022), increasing the impact of the 'war at home'.

Upon review of the wider literature, the parental experience of ADHD is invariably associated with conflict, strife, and battle. Parental narratives often involve "fighting talk" (Davis, 2018: 126), as they describe a constant need to fight for their children's needs to be met, fight for their children's ADHD to be recognised and legitimised, and fight against the impact of ADHD's symptoms.

### 3.5. Stigma, Blame, and Shame.

Many parents of ADHD children, both diagnosed and undiagnosed, experience stigma related to the ADHD behaviours additional to the diagnosis itself. Since Goffman's (1963) seminal work defining stigma as the 'disqualification from full social acceptance', the concept has undergone "explosive growth and theorising" (Hinshaw, 2009, 25) as a "constantly changing" process (Parker & Aggleton, 2003: 14). In popular mental health discourse, the concept of stigma has been simplified to encapsulate the "negative associations, experience,

and language” associated with a condition or diagnosis (Heads Together, 2021). However, this lay definition has been argued to prioritise face-to-face interaction and ignore macro-level social and political attitudes (Tyler & Slater, 2018). Nonetheless, the “destructive effect of being socially stigmatised” and the frequency of its appearance within the parental ADHD literature make it an important topic of discussion (Tyler & Slater, 2018: 729).

One of the main channels through which parents experience ADHD associated stigma is from schools. School related ADHD stigma is an international phenomenon, with similar negative experiences occurring in varied cultural environs. These areas include UK Mothers (Watson, 2011), Irish mothers (Carr-Fanning & McGuckin, 2018), low-income African American Parents (DosReis et al 2010), parents living in Hong Kong (Ho, Chien., & Wang, 2011) and mothers in New South Wales Australia (Peters & Jackson, 2008). Parents in the above studies refer to discrimination by schools due to their child’s ADHD related behaviours as well as the diagnostic label. Parents have attributed stigma and discrimination directed towards themselves as being linked to poor societal understanding of ADHD as many teachers hold outdated conceptualisations of the diagnosis (McIntyre & Hennessy, 2012). Parents may feel that their child, and they themselves, are pigeon-holed into misguided caricatures of what ADHD is, often influenced by inaccurate media representations of the condition (McIntyre & Hennessy, 2012). In practical terms, parents lose vital sources of support, such as being able to attend the local creche and early years settings, due to complaints from other parents about their child’s behaviour and diagnosis (McIntyre & Henessey, 2012). Moen et al (2014) concur, as parents in their study experienced limited understanding and acceptance from relatives and social networks regarding ADHD, although this was mitigated against when others had children with additional needs. Finally, Norvittis et al (2002) found that mothers of children diagnosed with ADHD believe that parents without ADHD children have greater negative views on ADHD.

Within lay discourse, the validity of ADHD diagnosis is often questioned as some declaring it to be an excuse for poor parenting (McIntyre & Hennessy, 2012). Within the UK, mothers state that their son’s ADHD related difficulties are often perceived as a direct result of their parenting ability (Harborne, Wolpert, & Clare, 2004). dosReis et al’s study (2010) 44% of participants were concerned about how society would label their child following ADHD diagnosis, with many stating that the label was seen in society as synonymous with problematic children and poor parenting. The internalisation of stigma and negative judgements of parenting ability have been found to be a primary contributor to parental feelings of shame and embarrassment (dosReis et al, 2012; Mikami et al, 2015). Mikami et al’s (2015) project into the impact of affiliate stigma on parent-child interactions found that when parents internalise a greater degree of affiliate stigma, there is a negative impact on

parent-child interactions and their child's social functioning. This is an important finding, as it shows that the way in which parents make sense of their experience, and the narrative that they utilise to understand ADHD, has real world implications on the impact of stigma and discrimination.

A further area of potential stigmatisation related to ADHD and parents is regarding parental decision making around medicating children with stimulant medication (DosReis et al, 2010). Parents must battle against historic negative media representations of ADHD medication, as well as against family members whose views these representations influence (Jackson & Peters, 2008). This process of 'mother blaming' has been found to be particularly prevalent from mothers-in-law (Harborne, Wolpert & Clare, 2004). With fears of medication making their children 'zombielike' (Lu et al, 2022) and 'drugged' (DosReis et al, 2010), there are very real perceived consequences regarding parental medication choices. Although there is a growing body of evidence regarding positive parental experiences discussed in Chapter 9.1.1 [Positive Narratives Regarding Medication], evidence suggests that parents experience significant apprehension that side effects such as appetite suppression (Bull and Whelan, 2006), weight loss (Hansen & Hansen, 2006), and sleep disturbance (Ahmed et al, 2013) will be used as evidence for further stigmatisation. It noteworthy that, although parents often point towards negative media representations of medication, many contemporary UK newspaper representations of ADHD have been found to focus on biological models of ADHD and encouragement of drug treatment (Horton-Salway, 2011). However, this does not discount the significant amount of conflicting information and ADHD related stereotypes present throughout wider internet and televised media in the UK (Horton-Salway & Davis, 2018). Although parents often attempt many other management options prior to medication use, many utilise stimulant medication due to its proven effectiveness at improving school-based performance and concentration (Cocoran et al, 2017b; Faraone et al, 2021). Parents of children with ADHD, like all parents of children taking medication, must make an informed decision by balancing the risks and benefits of a powerful pharmacological treatment. However, unlike many other medication choices, the decision-making process for commencing stimulant medication treatment in children is subsumed with fears of stigmatisation, discrimination, and years of fearmongering representations. Even when a decision has been carefully considered and researched by parents, many find it challenged by "well-meaning acquaintances" (Cronin, 2004: 86) or are shamed by others (Ghosh et al, 2016). Chapter 9.1.3 [Framing ADHD Medication: ADHD and Physical Illness] will present a novel finding suggesting that parents wish to reimagine and recontextualise stimulant medication as akin to medication for physical illnesses to minimise stigmatising experiences.

When attempting to mitigate and respond to the experience of stigmatisation, parents utilise strategies such as withdrawing from social situations, hiding the diagnosis, or by becoming ‘experts’ in ADHD to explain and challenge uninformed beliefs (McIntyre & Hennessy, 2012; Gwernan-Jones et al, 2015; Davies, 2014). Some mothers becoming the ‘final arbiters’ of ADHD, challenging the public and professionals following intensive ADHD self-education (Clarke & Lang, 2012). However, although some parents may be bolstered by the challenge that stigmatisation presents, many parents experience the detrimental social impact. In stark realisation of this concept, social withdrawal from significant others and withdrawal of their child from peers was present within 40% of participants in dosReis et al’s study (2010). As the experience of stigma towards ADHD can impact treatment adherence, treatment efficacy, parental wellbeing, and the wellbeing of the child, it is an area of significant importance in understanding the parental experience of having a child with ADHD (Mueller et al, 2012). Undeniably, the parental experience of stigma plays a significant role in understanding the diagnostic journey.

### 3.6. The Assessment Process:

The following section will review literature regarding parental experience of the lengthy and “arduous” process of assessment and diagnosis (Mcintyre and Hennessy, 2012: 70). It will discuss why pursuing and receipt of ADHD diagnosis is often felt by parents as necessary, followed by an exploration of the experience of parents throughout the assessment process.

#### 3.6.1. Why is a Diagnosis Needed?

As discussed, many parents experience a profound sense of guilt and shame regarding the ADHD related behaviours of their child. ADHD diagnosis is often perceived as a beneficial tool in accessing specific support (Klasen, 2000), but also a reprieve from intense feelings of guilt and shame as the label validates parental experience (Singh, 2005; Davies; 2014; Carr-Fanning & McGuckin, 2018; Ringer et al, 2020; Rasmussen et al, 2021). ADHD diagnosis is seen as “essential” (Carr-Fanning & McGuckin, 2018: 207) to supporting the child and empowering parents, likely due to its ability to explain the child’s behaviour (Halleröd et al, 2015) and grant greater awareness of manageability and meaningfulness (Fleischmann & Fleischmann, 2012). For UK parents, ADHD diagnosis has been found to reduce parental

self-blame (Brunton et al, 2014) by validating parental experience and indicating that the difficulties they have been experiencing are typical and expected given their child's medical needs. The framing of ADHD as a 'biological problem' with hereditary and neurological roots has been argued to play a role in the reduction of parental blame and shame (Ghosh et al, 2016), as parental perception of their children's difficulties is often in line with DSM-V (APA, 2015) guidance (Wong et al, 2018). This is unlike other psychiatric diagnoses, which are typically experienced as distressing to parents and "undermining to one's individual identity", (Perkins et al, 2018: 13) perhaps due to the benefits of brain-based discourses discussed in Chapter 2.3 [The Biomedical Construction of ADHD]. Post-diagnosis, mothers have been shown to recognise their son's behaviour as no longer anyone's fault, but a symptom of a recognisable medical condition (Singh, 2005). However, this benefit is not always shared by fathers, who are more inclined to perceive their child's ADHD related behaviours as a symbol of youthful masculinity (Singh, 2003). Due to ADHD's potential heritability, some parents find diagnosis allows them to better understand other members of the family, or begin seeking diagnosis personally (Ghosh et al, 2016). Although not a complete balm for blame, for many ADHD diagnosis gives some psychological respite (Harborne, Wolpert & Clare, 2004), allowing parents to begin a targeted information and knowledge gathering campaign to support their children (Pahlavanzadeh, Mousavi & Maghsoudi, 2018). The argument that medical diagnosis delivers meaning, allows one to negotiate illness experience (Bury, 1991), and alleviate the experience of blame (Jutel, 2009) will be explored further within Chapter 4 [Illness Narratives]. Some mothers of children with ADHD find it difficult to identify with typical sociological expectations and experiences of mothering (Bennett, 2007). Therefore, diagnosis can offer a shared sense of belonging with others alongside a medical understanding of their non-typical parental experience. Interestingly, the pursuit of diagnosis appears culturally and socially influenced, as UK mothers are more inclined to push for medicalisation and diagnosis when compared to Canadian counterparts, who often resist this process; perhaps reflecting differences in ADHD's medicalisation between the countries (Malacrida, 2004).

Diagnosis also increases accessibility for additional educational support for children as ADHD is specifically mentioned within UK government Special Educational Needs and Disabilities (SEND) guidance (GOV.UK, 2018). The labelling of a child as having SEND allows parents and schools to seek additional educational provision to ensure that the child's education is supported, commonly known as Special Education Needs [SEN] support. For children with ADHD, this support may include a specialised learning programme, additional teaching assistant support, smaller group working, and additional physical and emotional support (GOV.UK, 2018). When the impact of ADHD on education is significant, parents of

children with SEND may apply for an Educational, Health and Care Plan (EHCP) which identifies the health, social, and educational needs of a child, outlining support and granting a personal monetary budget for the child (Children and Families Act, 2014). Although rarer, EHCP's are generally sought when a child continues to fail to achieve in education even though other SEN support has been utilised by the school. An EHCP makes the agreed upon educational provision of the child a legal requirement, reducing the potential variability of SEN support in different areas (Children and Families Act, 2014). Although this additional provision is available, many parents of ADHD children find that access to appropriate post-diagnostic educational support for their children is challenging and limited (Sikirica et al, 2015). If the impairment experienced by the child requires support "much more than looking after a child without a disability" (GOV.UK, 2020), then additional governmental funding via Disability Living Allowance (DLA) can be applied for. In practical terms, this equates to between £24.45 and £156.90 a week, depending on the level of impairment and additional help that the child needs. This income can be invaluable, given that parents reduce their working hours or leave work altogether to fulfil the significant supervision requirements of their child (McIntyre & Hennessy, 2012). Evidence suggests that up to 23% of mothers and 18% of fathers of ADHD children are not currently working, in stark contrast to the population average of 3.7% (Rasmussen et al, 2021). Steyn et al's (2002) survey study of ADHD and DLA found that 19 of 32 parents were in receipt of DLA and found the money useful and supportive. Spending of this funding varied, allowing parents to finance specialist transport, outdoor trips, replace damaged clothes and furniture, and high-cost material rewards for behavioural interventions and improving their child's self-esteem. Many parents declared a need to "tire their children out" and "keep them occupied" by engaging in high levels of physical exercise such as swimming, a requirement seen as an additional cost to having an ADHD child (Steyn et al, 2002: 525). However, under-application for DLA is common, with many parents being unaware of eligibility until informed by a clinician or refusing to apply to avoid potential stigma. Media narratives of 'unscrupulous' parents pursuing assessment of ADHD for monetary gains continue to be a factor in the parental experience of the diagnostic journey (Goldberg, 2011).

Finally, ADHD diagnosis opens opportunities for medical intervention and treatment utilisation, typically in the form of stimulant medication (NICE, 2019). Discussed previously [see Ch.2.6], stimulant medication continues to be an area of considerable study (Kazda et al, 2021). There is significant evidence highlighting positive outcomes of pharmacological treatment for ADHD, including: Improved academic performance across the lifespan (Scheffler et al, 2009; Prasad et al, 2013; Coghill et al, 2014; Wang, Chen & Huang, 2015; Keilow, Holm & Fallesen, 2018), reduced injuries (Dalsgaard et al, 2015) and hospital

admissions (Dalsgaard, Nielsen & Simonsen, 2014), a reduction in criminal behaviour (Dalsgaard, Nielsen & Simonsen, 2014) and improved quality of life (Coghill, 2010; Coghill et al, 2017). Although there is evidence of harmful outcomes such as cardiovascular issues (Dalsgaard et al, 2014; Shin et al, 2016), reduced growth (Swanson et al, 2017) and weight loss (Faraone et al, 2008), stimulant medication remains the preferred treatment for individuals with moderate to severe impairment (NICE, 2018). Although considered less effective than medication treatments (Faraone et al, 2021), non-medication treatments such as behavioural modification, parental psychoeducation, and other psychological therapies also become available to parents following diagnosis. Given the well documented devastating repercussions across the lifespan linked to untreated ADHD such as poorer relationships and low self-esteem (Ginsberg et al, 2014), increased risk of substance (Lee et al, 2011) and alcohol abuse (Huntley et al, 2012), financial difficulty (Ginsberg et al, 2014), higher criminality (Young et al, 2014), increased mortality (Barkley, 2015), and increased comorbidity (Hamed, Kauer, & Stevens, 2015) the pursuit of a diagnosis and subsequent treatment becomes a matter of great consequence for parents on the diagnostic journey (Hamed, Kauer, & Stevens, 2015; Nicholson, 2018).

### 3.6.2. The Experience Of Assessment

ADHD assessment is often a laborious and lengthy process, where six month waiting lists can be considered “lucky” examples of “good fortune” (McIntyre & Hennessy, 2012: 75). The “clear postcode lottery” (ADHD Foundation, 2017: 8) evidenced by variable waiting times across the UK demonstrates how some parents face greater barriers to assessment than others. The “Lifetime Saved or a Lifetime Lost Report” (ADHD Foundation, 2017) found that 38% of parents of children eventually diagnosed with ADHD visited a GP on three or more occasions prior to referral in a process described as a “wait to fail” approach (Carr-Fanning & McGuckin, 2018: 207). Although NICE Guidance [1.2.7] (2019) recommends a period of “watchful waiting” to ensure moderate impairment, evidence suggests that parents postpone requests for medical intervention until the problems associated with ADHD are already significant (Moen, Hall-Lord, & Hedelin, 2014). The interaction between prolonged waiting lists, primary care practitioner refusal to refer to specialist services, and parental delays in help-seeking until problems are already impactful, leads to an experience of assessment in which parents are forced to watch their children fail in educational and social environments whilst waiting for assessment to begin (Carr-Fanning & McGuckin, 2018; Thevathasan et al, 2022). One potentially concerning reason for this failure by GP’s to appropriately refer is that

22% of parents state their GP doubted whether ADHD was a “real” condition (ADHD Foundation, 2017). Rowland’s (2016: 183) doctoral project evidenced a parental need to jump through “hoops and hurdles” such as behaviour checklists, parental training courses, and collecting of educational information prior to and throughout assessment. Parents describe a need to ‘justify’ their concerns to professionals throughout the assessment, proving that their worries are legitimate examples of genuine difficulties and not parental failure (Rowland, 2016).

Long waiting times for UK ADHD assessments continue to be cause for concern. The European Caregiver Perspective on Paediatric ADHD [CAPPA] study revealed that the average wait time from first specialist appointment to diagnosis was highest in the UK (Fridman et al, 2017). The mean time from first doctor visit to formal diagnosis of ADHD was 18.3 months within the UK, an increase of more than 10 months when compared to France (7.2 months), Germany (7.4 months) and Italy (3 months) (Fridman et al, 2017). Parents struggling with long waiting lists refer to a lack of co-ordination between services such as school, occupational therapy, mental health services and primary care as potential causes (Carr-Fanning & McGuckin, 2018). Given that the most cited reason for seeking assessment is that parents are “no longer coping” (Mandiaki et al, 2006: 189), longer waiting times increase parental distress alongside a higher likelihood of additional psychological, emotional, and familial problems (Thevathasan et al, 2022).

Once assessment begins parental experience remains inconsistent, with reports of powerlessness and distress being common due to mental health professionals failing to see parents as “humans with voices” or refusing to work “with them” (Carr-Fanning & McGuckin, 2018: 209). These findings have consistently recurred, with parents feeling dismissed by professionals during assessment and having their concerns rejected (Dosreis et al, 2010; Ho, Chien, & Wang’s, 2011; Laugesen et al, 2017). Parental experience of assessment is not exclusively negative, with some finding the process ‘speedy and effective’ once it had begun (Laugesen et al, 2017) and two of ten participants finding professionals to be helpful and supportive throughout the diagnostic process (Harborne, Wolpert, & Clare, 2004). In conclusion, the parental experience of ADHD assessment appears fraught with inconsistency, stress, and difficulty. Parents delay the journey out of fears of stigmatisation and a desire to avoid pathologizing their children’s atypical behaviour (Carr-Fanning & McGuckin, 2018), a process which ultimately increases the impact of prolonged waiting times and failures by primary care practitioners to appropriately refer to specialist services.

### 3.7. Mothers and ADHD

Thus far, discussion has non-discriminately explored the collective parental experience of ADHD. However, evidence suggests significant differences in experiences between mothers (the primary participants in research studies) and fathers (who are largely absent from the literature) (Cocoran et al, 2017a). Although many of the sampling strategies in the papers discussed thus far were open to both parents, the vast majority of participants are mothers (Cocoran et al, 2017a). This is a well-established phenomenon within the ADHD parental literature, as mothers often fulfil the role of the primary caregiver responsible for interactions with medical professionals and research engagement (Barkley, 2015), whereas fathers are largely absent (Brunton et al, 2014). A likely reason is due to the nature of gendered caregiving, where mothers are expected to have the primary responsibility of the child (Hays, 1996), especially if the child is disabled (Ryan & Runswick-Cole, 2008). In a concept explored at length in Chapter 8.1.1 [The Good, Heroic, or Valiant Mother], the societal expectation of the 'perfect child' and the 'good' mother' (Caplan, 1989; Malacrida, 2001: 145) positions mothers as responsible for the behaviour of their children (Blum, 2007). As mothers are typically blamed for their children's perceived 'failings' academically, socially, or otherwise (Blum, 2007), a hidden disability such as ADHD allows mothers to be more readily demonised due to a lack of visible reasoning for the child's difficulties. Western notions of "bad children equalling bad mothers" (Bennet, 2007: 97) allows society to simplistically position ADHD related symptoms as mothering failure, ignoring the nuanced complexity of parenting neurodiverse children. The theme of stigma, blame and shame previously discussed (Cocoran et al, 2017a) is appropriate when considering mothers, who experience blame by schools (Singh, 2004), GP's (ADHD Foundation, 2017) and family members (Harborne, Wolpert, & Clare, 2004). The existential and practical challenges (Bennet, 2007) of being a mother on the ADHD diagnostic journey forms the basis of Chapter 8 [The Mother], as many difficulties faced by mothers are not in relation to ADHD symptomology, but societally established inequalities in gendered caregiving (Runswick-Cole & Ryan, 2019) exacerbated by pursuing ADHD diagnosis.

To ameliorate the damaging impact of mother blame, mothers of children with ADHD often incorporate a labour-filled demanding mothering style, "individuated, rationally motivated and intense" (Clarke and Lang, 2012: 410). The process of intensive mothering often incorporates medicalized language and understandings of ADHD as a "cultural validation of expert guidance over the minutiae of child rearing" (Lee, 2008: 142). For the ADHD mother, where the commonly accepted metrics for success and 'good mothering' are often impacted

by the symptoms of ADHD, the utilisation of expert guidance becomes a balm for negative backlash and criticism from others (Pedersen, 2016). The ability to deploy research stating the expected educational impact of ADHD becomes an effective tool for mothers to defend their parental position and explain their children's difficulties (Brock, 2017). Mothers become the arbiters and negotiators of what ADHD means for their children (Clarke & Lang, 2012), using medical language to avoid the "difficulty giving a convincing explanation of their child's behaviour with any authority" (Brunton et al, 2014: 249). Unfortunately, even with the employment of 'expert' knowledge, mothers experience a 'societal silencing' when interacting in power structures such as the medical and educational arenas (Gwernan-Jones et al, 2015).

Where mothers of children with ADHD are often at the forefront of the literature, taking the lion's share of the caregiving responsibilities and attending most healthcare appointments, knowledge of fathers' experience is limited (Brunton et al, 2014). Not only underrepresented within ADHD academic literature, fathers are often absent throughout the entire diagnostic process (Singh, 2003).

### 3.8. Fathers and ADHD

As discussed, the experience of mothers dominates general parental research (Blum 2007; Davies, 2018) as well as ADHD focussed research (Davis, 2014; Fabiano & Caserta, 2018). Although some academics have specifically targeted fathers to combat this underrepresentation (Singh, 2003; Osvold et al, 2019), exploration of the experiences of fathers continues to be limited (Nicolia, Fabiano, & Gordon, 2020). The partial evidence we have suggests that fathers often discount the requirement of medical intervention for their son's ADHD related behaviours, citing similarities between their own childhood experience and their son's as "masculinity or boyishness" (Singh, 2003: 312). Singh (2003) argues that fathers who conceptualise their children's behaviour in medicalised terms may be required to re-evaluate their own history and identity, opting instead to deny potential ADHD. Fathers have also been found to be more demanding and power assertive with their ADHD children when compared to mothers (Johnston, 1996). When children are diagnosed and treated with medication, Singh (2003: 313) positions fathers within one of two broad camps: "reluctant believers" (fathers who feel generally positive of medical treatment) and "tolerant nonbelievers" (fathers who did not believe that the drug treatment or diagnosis was necessary but were tolerant of both in a non-interfering way). Since Singh's seminal work,

fathers have also been found to be largely absent from post-diagnostic behavioural parent training programs, though higher levels of fatherhood education is positively correlated with increased involvement (Nicolia, Fabiano & Gordon, 2020). It is not known whether an increase in a father's education level increases the likelihood of ADHD being framed within medicalised terms or whether there is some other mechanism at play for improving attendance. There is some evidence that incorporating an additional sport related element to ADHD treatment programs, such as father-son football practice, improved father's involvement with ADHD treatment (Mental Health Weekly Digest, 2007: Chang et al, 2013). Given fathers are less likely to be involved in the day-to-day care of their child (Gerdes et al, 2007), it also seems likely that fathers are less likely to be involved in the aspects of caregiving that places additional demands and stress on the child such as preparing for school or completing homework (Fabiano & Caserta, 2018). Fabiano and Caserta (2018) argue that this may answer why fathers often rate ADHD related behaviours lower on ADHD rating scales and why fathers may conceptualise ADHD as less disabling, as they are less likely to witness the daily struggles associated with routine tasks. Overall, the role and opinions of fathers are noticeably different to that of mothers and must be considered when exploring the parental experience of the ADHD diagnostic journey.

### 3.9. The Positives of Parenting and ADHD

Although literature on the parental experience of ADHD revolves around the challenges, difficulties and negative impact, there are also documented positives of parenting a child with ADHD. ADHD may be positively appraised by some parents, who see "higher levels of energy, creativity, agreeableness, empathy, willingness to assist others, and hyperfocus" as great benefits (Mahdi et al, 2017: 1219). Additionally, adults with ADHD describe positives such as "cognitive dynamism, courage, energy, humanity, resilience, and transcendence" (Sedgewick, Merwood, & Asherson, 2019: 243). It is reasonable assume that these adult experienced positives may also be experienced during childhood. McIntyre and Hennessy (2012) concur, as all parents within their study communicated positives regarding ADHD and their children, giving examples such as 'kind, caring, funny, individual, and having a zest for life despite the difficulties faced'. Ghosh et al (2016) found that parents would frequently describe their child with ADHD as 'fun, interesting or intellectually stimulating', bolstering the argument that having a child with ADHD can be both challenging and deeply fulfilling. For some parents, the associated challenges of being a parent of an ADHD child presents positive opportunities for personal growth (Brinkman et al, 2009), as the 'journey of

struggling' allows them to develop a stronger sense of parental competence and mental maturity in the face of difficulty. Parenting a child with ADHD may be an "emotional rollercoaster between hope and hopelessness" but, "it's not all bad" (Laugesen & Groenkjae, 2015: 170).

# 4. Literature Review Part 2: Illness Narrative

## 4.1. Introduction

The previous chapter reviewed literature regarding parents and ADHD, demonstrating how the experience is wrought with challenge and difficulty (Cocoran et al, 2017a; 2017b), due to emotionally onerous caregiving expectations and experiences which negatively impact parental stress, anxiety, and psychological wellbeing (Chuang & Theule, 2016; Durukan et al, 2017; Yan et al, 2018). The physically draining demands of supporting a child with ADHD often leads to physical and mental exhaustion (McIntyre & Hennessey, 2012) in a daily process of living described as a continuous series of 'battles' with schools, families, medical practitioners, and the public (Wolpert & Clare, 2004; Cocoran et al, 2017a). Stigmatising opinions towards ADHD were also evidenced, including 'mother-blaming' and a desperate fight to have children's difficulties validated and legitimised (Harborne, Wolpert & Clare, 2004; Watson, 2011; Davis, 2014). Seeking diagnosis is often seen by parents as "essential" in pursuing appropriate support for their child (Carr-Fanning & McGuckin, 2018: 207) and a potential balm for reducing experiences of guilt and shame (Klasen, 2000). However, the process of diagnosis is challenging, with disempowering and dismissive professionals (Laugesen et al, 2017), long waiting lists (ADHD Foundation, 2017), and 'wait to fail' approaches creating a maelstrom of stress and anxiety.

This chapter deviates from ADHD specific literature and reviews the wider sociological literature of illness work. As this project utilises a medical sociological paradigm informed by previous work within the field of illness narratives and biographical disruption (Bury, 1982; Williams, 1984, Singer, 2016; Rasmussen et al, 2020), this chapter discusses the development of these theories. Beginning with a discussion of illness work (Corbin & Strauss, 1985), the chapter critically evaluates the concepts of biographical disruption and reconstruction (Williams, 1984), chronic illness and meaning (Bury, 1982), the sociology of diagnosis (Jutel, 2009), and medicalisation (Conrad, 2006). Although primarily addressing work regarding physical chronic illness, the relevancy of these conceptual frameworks to the parental experience of ADHD diagnosis is justified. The chapter also explores recent sociological discussion regarding illness work and parents of autistic children (Singer, 2016;

Rasmussen et al, 2020), justifying the appropriateness of Rasmussen et al's (2020) parent-biographical spectrum model of biographical disruption and cohesion as an effective way to understand the parental experience of the ADHD diagnostic journey.

## 4.2. Illness Work

The concept of illness work, defined in Corbin & Strauss' seminal paper on the subject (1985), has been developed and applied to a variety of contexts since its conception. In its original form, illness work included the three main types of work that individuals faced when managing chronic illness at home: 'illness work' (work related directly to the illness such as diagnostic work and symptom management), 'everyday life work' (the typical roles and responsibilities of living everyday life such as cooking and cleaning), and 'biographical work' (developing and maintaining one's identity in the face of chronic illness) (Corbin & Strauss, 1988: 226). The following sections of this literature review explore the theoretical development of biographical illness work [Section 4.2] and the impact of medical experiences and diagnosis on one's personal identity and narrative [Section 4.3]. Given that parental identity is inextricably entangled in the biographies of one's children (Bray et al, 2014), parenting a child with a potentially disabling lifelong condition such as a neurodevelopmental disorder will be argued in section 4.2.1 to be equivalent or at least akin to a personal response to illness (Green et al, 2013; Singer, 2016; Rasmussen et al, 2020). This linking of parent-child biography forms the basis of the justification when linking non-parent related biographical illness theory to parents.

## 4.3. Biographical Illness Work

The impact of illness on individual narrative has a rich and complex history within sociological discussion (Parsons, 1951; Giddens, 1972; Bury, 1982; Charmaz, 1983; Corbin & Strauss, 1988; Frank, 1991; Williams, 2000). The biographical narrative has been argued to be the vehicle through which all experience is structured (Bruner, 1990) and the only way to describe "lived time" (Bruner, 1986: 12). The characterisation of a narrative typically involves the experiencing of a series of events and actions (Chronology) within environments (Scenes), in which a problem arises (Trouble) for the characters (People within the story), told through a series of literary devices conveying meaning within the story (Emplotment)

(Rushforth et al, 2021). Illness narratives are defined as narratives in which the 'trouble' experienced by characters is illness, and the associated problems or 'work' (Corbin & Strauss, 1988) in relation to that illness. Illness narratives are often reflexive accounts, influenced by cultural, interpersonal, and emotional factors, and delivered by subjective narrators who share stories not as objective chunks of data awaiting extraction, but as constructed accounts of experiences from storyteller to audience (Bruner, 1991). For some, illness shatters the innocence and expectations of what our life could be, altering the story of ourselves developed until that point (Frank, 1991). These alterations to our biographical narrative, brought on by illnesses which force one to reconsider the expectations of growing old, living pain free, getting a job, or contextualising personal identity, form the parameters of biographical 'work'.

It is first important to illuminate why sociologists interested in biographical work typically prioritise the experience of people with chronic illnesses (Bury, 1982; Williams 2000). Parson's (1951) seminal work on the 'sick-role' and illness outlined how sufferers of illness are socially exempt from fully contributing to society, granting permission to perform socially deviant behaviour under a series of four postulates. The first two postulates deem the sick person not responsible for assuming the sick role and consider them exempt from carrying out some or all normal social duties. The final postulates, however, determine that the sick role is only *temporary*, and that the sick person must try to get well by submitting to appropriate medical care (Parsons, 1951). Sufferers of chronic or prolonged illnesses are unable to fulfil these postulates, as the illness experience is not temporary, but continuous (Bury, 1982). Chronic illness can also bring into recognition the pain and suffering experienced in acute illness, alongside additional anxieties about future wellbeing and potential deterioration (Bury, 1982), creating a 'threat to life' which brings into consciousness aspects of being otherwise ignored (Frank, 1991). The chronically ill may also disrupt further rules of relationship and reciprocity, becoming increasingly dependent on others over time by not 'recovering' following medical intervention (Bury, 2001). The inability for sufferers of chronic conditions to fulfil the argued societal expectations required of 'sick' individuals provided fertile landscape for the development of new sociological theory in understanding the impact of chronic illness. Finally, Giddens's (1979: 123) statement that one can 'learn about day-to-day situations by analysing circumstances in which they are radically disturbed' and development of "critical situations" (the events that break down the assumed social fabric) became the backdrop from which the concept of biographical disruption developed (Bury, 1982).

Biographical disruption highlights the ways in which illness disrupts the narrative of ill individuals. For Bury (1982; 2001) disruption relates to the impact of illness on an individual's

social identity and moral status, the immediate cause and impact of the illness, and the core narrative of what sickness may mean to them on a deeper cultural level (Rushforth et al, 2021). Illness marks a “biographical shift” from a “normal trajectory of predictable chronological steps” to a “fundamentally abnormal and damaging one” (Bury, 1982: 171). Williams (1984) continued this theoretical work, developing the concept of ‘narrative reconstruction’ to explain how sufferers must reconstruct and reconstitute their narrative by repairing the damage on past- and present-self caused by illness. Narrative reconstruction also includes realignment of epistemic and ontological uncertainty experienced by sufferers of chronic illness, who ask not just ‘what is to come’, but ‘who or what they now are?’ (Williams, 2000). Both Williams and Bury explore how sufferers of chronic illness create meaning in their experience, developing explanations of the onset of their illness experience and interpretations of the discontinuity and disruption of their social lives. This ‘meaning making’ presents additional disruptive biographical work, as individuals spend considerable intellectual resources reconstructing their narrative to answer what illness ‘means’ to them. In the face of chronic illness, sufferers must develop answers to the following questions to attribute meaning to their experience:

- 1- What is the cause of my illness? What does it *mean* to have my illness from an objective biological perspective? (Williams, 1984)
- 2- How will the disruptive symptoms impact everyday experience? What will it *mean* in practical terms to live with illness? (Williams, 1984; Bury, 1991)
- 3- What will be the social significance of my illness? What will it *mean* in social terms? (Bury, 1991).

Answering these questions is a ‘risky process’ (Bury, 1991) as answers are likely to have a significant impact on the experience of the sufferer and consequent biographical impact. Furthermore, these questions present additional illness work since sufferers and others in their social environment may disagree on answers, creating a complex social situation in which the ill person risks disagreeing with those they rely on for illness related support. This leads some individuals to ‘test out the waters’ (Bury, 1991) by discussing an interesting news article which mentions their diagnosis, or by talking around the symptoms to develop an understanding of the listener’s position on the topic prior to self-disclosure. Therefore, the type of illness being experienced plays a significant role in this process, as people often have prior understandings and explanations of a condition, utilising biological and medical understandings (Bennett, 2007) or lay conceptualisations of the condition. This concept is explored further in section 4.3 [Diagnosis and Medicalisation].

It is important to note however, that although Bury (1982) and Williams (1984) demonstrated overwhelmingly disruptive experiences to chronic illness, other studies have described alternative responses in which biographical response was positively experienced (Faircloth et al, 2004; Ong et al, 2011). Williams's later argued that one should not overstate the "disruptiveness implied in the concept of biographical disruption" but see it as a "process of questioning about particular representations of ill health and experience" (Williams & Jones, 2017: 654), as both he and Bury examined the biographical response only in relation to rheumatoid arthritis. Since Bury (1982), additional forms of biographical illness work have emerged. For instance, it has been suggested that the experience of chronic illness can positively reinforce aspects of biography, as seen in the narratives of gay HIV-positive men actively involved in HIV political activism (Carricaburu and Peirret's, 1995). For some of these men, being HIV-positive was considered a form of 'biographical reinforcement' as positive HIV status reinforced their preestablished identities as homosexual men during the HIV/AIDS crisis. Faircloth et al (2004) also presented the concept of 'biographical flow', a process in which stroke sufferers integrated their illness as a part of on-going life. 'Biographical Flow' explains how the disruptive effect of illness is replaced by a flowingly constructed narrative in which the illness (in this case stroke) is accepted as a natural component of ageing (Faircloth et al, 2004). The following section will demonstrate how biographical illness work is a justified lens through which one can understand the parental response to childhood illness, reviewing contemporary concepts of parental biographical responses to illness (Rasmussen et al, 2020).

#### 4.3.1. Childhood Illness and Parental Biographical Disruption

Much of the sociological literature exploring biographical disruption focusses on the impact on personal narratives of unexpected, chronic, and deteriorating illnesses in otherwise healthy adults (Bury, 1982; Charmaz, 1983; Williams, 1984; Frank, 1991) with established "pre-illness identities" (Bray et al, 2014: 835). However, there is a growing body of discussion arguing that biographical illness work provides an effective means from which to understand parental experiences of childhood diagnosis and illness (Singh, 2016; Rasmussen et al, 2020). As parents are morally responsible for their children (Pejlert, 2001) and the parental experience is interlinked with that of the child (Ghosh et al, 2016), it is reasonable to contend that parental narratives are influenced by a child's experience. Furthermore, when childhood illness occurs and parents are required to take on additional, reduced, or new caregiving roles, this can be considered a disruptive experience (Giddens,

1979) or significant event in their own narrative (Harden, 2005). This experience can be significant and life altering, giving rise to additional concepts of parental biographical work.

Regarding the shattered biographies of parents following a son's suicide, Owens et al (2008) presented the experience as 'biographical disintegration', in which parental narratives are destroyed by a child's illness related behaviour. For carers of loved ones diagnosed with motor neurone disease, the "death sentence" diagnosis led to a form of 'biographical abruption', where parental narratives are put on pause (Locock, Ziebland & Dumelow, 2009: 1048). An alternative form of biographical disruption was experienced by parents of children undergoing surgery for a long-term condition, where some likened the additional independence gained by the child post-surgery as biographically disruptive as parental roles changed following increased child independence (Bray, Kirk & Callery, 2014). However, some parents within that study also presented a sense of 'biographical continuity', as they expected their current caregiving role to continue and saw surgery as an expected process when you have a child with a long-term illness. Within autism research, the parental experience following diagnosis has been framed as disruptive 'biographical work' (Singh, 2016: 1114), as some parents experienced 'devastation' upon hearing that the diagnosis was lifelong whilst others "challenged the medical perception of their children". A paper exploring parental biographical narratives following childhood autism diagnosis (Rasmussen et al, 2020), developed this concept even further. Given both autism and ADHD are classified as neurodevelopmental disorders often diagnosed in childhood, these developments are particularly relevant. Like ADHD, literature on ASD has shown that children are often misinterpreted as lazy and ill-mannered (Mogensen & Mason, 2015), leading to deep seated parental feelings of shame and guilt (Rasmussen et al, 2020). Rasmussen et al's (2020) biographical spectrum model, therefore, presents a framework from which to consider parental biographical response to childhood autism diagnosis. They present three core themes: "A Clash of feelings", "rejection of the need for biographical re-narrating", and "diagnosis as a means of gaining support". Some parents described feelings of grief and sadness that their child received a diagnosis of a chronic condition. The label disrupted their sense of self, whilst also giving clarification and understanding of their child's difficulties. This initial experience of narrative disruption (Bury, 1982) brought about by the diagnosis was followed by a period of re-evaluation and reconstruction of parental narratives akin to that presented by Williams (1984).

Inversely, parents who expected autism diagnosis found receiving the label both vindicating and beneficial to their pre-existing narrative. This positive experience of illness is presented as a form of 'biographical cohesion', as parents amalgamate diagnosis into the pre-established narrative of their child's difficulties, leading to quicker and less painful narrative

restructuring (Rasmussen et al, 2020). Interestingly, their second theme (Rejection of the need for biographical re-narrating) explored how some parents rejected both concepts of disruption and cohesion, opting to avoid re-narration by refusing to accept the diagnosis or by describing the label as “just a word”. This finding is of relevance to ADHD research, where fathers have been found to be more likely to disagree or discount diagnosis (Singh, 2004). The third and final theme explored by Rasmussen et al (2020) examines how autism diagnosis becomes a means of gaining support for the child. The necessity and benefits of gaining a diagnosis of ADHD has already been explored within this thesis [Section 3.6.1], though the similarities of experience between parents of children diagnosed with ASD and ADHD are striking; especially considering both sets of parents describe diagnosis as a means to access treatment (Carr-fanning & McGuckin, 2018) but also as a fight (Harborne, Wolpert & Clare, 2004; Rasmussen et al, 2020).

Rasmussen et al (2020) present a spectrum model of parental biographical disruption, where the extent of biographical re-narrating parents experience post-childhood diagnosis falls on a spectrum between biographical disruption and biographical cohesion. This spectrum model, and the interplay between disruption and cohesion, is vital in understanding the complexity of parental experience following childhood diagnosis. This study will utilise the model as an analytical tool to aid understanding of the experience of parents on the ADHD diagnostic journey. Given that timing, context, and circumstance may influence the likelihood of problematisation or normalisation of life altering events, it may be that parents oscillate across the model, sitting at different points on the parental-biographical spectrum depending on which part of the diagnostic journey they are on (Williams, 2000). The longitudinal aspect of this study allowed for development of this theoretical perspective, as Rasmussen et al (2020: 7) argue that “thicker” discussion will be gained through longitudinal enquiry focusing on the challenges within the family and societies instructional spheres.

#### 4.4. Diagnosis and Medicalisation

Thus far focus has been on the biographical response to illness and the associated biographical illness work (Corbin & Strauss, 1984). This section explores the sociology of diagnosis (Jutel, 2009), and the complexities and associated illness work presented by the diagnosing or labelling of illness. Through the experience of illness and consequent narrative reconstruction (Williams, 2000) uncertainty arises regarding the cause or potential impact illness can have (Bury, 1982). When attempting to alleviate these anxieties and reconstruct

what has been lost through illness symptoms, many search for an aetiological understanding of their experience, commonly in the form of medical diagnosis. Medicine has become culturally accepted as the societal structure capable of making significant statements on what can be classified as illness and what symptoms are acceptable. A visit to the GP and subsequent medical attention begins a process of justification, declaring the illness experience as 'abnormal' (Bury, 1982). For conditions such as ADHD, where referral to a specialist is required, the experience goes beyond the remit of general medicine and 'normal illness' (Bury, 1982). The required practical and conceptual efforts in confirming the illness experience as a diagnosable medical condition presents a further form of illness work (Strauss & Corbin, 1984), and has been depicted by Singh (2016) as the parental 'diagnostic quest'. This process is apparent across literature regarding ADHD and parents, as many are aware of something being 'wrong' with their child long before seeing medical professionals (Harborne, Wolpert & Clare, 2004; Ghosh et al, 2016; Rowlands, 2016). Parental life already disrupted by ADHD related symptoms, the search for understanding and meaning leads them to diagnostic assessment, where symptoms can be 'treated' with medication (Cocoran et al, 2017b). The additional legal requirements surrounding the controlled drug status of stimulant medication may even further legitimise the difficulties that parents and individuals diagnosed face, as even treatment is beyond 'normal' medication routines. Medical knowledge and attention can help to lessen the assault on selfhood associated with illness, whilst repairing the disruption left in its wake (Bury, 1991). However, medicalisation and diagnosis may only ameliorate some of the damage to the self, as societal stigma associated with a diagnostic label such as ADHD can be equally damaging (McIntyre & Hennessy, 2012).

Diagnoses provides a cultural expression of what society is prepared to accept as 'normal', and what should be considered abnormal and warranting treatment (Jutel, 2009). Diagnosis attempts to create order, organising illnesses into classifications, identifying treatment pathways, predicting outcomes, and enabling access to services in a way that gives the individual permission to be ill (Jutel, 2009). However, concerns have been raised against the concept of diagnosis. Although diagnosis allows medicine to direct resources and systematise health, it has been criticised as a tool used to control the treatment of individuals who do not necessarily fulfil the societal norm of the time (Conrad, 2007). Issues regarding diagnosis become salient when discussing ADHD, given the lack of a widely accepted aetiological cause (Faraone et al, 2021). Historically, King (1954: 195) declared disease and diagnosis as subject to modification following increases in knowledge, stating "what one epoch calls a disease is, to a later period, only a symptom". The framing diagnosis as being only relevant or appropriate to the specific technology and social values of the time

continues to be discussed, with Jutel (2009) describing medical diagnosis as a 'temporally situated phenomena'. Critics of diagnosis also point to its subjectivity, as Balint (1964) described the giving of a diagnosis as a process of negotiation where the clinician gives diagnostic 'options' for the patient to consider. However, the bounds and remit of this 'negotiation' are typically defined by the medical sphere, as patients may only propose potential illness or disease explanations of their altered experiences to be taken seriously (Jutel, 2009). Other critics of this supposed diagnostic collaboration include Foucault (1963), who declared that doctors must abstract the patient, ignoring their narrative in hunt for the truth'. However, counter to these claims there appears a growing trend indicating that the process of neurodevelopmental disorder diagnosis is becoming increasingly negotiable. Rasmussen et al (2020) found that parents undergoing autism assessment believed that their expertise and opinions as parents directly influenced the diagnostic decision. Davies (2014: 2018), Gwernan-Jones et al (2015) and Singh (2016) support this finding, as parents in their studies felt they played an integral role in the final decision of whether to diagnose. Interestingly, parents in Rasmussen et al's (2020) study who felt the process to be negotiable were also more inclined to question the trustworthiness of the diagnosis.

Nonetheless, diagnosis can be an empowering and beneficial tool, used to create a sense of collective identity for groups of people with a shared experience. Diagnostic classification allows groups of patients to self-identify as something larger than themselves, sharing experiences to reduce the isolation of illness, and the pain of challenging symptoms (Chiong, 2001). Medical diagnosis helps explain experience, reducing shame and giving individuals a socially accepted tool with which they can negotiate their experience and needs to the external world (Bury, 1991), allowing the individual to be 'treated' and not blamed (Jutel, 2009). For ADHD, parental experience of childhood diagnosis has been found to give a shame reducing (Ghosh et al, 2016), blame alleviating (Brunton et al, 2014) sense of collective identity (Singh, 2005).

#### 4.4.1. Medicalisation: An Argument Against Diagnosis.

Sociologists have historically directed significant concerns at current diagnostic models and the authority medicine holds over our social world. Although medicine's authoritative hold on our diagnostic ability has been reduced and 'whittled down' by increasing employment of nurse practitioners and other diagnostically responsible professionals, the issue remains that a very small number of professional groups have a significant amount of power to control what should be seen as deviant (Jutel, 2009). Diagnosis has been argued to be the

'foundation upon which the strength of a professional rests', where medical professionals perform the role of powerful 'custodians to the label of deviance' (Freidson, 1972). Many have argued that the medical sphere has overstepped its boundaries and attempts to utilise classification tools such as diagnosis to moralise and exercise social control, a concept historically defined as medicalisation (Freidson, 1972; Zola, 1972). Conrad's (2007: 5) redefining of medicalisation describes the process as 'seeing' in medical terms, that which would normally or previously have been considered a non-medical issue, or to "make something medical". Medicalisation is not an all-or-nothing concept, but a process towards which conditions become *more-* or *less-* medicalised over time (Conrad, 2009). The medicalisation of motherhood and child rearing encompasses a reduction in the distance from doctor and parent (Zola, 1968), as medical advice on feeding, childbirth, and child rearing has become normalised (Jutel, 2009). As an example, the symptomatic behaviour of children with ADHD is often declared proof of a mother's inability to appropriately care for the needs of the child, and not the manifestation of expected symptoms (Blum, 2007). The medicalisation of ADHD recontextualises 'deviant symptomatic behaviour' and perceived parenting 'failure' into medically explained phenomena.

Conrad (2006; 2009) is often considered one of the primary advocates for the claim that ADHD has become the victim of medicalisation. In his scathing paper on deviance and hyperkinesis (Conrad, 1975), he argues that the treatment for hyperkinesis (ADHD) existed long before the conceptualisation of the disorder, and that pharmaceutical companies were the pivotal driving force in the disorders' 'creation'. He claims these 'moral entrepreneurs' were financially incentivised to present impulsive and hyperactive behaviour as medical problems in need of treatment. Conrad does describe some benefits to the medicalisation of this behaviour, as children were less likely to be labelled as bad but instead were victims of a medical disorder of which they had limited control. Furthermore, their parents can find a minimisation of guilt due to the apparent organic nature of the difficulties. However, Conrad argues these benefits pale in comparison to the four core issues around the medicalisation of deviant behaviour: (1) The problem of expert control, (2) medical social control, (3) individualisation of overarching social problems and (4) the depoliticization of deviant behaviour (Conrad, 1975: 19-20). Issues around expert control relate to the removal of issues from the public domain once they are considered medical in nature. For ADHD, the 'problem' of ADHD has become medical, presenting greater challenges for critical perspectives such as the neurodiversity movement (Singer, 2016) to discuss whether ADHD 'symptoms' are potentially normal deviations of childhood. The opportunity for discussion on the matter has been stolen, according to Conrad, by medicine. Concerning point (2), Conrad argues that when a behaviour is not complementary to the dominant value system,

medicalisation allows for the suppressing of that behaviour through psychopharmacology, of which adverse side effects have previously been discussed (Faraone et al, 2021). Conrad argues that the medical assumption that any deviance from the norm should be subdued or removed is morally unjustified, a position supported by Ben-Yehuda (2015), who argues that deviance is a vital component of true social change, and by Goode (2015) who declares deviance a potentially positive force to challenge the status quo and exact meaningful change in society.

The individualisation of social problems is also of interest, as Conrad (1975) argues that increases in medicalisation leads to a 'victim blaming culture' where the individual is deemed to be the problem and not the society within which they reside. This criticism has become a primary tenet of the neurodiversity movement (Singer, 2006), and a position taken by many parents (Cocoran et al, 2017a) who query whether responsibility should lie with the curators of neuro-inclusive environments and not the ADHD child. Finally, point (4) relates to the depoliticization of deviant behaviour. Simply put, through the process of defining the hyperactive child as "hyperkinetic", we can ignore the meaning of the behaviour within a social system and are less likely to adapt said social system (Conrad, 1975: 20). A child with an ADHD diagnosis may exhibit inattention within the classroom, where point (3) contends that the issue is then likely to be seen as the problem of the child, point (4) argues that identifying that behaviour as related to the child's hyperkinetic disorder means the context will be ignored; we are less likely to query whether the teacher is ineffective, or the lesson is poorly written. In conclusion, regardless of the way in which one conceptualises medical diagnosis, parents on the ADHD diagnostic journey are on a path in pursuit of a medical explanation of their children's difficulties. The process of seeking diagnosis, alongside the conceptual work in considering the meaning of diagnosis, represents an important form of parental illness work which proves vital in understanding the parental experience of childhood illness (Singh, 2016).

This chapter has explored the concept of illness work and reviewed the literature of two sociological concepts: Biographical illness work and the sociology of diagnosis. The following chapter discusses the overall research framework, detailing both research methodology and research methods.

# 5. Research Framework

## 5.1. Introduction

Chapters 3 and 4 comprised two distinct literature reviews relevant to the parental diagnostic journey of ADHD. Chapter 3 reviewed the literature regarding parents and ADHD, evidencing the importance of diagnosis (Carr-Fanning & McGuckin, 2018) and the practical and emotional challenges faced by parents (Cocoran et al, 2017a). Chapter 4 discussed the sociological literature regarding illness narratives and illness work, suggesting Rasmussen et al's (2020) parent-biographical spectrum model of biographical disruption and cohesion as a useful tool in addressing the research questions.

This research framework chapter details the research methodology of this study, reflecting on the decision-making process and practical application of research methods. The chapter outlines the research process, giving a transparent account of methodological decision-making, and critically appraising the chosen research methods to give a transparent account of the research process. Section 5.2 begins with a review of the research questions, followed by an overview of the philosophical position of interpretivism utilised within this thesis. The inclusion of philosophical and methodological considerations allows for transparency in understanding how underlying philosophical assumptions may influence the project. Section 5.2 concludes with an analysis of the narrative approach to qualitative research.

Section 5.3 explores research methods, detailing the sampling, recruitment, transcription, and research ethics processes alongside a critical review of serial interviews as a method of data collection. Consideration is given regarding the impact of the UK Covid-19 pandemic and subsequent national lockdown, requiring a change from in-person to digital interviews. Influenced by Cutcliff and Goward's (2000) paper, section 5.4 presents a reflexive account of the researchers' experience as a mental health nurse, exploring the transferable skills and differences between mental health nurses and qualitative interviewers.

Sections 5.5 discusses data analysis, giving a transparent description of the steps and principles used to establish a 'roadmap' of the sociocultural narrative analysis approach utilised. The final sections of this chapter [5.6-5.9] contextualises the findings chapters, defining the use of the term narrative 'plot' and outlining the individual journeys of each parental participant.

## 5.2. Methodology

### 5.2.1. Introduction

The following section will detail the methodological underpinning of this research project, reviewing the research questions and discussing the philosophical position of interpretivism and its influence on the project. There will then be an exploration of the qualitative approach to research, with a more detailed discussion on the evolution, benefits, and criticisms of the narrative approach to qualitative research.

### 5.2.2. The Research Question

The difficulty for ADHD's existence to be confirmed as an objectively and quantifiably defined medical phenomena may pose 'challenges' to investigation (Carpenter-Song, 2009), especially for research utilising a positivist empirical paradigm arguing for a single objective reality (Rowlands, 2016). However, this quantifiable ambiguity presents a "ripe condition for inquiry" (Carpenter-Song, 2009: 61) for those wishing to develop understanding of the parental experience of ADHD and the oft nebulous parental conceptualisations of the diagnosis (Rowlands, 2016). When developing the research questions, it was necessary to ensure that the potential answers presented an original contribution to knowledge appropriate for a doctoral project. Although the corpus of ADHD literature is extensive, Chapter 2.3 [The Biomedical Paradigm of ADHD] demonstrated how much of this research prioritises understanding ADHD from an empirical biomedical perspective (Barkley, 2015), with limited exploration of the parental experience and few papers utilising a narrative approach (Lundin, 2020). Research exploring the qualitative experience of parents of children with ADHD often focuses on daily lived experience (Hallberg et al. 2009; Brunton et al, 2014; Rowlands, 2016; Mofokeng & Van Der Wath, 2017), or decisions regarding medication use (Charach et al, 2006; Hansen & Hansen, 2006; Brinkman et al, 2009). The experience of parents as they traverse the ADHD diagnostic journey, alongside the parental response to childhood diagnosis, provided a rich untitled landscape for inquiry which led to the following research questions:

- 1- What stories do parents tell regarding this journey?
- 2- What are the parental needs and experiences across the ADHD diagnostic journey?
- 3- Do these needs and experiences change across the journey and, if so, how?

#### 4- How do parents make sense of the ADHD diagnostic journey?

The development and choice of research questions make philosophical and epistemological assumptions which influence the design and conduct of the study, including approaches ensuring validity and rigour. The following two sections explore these philosophical assumptions, outlining the influence and interpretation of interpretivism on the project followed by a discussion of the narrative approach as an effective and appropriate theoretical base with which to answer the research questions.

### 5.2.3. Philosophical Position - Interpretivism

The outlining of the theoretical and philosophical lens through which research is being completed is vital in ensuring that the “frame of mind” (Josselson & Lieblich, 2003: 260) of the research is understood and the theoretical “language” is appropriate. To navigate the “dilemmas, challenges, complexities and puzzles” in the “swampy lowland” (Kim, 2016: 31) of qualitative research, Kim argues that researchers must outline their ‘macro level’ theory prior to exploring the micro level theory of research methods. The ‘macro’ level theory (Kim, 2016) utilised by this project is an interpretivist paradigm, within which one declares that experience and knowledge of the world is not objective but appraised through our own “subjective and cultural perspectives” (Yardley, 1997: 217). Unlike positivism, which argues for the objective nature of knowledge and the ability of the scientific method to understand this knowledge, interpretivism declares a lack of objective truth, citing that knowledge is created and interpreted by ourselves. Although all research must be ‘interpreted’ through the lens of human understanding, the interpretative paradigm focusses on the generated knowledge of meanings, often relative to time, context, culture, and the value base of the individual (Pizam and Mansfeld, 2009). This position lends itself to a qualitative research approach, where one can attempt to understand the lived experiences of others not obfuscated by requirements to fulfil quantified measures of statistical power. When exploring the lived experiences of parents of children on the ADHD diagnostic journey, it is impossible to objectively understand and explore those experiences in a truly meaningful way with statistics. Although one could rate and score the intensity of emotions and frequency of their being felt, quantitative research does not adequately capture the quality and meaning of these experiences and their impact on the individual’s life. Like Rowlands (2016) and Davies (2014), this project wishes to capture the subjective parental accounts of ADHD, opening a window of understanding into the lived experiences of others through the subjective use of stories and narratives. Interpretivism allows one to interpret the told stories of parents to

grant time-sensitive subjective truths and gain knowledge into the ethereal and unique nature of human experience.

#### 5.2.4. Narrative Approach

Narrative research approaches are increasingly prevalent within sociological research, in part due to the capacity to analyse the lived experiences of individuals through texts, storytelling, and narrative realities (Hyvärinen, 2016). The approach utilised within this thesis studies “narrative realities” (Hyvärinen, 2016: 38), arguing that individuals can construct and give meaning to their experiences through the medium of storytelling (Adama, Sundin & Baynes, 2016). The narrative approach combines the cultural characteristics of ethnography and the heuristic aspect of phenomenology (Adama, Sundin & Baynes, 2016) into a methodology where narratives have become edited versions of reality (Reissman, 1990). Narrative methodologies acknowledge that we as humans understand ourselves “inescapably in narrative (Taylor, 1989: 51), and that the telling of personal stories is a ‘universal’ (Bury, 2001) way to understand the moment to moment living out of our lives (Johnson, 1987). Stories form the basis of identity, granting pathways to understanding cultures (Plummer, 1994) and providing us with ‘objects’ which carry traces of human lives (Andrews, Squire & Tamboukou, 2013). Stories present us with psycho-socio-cultural resources with which to develop understanding into the lives and experiences of others (Phoenix, Smith & Sparkes, 2010). The narrative approach of this thesis positions stories as the focus of inquiry and the primary object of interpretation (Phoenix, Smith & Sparkes, 2010), shedding light on the lived individual experience of participants (Creswell, 2013). Although a phenomenological approach could also have been beneficial in exploring how the parental experience of the ADHD diagnostic journey is ‘perceived’, ‘described’ and ‘felt’ (Patton, 2002; Marshall and Rossmann, 2011), a narrative approach allowed for greater exploration into the development of the story across time and the narration of the disruptive (Grbich, 2013) ‘turning points’ (Creswell, 2013) illuminated by narrative. However, as ‘narrative’ has become a generalised, abstract, and theoretically dense concept (Hyvärinen, 2016), clarity is necessary regarding how the term is used.

### 5.2.5. Defining Narrative

Inconsistencies in the definition and boundaries of what constitutes 'narrative' have led some to suggest that there exists a problematic position in which 'everything' can be considered narrative without necessary theoretical consideration (Phoenix, Smith & Sparkes, 2010). Andrews et al (2013) echo this sentiment, declaring that there is no automatic start or end point within narrative research given the lack of a unifying definition. Within sociology, narrative has been conceptualised as both a noun synonymous with "story, account, or chronicle", and an adjective to describe the "process of relating a continuous account of a set of events or processes" (Williams, 1984: 177). Others have declared narrative as different to other forms of discourse due to their "sequence and consequence", as events within narratives are "selected, organised, connected, and evaluated as meaning to both teller and audience" (Riessman & Speedy, 2007: 430). Although debate does exist regarding whether the terms 'narrative' and 'story' are theoretically identical concepts or separate entities (Polletta et al, 2011), this thesis opts to use these terms interchangeably.

Holstein and Gubrium (2012) outline the early sociological trend of narrative research to focus on rigid structuralist approaches to story, in which the organisation and structure of the narrative are key to its definition (Labov & Waletzky, 1967; 1997). Labov and Waletzky (1967; 1997) outline five necessary sociolinguistic features within personal narratives, stating that the following features must be fulfilled to consider something narrative: Orientation (a process of information giving to the listener detailing the who, what, where, and when), complication (the problem or action needing to be resolved), evaluation (the point of the story), resolution (the result of the problem), and the coda (a return to the present moment). Labov and Waletzky's (1967) structuralist approach has faced criticism due to the requirement for events to be narrated in the order in which they occurred, an issue felt to stifle the exploration of other aspects of narrative inquiry (Holstein and Gubrium, 2012: 3). Polletta et al (2011: 111) point towards "plot" as the core component in defining narrative, as plot grants structure and meaning to a series of otherwise arbitrary events and experiences. Narratives explore the "cause and effect" of events (Polletta et al, 2011: 111), unlike explanations which utilise logic and proof (Polkinghorne, 1988). Williams (1984) presents two forms of narrative: 'routine' and 'reconstructed'. The routine narrative relates to observations, comments, and asides of the happenings within our lives, making the mundane incidents we experience intelligible and plausible with continuous accounting, i.e., "this happened, then this happened". However, when the orderly sequence of facts is fractured, routine narrative is lost, and the story must be reconstructed. The storyteller attempts to repair story ruptures by reordering and realigning past and present self within

society (Williams, 1984). Therefore, the primary consideration when exploring narrative is not necessarily *what* is talked about, but what *choices* the storyteller makes in delivering their narrative (Reissman, 1990). Accounts lacking the structured chronological requirements of Labov and Waletzky (1967) become interesting because of their lack of chronology, illuminating us to the storytellers perspective (Holstein & Gubrium, 2012) and the meaning they attribute (Polletta et al, 2011). Stories supply more than simply what happened, but grant insight into emotions, beliefs, interpretations, attitudes, and experience (Bruner, 1986; Polkinghorne, 1988; Gubrium & Holstein, 1997).

Interaction between storyteller and audience is also integral to narratives, as meaning is constructed in both the 'telling' and 'hearing' (Plummer, 1994). Narrative is a collaborative enterprise, a co-constructed entity derived from the symbiotic relationship between storyteller and listener. Therefore, effectively understanding stories requires knowledge of the social and cultural world of the storyteller to grasp the gravitas of what is being said, and any potential implications and deeper meanings (Plummer, 1994). Consequently, the hearer of the story impacts on how the story is heard, as well as how it is told, coaxing and 'seducing' the stories through probing questions, verbal and non-verbal reactions, and other interpersonal techniques (Plummer, 1994). Narrative researchers must consider whether the objective of inquiry is the factual moments of experience within the narrative, often referred to as "life as lived" (Rosenthal & Fischer-Rosenthal, 2004: 264), or the attached meanings and construction of the story regardless of factual content, the "life as told" (Andrews, Squire & Tamboukou, 2008). This thesis aims to explore the way in which parents on the ADHD diagnostic journey describe their experiences and construct a story to make sense of their journey, prioritising the 'life as told' and the social "power" of story (Holstein and Gubrium, 2012: 7). Narrative allows one not only to study experience as story, but also gives voice to those often unheard (Connelly & Clandinin, 1990; 2006). This approach to narrative enables the thesis to explore the social, cultural, ideological, and experienced life of the parents (Polletta et al, 2011), whilst also illuminating how they conceptualise their own biography; answering whether they see their own story as an "as lived" chronology or as a series of important moments and turning points 'told' in a non-chronological manner (Grbich, 2013). This approach requires the researcher to 're-story' (Cresswell, 2013) the parental narratives, sifting through the account in search of key themes and understandings, rewriting them into digestible formats, and comparing them to the stories of others. The re-storying process is particularly important when working with large sections of narrative data such as those found within this project, as the sometimes 60+ minute interviews broach vastly different topics, concepts, and temporal points. Narrative researchers must 'tease out' story sections which directly relate to the research questions, repackaging the information in a way intelligible to

wider audiences without losing the 'essence' of the story (Cresswell, 2013). This concept will be explored further in Section 5.5 [Narrative Analysis], where this thesis' approach to handling narrative data is discussed. In conclusion, as this project aims to develop understanding into the lived and storied experiences of parents on the ADHD diagnostic, a narrative approach is an effective and theoretically appropriate methodological choice.

## 5.3. Research Methods

### 5.3.1. Introduction

The following section on research methods details the research project's practicalities and processes, critically evaluating the use of and effectiveness of research methods employed. This section will begin with a discussion of recruitment and sampling, outlining the decision-making processes and associated challenges. Following is a detailed analysis of serial interviews as a method of data collection [5.3.4], and a transparent account of the difficulties of data collection during the covid-19 pandemic, UK national lockdown, and consequent halting of all ADHD assessments within North-East England. Section 5.4 will critically explore the transferable skills and differences between mental health nursing and qualitative research, utilising Corbally and O'Neils' (2014) paper as a framework.

### 5.3.2. Sampling and Recruitment

A purposive and convenience sampling strategy was employed to effectively identify the 'closely defined homogenous group' most appropriate for answering the research questions (Smith and Osborn, 2015). Purposive sampling reduces probability that data collected is not relevant to the research questions (Marshall & Rossman, 2011), as participants are targeted for recruitment due to specific attributes. This necessitated that all participants be a parent on the ADHD diagnostic journey. The sampling strategy did not attempt to recruit a statistically significant and representative sample of the targeted population (Ritchie et al, 2003), but to recruit a participant group of appropriate size for a qualitative doctoral study. Like other projects exploring ADHD and parents (Gray, 2008; Rowlands, 2017), there were significant difficulties in recruiting participants which necessitated a convenience and

snowball sampling strategy. Recruited participants would suggest other potential participants, often friends or other members of parental support groups.

Inclusion criteria aimed to allow the greatest number of appropriate participants whilst being practical and pragmatic. The inclusion criteria were as follows:

*Participant must:*

1- *A) Have a child who has recently been referred for assessment of ADHD*

*Or*

*B) Have a child who has recently received a diagnosis of ADHD*

Given that the research questions were interested in the parental experience of the ADHD diagnostic journey, it was important to ensure this was represented within the criteria. However, the addition of having a child who has been “recently” referred for assessment or has “recently” received a diagnosis was of particular importance. Given that ADHD assessments can take up to two years from GP referral to diagnostic meeting (ADHD Foundation, 2017), it was vital that the referral process had already begun to ensure sufficient time for assessment of the child to be completed in time for three interviews. Criterion B required that a diagnosis be “recently” received, this was to ensure that the period captured was during the diagnostic journey and not following a significant passage of time post-diagnosis.

2- *Be English Speaking*

Unfortunately, due to a lack of budget for translation services, participants were required to be able to fluently converse in English.

3- *Live in the North-East of England*

The criteria that participants live within the North-East of England was a practical consideration as it would ensure that travel to and from interviews would not be unnecessarily onerous. However, following the national lockdown and switch to digital methods of interviewing, this inclusion criteria became less relevant. Given recruitment was complete prior to national lockdown, it was not necessary to re-evaluate this criterion.

4- *Be the legal parent of the Child*

The research exploring parents and ADHD often include concerns around biological heritability and mothering self-blame and shame (Cocoran et al, 2017a). The inclusion of both biological and non-biological parents was important as there may have emerged a

difference within parental narratives. However, although children with ADHD are significantly more likely than average to be labelled Looked After Children [LAC] (Willis, Dhakras, & Cortese, 2017), no foster or adoptive parents were recruited within this project.

### 5.3.3. The Recruitment Process

The recruitment process for this project was a protracted experience, lasting almost 30 months due to unforeseen complications with NHS partners and the devastating impact of the Covid-19 pandemic and national lockdown. Recruitment occurred in two distinct ways: Non-NHS site recruitment and NHS site recruitment.

During the recruitment of Non-NHS participants, I contacted a variety of supportive social care and charitable services likely to be involved with parents of children on the diagnostic pathway. These services included: Newcastle Skills for People, Newcastle Sure Start: Family Hubs East, West, and Central, The North-East Adult ADHD support group, “Pass it on Parents” Newcastle, ADHD Wise National ADHD charity, and the ADHD Foundation. During contact I gave a presentation on the research project and the inclusion criteria to staff within these organisations. I then handed out participant information forms [Appendix A] and requested staff disseminate these to potential participants. Parents interested in involvement then contacted myself via email, followed by a telephone or email conversation answering questions and explaining the project. Once a parent had confirmed involvement, the research consent form [Appendix B] was sent for parents to complete and either email to myself or bring to the first interview.

For the recruitment of participants within NHS premises, this process was very similar though required IRAS approval. Recruitment was focussed within Northumberland, South Tyneside, North Tyneside, and Newcastle and Gateshead Children and Young People’s services [CYPS]. Following the research presentation, nurses within neurodevelopmental assessment pathways were requested to hand out participant information sheets to parents who might be interested at the start of the assessment process for ADHD. It is noteworthy that none of the seven parental participants were recruited from NHS premises. The lack of participants from NHS premises was unusual, and when I contacted these NHS teams it was discovered that nurses had “forgotten” to hand out the forms or had not been informed by those who attended the presentation for over 6-months. Once this issue was resolved, the Covid-19 pandemic and lockdown began the following week, leading to all ADHD assessments and face-to-face appointments with CYPS teams to cease. The result of these

difficulties is that all participants within this project were recruited from ADHD charitable services or via snowball sampling. Nonetheless, five of the seven parents received their child's assessment for ADHD through the above NHS mental health teams.

Although it may have improved credibility and a greater diversification of the sample to have waited for greater demographic variation, ultimately pragmatism, timeliness, and the impact of the Covid-19 pandemic required the sampling strategy to accept these potential shortfalls to ensure the study was completed within the appropriate timeframe. The outcome of these challenges in recruitment was that the sample is particularly homogenous regarding gender, ethnicity, and sexual orientation; with all parents being white, cis-gender, and heterosexual. The absence of parents from diverse minority groups is a limitation, as findings are unlikely to reflect the additional intersectional challenges faced by these groups such as: racial bias and the dual stigma of racial diversity and ADHD (Emmanuel et al, 2022; Paidipati et al, 2022); the experience of stigmatisation and victimisation of ADHD children of same-sex parents (Sullins, 2015), and the currently unknown and relatively unexplored (Conway et al, 2022) experiences of trans and non-binary parents. A research sample is said to be defined by those who are 'prepared to be in it' (Smith & Osborn, 2015), a consideration particularly salient given the majority representation of participants working within health and social care environments. Of the 7 parents there includes: a social worker, older person's psychiatric nurse, ADHD specialist nurse, a drug and alcohol worker, a nurse working within children's mental health, a home carer, and an occupational therapy student (Demographic information presented in the table below). Details of each parent will be given in section 5.7, but it is important to acknowledge that the parental professional background appears to play a role in willingness to become involved in the project during the emotionally turbulent period of the ADHD diagnostic journey. Furthermore, although inclusion criteria required only that the person be a "parent or caregiver", only one participant was a father, an issue typical within ADHD research dominated by the responses from mothers (Singh, 2003; Rowlands, 2017). The disproportionate inclusion of mothers in ADHD research has seen much discussion (Singh, 2004; Horton-Salway, 2013; Davies, 2014), and the absence of fathers in research and caregiving is discussed throughout this thesis [3.8: Fathers and ADHD & 8.1.4: The Informed and Insider Father].

### Demographic Information

Name	Age	Profession	Parental Diagnosis	Child Information
Sharon	41	CAHMS Nurse	Yes	Son (9)
Pam	39	Nurse	No	Son (8)
Rachel	43	Home Carer	No	Daughter (12)
Debbie	45	Social Worker	Yes	Daughter (16)
Jane	41	Occupational Therapy Student	Yes	Daughter (9)
Cath	44	ADHD Specialist Nurse	Yes	Son (14)
Phil	46	Drug and Alcohol Worker	No	Son (6)

### 5.3.4. Serial Interviews

Data collection involved three serial interviews over a period of up to two years to capture changes in narrative over a prolonged time period. Interviews are an effective method for qualitative researchers to gather large amounts of data regarding a particular issue (Marshall & Rossman, 2011) and can be considered a “construction point of knowledge” (Kvale & Brinkman, 2009: 2). The flexibility of interviewing allows for more considered responses from participants and access to their views, interpretations, understandings, experiences, and opinions (Byrne, 2004). As this research aimed to capture the changing sense-making stories told by parents about their experience, it was important to gather data at different temporal points. The use of serial interviews allowed stories to be captured during significant ‘moments’ during the ADHD journey (referral, assessment, diagnosis, and post-diagnostic life), and allowed for parental ‘evolving needs’ to be better understood (Murray et al, 2009). Serial interviews also allow for ‘rich insights’ into the multifaceted roles parents take within families and communities and are beneficial for capturing the variation over time of complex issues (Read, 2018). This was evident in Debbie’s narrative when she discussed the

challenges of being a social worker, mother, mother of a child with ADHD, and an adult with ADHD.

As stories included parental experiences of children's mental health, sensitivity and understanding of the potential trajectory of the ADHD journey was important (Murray et al, 2009). However, the interview process was not always a comfortable and smooth conversation, requiring a high level of flexibility from the interviewer (King, Horrocks & Brooks, 2019). Interview participants may be unwilling or uncomfortable sharing some details of their story; particularly if they feel that it will portray themselves in a negative light (Marshall & Rossman, 2011). Therefore, a further justification for serial interviews was to enable participants and researcher to develop a more trusting relationship due to repeated contact. Read (2018) argues that serial interviews permit participants to 'open up' to a greater degree over time, avoiding the potentially bias results of single-session interviews. This increased trust allows for deeper discussion of more socially stigmatised, embarrassing, or sensitive topics within participant private accounts (Murray et al, 2009). The previously unspeakable becomes 'speakable'. Given the previously discussed stigma associated with ADHD diagnosis, serial interviews were felt to be an effective way to explore the complex and ill-defined issue of parental identity in the face of psychiatric diagnosis (Read, 2018). The serial interview also counteracts some criticisms associated with the generic single-session narrative interview. Participants forgetting specific details or reinterpreting past events through their current lens is less impactful within serial interviews, as researchers can reflect on previous discussions and address inconsistencies in the narrative discovered through transcription and analysis (Murray et al, 2009). The interviewer can also return to intellectually interesting tangents that may not have been developed fully within previous interviews. Finally, multiple interviews can be seen as a more empowering research process for participants, as some have criticised the potentially exploitative practice of 'drive by interviewing' for single interview studies (Chamberlain, 2012).

### 5.3.5. The Interview Process

The importance of trust within qualitative interviews is vital to ensuring these intimate encounters are effective methods of data collection (Marshall & Rossman, 2011). However, when one is employing qualitative interviewing as a method of data collection, it is important for the interviewer to be mindful of their own stance in relation to the social, political, and cultural context; otherwise known as researcher positionality. The interview arena becomes a shared space, in which researcher and participant come together to impact on the

research process (Bourke, 2014). This process is influenced by the identities being enacted by both individuals. For instance, as a researcher attempting to understand the parental experience of ADHD, participants may consider me as an outsider attempting to delve into their 'inside world' (Crang, 2003). Alongside, my not being a parent at the time of data collection positions myself as an 'other' who may lack understanding of parental experiences which other parents may possess. Like Brown (2019), who utilised her maternal identity to establish legitimacy with pregnant teenage participants, my personal experience of ADHD and professional experience working with ADHD parents became important in establishing rapport and trust. Once a participant was aware of my personal interest and experience within the ADHD 'world', there would often be a softening of their demeanour and an increase in inclusive language. Debbie's comment below where she emphasises the word "you" to demonstrate her acknowledgement of my awareness of having ADHD exemplifies this process.

### **Debbie- Prior to Interview 1**

*"Well, **you** know what it's like"*

Thompkins et al (2008) liken the positionality of researcher and participant to that of the doctor-patient relationship as researchers often hold a position of supposed expertise. As Brown (2019: 272) states, non-hierarchical relationships are impossible if participants perceive the researcher as "having power". This became a salient consideration within this project, as my own experience as a medical professional engaging with parents of ADHD children may have increased the risk that the interview falls into an expert-patient dynamic, instead of a researcher-participant dynamic of co-creation. It was important to support participants and establish a shared space in which the interview was seen by both interviewee and interviewer as co-operative and co-constructed. Nonetheless, technical expertise in the field being studied can be advantageous as it allows the researcher to garner trust from participants that they have the capacity to engage with the topic of discussion from a place of awareness and knowledge (Thomkins, Sheard, & Neale, 2008). However, my technical and clinical expertise also presented some challenges for myself as a junior researcher as some participants began information seeking for coping strategies and advice once aware of my clinical background. Interestingly, this typically occurred once the interview had concluded, and the digital recorder had been turned off; parents appeared to adjust their perspective of me from 'The Researcher' to 'ADHD Expert'. This unexpected experience was of note when talking with Pam post-interview, as she requested the digital recorder be turned back on as our discussion had sparked further stories which she wished

to share. As I was new to qualitative interviewing, I found this process challenging to navigate as I was not initially confident in determining whether post-interview advice giving would be appropriate from a research perspective, whilst also needing to maintain my duty of care as a qualified nurse in line with NMC (2018) guidance. I ameliorated this by engaging in regular supervision with my supervisor after each interview, reflecting on my building confidence as a researcher. This 'turning inwards' of attention allowed for a more reflexive approach to data collection and a greater awareness of the potential impact that any role changes may have had (Corlett & Mavin, 2019). I would also reflect on the questions asked during the interview and determine whether they were effective for eliciting responses that added to the data for the research question, or whether they were more akin to the clinically significant questions I would ask as a nurse. As more interviews were conducted throughout data collection, it became more intuitive and comfortable to embody the role of the narrative researcher and this positional conflict faded into the background. Overall, my experience as a mental health nurse and my being a person diagnosed with ADHD proved beneficial in accelerating the trusting relationships necessary for effective interviewing and I believe allowed participants to feel comfortable sharing vulnerable stories.

The practical process of conducting interviews typically followed a consistent format. Once I had arrived at the location of the interview it was important to begin immediately establishing a rapport and building trust. One of the ways in which rapport was established was with the use of small talk and by discussing what they could expect from the interview, answering questions they may have. Following this initial rapport building, it was important to confirm informed consent was given and consent forms were complete. Participants were offered a verbal explanation of the consent documentation as English literacy skills were not assumed. The end of the pre-interview discussion involved the setting up of two Dictaphones with which to record the interview. The use of two Dictaphones to reduce the impact of any technical difficulties often became a moment of shared enjoyment as we laughed at the fallibility of technology.

An interview topic guide [Appendix D] was developed to determine the questions asked within each interview. The decision of which questions to include within the topic guide was informed by questions from other similar narrative studies, alongside intuitive questions aimed at eliciting narrative responses e.g., "How does it feel to be on this journey?". Following the first set of interviews, additional questions were added to the topic guide to purposefully explore interesting concepts which arose within early interviews. When asking the first interview question I was mindful that the participant could be feeling awkward, anxious, or wary of what might be asked. Therefore, the first question ("Would you be able to give me some background information about who you are and who is currently going through

the ADHD diagnostic process?”), was designed to illicit more factual responses in the hope that the participant would be at ease. This decision was informed by McGrath et al’s (2018) tips for conducting qualitative interviews, which state that interviewees may expect the interview to be invasive or difficult. The below extract gives an example of how one participant used the above question to give four very important pieces of information: the age of her daughter, her previous CAHMS involvement, and evidence that mum is aware of the changes in the diagnostic label.

**Debbie 8-9**

*The assessment is for my daughter, she’s 16, she’s been to CAHMS in the past. We thought she must have ADD, it’s not called that anymore, is it?*

The first interview question often resulted in respondents giving prolonged, in-depth responses on a variety of topics. Some parents gave detailed chronologies of their children’s life from birth, whilst others began talking about demographic information and deviated into a narration of their own emotional experience. Following the first interview question and once the participant appeared to be more comfortable, open-ended questions were asked to allow for the narration of stories. For instance, the question “what does it feel like to be pursuing an assessment of ADHD?” often led to prolonged narratives, with some parents talking without break for over twenty minutes. Once the interview was flowing, I would then utilise probing questions to explore in greater detail areas of particular interest or to gain greater depth of information (Morrissey & Callaghan, 2011). For instance, within Pam’s interview she made the seemingly innocuous statement “*maybe I should have fought for him more*”, to which I followed with the probing question “Do you feel like you need to fight for this assessment?”. This was followed with an incredibly emphatic response by mum, which led to Pam exploring the emotional turbulence she was feeling and a significant opening of the interview into emotionally vulnerable content.

Closing interviews was typically a natural process, though has been described by some as a “technical operation” (Thompkins, Sheard, & Neale, 2008: 26). Often, interviews would come to a comfortable close once conversation had changed to the future and with it the planning for a future interview, the allotted time was upcoming or had already been passed, or the conversation had shifted and was no longer related to the research questions. Natural endings to qualitative interviews are common, typically due to time constraints or conversational shifts (Thomkins, Sheard, & Neale, 2008). It is unsurprising that for some parents, the interview was a therapeutic experience in which they were able to tell their story unhindered, leading some to not wish it to end. It was important to be flexible and responsive

to participant needs and wishes, extending interview timeframes when appropriate, although this had little impact on data collection as only one interview was prolonged to last 90 minutes.

### 5.3.6. Criticisms of Interviews as a Method of Data Collection

Although interviews are often an effective method of qualitative data collection (Kvale & Brinkman, 2009; Marshall & Rossman, 2011) criticisms have been raised regarding their use. Hammersley (2003: 119) describes how qualitative researchers have become “obsessed” with interviews through the romantic impulse that interviews capture “genuine voices” and “reveal secret personal realities”. This notion is described as misguided (Hammersley, 2003), as interview voices are declared not to be authentic truths but “methodologically constructed social products emerging from reflective communicative practices” (Holstein & Gubrium, 2002: 11). In answer to this criticism, this project is not concerned with the objective truths present within stories but with the way in which parents construct sensemaking stories and the “work” that these accounts do in exploring their experience (Hammersley, 2003: 122).

A similar criticism has also deemed contemporary sociology to elevate data gained from individual experience as more ‘authentic’ (Atkinson & Silverman, 1997; Silverman, 2017). This ‘romantic’ study of the experiential may place qualitative researchers in competition with non-scientific professionals such as journalists, talk-show hosts, and podcast hosts in an endeavour to capture experiences in the wider ‘interview society’ in which “wars and elections are won due to compelling narratives” (Silverman, 2017: 156). However, although the questions being asked may be similar or even identical across these interviewing professionals, I argue that it is the rigorous process and criticality of data analysis that makes qualitative research legitimate. Silverman (2017: 145) appears to agree when they state that “everything depends on the quality of data analysis”. The qualitative interviewer can no longer simply list the features of an interview response but must analyse the identities evoked, examining the cultural importance and outcomes of talk.

### 5.3.7. Covid-19 and the Transition to Digital Interviews

Like many research projects using in-person methods of data collection, the Covid-19 pandemic and subsequent national lockdown required interviews to transition to a digital medium (Lobe, Morgan & Hoffman, 2020). Fortunately, as I was already confident and competent using the telecommunication platforms Skype, Microsoft Teams, and Zoom, and their being an effective and flexible manner of data collection (Cater, 2011), the transition to digital interviews was relatively simple. Online methods of data collection have the potential to replicate, complement, and improve upon traditional methods (Braun, Clarke and Gray, 2017), allowing a greater degree of flexibility to both researcher and participant (Cater, 2011) whilst reducing costs via free to use software packages (Archibald et al, 2019). In line with university policy, I opted to use Skype for all participant interviews. There is some evidence to suggest that many research participants prefer Zoom interviews over those performed in-person and over telephone (Horell et al, 2015; Archibald et al, 2019), and Skype participants have been found to be more responsive than those in person (Deakin & Wakefield, 2014). However, rapport building may be more challenging in online interviews (Cater, 2011), especially when connectivity issues arise which impact on the flow of conversation (Archibald et al, 2019). Furthermore, poor bandwidth, outdated hardware, and poor audio and video quality may also hinder the interview process (Deakin & Wakefield, 2014), especially if total disconnection occurs. Although this was a minor issue within this project, the interview with Debbie did involve a dropped call, which led to participant frustration and may have altered the telling of the story at that time. One must also consider Weller (2016), who argues that the 'greetings and leavings' of digital interviews are often focussed on technicalities rather than rapport building small talk. It was therefore important that once technical discussion at the beginning of the interview had concluded, I began the rapport building process in earnest prior beginning recording. Digital interviews may also impact on the researcher's ability to respond to non-verbal cues due to having limited vision of the participant (Deakin & Wakefield, 2014), a limitation which can be ameliorated by a researcher being conscious of participant facial expressions and tone of voice (Seitz, 2015). Fortunately, my background as a mental health nurse proved invaluable in both developing a sense of rapport in these unusual circumstances and using the nursing 'art of noticing' to assess participant experience (Watson & Rebar, 2014).

Digital interviews also risk having an individual enter the room and be recorded without their explicit consent, or that the background of a participants' living space may be visible when not desired (Cater, 2011). Both issues were ameliorated as much as possible, with participants being advised to use the 'blur background' feature on Skype to ensure increased privacy. Regarding others entering the interview space, this was prevented in the same way as face-to-face interviews. Participants were asked to ensure that others within the

household were aware of the interview taking place and that they knock on the door so that the recording device could be stopped.

Although digital interviews were not the first choice regarding data collection, they represent the 'next best thing' (Archibald et al, 2019) and were effectively used throughout the project. Fortunately, all participants had the computer equipment or mobile telephone required to engage with digital interviews, and there were limited technical difficulties. There was limited difference in structure comparing in-person to digital interviews, as once connection had been confirmed I would follow the interview process already outlined. Nonetheless, the transition from in-person to digital interviews was of limited impact to the overall undertaking of this research project and I am grateful that the potential problem of data collection during a pandemic was not onerous.

### 5.3.8. Ethics

Given the potentially difficult and emotional conversation topics around parenthood and childhood diagnosis, significant consideration was given to ensure that this project was undertaken in an ethical, compassionate, and sensitive manner. Ethical approval for non-NHS recruitment was granted by Northumbria University's internal ethics committee. However, as recruitment was initially hoped to be gained through NHS services, approval was sought via the Integrated Research Application System (IRAS). There were particularly salient ethical considerations in relation to this project which were important to address: The potential of emotional impact on parents during interviews and potential safeguarding or safety issues arising during interviews at participant's homes.

Discussing childhood mental health, parenting, and childhood disability can be a potentially upsetting experience for parents. During interviews it was imperative to utilise a compassionate, non-judgemental approach in both demeanour and language to ensure sensitive topics were treated appropriately. My background as a mental health nurse within CYPS was of huge benefit and granted me an array of strategies to discuss children's mental health and ADHD diagnosis with the appropriate degree of knowledge, sensitivity, and validation. Guided by the NMC Code of Conduct (NMC, 2018), I am confident and skilled in having emotionally sensitive conversations and can support and de-escalate parental distress with competence. To reduce potential burden to participants, all interviews were performed at a time of their choosing and could be cancelled at any time. If a parent were to get distressed and it was felt to be inappropriate for the interview to continue, the

recorder would be turned off and the participant would be emotionally supported. If a parent were to become verbally or physically aggressive, I am skilled in ensuring my own safety when lone working and was confident in my ability to remove myself from risky situations. I also utilised a text-in/text-out system with my supervisor so they were aware of when I had entered and left a participant's home. Regarding potential safeguarding concerns, if a parent were to disclose a safeguarding risk to self or others then appropriate safeguarding procedures would be followed, such as referral to local safeguarding teams or the police and/or mental health crisis services if I felt there was an immediate risk. At the end of every interview, participants were asked if they needed any additional support and could be directed towards psychological wellbeing services if necessary. However, it is important to note that there were also significant potential benefits to parents who were able to have their stories heard in a validating and open space. This experience may alleviate feelings of stigmatisation and shame and was described by many parents as "therapeutic".

Additionally, although ethical issues related to in-person interviews are shared with online mediums (Cater, 2011) additional considerations arise when using digital interviews. When considering participant consent, Cater (2011) and Lobe et al (2020) state that consent forms should be witnessed when possible and should be returned via email prior to first interview. As consent forms were already signed by participants in-person and prior to digital interviews, I emailed the amended consent form to each participant in line with Lobe et al's (2020) recommendations and would discuss this on camera before turning the Dictaphone on.

Finally, regarding data storage all recorded data was immediately transferred from Dictaphone to a password protected computer as soon as possible following the interview. Data was saved on a cloud based encrypted university computer in accordance with GDPR protocols and will be held for the shortest period possible prior to deletion. As narrative research often includes significant detail of the experiences of a small sample of individuals in small area, there is an increased risk of potential identification of study participants when compared with other methods. To ensure confidentiality, all participant and family names were anonymised within the transcription process and small demographic details were altered to ensure that participants were not easily recognisable within the thesis. The increased risk of identification was also brought to the attention of participants during the recruitment and consent taking process. Consent was gained to utilise anonymised quotations within the participant consent forms [Appendix B].

### 5.3.9. Transcription

As soon as possible following interview, transcription using Microsoft Word began. Although originally hoping to transcribe all interviews personally in order to be as immersed in the data as possible, there became a practical health issue with which it became difficult and painful to transcribe. It became practical and pragmatic to utilise a research transcription service for seven of the total interviews until I was able to access speech-to-text software to complete the rest of the transcription. Immersion with these transcripts included reading through the transcript and listening to the recording. Initial analysis of transcripts took place immediately, allowing for emerging concepts to be further tested and developed in subsequent interviews (Murray et al, 2009). During this process, notes were written, and sections highlighted which were felt to be of importance to aid future analysis. The process of transcription was in itself a method of construction, as choices in transcription inevitably impact data analysis (Hammersley, 2010). For instance, not including non-word elements or gestures, and not representing intonation, pitch, pace, or speech direction was a conscious choice throughout transcription, as avoiding the detailed minutia of socio-linguistic or conversational analysis was deemed appropriate and pragmatic. The transcription became a representation of which words were spoken by the participant, but also a construction of how the interviewer heard those words and interpreted them (Hammersley, 2010). When interacting and employing transcription services, I requested that they follow as many of these transcription processes as possible to ensure consistency across transcript format.

### 5.3.10. Trustworthiness and Rigour

It is vital for narrative researchers to demonstrate the steps taken to confirm trustworthiness, credibility, and rigour of a research project to ensure the work is of high-quality (Greenhalgh, 2016). Rigour and trustworthiness are established within narrative research by giving a “convincing interpretation” (Greenhalgh, 2016: 5) of the data with credibility, dependability, transferability, criticality, and plausibility (Lincoln & Guba, 1985; Loh, 2013). Credibility in narrative research is gained through prolonged engagement with study participants (Loh, 2013), going beyond a superficial approach to the data to gather a ‘thick descriptions’ (Lincoln & Guba, 1985) in ‘rich’ detail (Greenhalgh, 2016). By utilising prolonged serial interviews, this study was able to capture rich detail via prolonged engagement not just within individual interviews, but across the timespan of the diagnostic journey. The longitudinal nature of this project provided the ‘thicker’ descriptions of parental experience

Rasmussen et al (2021) hoped for in their recommendations for future study of parental biographical response to diagnosis.

Member checking and peer validation represent additional tools for increasing credibility in narrative research (Loh, 2013; Greenhalgh, 2016). Seeking validation from scholars and professionals familiar with the themes and theories applied to the research project is helpful, (Kvale, 2007: 125) as the researcher's interpretation of the data may go "beyond the subjects' self-understanding around what they think and feel about the topic (Kvale & Brinkman, 2009: 253). Furthermore, validation from the "primary intended users and readers of the study" (Patton, 2002, 561), or audience validation (Loh, 2013), presents additional methods of credibility. Prior to submission, study findings were presented to two ADHD specific conferences in which ADHD researchers, clinicians, and parents of ADHD children were in attendance and feedback was given on the plausibility and transferability of the findings. These deliveries, alongside a prolonged interview with the CEO of a major UK ADHD charity on the study findings were used to ensure credibility. Peer- and audience-validation were also used to ensure findings were believable, rang true, and resonated with study consumers (Loh, 2013: 10), as narrative research must demonstrate verisimilitude or plausibility (Greenhalgh, 2016). This thesis includes four chapters to present findings to recruit the reader and allow them to enter the world of study participants. The final way in which trustworthiness and rigour is established within the project is through confirmability and criticality. Chapter 5.5 [Narrative Analysis] details the data analysis process, giving an in-depth description of analysis to enable transparency and repeatability of the analytical process. That section, alongside Chapter 1.4 [My Story and Authorship] demonstrates the high degree of researcher reflexivity required to produce high-quality, critical qualitative research (Greenhalgh, 2016).

## 5.4. Transferrable Skills and Differences Between Mental Health Nurses and Qualitative Researchers

The attraction towards research utilising interpretive methodologies is typical for individuals with Mental Health [MH] nursing backgrounds. It has been suggested that the training, skills, and philosophical approach associated with effective MH nursing is directly transferable to qualitative research (Cutcliffe & Goward, 2000). MH nurses and narrative researchers both aim to interpret and understand the rich "socially led" (Moen, 2006: 56) stories of individuals to enact positive change in the world (Gudmundsdottir, 2001). Others have added to this

perspective, arguing that “good nursing is influenced by understanding narrative in context” (Corbally & O’Neil, 2014) and that MH nursing is best defined as an interpretive, social constructionist perspective aiming to understand social processes and interactions (Rasmussen, Muir-Cochrane, & Henderson, 2015). Fundamentally, nurses interpret stories daily (Corbally & O’Neil, 2014). Consequently, my own comfort and expertise is rooted in engagement with others, leading me to be drawn to methodologies which privilege this perspective.

The following section explores this concept, discussing the similarities and differences between the qualitative researcher and the MH nurse whilst considering the impact of my nursing background on the project. This section is influenced by Cutcliffe and Goward’s (2000) paper on the topic and uses their three core themes to structure the discussion. Their three themes are: ‘The Use of Self’, ‘The Creation of an Interpersonal Relationship’, and ‘The Ability to Accept and Embrace Ambiguity and Uncertainty’.

#### 5.4.1. The Use of Self

The use of self is integral to MH nursing, so much so that courses have been designed to help nurses develop the therapeutic use of self in the UK, Norway, and Quebec (Froggett, Ramvi, & Davies, 2014). MH nurse education prioritises reflexivity and self-awareness (NMC, 2018), as nurses purposefully make use of ‘themselves’ in clinical interactions (Cutcliff & Goward, 2000). This manner of utilising the ‘self’ is akin to that of the qualitative researcher, as both roles bring their own knowledge and experiences into the interaction, using themselves as a tool for information collecting. The skilled qualitative researcher must “ask good questions in the right way” (Rubin & Rubin, 2005: 129) by having prior knowledge and effective interview preparation, a statement no less true for MH nurses. In both roles, it is the individual who collects data through a variety of means, interpreting and developing understanding through their personal experiences whilst also being self-aware of how their own experience may shape these interpretations. Although qualitative researchers and MH nurses participate in interactions with others from a position of co-creation and collaboration, they also both often have the final say in how the encounter is interpreted; be that qualitative data analysis or nursing care plans.

For the qualitative researcher, interviews in which the participant does not provide sufficient or appropriate data to analyse may be seen as ‘failed’ and discarded (Roulston, 2014), whilst MH nurses may see a lack of willingness to engage in the interaction or ineffective

communication as important clinical information. Although difficulties and disfluencies in participant/patient responses may be experienced as 'problematic' to both researcher and MH nurse (Roulston, 2013), highly skilled individuals in either position may see these interactional issues as opportunities for insight into the lives and experiences of others. Both professionals benefit from developing attentional depth within interactions, and the ability to recognise subtle changes in others, known as the 'art of noticing' within MH nursing (Watson & Rebar, 2014), demonstrates further evidence of how each role uses the 'self'.

However, when considering the 'self' in qualitative interviewing and MH nursing, there is a noteworthy distinction. For the MH nurse, where personal and professional worlds simultaneously inform each other (Arbon, 2003), it becomes difficult to say where the "personal ends and the professional begins" (Ramvi, 2015: 1). The content of a nurse's care is said to be directly dependent on their own life story (Gastmans, 1999; Iranmanesh et al, 2018), and nursing is often considered to be something that one "is" as opposed to something that one "does" (Ramvi, 2015). This perspective presents nursing as an identity or and not simply a profession or temporary role. In contrast, 'qualitative interviewer' can be considered a time- and environment- limited role which a person inhabits during the interview. Seldom is a person's selfhood so enmeshed in a professional role than that of the nurse. The nursing use of self, therefore, may be considered a more deeply personal experience than that of interviewers. The interviewer may return home from work and return to being 'themselves', whilst the nurse will always be a nurse (Ramvi, 2015, McCorckle, 2019).

#### 5.4.2. The Creation of an Interpersonal Relationship

To gather rich and reliable data, the MH nurse and qualitative researcher must do more than simply ask the right questions. They both must be skilled in creating, developing, and maintaining effective interpersonal relationships. The development of strong, trusting interpersonal relationships is one of the cornerstones of high-quality nursing care, effective assessment, and the creation of shared clinical understandings across all aspects of MH nursing (Morrissey & Callaghan, 2011; Browne, Cashin, & Graham, 2012). Consequently, the ability to create effective interpersonal relationships is a skill MH nurses are typically skilled and confident in (Cusack, Killoury, & Nugent, 2017). For qualitative interviewers this skill is equally valuable, as interviewers must be skilled in making participants feel safe and at ease when discussing sensitive topics with strangers (Knox & Burkard, 2009; Dempsey et al, 2016). Strong relationships developed over the research study may "encourage a level of

disclosure unparalleled in self-reports or snapshot examinations” (Tracy, 2013: 5) and may help participants to ‘open up’ (Read, 2018) and discuss sensitive issues to a deeper degree (Murray et al, 2009). In both roles, skills such as using appropriate eye contact and non-verbal gestures (Bolderston, 2012) become effective tools in creating a safe interview space within which trust can be built (Morrissey & Callaghan, 2011). A sense of trust and empathy is vital to ensure effective and intimate interview encounters (Marshall and Rossman, 2011; McGrath, Palmgren, & Liljedahl, 2018). My own MH nursing experience proved invaluable when conducting interviews, as developing effective and therapeutic interpersonal relationships is an area of competence. This experience allowed for a blossoming of trust and at times an “embryonic experience of my participants” (Cutcliffe & Goward, 2000: 595).

However, there is also a risk that the MH nurse or qualitative researcher may become overly immersed in the world of the participant, losing sight of the bigger picture. The effective interviewer avoids complete immersion, whilst still being part of that world; affected by it (Cutcliffe and Goward, 2000). The interviewer must “co-exist across two worlds, to gain the perspective of the participant in their world, and their own unique perspective from the world outside of the participant” (Cutcliffe & Goward, 2000: 596)”. In MH nursing, the ability to avoid total immersion in patient experience is not only a theoretical consideration but a vital requirement in ensuring self-care and career longevity. The importance of keeping appropriate professional boundaries and being empathetic but not fully immersed in another’s often painful experiences represents a ‘balancing act’, as one attempts to maintain professional distance whilst being personal (Ljungberg et al, 2017).

Whilst similarities exist regarding the creation of an interpersonal relationship by MH nurses and qualitative interviewers, there is an important difference. The therapeutic relationship between nurse and patient is the foundation of all nursing intervention (Peplau, 1956; 1991). The relationship allows for the collection of data and building of trust, but also delivery of clinical interventions which may do harm (Dziopa & Ahern, 2009) or which may be forced upon the patient against their wishes (DOH, 2007). One cannot remove the importance of relationship building from nursing, for building interpersonal relationships is not a choice but a necessity (NMC, 2018). Alternatively, although interpersonal relationships are important for qualitative interviewers to gather data, researchers have an option unavailable to MH nurses. If an interpersonal relationship is unable to be established to perform an interview, the researcher may remove the person from the project and seek more willing participants. This option is absent from MH nursing, where nurses must be skilled in creating relationships with all patients, including those uninterested, unwilling, or even hostile. Ultimately, being unskilled in creating interpersonal relationships is problematic for qualitative researchers but proves catastrophic to MH nurses.

### 5.4.3. Accepting and Embracing Ambiguity and Uncertainty

The world of the MH nurse is filled with uncertainty and chaos (Pomare et al, 2018). It is a career in which objective truth is often elusive or even foolhardy to pursue, where treatment effectiveness is obscure, and patient issues are multifaceted and complex (Cutcliffe & Goward, 2000). MH nurses must be able to accept and become comfortable with ambiguity (Stilos, Moura, & Flint, 2007) due to ongoing uncertainty around decision-making, their professional role, and other external factors (Pomare et al, 2018). When working with patients, MH nurses must reduce ambiguity by creating formulations of patient experience, developing a shared understanding and language of the issue. For the qualitative researcher this may feel familiar, as interpretive research aims not to uncover objective truth, but to understand the contextual truth and meanings construed and constructed via interactions with participants (Cutcliffe & Goward, 2000). MH nurses and qualitative researchers must acknowledge that they deal with incomplete accounts of experience due to non-perfect memory and the other person's desire to portray themselves in a particular way (Randall & Phoenix, 2009). For both roles, the concept of 'truth' within narratives and patient/participant accounts is "overly simplistic and increasingly problematic" (Randall & Pheonix, 2009: 125), leading both to prioritise the co-created story developed during interview. Consequently, the ability to accept and embrace ambiguity and uncertainty proves a beneficial tool to both MH nurses and qualitative researchers.

However, as with the previous two themes there exists an important difference in relation to ambiguity across the two roles: potential outcome. Where difficulties associated with ambiguity within qualitative research may prove theoretically challenging, ambiguity in MH nursing can be life or death. MH nurses often must tolerate uncertainty of whether a patient will take their own life prior to their next visit, or whether a patient with a violent past is safe to visit alone. Where the conclusion of the interpretation of stories for qualitative research may involve an academic paper or policy adjustment, the outcome of the interpretation of stories for MH nurses may be more immediate and visceral, as a misinterpreted patient narrative around the risk of suicide or thoughts of self-harm could lead to catastrophe. Although Cutcliffe and Goward (2000) suggest that MH nurses and qualitative researchers must become comfortable with ambiguity and uncertainty, they fail to acknowledge that the stakes and risks associated with ambiguity are significantly higher for MH nurses.

#### 5.4.4. Concluding Thoughts

Although Cutcliffe and Goward (2000) present the three themes above to evidence the similarities between MH nurses and qualitative researchers, there are some additional shared skills which were not explored. Regarding communication skills, both MH nurse and interviewer must be skilled listeners (Cusack, Killoury., & Nugent, 2017), who can use probing questions to explore another's experience, (Morrissey & Callaghan, 2011) whilst having an open and curious attitude (McGrath, Palmgren, & Liljedahl, 2018). Both nurse and interviewer must be prepared to encounter uncomfortable emotions and know when to stop the encounter to reduce harm (Varpio & McCarthy, 2018). Additionally, consent, confidentiality, and privacy are equally important in ethical nursing and ethical research (Bolderston, 2012). Finally, both MH nurses and qualitative interviewers acknowledge and prioritise the importance of having an open and honest approach to hearing the stories of others (Giger, 2017: McGrath, Palmgren, & Liljedahl, 2018).

In conclusion, this section has explored the potential reasons why my experience as a MH nurse influenced the choice to use a narrative research methodology. Using Cutcliffe and Goward's (2000) three themes, it has explored the similarities between MH nurses and qualitative researchers, demonstrating how a background in MH nursing is beneficial to those wishing to conduct qualitative research. Finally, this section has built upon Cutcliffe and Goward's (2000) work, demonstrating significant differences between MH nurses and qualitative researchers regarding the 'Use of Self', 'The Creation of an Interpersonal Relationship', and 'The Ability to Accept and Embrace Ambiguity and Uncertainty'. The following section will explore the analytical approach used by this project, detailing the use of narrative analysis.

### 5.5. Narrative Analysis

The following section explores how data was analysed utilising a sociocultural method of narrative analysis. It begins with a brief comparison of sociolinguistic and sociocultural narrative analysis approaches, followed by a detailed account of the data analysis procedure. In broad terms, narrative analysis allows researchers to engage with data in storied forms with greater rigour, validity, and complexity (Holstein & Gubrium, 2012). Narrative analysis captures the "ubiquity and centrality of storytelling" (Katriel, 2012: 273) by approaching stories as cultural and social performances rather than "abstracted textual

products” (Katriel, 2012: 274). As literature on narrative analytical approaches becomes increasingly expansive (Holstein & Gubrium, 2012), researchers must define the boundaries and procedure of analysis used to ensure repeatability and clarity. A plethora of methods of narrative analysis are available to narrative researchers (Labov & Waletzky, 1997; Plummer, 1983; Reissman, 2008; Grbich, 2013), though these approaches broadly fit into two overarching perspectives: Sociolinguistic or sociocultural narrative analysis.

### 5.5.1. Sociolinguistic Narrative Analysis

Sociolinguistic narrative analysis, and other text-based approaches such as discourse analysis, analyse the “organisation, characterisation, modes of emplotment, themes and other textual features within story” (Gubrium & Holstein, 2009: 17). Sociolinguistic approaches explore the temporal ordering of narratives, coherence, and structural makeup (De Fina & Georgakopoulou, 2012), analysing the minutiae of structure and content to determine how the storyteller conveys meaning and explores ideas (Boréus & Bergström, 2017). Sociolinguistic approaches have been influenced by Labov’s (1967) seminal work on narratives within inner city environments.

A predominantly sociolinguistic method of narrative analysis was deemed unsuitable for the purposes of this study. Although useful for breaking down narratives into their constituent parts, mapping them into units and exploring common properties via tools such as discourse and conversational analysis (Grbich, 2013), a Labovian sociolinguistic approach was felt to be overly interested in analysing the specifics of story delivery, formulation, and structure (Labov, 1972). This risks missing the broader interpretive frameworks and contexts that people can use to shape their understanding of everyday experiences (Grbich, 2013). The sociolinguistic approach was felt overly formulaic in what is considered narrative, from Labov’s (1972: 360) “sequence of two clauses temporally ordered” to Labov and Waletzky’s (1967; 1997) five required features discussed in section 5.2.5. From this perspective, if the story given by the storyteller does not fit to the model it may be considered a “bad” narrative (Andrews, Squire & Tamboukou, 2013). However, this research project is interested in the individual and personal stories of parents and the process of meaning-making and sense-seeking over time, including the similarities and differences across multiple participant’s narratives. It aims to develop an understanding of how these narratives are created, changed, and crafted, how parents tell these stories, and the performative nature of stories. Further, the sociolinguistic approach has been criticised for discounting, or failing to account for, the influence of the interviewer, and the co-constructive process of crafting a narrative

that may occur during interviews (Andrew, Squire & Tamboukou, 2013). Although the primary method of narrative analysis was sociocultural in nature, section 10.2 [The Development and Structure of the Diagnostic Journey Narrative] will utilise a more structural analytical approach to discuss how parental narratives of the ADHD diagnostic journey engage with particular plots in both temporal and non-temporal ways.

### 5.5.1. Sociocultural Analysis

Unlike sociolinguistic approaches, sociocultural narrative analysis aims to transcend language structures and textual minutiae to delve into the wider “interpretative frameworks” individuals use to make sense of experience (Grbich, 2013: 221). Sociocultural analysis explores the interaction between narrative and cultures, explicit in its understanding that narrative genre and content differs across peoples (De Fina & Georgakopoulou, 2012). These approaches see narrative in relation to the values and ideals of differing cultures, exploring communicative style to conceptualise the relationship between experience, story, and culture. Stories become meaningful entities, where past, present, and future can be analysed within cultural and social frameworks (Grbich, 2013). Sociocultural narrative analysis was felt to be useful in analysing the stories of parents on the ADHD diagnostic journey as it would allow for consideration of cultural elements. These included the difference in narratives between fathers and mothers, the impact on motherhood self-conceptualisation, and the cultural role of medication to treat neurodevelopmental conditions. Sociocultural analysis has been used effectively to demonstrate how parents engage in ‘cultural communities’ when rearing children, and how parents with practically different experiences face similar cultural and social experiences (Jones & Mistry, 2019). The shared experience of having a child on the ADHD diagnostic journey could be considered a ‘cultural community’ across participants, presenting a rich area for inquiry. For sociocultural narrative researchers, the ‘performance’ (De Fina & Georgakopoulou, 2012) of story becomes relevant, as research narratives may also represent examples of larger social change movements (Plummer, 2001). The ‘interpretive communities’ within which stories operate can highlight and fuel cultural shifts towards increased representation and power for the disenfranchised (Andrews, Squire, & Tamboukou, 2013). In conclusion, a sociocultural narrative analytical approach was considered the most appropriate in answering the research questions and understanding the lived experience of parents on the ADHD diagnostic journey.

### 5.5.2. Analysis procedure

Sociocultural narrative analysis is often less formulaic than sociolinguistic, so much so that there is “no right way” to do it (Grbich, 2013: 225). Due to significant variation in approaches to data analysis across narrative analysis (De Fina & Georgakopoulou, 2012), it is important to clarify the specific approach used within this thesis. The analytical procedure employed is an alteration of Grbich’s (2013: 222) five stages of sociocultural narrative analysis, adjusted to suitably answer the research questions. The creative processes involved in constructing a bespoke approach to analysis is one of the primary benefits of utilising a sociocultural approach (Richardson & St Pierre, 2005). Below is a brief outline of the six analytical stages adapted from Grbich (2013) and used to analyse the data, followed by a detailed discussion of each stage.

**Stage 1:** Explore content and context of the overall transcript by reading and listening to the full transcript multiple times. This process was used to capture the essence of the overall transcript and begin to tease out theoretically interesting and important points.

**Stage 2:** Identify the beginning, middle, and end of the whole narrative across all three interviews. Making careful note of the order of topics and events discussed within each narrative segment. This allows for the creation of a transcript map of each individual participant’s overall narrative and the extraction of “micro stories”.

**Stage 3:** Analyse the “micro stories” within each transcript map for similarities, trends, and differences in content and structure. Use this information to develop narrative “plots”.

**Stage 4:** Look for similarities in plots and structure *across* narratives. Including plot structure and order.

**Stage 5:** Explore the use of various plots in the overall narratives of all parents, giving particular attention to how plots become sensemaking devices. Analyse the use of various plots and narrative structure through the theoretical lens of biographical cohesion and disruption.

**Stage 6:** Consider the impact of the researcher’s role as audience member within storytelling and analysis.

The following six sections will explain the above stages in greater detail, with particular attention on the purpose and practical application of each stage.

### 5.5.3. Stage 1

Within stage 1, I would develop an understanding and “feel” of the overall transcript. This involved taking all three interview transcripts and linking them together into the 'overall narrative'. Following initial transcription, I would read through the transcription both with and without the initial bold sections included during transcription to get a sense of any immediately apparent concepts. This was an iterative process, which included multiple passes through the data to get a “feel” for the data and the overall experience of each parent. It often became apparent that there were topics that would repeatedly appear within this initial read through. For example, medication took up a large portion of the discussion in Phil’s transcript and a note was made regarding this impression to inform future stages. These initial impressions of the transcript would then be discussed in PhD supervision, where text extracts would be explored and translated into micro-stories and plots as discussed in stages two and three of analysis. This process was helpful in establishing which concepts and topics were discussed at greater rates or intensity by parents.

### 5.5.4. Stage 2

Stage 2 of the analytical process was the most time-consuming, involving the highest level of immersion with the data. Stage 2 began by identification of the flow of the overall narrative and a segmenting of the sections loosely described as the ‘beginning’, ‘middle’, and ‘end’ of the overall narrative. This was done to get a general sense of each parent’s individual diagnostic journey and allowed reflections on the organisation and development of the overall story arc (Boréus & Bergström. 2017). Following this, the transcript was read multiple times to immerse oneself within the data, followed by a noting of topics and events that were discussed within each narrative segment. This included the extraction of smaller ‘micro stories’ of specific parental experiences, thoughts, or feelings which were developed into narrative ‘plots’ in stage 3. Each of these ‘micro stories’ were analysed using four core questions:

- 1- Why is the person telling me this?
- 2- Why are they telling it now within the overall story?

- 3- Have they provided examples of their claim?
- 4- How are they presenting themselves within the story?

These four questions allowed for deeper exploration of the sensemaking processes utilised by parents, including the presentation of their narrative towards myself as audience. As an example, this section of Debbie's interview can be viewed as an isolated 'micro story'.

### **Debbie 83-87**

*“Well, the thing is it's been really really upsetting and really stressful and I've been really down about it to be honest. Cause I just think, like as a mum you just blame yourself for everything. And a mum with ADHD you blame yourself even more. So, then I thought, why did I not fight CAHMS more, why did I not, I knew they were talking rubbish when I walked out of that room 3 years ago? Why did I let them do that?”*

Prior to this section, Debbie has presented herself as a strong and valiant mother [See Chapter 8.1], who has had to fight against “The System” [See Chapter 7.1] personified by CYPS. However, this micro story gives insight into an element of Debbie's experience, in which Debbie is a vulnerable victim to societal mother blame and experiences guilt at not fighting harder during previous assessments. These micro stories, developed into narrative plots within stage 3 of analysis, demonstrate the creation and changing nature of the parental narrative regarding experience on the ADHD diagnostic journey. This process was repeated multiple times for each transcript to extract as many of these micro stories as possible. Intuitive competence was utilised to determine what was considered a micro story, though they generally took one of the following forms: parental participants explaining their emotional response to a situation, the participant telling a story with the purpose of presenting themselves in a particular way, or to tell a story about one aspect of their experience.

### **5.5.5. Stage 3**

Stage 3 involved the assembling of micro stories across all participants which were similar in theme and content into a separate document for further analysis. Micro stories were

analysed for theme and content, alongside the purpose of the story and the narrative structure. The various collections of similar micro stories were then condensed into what will now be described as narrative 'plots'. These overarching plots were then broken down into more defined subplots to increase specificity. For instance, Debbie's micro-story above was incorporated into the overarching plot of "The Mother" [Ch8.1], then refined into the subplot of the "Guilty, Broken and Fragile Mother" [Ch 8.1.2]. Stories told utilising this plot and subplot were personified by examples of mothers in the story being broken down by the difficulties associated with the ADHD diagnostic journey, such as experiencing blame and shame internally and by external sources. Each of the four findings Chapters [Ch 6-9] will explore the parental use of narrative plots and subplots and discuss their meaning and analyse their use. A summary of the twelve initial narrative plots and the refining of these into the seven core plots discussed in the findings chapters will be included after a discussion of each stage [Ch 5.6].

#### 5.5.6. Stage 4

Stage 4 analysed similarities in plot usage and structure across all transcripts. This involved exploring similarities in the flow and utilisation of various plots across the entire participant group, exploring parallels or disparities in the order and way in which parents used plots within overall narratives. Within stage 4, plot definitions were refined and solidified by exploring the plot usage *across* all transcripts. This was an iterative process, in which similar plot types (i.e., "The Parent Against The System", "Subverting The System", "The System Breaks You") were brought together under an umbrella or overarching plot, in this case "The System". Once the defining of the plots had been finalised, each individual transcript was adapted into a story 'plot map' to visualise the plot usage over time. The plot map is intended to be a concise capturing of the flow of the overall narrative and the use of plots from beginning to end. The creation of a plot map involved the laying out of all plots utilised by each parent across the three interviews in chronological order. This allowed for a simplification of the data into a succinct story arc across the three interviews, for some participants a time frame spanning almost two years. The visual nature of the plot map gave clarity into potential similarities and differences between participant stories within stage 5 of analysis.

### 5.5.7. Stage 5

Stage 5 of the analytical process examined the use of plots by all parents, giving attention to how the plots were used as sensemaking devices. Participant narratives were then analysed to determine whether there were any patterns or order in the various plot usage within and across participant stories. During this stage, Rasmussen et al's (2020) spectrum model of parental biographical disruption and cohesion [See Ch 4.2.1 Childhood Illness and Parental Biographical Disruption] was used as an analytical tool to analyse the parental biographical response to their children's ADHD diagnostic journey. Once this had been completed for each individual parental participant, it was then explored whether the structure and utilisation of the various plot points give insight into how each parent, and the parents collectively, attempted to make sense of their journey. This cross-parental plot analysis sought patterns and transferable elements across the sample, whilst also analysing whether specific plots could be indicative of disruptive, cohesive, or other types of biographical response.

### 5.5.8. Stage 6

Within the final stage of data analysis, I actively reflected on my own role during data collection and analysis. In this stage I would reflect on the potential influence that I may have had during the interviews (such as which questions I had asked or not asked to different participants) and consider my individual relationship with each participant. During this stage, the plot of "And Yet, My Child is Amazing" was discounted as an overarching plot as I recognised that my desire for there to be more emotionally positive finding was not backed up with sufficient evidence within the data. Further outcomes of Stage 6 of analysis were discussed in the reflective discussion in Chapter 1 [1.4: My Story and Authorship].

## 5.6. Focusing of the Plots and Plot Summary

As mentioned in section 5.5.5, twelve narrative plots were initially extracted from the data. Although these plots were eventually reduced to seven overarching plots, it is hoped that transparency with the process of data analysis and justifications for these reductions will be of interest.

A summary of the initial twelve plots is presented below:

1. **There was a Problem:** Parents describe an awareness of their children having a “problem” pre-diagnostically. This plot was utilised early within overall narratives to justify the decision to begin the diagnostic journey
2. **The Diagnosis:** This plot explores the concept of diagnosis within the life of the family. The pursuit, concept, and receipt of a diagnosis is presented as an integral element in parental narratives.
3. **The System:** Parents merge the systems of healthcare and education into “The System”. The System is a major antagonist and source of dissatisfaction in parental narratives.
4. **The Fight:** A pervasive plot used by all parents to present the ADHD diagnostic journey as rife with conflict and battles, often with education and healthcare professionals, but also within families and society more generally.
5. **The Journey is Emotionally Challenging:** Parents describe the diagnostic journey as one involving intense emotions, both positive and negative. Parents narrate experiences of being lost at sea, breakdown, and isolation.
6. **The Mother [and Father]:** This plot explores how the diagnostic journey requires parents, particularly mothers, to consider their identity and self-conceptualisation as a mother or father.
7. **School is Important:** Explored whether parents considered school and education important for their children. The parental perception of schools importance was used as a justification for decisions throughout the journey.
8. **I Need to Parent Differently:** Every parent told stories of having to parent differently due to their children’s ADHD.
9. **Narratives Regarding Medication:** This plot explores how parents narrate the importance of, and decisions about, ADHD medication.
10. **ADHD is Different:** This plot emerged to explain how parents compare their ADHD children to other children, describing ADHD as making their children ‘different’. This

plot was also used by parents to discuss how ADHD is treated differently to other medical issues within society, often comparing ADHD to physical disability.

**11. The Balancing Act Between Disability and Difficulty:** All parents presented some reluctance to use disability language when describing their child. This plot explores the balancing act that parents traverse when conceptualising their child's additional needs in the context of disability and difference.

**12. And Yet, My Child is Amazing:** Where much of the narrative around ADHD focusses on difficulty and detriment, this plot was used by many parents to demonstrate that their experience was "not all bad". Parents would extol the positives of ADHD and challenge their own negative presentations of ADHD with a counter-narrative of positivity.

Although the above plots were felt to be evidenced in the data and worthy of discussion, as data analysis continued two considerations emerged. The first was a practical issue, as discussing twelve total plot points, and numerous associated subplots, within the allotted word limit of this thesis was deemed unrealistic. The second consideration was that there began to emerge a widening rift between above the twelve plots and the final condensed seven plots (discussed below) in terms of depth. It became evident that the final seven plot points were more widely represented across **all** parental narratives and aspects of the five discarded plot points were amalgamated into the seven final plots. Below is a brief justification of why plots were **not** included in the final seven:

**The Journey is Emotionally Challenging:** This plot had significant crossover in content with the overarching plot of "The Fight" [Ch 7.2] and the mothering subplot "The Guilty, Broken, and Fragile Mother" [Ch 8.1.2]. This plot was removed on this basis and was incorporated within other plots/subplots.

**School is Important:** In a similar vein to the above, this plot was felt to have considerable crossover with the overarching plot of "The System" [Ch 7.1]. This plot was also of limited inclusion in some parental narratives.

**I Need to Parent Differently:** Although this plot was present within many parental narratives, when analysing the content of the various excerpts utilising this plot it was felt that the need to parent differently was often discussed with relation to living with ADHD more generally, as opposed to being specifically regarding the diagnostic journey.

**ADHD is Different:** The two distinct elements of this plot were subsumed by other plots. Examples of parents comparing their ADHD child with other children was incorporated into the plot “There was a Problem” [Ch 6.1]. Stories in which ADHD is considered “different” to other illnesses and disabilities were incorporated in the plots “The Balancing Act Between Disability and Difference” [Ch 9.2] and the subplot “Framing ADHD Medication: ADHD and Physical Illness” [Ch 9.1.3.].

**And Yet, My Child is Amazing:** The exclusion of this plot was surprising. Given that ADHD research is typically dominated by negative portrayals, often due to no question regarding positives being included in data collection, it was expected that parents would utilise the opportunity to explore this aspect of ADHD more readily when specifically asked a question regarding positives. Ultimately, the positives of ADHD were not explored in great depth by parents and this plot was not felt to have been discussed in great enough depth or frequency across all the parental narratives to warrant significant discussion.

Once the above plots were excluded from data analysis, the final plots and associated subplots were finalised. The titles of final plots and sub plots are as follows:

**1. There was a Problem**

Subplots

A “Problem” in Infancy

A “Problem” at School

**2. The Diagnosis**

Subplots

Diagnosis as Understanding

Diagnosis as a Means of Accessing Support

The Emotional Impact of Diagnosis

**3. The System**

Subplots

The Parent Must Work Within The Confines Of The System

The System is Broken

The System Breaks You

Subverting the System

#### **4. The Fight**

#### **5. The Mother**

##### Subplots

The Good, Heroic, or Valiant Mother

The Guilty, Broken, or Fragile Mother

The Informed or Insider Mother

The Informed and Insider Father

#### **6. Narratives Regarding Medication**

##### Subplots

Positive Narratives Regarding Medication

Stories of Trepidation

Framing ADHD Medication: ADHD and Physical Illness

Medication Isn't Always the Answer

#### **7. The Balancing Act Between Disability and Difficulty**

##### Subplots

Initial Rejection of Disability

Tentative Acceptance of Disability Language

Non-Medical Paradigms and a Search for a Balanced View

These final seven plots and associated subplots were the most effective at personifying and explaining the lived experience and sensemaking process of the ADHD diagnostic journey across parental narratives. These 7 plots will be explored in detail within the findings Chapters [6-9].

## 5.7. Plots and Characters

Within this section the concept of the narrative ‘plot’ will be explored, defined, and distinguished from the similar concept of the qualitative ‘theme’. This discussion will be followed by a summary of each of the study participants.

### 5.7.1. Defining Plots

Some readers may be curious how the narrative plot differs from the more commonly explored ‘theme’ utilised within thematic analysis. Although some similarities do exist across the two concepts, this section will demonstrate the uniqueness of plots used within a sociocultural narrative analysis context.

‘Themes’ have been defined as patterns of shared meaning, often governed or supported by central organising concepts (Evans, Adams, and Hall, 2016; Braun and Clarke, 2019) or as an “idea or concept that captures and summarises the core point of a coherent and meaningful pattern in the data” (Braun and Clarke, 2006: 1). Schrap and Sanders (2018) describe themes as the capturing of salient aspects of data in patterned ways. The purpose and utilisation of themes is therefore similar to that of a narrative plot, as both aim to capture and summarise patterns and central concepts within the data. However, though there are noteworthy similarities, important differences exist.

The primary difference between plot and theme is that a plot is specifically interested in the purpose and presentation of the information within the context of a narrative or story. Where a theme can be inclusive of any data found in the dataset, both in quantity and context, a plot is exclusive to data which includes a storyteller presenting themselves or others within a wider narrative. Unlike themes, plots must have “characters” who are “doing” or being “done to”. The primary characters within plots are often, but not always, the participants themselves, as they narrate their experience in storied forms. A plot is therefore the presentation of a story pattern within the narrative and the *how* and *why* of the personal presentation of the characters. As discussed in section 5.5.4 [Stage 2 of Analysis] and 5.5.5 [Stage 3 of Analysis], the overarching plots of a narrative are made of up of multiple ‘micro-stories’. These micro-stories were amalgamated into the wider narrative plot after being scrutinised in the context of four questions unique to narrative analysis:

1: Why is the storyteller telling me this?

2: Why are they telling it now within the overall story?

3: How do they deploy evidence for their claims?

4: How are they presenting themselves?

Once these questions had been answered and plot formed, the plot itself can be scrutinised in its utilisation and usefulness for the overall narrative. For instance, one can ask how does the plot used by this specific storyteller [participant], influence and direct the overall narrative that is being given across the entire participant dataset.

Overall, although themes and plots are similar in concept and in practice, plots are exclusive in their necessity that they be interlinked with characters and story. The use of a plot is an active and typically purposeful process when compared with the qualitative theme. With this in mind, the primary characters within the parental narratives were the parents themselves, meaning that a brief description of the seven participants may be beneficial in enhancing understanding and giving additional context to their use of plot.

### 5.7.2. The Characters

Details have been altered and anonymised to maintain confidentiality.

**Sharon** – Sharon is the mother of a 9-year-old son who was diagnosed with ADHD during the study. Sharon sought assessment privately as she felt that NHS services are not to the highest standard. Prior to her son's diagnostic journey, Sharon received a recent diagnosis of adult ADHD. Sharon has experience working within CYPS, though she currently works elsewhere in healthcare. Sharon's main hope from the diagnostic journey was that her son trial ADHD medication given its effectiveness for her own difficulties. However, Sharon's story included a significant amount of worry due to her son expressing feelings of suicidality and engagement in self-harming behaviour.

**Pam** – Pam is the mother of two children, a son aged 8 and daughter aged 5. The focus of the study for Pam was her son's diagnostic journey. Pam was particularly concerned about long NHS waiting times and sought private assessment. During the study time Pam's son was diagnosed with ADHD and ASD. Pam worked as a mental health nurse within dementia services and expressed limited knowledge on ADHD, though following her sons diagnosis sought employment in ADHD services to help other families like hers. Pam sought diagnosis to better understand and support her son as she worried that he was having difficulties that other children his age did not. Pam described the diagnostic journey as an incredibly positive and uplifting experience where she felt supported, and her son was understood.

**Rachel** – Rachel is a single mother of 4 children (three daughters and one son) aged 26, 17, 14, and 2. The focus of Rachel's experience was her twelve-year-old daughter who was diagnosed with ADHD. This was Rachel's first experience with CYPS. During the study time Rachel worked as a care worker and cleaner at a local hospital. Rachel's journey included significant periods of waiting and limited to no contact from CYPS. During the Covid-19 pandemic and national lockdown, Rachel did not feel comfortable with her daughter starting medication and going into clinic which postponed her journey significantly. Rachel tells a story filled with challenge as her daughter was often violent and aggressive towards her.

**Debbie** – Debbie is a mother of two children, a 16-year-old daughter and 12-year-old son. Both Debbie's children have been diagnosed with ADHD, with her daughter going through the journey during the study time. Following the diagnosis of her son a few years ago, Debbie sought out personal assessment and was diagnosed with adult ADHD. Debbie described an incredibly negative experience of CYPS and assessment as her daughter was previously assessed for ADHD and told she did not meet the criteria for diagnosis. Debbie currently works as a social worker though during the study time went on sickness leave from her job which she states was due to the significant amount of stress that the diagnostic journey was causing her and her daughter. By the end of the study, Debbie's daughter was diagnosed with ADHD, which Debbie expected, but she was also diagnosed with ASD and dyslexia, which Debbie found upsetting and unexpected. Debbie's primary reason for the assessment of her daughter was so that she could begin medication to support her with her GCSE's.

**Jane** – Jane is the mother of two daughters aged 11 and 9. Jane's eldest daughter was previously diagnosed with both ADHD and ASD, and the diagnostic journey of her 9-year-old daughter was the focus for this study. Jane's daughter was diagnosed with ASD, though a diagnosis of ADHD was not given during the study timeline. Jane disagreed with this vehemently, believing that her daughter also has ADHD. At the time of the final interview Jane was in the process of referral for a second opinion assessment of her daughter. During the study time Jane began studying nursing at university to better support her daughters and others like them. Jane describes ADHD as a new stage of evolution, believes that society and the world are the core problem, and that society should fit to her neurodiverse children instead of children needing to fit into society.

**Cath** – Cath is the mother of two sons (aged 17 and 14) who both have a diagnosis of ADHD. Cath's eldest son was diagnosed previously and her youngest son was the focus for the diagnostic journey and was diagnosed with ADHD during the study period. Cath and her husband have also both received a diagnosis of adult ADHD since the diagnosis of her

eldest son, which has led to a strong sense of familial neurodiversity identity. It is particularly noteworthy that both Cath and her husband are ADHD specialist nurses and have a significant knowledgebase regarding ADHD and ADHD provision in the local area. For Cath, ADHD was both a strength and a challenge for her children, with the primary problem being a lack of appropriate ADHD specific support.

**Phil** – Phil is the only father involved within the study and is the parent of two children (a son aged 6 and daughter aged 1). During the study period Phil's son was diagnosed with ADHD and social communication difficulties, which was unsurprising and expected for Phil. Phil is a qualified mental health nurse and considers himself to have a good understanding of children's mental health and ADHD due to experience working in the area. Phil's primary goal for the diagnostic journey was to seek medication for his son to improve his academic capacity.

## 5.8. Presentation of the Study Findings and Discussion

The presentation of the findings and discussion of this thesis will be broken into the following four chapters. Chapters 6 to 9 are findings chapters which will discuss the seven core plot findings as outlined in section 5.6 of this thesis. These four chapters [6. A Problem and a Solution, 7. The System and The Fight, 8. The Mother, and 9. Medication, Disability and Difference] will detail and analyse the thesis findings, discussing their relevancy and connection to the wider discussion within both sociological and ADHD related literature.

Chapter 10 is a two-part discussion chapter. The first part of the chapter will give an analytical discussion of the development and structure of the parental diagnostic journey narrative, exploring the sequential and chronological usage of narrative plots across parental narratives. The second part of the chapter will consider the findings of the thesis in the wider context of parental 'illness work' (Corbin & Strauss, 1985; Singer, 2016).

## 5.9. A Return to the Project Aims and Research Questions

Prior to a presentation of study findings and discussion, it is important to reflect on the original project aims and research questions. This doctoral project aimed to develop understanding into the parental experience of the ADHD diagnostic journey. Although previous studies have explored the parental experience of having a child with ADHD

(Mcintyre & Hennessey, 2012; Rowland, 2017; Cocoran et al, 2017a; Cocoran et al, 2017b), or of the parental experience of a child being diagnosed with ADHD (DosReis et al, 2010; Carr-Fanning & McGucking, 2018), there is a dearth of literature exploring the parental experience of the entire diagnostic journey. This project seeks to begin to fill this literature gap using a longitudinal study of the overall diagnostic journey. To achieve this, the primary research questions were as follows:

- 1- What stories do parents tell regarding this journey?
- 2- What are the parental needs and experiences across the ADHD diagnostic journey?
- 3- Do these needs and experiences change across the journey and, if so, how?
- 4- How do parents make sense of the ADHD diagnostic journey?

This thesis argues that parents express their needs and experience during the ADHD diagnostic journey in storied forms. These overarching narratives are constructed using smaller micro-narratives which explore parental experiences or present evidence of parental needs. From this starting point, micro-narratives similar in theme and content were joined together to form narrative 'plots'. Narrative plots were often related to significant times and experiences throughout the ADHD diagnostic journey and can give insight into the needs of parents during this time. The findings suggest that parents make sense of their journey both retrospectively and 'in action'. Parental narratives often reflect on previous experiences and give examples to support their position. However, parents were also found to make sense of their journey during the storytelling process itself, reflecting and exploring their own needs in real time. Although each parental narrative was unique, significant similarities emerged across each story, outlined by the seven core plots. The following chapter will present the findings in relation to two of these core plots: Plot 1 "There Was a Problem" and plot 2 "The Diagnosis".

# 6. A Problem and a Solution [Plots 1 & 2]

## 6.1. Plot 1: There was a Problem

All journeys have a beginning. A starting point or catalyst from which the process commences. The first plot to be explored, “There was a Problem”, encapsulates the way parents narrate the beginning of their ADHD diagnostic journeys. Though the exact moment of this beginning was not always obvious or explicit, stories reflecting on the beginning of each parental diagnostic journey emerged as a major narrative plot utilised by all parents. Whilst every experience of this beginning is unique for each parental participant, occurring at different moments in their children’s lives, the storied presentation of this beginning across the parental narratives was ubiquitous and shared. The journey of contemplating, seeking, and eventually receiving a diagnosis and treatment for ADHD requires parental action, as the necessary engagement with education, health, and social care professionals throughout this process cannot occur in passivity. However, action requires justification and the first narrative plot to be discussed “There was a Problem” epitomises the presentation of every parental narrative’s justification, catalyst, or jumping off point from which their diagnostic journey began. “There was a problem” encapsulates the story plot, generally given early in the first interview, within which the parent presented evidence of a “problem” faced by their child which needed to be overcome. This section will explore how these “problems”, often taking the form of perceived differences of their child compared to others or relational, social, and/or educational difficulties, are presented by parents as the beginning and justification of their ADHD diagnostic journey.

### 6.1.1. A “Problem” in Infancy

Within their narratives, parents spoke of early awareness of there being a “problem” that impacted their children and required investigation. This awareness is captured in the subplot “A Problem in Infancy”. For Rachel, Sharon and Pam, the primary awareness of a “problem” was said to be present from a very early age.

### **Rachel 13-20**

*I've noticed that for a long time that there was **something wrong**. But I thought it was actually me. Cause when she was born, she was late. She wasn't early. And when I got her home, all she done was cry. From the day of coming out she just cried. No matter how much you comforted her or changed her and fed her and held her. Nothing would make her happy, and then as she was getting on, I noticed that she wouldn't smile. She wouldn't laugh. She wouldn't giggle until she was about 1 and a half, and that for me, that's **not normal**. You know I've got older kids and **she was different. That's how I knew she was different***

### **Pam 9-14**

*There's always been **something** about my son, Since being an infant **he's just not done what the books said he was supposed to do**. I've always had to like, be very person-centred towards him. I've tried my best and I think I'm doing a good job, but like, **he's different**. I think sometimes you think "am I doing something wrong?" and I find a lot of people judge and there's judgement, but I suppose that's why am I'm on the pathway.*

In both accounts, given within the first few minutes of the initial interview, Pam and Rachel describe an awareness of something being "different" about their children at an early age. Their accounts of these early concerns take on a nebulous aspect as their experience of their children's differences are described in loose and vague terms such as something being "wrong", and the child not doing "what he was supposed to do". Neither mother uses the term ADHD when exploring their early awareness of the "problem", but instead use the subplot of "A Problem in Infancy" to highlight that their current anxieties, and consequent existence on the ADHD diagnostic journey, are occurring due to longstanding concerns, not simply a current whim. Parental awareness of childhood difference at an early age has been reported in other work exploring parental experience and ADHD (Hammerman, 2000; Corcoran et al, 2017a). Evidence suggests that some parents of children with ADHD assert recognition of a 'problem' since birth (Hammerman, 2000) or of their children being 'different' by age 3 (Parker, 1994; Corcoran et al, 2017a). Spencer et al (2021) describe this experience as 'normalisation and hesitation' once a parent realises their child is different.

It is noteworthy that when presenting a growing awareness that their children were 'different' both mothers describe a questioning of their own parental ability. Rachel declares that she "*thought it was actually me*" and Pam queries whether she is "*doing something wrong?*". The experience of mothering identity and the concept of "good" and "guilty" mothers will be explored in depth within Chapter 8 [The Mother]. However, regarding the plot "There was a Problem", this early experience of blame and responsibility is of interest as it demonstrates further evidence to how and why the diagnostic journey began. Parents in Carr-Fanning and McGuckin's (2018) project regarding their experience of their children's ADHD diagnosis presented similar findings. In their study, childhood difficulties associated with ADHD symptoms were felt by parents to be attributed to a lack of "parenting ability", which the authors argue led parents to declare that these difficulties were "clear problems from an early age" prior to the current behavioural difficulties, combatting this assault on their character (Carr-Fanning & McGuckin, 2018: 206). DosReis and Meyers (2009) also reflect on this issue, stating that parents of ADHD children recognise their children's out-of-context and atypical behaviour and then commence answer-seeking behaviour to understanding this phenomenon. For Pam and Rachel, awareness began in early infancy, however, most participants described school as the beginning of their recognition of a "problem".

### 6.1.2. A "Problem" at School

The link between ADHD and school difficulties is an area of significant exploration across the literature (DuCharme, 1996; Bull and Whelan; 2006; Brinkman et al, 2009; Seawell, 2010; Eccleston et al, 2019). Although much of this work was conducted with parents of already diagnosed children, pre-diagnostic academic difficulties are referred to within all cited studies. For parents within this thesis, the plot "There was a problem" often included examples of pre-diagnostic academic difficulties as the earliest realisation of their children's additional needs, and the primary driving force to seek assessment and diagnosis. These stories are captured in the subplot "A Problem at School". The academic 'problems' presented by parents varied across educational environments, though it is noteworthy that all examples included some indication that their child was 'struggling' or 'falling behind'.

For Cath and Debbie, difficulties their children were experiencing in relation to educational examinations were cited as a major contributing factor to their decision and justification to commence the ADHD diagnostic journey. They both discuss their children's significant challenges regarding General Certificate of Secondary Education [GCSE] exams as the core "problem".

### **Cath 33-36**

*It never became an issue until he went to high school and then he really started to struggle with the organisation, with his focus. When it came to doing **written work and exams he really struggled.***

### **Debbie 26-30**

***She's got to her GCSE's, and everything is sort of falling apart in her life** and she broke down crying about 6 months ago and said "mum, I need help, I can't listen in any of my lessons I can't focus when people are speaking to me, I'm really concentrating but it's not going in".*

Cath and Debbie's focus on GCSE examinations as a major catalyst for their children's difficulties is perhaps unsurprising, given that higher levels of ADHD symptoms are linked to "significantly poorer academic outcomes" when compared to those without ADHD (Birchwood & Daley, 2012: 228). In their report, Birchwood and Daley (2012: 229) also state that ADHD symptoms are "almost as important as cognitive ability and motivation in predicting GCSE performance". Within Cath and Debbie's stories, their children's GCSE performance and related stress are presented as the primary driving force in their commencement of the ADHD diagnostic journey. However, for Phil and Sharon, their first recognition and utilisation of the subplot "A Problem at School" is narrated as occurring earlier within their children's schooling, centred around reading difficulties

### **Phil- 91-105**

*He's about a year to 18 months behind academically at school. His writing is quite basic. He doesn't have enough attention to actually learn to read. Although he does recognise words and stuff like that, but learning to read, he doesn't seem to want to do it now... He just hasn't got the attention to be able to sit and learn for any period of time. I mean, trying to teach him the alphabet, you get maybe a third, two thirds of the way through and he has lost interest. His attention has gone elsewhere.*

### **Sharon 8-17**

*So, I guess it started when he was in year one, I noticed that he **struggled to concentrate** when he was doing his reading books. Daydreaming. We've known since he was a baby, we've all known that in the family.*

Within Phil and Sharon's stories, their children's difficulties learning to read is seen as the original "problem" when using this subplot. Although they cite reading difficulties, both parents also specify that these difficulties were felt to be due to concentration problems as Sharon's son "*struggled to concentrate*" and Phil's son's "*attention has gone elsewhere*". Like Cath and Debbie's acknowledgement of GCSEs as a 'problem' and the corresponding evidence linking poorer GCSE performance and ADHD symptoms (Birchwood and Daley, 2012), Phil and Sharon's focus on reading as a primary issue is further evidence of parental awareness of typical ADHD related difficulties prior to diagnosis. Multiple studies have revealed links between children diagnosed with ADHD and reading difficulties (Wadsworth et al, 2015) or co-occurring reading disability (Faraone et al, 1998; Willcutt et al, 2005). However, the present study findings indicate that parents of children on the ADHD diagnostic journey are not only pre-diagnostically aware of their children's commonly associated ADHD related difficulties, but that these difficulties are narrated as the primary 'problem' needing to be investigated and the justification for the diagnostic journey itself.

A final way in which parents utilised the plot of "There was a Problem" in relation to the subplot "A Problem at School" is presented by Jane:

#### **Jane 34-40**

*At her new school, they started spotting that **she was so significantly behind**. They started to get phonics interventions in place. The school were giving her a bit more support, but she was in different groups, and she was being taken out of the class a lot. So, we kept pushing the school and letting them know what the problems were, and talking to the doctors and things, and talking to the nurse at the GP surgery, who made a referral when she was in Year 3.*

Jane's excerpt presents further parental engagement with the subplot of "A Problem at School". Unlike previous examples of reading and examinations, Jane's story gives a broader and more general presentation of the 'problem', explaining how her daughter was "*significantly behind*" and how school were introducing increasing amounts of educational interventions. Jane also explores how she played an active role in commencing the diagnostic journey due to these problems, as Jane and her partner "*kept pushing the school*" and engaging with healthcare professionals.

### 6.1.3. Conclusion

In conclusion, all parental narratives began with some iteration of the plot “There was a Problem”. Stories of a “problem” to be overcome and the deployment of evidence to support this claim allowed parents to give a justification for their decision to begin the diagnostic journey, a reason for their emotional or challenging experiences, or as a counterargument to the potential that they had failed or made mistakes as a parent. The finding of this plot, especially when considering Pam and Rachel’s presenting of this plot as present in early infancy, is in direct contrast to Pajo and Cohen (2013) and other ADHD researchers, who found that parents usually seem unaware of, or unconcerned with, any problem with their child before the school years (Blum 2007; Cohen 2006; Leslie et al. 2007; Malacrida 2001). Although there was some focus on early infancy in relation to the “problem”, the dominant utilisation of this plot was regarding educational difficulties. Every parental narrative within this study included examples of school based ‘problems’, often presenting these issues as contributors to commencement of the diagnostic journey. For most parents, although there may have been awareness of the problem prior to their children’s engagement with the educational system, academic difficulties were regularly cited as the primary rationale in starting the diagnostic journey. It appears that there are two major factors at play within this phenomenon.

In the first instance, symptoms of ADHD have been found to have significant negative impact on academic performance across the lifespan of education (May et al, 2020), with concentration, inattention, hyperactivity, and organisation having the greatest impact (Corder et al, 2015; Galera et al, 2009). Problems in academic attainment are often cited as one of the most prominent negative aspects of living with ADHD (Frazier et al, 2007), and links have been found between ADHD and reduced literacy and increased special educational provision (May et al, 2020). A large cohort study of 600,000 children in Denmark also found that both males and females diagnosed with ADHD achieved lower mean grades and were statistically “significantly less likely” to undertake their final school exam (Dalsgaard et al, 2020: 800). These issues, coupled with poorer GCSE performance (Birchwood and Daley, 2012), create an environment where children with ADHD, diagnosed or pre-diagnostically, are significantly more likely to experience school-based difficulties.

Simultaneously, increasing awareness of their children’s negative educational experiences and academic difficulties were acutely experienced by parental participants. Issues with education and learning were presented as major “problems” within parental stories using the plot of “There was a Problem”. These issues often led to increased parental involvement in

education and healthcare in a parental attempt to ameliorate their impact. Increased parental involvement and concern in children's education is a major objective in educational policy and has been argued to have become increasingly salient for parents across the world (Pomerantz et al, 2007). Increased parental involvement has been found to have significant positive effects on general academic performance in typical school populations across multiple meta-analyses (Fan & Chen, 2001; Jeynes, 2005, Wilder, 2014; Tan, Lyu, & Peng, 2020), and has become a typically accepted positive phenomenon within Western education. Although there is some evidence that increased parental involvement does not buffer against the negative effects of ADHD on academic difficulties (Jaida et al, 2022), the findings of this study suggest that parents are acutely aware of their children's academic difficulties. Within the participant narratives, the interaction between this increased awareness and the reality of their children's academic difficulties is captured within the plot "There was a Problem". To investigate and resolve these 'problems', parents describe a quest in which they search for a solution and, given "people go to the doctor to find out what is wrong" (Jutel, 2009: 293), the potential solution to these problems is personified in the next plot: The Diagnosis.

## 6.2. Plot 2: The Diagnosis

Perhaps the most prominent and wide-reaching plot utilised by parents was regarding the impact of seeking and receiving a diagnosis. “The Diagnosis” was, perhaps unsurprisingly, a prominent feature within parental narratives given that the primary outcome of the diagnostic journey was expected to culminate in a diagnosis of ADHD. The plot of “The Diagnosis” is used by parents to narrate the meaning and conceptualisation of ADHD diagnosis, often including examples of benefits granted by a diagnosis alongside the emotional impact of the experience. Diagnosis was strongly associated with increased understanding and was presented as a necessary means by which the child could access additional support. Three subplots underpin the overarching plot of “The Diagnosis”: “Diagnosis as Understanding” [6.2.1], “Diagnosis as a Means of Accessing Support” [6.2.4], and “The Emotional Impact of Diagnosis” [6.2.5].

### 6.2.1. Diagnosis as Understanding

Parents tell stories about how the journey towards, and eventual receiving of, an ADHD diagnosis was a quest for increased understanding of their children’s needs and their child’s experience. Parents often cited that increased understanding through diagnosis could be gained either **for** the child, **of** the child, or **for** others. Regarding increasing understanding **for** the child, Cath explains:

#### **Cath 1335-39**

*I used to worry before he had the diagnosis. He had lots of issues with anxiety. He would get quite low. Comfort eating. But I feel more positive now he’s got a diagnosis because **he can understand** why he might struggle and understand the reason for why he struggles.*

For Cath, ADHD diagnosis was presented as a way her son could make sense of his challenging ADHD related experiences, giving them meaning and granting additional understanding. This process represents reestablishment of “credibility in the face of the assault on selfhood” (Bury, 1991: 455) brought on by the unusual or atypical illness experiences that ADHD presents. For Cath, this additional understanding enables her son to reframe and re-evaluate experiences he finds difficult due to ADHD and hopefully improve

his self-confidence and esteem. The concept of a diagnosis increasing understanding **for** the child was also argued by Debbie in her first interview:

**Debbie 466-74**

*Doesn't everybody need to know what they are? It's like the core of you isn't it? Whether you like it or not it makes you who you are. Whether it's your curse or your whatever. It makes you who you are. So **how could you understand yourself if you don't know what's making you tick**. Her friends all call her ditzzy. If you know her, you would think she was thick, you'd think she was thick as shit you really would, some of the stuff she comes out with is like. What the hell? You just think how can an intelligent girl think those things, **I think for her it would be really good for her to think "I'm not just this scatty ditsy girl"**.*

For Debbie, ADHD diagnosis represents an important tool with which her daughter could learn “*what's making her tick*”. Similarities exist between the way Cath and Debbie utilise this subplot, as both feel that the receiving of an ADHD diagnosis would allow their children to perceive themselves differently. For Debbie, diagnosis allows her daughter to re-evaluate herself as “*not just a scatty ditsy girl*”. Additionally, diagnosis presents an almost existential perspective for Debbie when she declares that you couldn't understand yourself if you “*don't know what's making you tick*”. During Debbie's first interview, she strongly believed that the receiving of a diagnosis would be a positive thing for her daughter to be able to make sense of some of her difficulties. However, in a later interview further along Debbie's journey, she recanted on this statement, stating that when her daughter did receive a diagnosis of ADHD it negatively impacted her own understanding of herself.

**Debbie 832-835**

*She tried to talk to her friends about her diagnosis and they weren't interested obviously because they're 16-year-old kids. She said that nobody understands that my whole life has changed and I'm 16 and **I don't know who I am anymore**. It's really knocked her. Maybe it was a mistake pushing for it all?*

This passage demonstrates how, although parents may assume and hope for additional understanding **for** the child post-diagnosis, the opposite may be true. Like other parents such as Cath, Pam, and Phil, the assumption of increased understanding post diagnosis was used by Debbie as justification in seeking a diagnosis of ADHD. Unfortunately for Debbie and unlike other parents, this expectation did not come to fruition. The negative experience and lack of understanding that her daughter experienced post-diagnosis led Debbie to

question the entire process of seeking diagnosis when she states, “*maybe it was a mistake pushing for it all?*”. Parental use of this subplot corroborates with evidence of increased self-understanding for the person diagnosed as a diagnosis of ADHD has been found to explain difficulties faced in a positive manner (Halleröd et al, 2015) and grant greater awareness of manageability and meaningfulness (Fleischmann & Fleischmann, 2012). However, like Debbie’s daughter’s experience, a diagnosis may also be negatively experienced as evidence of being “mad, bad, and out of control” (Ringer, 2019: 220) or different from others (Hallberg et al, 2008).

### 6.2.2. Understanding For the Parent

Parental engagement with the subplot of “Diagnosis as Understanding” also captures the way parents describe ADHD diagnosis as beneficial in helping them better understand the needs and experiences of their child.

#### **Pam 122-133.**

*Interviewer: What would a diagnosis of ADHD give you?*

*Pam: **Understanding. Understanding him better.** Hopefully, some advice on what to do to help him deal with that. ... **I think it would help us to help him better.** Moving forward, I know there’s an increased risk of alcohol and drug misuse so like. Maybe just some help around giving him education and guidance around that. To help him understand himself better. Some education for him as well to get support for him*

*Interviewer: What would it mean to you?*

*Pam: **It would mean I would understand him better. It would mean I wasn’t a bad mam. I’ve been a good mam. I just didn’t know or understand him.***

Pam’s excerpt demonstrates her perception of diagnosis as a tool with which she could better understand and effectively support her son. The diagnosis would allow Pam to recontextualise and understand her sons needs and effectively target support, a benefit commonly associated with diagnosis (Jutel, 2009; Carr-Fanning & McGuckin, 2018). Pam also states that diagnosis would mean she “*wasn’t a bad mam*”, a perspective explored

further in Chapter 8 [The Mother]. Nonetheless, ADHD diagnosis has been associated with reductions in mothering guilty and shame (Gwernan-Jones et al, 2015; Davies, 2018). Potentially due to the ability to engage in biological repertoires of understanding ADHD and recontextualise the child from 'poorly behaved' to a child with a medical condition. Cath further explores this subplot:

**Cath- 92-98**

*Interviewer: What was your hope going through the assessment and assumedly to diagnosis?*

*Cath: To **understand their needs**, whatever comes out of this, it's about where you might struggle. But where your strengths are as well and it's about how we can use your strengths but also about how we can help you with places where you struggle. and if it isn't ADHD, what is it? What is it that's causing this difficulty and upsetting you? What is it that causes you distress? Why do you struggle to follow instructions and brush your teeth and remember to do those simple things that most kids have got nailed by the time their sort of 7-8?*

Like Pam, Cath clearly states that her primary hope for the diagnostic journey is to better understand her children. Both mothers hope that the journey would give them an increased understanding and awareness of their children, alongside their specific needs. This desire to understand *through* diagnosis was present across all parental narratives and a diagnosis of ADHD is seen by parents as a useful way to understand their children's idiosyncratic behaviour, non-typical needs, and challenging experiences. This subplot is validated from previous studies in which the parental pursuit of diagnosis has been described as a 'battle for understanding' (Harborne, Wolpert & Clare, 2004).

### 6.2.3. Understanding For Others

The final iteration of the subplot "Diagnosis as Understanding" can be seen in Jane's narrative, where ADHD diagnosis is perceived as necessary so that wider society would understand and treat her daughter better.

**Jane 981-84**

*With my youngest she gets the support that she can get for society's expectation. Because once her sister got her labels, **the world changed**. It doesn't change us,*

*and it doesn't change her. It doesn't change how we treat her. It **changes how outside accepts her.***

For all parents, the diagnostic journey was a journey of sensemaking and understanding. Prior to receiving any diagnosis, parents would discuss hopes that the journey would bring additional understanding. For Jane, the seeking of a diagnosis of ADHD for her second daughter was felt to be a necessary process to allow the outside world, and society more generally, to understand and accept her. Jane argues that the understanding gained from a diagnosis is not necessary for her or her daughter but is an unfortunate requirement within a society that requires diagnostic labels to accept difference. The diagnosis became “Understanding for **Others**”.

Overall, the subplot of “Diagnosis as Understanding” encapsulates how parents see an ADHD diagnosis as an informative and beneficial tool of understanding **of, for, and towards** their children. The concept of diagnosis as legitimation demonstrates how diagnosis helps individuals “gain control over their condition”, “establish a proper sense of perspective on their experience” and to “re-establish credibility in the face of the assault on selfhood” (Bury, 1991: 455). The process of re-establishing credibility via diagnosis is apparent within the subplot of “Diagnosis as Understanding”, as diagnosis is presented by parents as a way for others to “understand” their children better and to bring context to their children’s challenging and unusual experiences. This understanding typically includes the assumption that their children will receive additional societal permissions to be different due to their ‘ill/diagnosed’ status (Parsons, 1951; Jutel, 2009). Although the term ‘ill’ may not be wholly appropriate within the context of ADHD due to linguistic issues previously explored [Ch 2.7 A Note on Terminology: Illness and Disability], the diagnosis of ADHD was seen by parents to legitimise their children’s difficulties and *differences* within society. ADHD diagnosis represents a ‘claim for exception’ (Parsons, 1951), indicating that the ADHD child is different from the typical child and requires alternative expectations and management. There is some evidence suggesting that the parental hope of increased understanding blossoms into fruition, as teachers have been found to accept poor or undesirable behaviour more readily from children diagnosed with ADHD by recontextualising (or perhaps understanding) the behaviour as medical in nature (Rogalin & Nencini, 2015; Moore, Arnell, & Ford, 2017).

#### 6.2.4. Diagnosis as a Means of Accessing Support

Parental narratives also included examples their children's additional support needs within educational, home, and social environments. However, although parents felt that their child needed additional support due to what they pre-diagnostically perceived as ADHD related difficulties, many found this support challenging to access without a diagnosis. Parents presented stories describing ADHD diagnosis as a necessary bureaucratic measure to access specific support by legitimising their children's needs:

##### **Debbie 432-438**

*I just want the diagnosis that I think she should get, then I won't be wanting anything, I want her to be able to help herself and then we can do what we need to do. **I mean really CAHMS is just a means to a diagnosis and then if you choose it, medication, isn't it?** It's more getting the label for school isn't it, so then school can give you the help you need?*

Debbie's belief that educational support is not forthcoming without diagnosis is corroborated by Jane:

##### **Jane 344-347**

*Her sister wasn't given any support until she had her diagnosis letter. Schools wouldn't do anything until there was a diagnosis letter. It's all about funding for schools.*

The subplot "Diagnosis as a Means of Accessing Support" captures parental narration of a wider sociological phenomena in which diagnosis represents a socially accepted tool for negotiating and communicating experience to the wider world (Bury, 1991). Medical diagnosis allows access otherwise unauthorised social privileges and support such as illness leave, reduced workloads, and financial aid (Jutel, 2009; Singh, 2016). Within this study, the 'unauthorised social privileges' being sought via diagnosis were predominantly school related, such as additional exam time, classroom support, and acceptance from teachers that their child may have difficulties other children do not. These examples personify the backbone of common non-medication school-based interventions beneficial for children with ADHD (Barkley, 2015), yet were often denied to children of parents within this study prior to diagnosis. Parents engage with this subplot pre-diagnostically to explore their hope that diagnosis will grant access to support and post-diagnostically to reflect on the unfortunate

reality that access to support occurred only after a diagnosis was given. The necessary parental ‘illness work’ (Corbin and Strauss, 1988) performed throughout this process of diagnosis and support seeking forms a significant portion of the discussion within Chapter 10.3.2 [The Diagnostic Quest]. Accessing additional school-based provision was presented by Phil as the primary benefit of diagnosis:

**Phil 821-825**

*What I see, in the sense that the diagnosis is there now, it will help him educationally. It will get him the help he needs. That is the only reason we have gone down the route, is we can see him struggling educationally.*

As academic difficulties are commonly presented as the primary concern for parents of children with suspected ADHD [Ch 6.2.2: There Was a Problem], it is logical that parents seeking diagnosis do so in hope of accessing additional school-based provision. This study’s findings suggest that parents see ADHD diagnosis as *useful* for targeting additional support, but also as *necessary* to subvert practical barriers in accessing these supports pre-diagnostically. The concept of “Diagnosis as a Means of Accessing Support” is prevalent throughout the parental literature on ADHD, given that a diagnosis allows for additional governmental assistance in the form of SEN support, Disability Living Allowance [DLA] (Gov.UK, 2020), and protections under the Equality Act (2010). The findings of this study supplement previous research in which parents faced challenges in accessing support without diagnosis (Cocoran et al, 2017b). Furthermore, 67% of the 3,616 caregivers in Fridman et al’s (2017) European study felt that schools could do more to help those with ADHD, indicating continued dissatisfaction with school-based support for ADHD children.

### 6.2.5. The Emotional Impact of Diagnosis

The final subplot utilised by parents under the overarching plot of “The Diagnosis” demonstrates the emotional impact of pursuing and receiving a diagnosis. Pam and Rachel’s excerpts show how ADHD diagnosis can be a significantly positive emotional experience:

**Pam 376-385**

*I’ve been questioning, what are we missing here? Have I been doing something wrong? ...he gets very frustrated at himself, has low self-esteem and puts himself down. You think hang on, you praise him, what are we missing, are we doing something wrong? There’s always been a bit of a difference, a something that we’re*

*missing, I know that I can get a bit anxious sometimes so is he getting it off me? But now I think, God actually **we've been doing such a good job** and not even realising it... I think without realising it we have been supporting and scaffolding him and doing things really well. **I actually feel really good about myself now we've been doing all right***

It is evident how confirmation of her son's ADHD diagnosis enables Pam to recontextualise and reconstruct her self-image and confirm her mothering ability. The diagnosis provides Pam with the answers of "*what are we missing?*", ameliorating anxieties around her parenting decisions and reducing feelings of self-blame and shame. This process of biographical reconstruction and cohesion (Williams, 2000; Rasmussen, Pederson & Pagsberg, 2020), alongside further self-biographical illness work (Singh, 2016) will be explored in depth in Chapter 10.3.3 [Biographical Illness Work]. For Rachel, the following excerpts exemplify the significant impact of having a previously inconclusive assessment and then having a professional support her feelings regarding ADHD:

#### **Rachel 131-136**

Rachel reflecting on how a diagnosis was not given on the initial assessment

*It felt like a kick in the teeth and getting put back to square one. I was hoping that this is it, this could be it. It's like when you find out that it's not, it's like someone has just **ripped your insides up** and dumped you back in the ocean and made you swim to the shallow end. I'm thinking **I don't know how much more I can go through** because I just need the proper help for her.*

#### **Rachel 147-154**

*When he says it looks like ADHD but it's harder to diagnose in a girl because of how they are personality wise and stuff like that. I'm thinking...it was just a relief... all of them doors that opened...it's took so long and so much energy that I thought my god, is it for real? Ya na? Are you's sure? He's like yeah it's definitely ADHD. I've waiting all them years just to hear that from a professional **it was everything, it was everything I wanted to hear so that I knew that I wasn't going mad.** so, everything starts here now seen as though I've got that diagnosis. Hopefully life is going to be easier for her because I know it hasn't been easy for any of us*

The contrast between the two passages is palpable as Rachel describes not receiving a diagnosis as a viscerally emotional experience where professionals "*ripped your insights up*

*and dumped you back in the ocean*". The positive affirmation experienced once a diagnosis is suspected is equally evident, as "*doors open*" and Rachel could confirm she "*wasn't going mad*". These findings echo previous studies on the parental experience of their children's ADHD diagnosis, where diagnosis is experienced as legitimising and validating of the difficulties and challenges faced by parents (Carr-Fanning & McGuckin, 2018), whilst also granting an increased sense of parental control (Klasen, 2000). The shame and guilt reducing benefits of ADHD diagnosis are well documented (Cocoran et al, 2017a), as medical diagnosis allows children's difficulties to be reframed as a symptom of the condition and not the parent's fault (Singh, 2005; Gwernan-Jones et al, 2015; Ghosh et al, 2016). The subplot of "The Emotional Impact of Diagnosis" adds to existing literature, strengthening the claim that parents experience reductions in self-blame through ADHD diagnosis (Brunton et al, 2014). This transformative emotional experience is evident in Pam's re-evaluation of her parental ability post-diagnosis:

**Pam 380**

*We've been doing such a good job and not even realising it*

## 6.2.6. Conclusion

The plot of "The Diagnosis" encapsulates the multitude of ways in which parents explore and narrate their perceptions, needs, and experiences regarding ADHD diagnosis. Diagnosis is perceived as a method of increasing understanding and a necessary measure in accessing appropriate support. ADHD diagnosis allows parents to reconstruct and reframe the maelstrom of difficult emotions experienced across the diagnostic journey and develop a more coherent and stable biographical identity (Bury, 1982; Corbin & Strauss, 1988). Unlike psychiatric diagnoses, which are typically experienced as distressing and "undermining of one's individual identity" (Perkins et al, 2018: 13), all parents within this study found the label of ADHD meaningful and empowering. A discussion on why parents within this study experienced an almost universally positive response to diagnosis will be presented alongside examples of each parental response in Chapter 11.3.4 [Self-Biographical Illness Work].

It is worth noting that in two of the interviews, once the recorder was stopped, parents expressed some concerns regarding the potential for their children to face stigma and discrimination once diagnosed with ADHD. The experience of stigma (Goffman, 1963) towards ADHD is well documented within the wider literature (Koro-Ljungberg & Bussing,

2009). The risk of social stigma around ADHD has been associated with social rejection from adults towards children (Martin et al, 2007) and social aversion amongst undergraduates (Canu, 2008). Metzger and Hamilton's (2020) paper also explored how teaching staff are less likely to acknowledge above average performance and more likely to acknowledge poor performance for children with ADHD, regardless of actual demonstrated ability. However, the findings of this study suggest that parents were significantly more concerned with the negatives of not receiving a diagnosis, than the potentially damaging stigma related outcomes of receiving one. The following passage by Pam given in the final interview encapsulates the true power of diagnosis and incorporates all subplots in a succinct manner:

**Pam 841-843**

*That has been the healing thing. **The diagnosis.** Purely from there, you get to understand, you get support, and you can build on that. And that is **IT** from then on. People take you seriously and you're not just a neurotic mother*

Where this chapter explored the parental experience of a “problem” [Plot 1: There Was a Problem] and the journey towards a “solution” [Plot 2: The Diagnosis], the following chapter will explore the parental experience of the diagnostic journey within the context of the overarching system within which it operates. The plots of “The System” and “The Fight” will be presented as narrative devices used by parents to explore their experiences of engaging with the systems of healthcare and education, and the conflict laden nature of the diagnostic journey.

# 7. The System and the Fight [Plots 3 & 4]

## 7.1. Plot 3: The System

The third plot to be explored is “The System”. Parents utilise the plot of “The System” to explore interactions with, and experience of, the complex interlocking networks of the healthcare and education systems. These stories were often filled with negative experiences, distressing emotions, and everyday practical challenges. Within “The System”, four distinct subplots emerged: “The Parent Must Work Within the Confines of the System”, “The System is Broken”, “The System Breaks You”, and “Subverting the System”.

### 7.1.1. The Parent Must Work Within the Confines of The System

Parents utilise the subplot “The Parent Must Work Within the Confines of The System” to explore how they are forced to interact with various systems relevant to the ADHD diagnostic journey. Regarding healthcare and the perceived importance of medical diagnosis previously discussed [Ch 6.2: The Diagnosis], parents feel forced to interact within the boundaries and limitations of the system of healthcare to have their difficulties “seen”. Freidson’s (1972) assertion that health professionals are ‘custodians of the label of deviance’ rings true, as parents experience a need to legitimise their experience through interaction with medicine. Although interaction with these systems is necessary during the ADHD diagnostic journey, stories regarding their constricting nature were often filled with dissatisfaction. For instance, Phil describes the multitude of practical problems he experienced due to his needing to fit within the system, as opposed to the system adapting to his needs as a father and service user.

#### **Phil 1480- 1487**

*The only frustrating thing I find at the moment is that they know when my son’s prescription ends, you get 28 days at a time. Yet you have to ring up 10 working days in advance, halfway through your current prescription, for it to be sent to the wrong chemist.... twice.*

*And then I think, the thing at the moment that I do struggle with, and I have brought up is that, so I work in the centre of Newcastle, so to give me an 11,12,1,2pm appointment means its halfway through my working day. So, to come away from work there's no point in going back, so you lose that chunk of time.*

### **Phil 1497-1500**

*One day I said, not Wednesday because Wednesday is the day I spend working for another team. So, if I'm not there on that Wednesday I miss it. It's really frustrating that you say that to somebody, they say they'll let the consultant's secretary know, and the next appointment totally disregards you.*

As can be seen, the processes and procedures regarding prescription ordering and appointment booking were practical frustrations for Phil, as he is forced to work within the confines of the administrative system of the NHS. Rachel and Debbie's exploration of this subplot give different perspectives. Debbie explores how her partner had to navigate this complex system alongside her, and how many parents must "just accept" what is happening throughout the journey.

### **Debbie 1256-1262**

*He's just an ordinary guy trying to navigate this system and support the kids and you know, some parents must be really disadvantaged because of that. They probably bow down to their authority. We think as these people as very eminent, intelligent, and powerful people. They are very powerful. They are in a position of power, where people believe in them and listen to them and for a lot of parents. They can't argue with it or whatever, they just accept what they say.*

The acceptance that Debbie explores is also present within Rachel's excerpt, where she had to "play the waiting game" and "see what happens" instead of having her needs met.

### **Rachel- 124-129**

*It was a slippery slope, because obviously I know that she isn't the only person on their list, but waiting for appointments and stuff like that, **I had to be patient and play the waiting game.** It was no good being on their back 24/7 "I need this done, I want it done now, I want her assessed" because I'm not like that. I thought I'll just wait and see how far I can go with the school. I thought we'll see what happens.*

Across the participant sample, there was a shared understanding that parents who sought ADHD diagnosis for their children had to work within a system that failed to take their individual needs into account, and that they could expect procedural inefficiencies and long waiting times. The expectation that those experiencing medical issues must engage with wider systems of healthcare and education to have their experience seen and legitimised has seen recent discussion (Rushforth et al, 2021). Although there is some argument that ADHD may be negotiated outside of the jurisdiction of medicine (Conrad & Potter, 2000), the reality for parents within this study was that they feel forced to interact with a medical system that gives insufficient support. This issue has seen discussion within wider disability studies, as parents describe “agonising and prolonged experiences with institutions such as education, healthcare, and welfare, and wider structural hostility” (Thomas, 2020: 454). However, these minor, often practical, confines were paltry concerns for parents when compared to the following subplot, “The System is Broken”.

### 7.1.2. The System is Broken

Where the previous plot explored how parents felt restricted and forced to interact with “The System”, this subplot is focussed on parental stories describing “The System” they are forced to interact with as fundamentally broken. All but one parent was vocal about their dissatisfaction and anger at the ‘broken’ healthcare and school systems. This subplot was used multiple times by most parents and was often accompanied by highly expressed emotions such as anger and sadness. For some parents, the system is unequivocally unfit for purpose:

#### **Debbie- 192-198**

***The system is all wrong. You shouldn't have any kid waiting for nearly a year, because what you've got to remember is what they've gone through before they've even got to that stage as well. It's not like one day you wake up and go "oh I think my kids got ADHD I'll go to the doctors and them diagnosed". These people have lived with like, constant clobber probably, for a good few years before they even get the referral to CAHMS. and then to be told you have to wait nearly another year for a diagnosis, and then for some people they have to fight for that, it's just mad isn't it? I don't think it's a very good system, it doesn't work, there's no common sense there.***

### **Jane 1469-1473**

*It's a shit system. I feel, it's a bit too conveyor belt like, and if you are not a parent of a kid that is lashing out in the classroom and kicking the teachers and throwing things. If you are not a 'behavioural difficulty' in a classroom, the schools don't refer you.*

### **Pam 610-614**

*I think it's wrong. It's **just wrong the way the whole system is**. The kid shouldn't have to wait 3 to 5 years, the waiting list at the minute I've been told. And we had to pay a lot of money, but we don't mind. But you do think that this is just wrong, these are children. This is where the money should be*

As can be seen, parents utilise damning and negative language to describe systems linked to the ADHD diagnostic journey. O'Conner et al (2018) explores how current models of mental health admission policies leads to individuals falling through the cracks, an issue which both Jane and Debbie feel is present within the ADHD diagnostic process. Debbie's concern that kids are waiting up to a "year" is unfortunately a relatively optimistic portrayal of the current experience of the ADHD diagnostic system within the UK. Current estimates of waiting times for children and parents seeking ADHD diagnosis range from one to over five years, with huge disparities between mental health trusts (Roughan & Stafford, 2019); an issue described by national news outlets as "scandalous" (Lindsay, 2020). Failure of the UK healthcare system to provide appropriate provision for childhood ADHD diagnosis fuelled a national expert consensus statement (Young et al, 2021) pointing to cultural and structural barriers across all aspects of the ADHD healthcare system. The organisation of ADHD assessment pathways has been described as inconsistent (Paidipati et al, 2022), inequitable (Lu et al, 2022), unfriendly (Spencer et al, 2021), and misleading (Young et al, 2021) due to unacceptable waiting lists and structural barriers. Parental engagement with the subplot of "The System is Broken" validates these findings and suggests that parents are acutely aware of these systemic failures. Phil explored his frustration in relation to inconsistent waiting times:

### **Phil 37-45**

*Little bit annoyed that the last time we spoke to the assessor was towards the end of June [1 month prior] and it was kind of, "oh well, I've got as much as I can for the moment, I'll give you a ring next week". I ended up chasing it up because it's like...that's a little bit more than a week. I understand people are busy. Been in the*

*service, worked in the service, know how demanding it can be, but over a month is NOT a week. Even if it's just a quick email. I'm on the trust email as well. Just a quick email to say "look, things are just taking a bit longer". That would have been fine.*

Although the consensus statement focussed on long waiting times, unavailable services, and blame or dismissal towards parents (Young et al, 2021), this thesis adds to the body of knowledge by demonstrating an additional point of significant frustration within the "Broken System": inconsistency with care co-ordinators. The care co-ordinator is responsible for the overall delivery and ordering of the service user's diagnostic journey. They are the point of contact for queries and the individual who will compile the evidence for diagnostic assessment. Parental dissatisfaction with care co-ordination was presented as further evidence for "The System is Broken":

**Jane 1193-1197**

*They just tell you what they think you want to hear at least that's what I think. So you're not on the list and you're not waiting, maintaining their targets, that's what it feels like. Then we had another meeting with "Jenny", and "Jenny" said she is not going to be the care coordinator anymore so that is now three care coordinators that my daughter has had. She has had no consistency through her assessment process.*

**Cath 1433-1436**

*He was diagnosed, given one care coordinator, then we got another one. We got a letter just a couple of days ago saying that he's now got a new care coordinator. So, his next appointment will be with a different person.*

Thomas's (2020) thesis regarding the stories of parents of disabled children explored how parents spoke of a healthcare system in which staff lacked not only the experience and training to support disabled children, but also the ability to "see" children and their needs. His findings are replicated here in relation to the ADHD diagnostic journey, as parents see inconsistencies in care co-ordination as a disregard for their and their children's needs. Pam sums up "The System is Broken":

**Pam 803-804**

*It's not just crap, its worse than crap. It's neglectful. It's awful. It cannot be right.*

The next subplot represents an unfortunate by-product stemming from the previous two subplots. The consequence of parents being forced to work within the confines of a broken system leads to a third subplot: “The System Breaks You”.

### 7.1.3. The System Breaks You

The disastrous results following interactions with the broken system featured in all parental narratives. This subplot was used by parents to tell stories of how forced involvement with the broken system can “break” you emotionally. It is important to differentiate between this subplot and the overarching plot of “The Fight” [Ch 7.2], as although there are some similarities, there is also an important difference. “The System Breaks You” includes stories from parents specifically regarding the “system”, alongside its emotional impact on parental experience. Although parents may tell stories of their “fight” with the system, the process of the system breaking you can be active, in which parents are burned out by their fight with said system, or passive, when parental emotional reserves are steadily eroded over time by the crushing weight of the system. Across the literature, issues regarding the systems of healthcare and education and their ability to meet the needs of parents and children experiencing disability are well documented. Dodd (2016: 149) describes our current medical and political experience as “disablist austerity, in which negligence and poor experience for people with disabilities and/or difficulties are so pervasive that it appears to be a political choice”. The political system of ‘disablism’ is discussed by other disability and ADHD scholars such as Thomas (2020), who argue that parents must operate within a societal system where parents are ground down by unfair practice. It is hard to overstate the high levels of emotional distress that parents described during interviews when explaining their experience of the “System Breaks You”. Below, interaction with CYPS is likened to being bullied to the point of suicide by Jane, as “*destroying me*” to the point of long-term sickness by Debbie, and the development of mental health difficulties by Pam.

#### **Jane 1419-1425**

*It’s almost like they need to get me to break a different level. It’s like I would imagine, it is like being targeted to the point, like kids are bullied. It feels like maybe the kids who are bullied to the point of suicide. “You’ve got to do this, you gotta do that, you’re a shit parent”, but they make you feel like that constantly. They make you feel like you’re letting your child down, at CYPS and at school.*

*Interviewer: Is it a system that does that or individuals?*

*Jane: I think it's the system*

### **Debbie 1307- 1313**

*I ended up going off sick from work to be honest, I just thought. **The system broke me, it finished and destroyed me.** And I'm a really strong person but I just thought I can't. It was because I was going through a tribunal with her brother's educational plan and everything. So literally all my time was spent trying to get services for the kids and the support they needed.*

Young et al's (2021: 17) statement that "prejudice and a lack of understanding influence all levels of the healthcare system" is relevant. The negative experience of parents 'broken' by "The System" was narrated as perpetual and all-encompassing. Where the above passages are examples of when parents were broken by the system, Pam engages with this subplot to discuss her avoidance of this outcome and describes the pursuit of private assessment as salvation from the negative impact that the "The System" was having. In her final interview, Pam reflects on the beginning of her journey and the interactions with educational and healthcare systems, alongside the mental anguish that they caused.

### **Pam 780-782**

*It's saved me. I was on the brink of insanity. I quite openly say that, I can feel the emotion right now \*mum begins crying\*. There were so many things, the confusion, the guilt, it's awful. I feel embarrassed about it. It's what it is. That's how it was for me.*

For Pam, the system had begun breaking her down, and the result of her being completely broken was perceived as inevitable had she continued the diagnostic journey within "The System". Fortunately, Pam avoided this outcome and had a positive emotional experience during her journey due to her ability to avoid and 'subvert' the system. "Subverting The System" describes the fourth subplot within the overarching plot of "The System".

#### 7.1.4. Subverting The System

##### **Debbie 182**

*We jumped the queue cause I'm a gobby parent*

Given the confining and emotionally damaging nature of the broken system, parent narratives included stories of their attempts to avoid or 'subvert' problems inherent within the system. Parents utilising this subplot spoke of subverting the system through proactive, and occasionally provocative, behaviour aimed at minimising the negative impact of the broken system, or in Sharon, Pam, and Debbie's cases, avoiding that system altogether through private assessment. Cath and Debbie's stories of "Subverting the System" included examples of their needing to challenge what they felt was unacceptable waiting times for appointments, and what they did to confront this antagonistic force. Mothers have been described as needing to "escalate their resistance" (Gwernan-Jones et al, 2015: 290) to have their children's needs met within healthcare and education systems. This was apparent within Debbie's story where, once she felt that the system was being unhelpful, she began to increase her resistance.

##### **Debbie 39-43**

*I had this idea, this miracle idea that I was going to sort of ask for all of her records from the last time, just to sort of shit CAHMS up a little bit, so I contacted the manager and said I wanted access to her records so that I could see everything that had been written about her, and about me obviously. And funnily enough, we got an urgent appointment and I have got her records.*

Once Debbie found that access to records had not fully fulfilled requirements, she continued to escalate her resistance, further subverting the system:

##### **Debbie 913-917**

*Debbie: So, I wasn't happy so I rang my MP. I wrote to my MP about my contact with CAHMS*

*Interviewer: What were you hoping to achieve with that?*

*Debbie: NOTHING! Nothing is going to change but I just think it's disgusting that there are kids out there who are really suffering and there's no help for them.*

It is interesting that Debbie continued with this subversive action whilst acknowledging her perceived futility of the action. Debbie appears to accept what Gwernan-Jones et al (2015)

argue is the unfortunate reality for mothers; that mothers' ability to enact change is limited by power situated within the situations and institutions (or 'Systems') that exist. Cath's stories of "Subverting The System" following a failure to secure a medication appointment for her son also take on a confrontational aspect:

**Cath 562-574**

*They gave him his meds and said we'd see you in 6-8 weeks and the next thing an appointment comes in November [3 months later]. I had to ring up again as I did with his brother and say you're starting this kid on medication that can impact on their cardiac function and blood pressure, you can't leave them 3 months before you do their blood pressure. Today was 7 weeks after his last appointment, so we were just within the 6-8 weeks. But we only got that because I had to fight for it, and you shouldn't have to fight*

However, individual examples of "Subverting The System" in smaller practical ways was often insufficient. Some parents describe subverting the system altogether, avoiding it via private diagnostic assessment. It is interesting that although parents would portray CYPS and school as part of "The System", often private healthcare organisations were not included these terms and were narrated as separate and more supportive entities, potentially due in part to reduced waiting lists:

**Debbie 700-703**

*I was panicking about her GCSES because of the timing. So, I had made a decision to take her for a private assessment, because I just thought CAHMS, even if they hadn't put her on the waiting list it was just going to be too late and they wouldn't do it quick enough. So, I took her up to Scotland!*

**Sharon 126-131**

*Why did I choose to go private? Okay, because I used to work in the local CYPS and I wouldn't have my son go. . .But I'm not having him passed around by multiple clinicians, which was my experience when I worked there for these kids. To be no further forward in months or even years' time.*

**Pam 168-179**

*So, the reason that we have gone private. We did consider the NHS route and there is a referral in at the moment for that. But my concern is the waiting list. I just can't wait. I feel like he's waited long enough, and we need to know now. I also, I feel like I'm more **guaranteed a better service if I go privately**, and I would know for sure.*

*For me, I want **the best** for him, and I can't wait 2-3 years and not get the best quality. I feel private will be a better quality service. I've sourced the best top-quality guy I have every confidence in. But on the other hand, going private I feel resentful. I shouldn't have to do this. But I feel like I have to do this because I want the best for him, it's a lot of money. But he's worth it. You know? It's going to change his life potentially, it's going to be brilliant. To know what his strengths are and how to help him. So, it's worth it. Its mixed. I feel a little bit of resentful because I feel like I have to do this to get the best, to understand now. But I think that it's the right option, yeah because I've waited long enough. It's not good enough, **the NHS for kids it's just not good enough.***

For Debbie, Sharon, and Pam, private assessment was presented as the most effective way in which parents can avoid overarching issues with “The System”. Although each mother expressed discomfort and displeasure at the need to seek private diagnosis, private assessment represents the ultimate form of “Subverting The System”. The following overarching plot has similar themes and content to “The System” but exemplifies the broader experience of “The Fight”.

## 7.2. Plot 4: The Fight

### **Debbie 488**

*It's not just a thing. It's **everything***

Discourses of fighting and conflict are prevalent across literature exploring the experiences of parents of children with medical diagnoses (Thomas, 2020). The plot of “The Fight” encapsulates parental experiences of adversity and conflict across a diagnostic journey framed as a battleground within which parents must fight for their own, and their children's, rights. Although similarities exist with the subplot of “The System Breaks You”, the plot of “The Fight” is not specific to one aspect of the journey (i.e., interactions with the system) and includes all perceived and actual conflict. Parents utilise “The Fight” to tell stories of fighting the everyday disruption associated with living with an ADHD child as well as conflicts across the diagnostic journey. The ‘burdening experience’ (Corbin & Strauss, 1988) of everyday illness related tasks is present in Phil's story:

### **Phil 1431-1434**

*Obviously, you give up a lot more time because it takes a lot more time. Things that a normal 7-year-old to do a task might take 10 minutes, with him it might take 30 minutes. So, you do **have to give more**, so you put more responsibility on yourself to help them get to that outcome.*

Phil's use of "The Fight" explores the disruptive impact of his son's ADHD related experiences akin to Bury's (1991) depiction of illness as disruption. Furthermore, Phil's reflections of the everyday disruptive events brought on by his child's 'illness' demonstrate a form of biographical reconstruction (Williams, 2000) as Phil considers the everyday practical 'meaning' associated with having a child with ADHD. "The Fight" also captures the parental experience of exhaustion:

### **Sharon 232-235**

*As a household it's made me realise how hard we've had to work to cope to get along. It's been difficult, it's been challenging, but we all love each other. But on reflection I think Jesus Christ, how have we managed?*

### **Phil 1461-1463**

*It is a huge struggle. We even sometimes get to the end of the day and think "thank god he's gone to bed". Not because he's been naughty or anything like that, it is just sometimes very very tiring because you're on the go all the time.*

The difficulties associated with living with a child with ADHD are well documented (Cocoran et al 2017a) as parents describe family life as "chaotic, conflictual, and exhausting" (Kendall, 2017: 842). Parents in Kendall's study described "out-of-control hyperactivity, aggression, emotional and social immaturity, academic underachievement, family conflict and rejection" as primary causes for their experience. In contrast, participants within the current study described a general feeling of exhaustion due to the additional support required of them as parents. However, Rachel's use of "The Fight" is more directly in support of Kendall's (2017) findings:

### **Rachel 75-80**

*She would threaten you. She threatened to stab me with a pair of scissors, she threatened to get a knife and stab me, hit me with a remote, throw a book at is [sic].*

*She would threaten to stab the older girls. So, you know what I mean it hasn't been easy, an easy road to be on. I never really had a good day with her, you used to walk on eggshells.*

### **Rachel 229-232**

*My mam would say that you have to get in touch with someone, you know. I know it's hard, but have you **ever thought about putting her up for adoption**. I was like no. I cannot. As hard as it was, I used to go home and think "should I?" and I know that sounds really horrible doesn't it?*

Rachel's story demonstrates the untenability and absolute despair of some parental experiences of "The Fight" in relation to their children's ADHD related difficulties. Although Rachel's examples are not directly related to the ADHD diagnostic journey, "The Fight" was frequently used by parents when discussing the constant daily struggle of being on the diagnostic journey. "The Fight" captures the all-encompassing parental conflict of fighting for their children in an 'inhuman' (Ryan, 2017) society within which certain people do not count. Parents often explored their everyday dehumanizing and difficult experiences with a lack of specificity, using this plot to discuss their experience of systems and social environments collectively:

### **Jane 1392-1399**

*As a parent, the whole thing is beyond difficult. It's beyond hard. It doesn't matter how much you fight. You've got to fight and fight, and fight, and fight. I'm sure all parents fight for their kids but, it's not ever easier than you anticipate. You go in, I went into this whole journey knowing that I was going to have a fight because my kids need support. And yet, it doesn't matter how prepared you are for your fight, and how driven you are by the fact that your kids need something, and you have that maternal instinct. The fight is always harder. You've always got to dig so much deeper than you've got. It's almost like, **every service has to see you break** as a whole unit, as a whole family before they will provide any support.*

### **Jane 1407-1409**

*The fight that you need, and the fight that you need to have on your own is just hellish. It's exhausting, it affects everything about everything. It's completely and totally encompassing of everything that you have an everything that you are.*

Jane's framing the "The Fight" takes on an almost visceral tone as she repeatedly uses the word "fight" to signify her frustration. The parental experience of exhaustion and despondency present within these findings is evidenced across the literature, described succinctly within Cocoran et al's (2017a) meta-analysis as: 'exhausting, isolating, anxiety filled, irritating, frustrating, anger and resentment inducing, despairing, and filled with feelings of powerlessness, grief, guilt, pressure, stress, and suicidality'. Davies (2018, 126) thesis on parental ADHD narratives also heavily featured the language of battle, which she describes as "fighting talk". Although there is limited exploration of the parental experience of the ADHD diagnostic journey itself, parental exhaustion and ADHD are a common occurrence (Ghosh et al, 2016). The additional complexity of parenting following disruptive illness experiences (Bury, 1991) presents as a 'literal sapping of parental energy' (Mcintyre and Hennessey, 2012). Parental help-seeking for ADHD children can be a journey of "pleading, proving and compliance through a series of "hoops and hurdles" (Rowland, 2016: 175). Rowland's 'hoops and hurdles' were also present within parental narratives in this study as Cath describes her journey as akin to a gameshow renowned for its purposeful complexity:

**Cath 1566-1572**

*It's a bit like, it always makes me think of you know like the Krypton Factor? The physical thing at the Krypton Factor, where you had to throw yourself over nets? That's what it feels like. There are certain things that you can do no problem, like the balance beams and stuff like that, "Oh, this is easy," and then the next thing you look up and you've got a heaping big wall, and you think, "Well, how the hell do I get over that on my own? I'm going to need some support, I'm going to need some help,"*

"The Fight" as described thus far has been presented in general terms, where parents have had to "Fight and Fight" without necessarily exploring specific situations. There are some explanations as to why this may be. Harborne, Wolpert and Clare (2004) found that parents need to convince professionals of their children's difficulties in a battleground of justification, an issue echoed in Carr-Fanning and McGuckin's paper (2018) which states that parenting ability is perpetually and insidiously questioned throughout the diagnostic process. During school interactions, it is documented that parents of children with ADHD experience conflict with teachers as the norm (Gwernan-Jones et al, 2015). Parents, predominantly mothers, must fight for their children's wellbeing at school (Honkasilta, Vehakoski, Vehmas, 2014) in an environment of blame and shame (Moen, Hall-lord, Hedelin, 2014). Pam discussed how she felt the necessity to harass school to ensure appropriate provision for her son, leading and directing their care:

### **Pam 95-99**

*I just feel like I've had to really get onto the school. I'm ringing them, emailing them, getting onto them all the time. They're finally putting in provisions because he has sensory issues as well. So yeah, I feel like **I'm fighting**. I've had to put the pieces together, nobody else has. Now I'm trying to do everything I can and it's a bit like AAAH! Tough*

Pam's experience of having to "*put the pieces together*" also required her to convince the school of her son's needs. Parents of children with ADHD are regularly found to have to be the arbiters of 'truth' as they must convince teachers of the 'evidence' that their children are deserving of support and have a legitimate medical need (Malacrida, 2001). Gwernan-Jones et al (2015) describe this process as parental engagement in Foucaultian 'truth games', where medical claims are utilised as truth (Malacrida, 2001) against the school's belief of the difficulties being evidence of 'familial deviance' (Gwernan-Jones et al, 2015). Where Pam and other 'informed mothers' [See Ch 8.1.3] may feel confident with parent-teacher conflict, parents uninitiated in the language of ADHD 'truth' experience a losing battle:

### **Rachel 100-104**

*I even talked to school about my suspicions and the school seemed to brush it under the carpet ... I'm basically just batting my head against a brick wall constantly until somebody actually heard what I was trying to say*

These findings evidence the unfortunate conflict laden reality for parents of children on the ADHD diagnostic journey. There is evidence that the general daily experience is a constant battle against schools (Harborne, Wolpert & Clare, 2014; Moen, Hall-Lord, & Hedelin, 2014; Gwernan-Jones et al, 2015), professionals (Rowland, 2016), other family members (Mikami & Pfiffner, 2008), and society more generally (Watson, 2011). However, these findings add to this unfortunate list, as parents within this study describe the diagnostic journey itself as a constant, oft debilitating fight. One of the interesting aspects of parental utilisation of "The Fight" is not clear within the excerpts themselves and requires additional explanation. Although the content of stories was emotionally upsetting and evidence of great injustices and violence faced by parents, these stories were often told in a blasé manner. The impression given was that these instances of conflict, discrimination, and upset, were so commonplace that they no longer warranted undue emotion and were narrated as typical and predictable experiences. The nonchalant delivery was sometimes interspersed with incredulous laughter, as parents recognised the unfair and unjust reality of their experience during storytelling. The parental experience of the ADHD diagnostic journey was so

interlinked with conflict and struggle that participation within interviews allowed parents to reflect in-action on the injustice of their experience.

Sociologically, the 'work' of receiving any diagnosis is described by Strauss et al (1985) as the time, resources, and emotional experience required throughout the process. Parents of children seeking ADHD diagnosis are required to perform additional illness 'work', in part to the framing of ADHD as a 'hidden' and 'contested' illness (Jutel, 2009; Jutel, 2011), but also owing to the societal acceptance that questioning ADHD's diagnostic credibility is an acceptable epistemological position for the layman to hold (Cronin, 2004). The difficulties experienced by individuals and parents of those with contested illnesses is well documented (Barker, 2008), however, parents seeking ADHD diagnosis must not only contend with difficulties associated with contested and hidden illnesses, but also against an onslaught of media questioning the validity of the diagnosis (McIntyre & Hennessy, 2012). Southhall's (2007) ADHD-critical book *The Other Side of ADHD: Attention Deficit Hyperactivity Disorder Exposed and Explained* is a salient example of overt challenging of ADHD and parents seeking ADHD diagnosis. Regardless of the quality of Southhall's book, which she states is an "unapologetically one-sided" argument (Southhall, 2007: 169), it symbolises an indirect attack on the parental decision to pursue ADHD diagnosis and have their children's difficulties legitimised and 'seen'. The lack of scientific consensus on ADHD's cause has created an "ADHD Enigma" (Wright, 2012: 18) society, where everyone has an opinion, and all opinions are valid. Finally, evidence suggests that parents of ADHD children experience greater levels of frustration and depression, alongside increased chaos and variability in caring tasks when compared to children of other hidden illnesses such as cystic fibrosis (Cronin, 2004). Cath's excerpt below demonstrates a salient example of injustice, discrimination, and conflict arising from negative societal perceptions of ADHD:

**Cath 1188- 1191**

*My oldest had a really nasty experience because he disclosed. He got a job working a few hours a week in a Chinese takeaway. He disclosed to them that he had ADHD and ASD and they sacked him for having ADHD. I said to him, "It's entirely up to you how you deal with it. We can take it further. She has breached the Disability Discrimination Act. Or you can take it as a learning experience. It's up to you." He didn't want to take it any further*

Like many parents of disabled children, parents on the ADHD diagnostic journey must transition from "worrier, to warrior" (Ryan & Runswick-Cole, 2008: 204) or face becoming invisible (Davies, 2018) and downtrodden by the demands of the journey. "The Fight"

captures the ever-present, crushingly difficult, and exhausting conflicts of parents on the ADHD diagnostic journey.

# 8. The Mother [Plot 5]

## 8.1. Plot 5: The Mother

Both neurodiversity and ADHD specific literature has long been interested in the framing and experiences of mothers of diagnosed children (Malacrida, 2001; Cronin, 2004; Singh; 2004, Runswick-Cole & Ryan, 2019). Given six of the seven participants within this study are mothers, it is unsurprising that the role and conceptualisation of the ‘Mother’ emerged as an overarching narrative plot. Although this study included mothers and a father, parental narratives primarily explored the mother character and motherhood during the diagnostic journey. Stories regarding parental self-concept, roles, and responsibilities were rarely general, forgoing non-gendered terms such as ‘caregiver’ or ‘parent’ and utilising moralistic gender terms such as ‘good’ or ‘bad’ mother. Focus on mothers is perhaps unsurprising given that childcare is often seen as the primary responsibility of the mother (Hays, 1998; Pederson, 2016) and a mother is expected to subject herself to the “ideal” (Silva, 1996: 10), forgoing her own needs for the good of the child. Four subplots emerged from the data regarding the overarching ‘Mother’ plot. “The Good, Heroic, and Valiant Mother”, “The Guilty, Broken, or Fragile Mother”, and “The Informed or Insider Mother” are all subplots related to traits or mothering identities which emerged within parental narratives. The final subplot. “The Informed or Insider Father”, explores how the conceptualisation of fathering identity differs from that of mothers.

There is a rich landscape of work exploring the concept of motherhood in modern day society. Hays’ (1998) ‘intensive mothering’ describes modern mothering as a gendered model of caregiving in which mothers expend “a tremendous amount of time, energy, and money in raising their children” (Ennis, 2014: 3). This model of intensive mothering or “new momism” (Ennis, 2014), argues that childcare: is ‘primarily the responsibility of the mother’, must be ‘child-centred’, and that ‘children must exist outside of market valuations of worth’ (Hayes, 1998). Therefore, if a mother wishes to do anything other than ‘be a mom’, they must first “prove that they are a doting and totally involved mother first” (Ennis, 2014: 4). For the modern-day mother, childcare is an all-consuming practice in which the mother must be effective, informed, and self-sacrificing. Typically, ‘good’ mothers are those who are highly involved in the minutiae of their children’s lives whilst sacrificing personal selfhood and identity (Bell, 2004; Damske, 2013), whereas ‘bad’ mothers fail to meet this exceptionally

high standard. Unsurprisingly, Pederson (2016: 34) argues it is “essentially impossible” for the average mother to do all that is required of her to fulfil the ‘good mother’ ideal, and that mothers are set up to fail in modern society.

For mothers of disabled or ill children, fulfilling the ‘good mother’ ideal becomes increasingly difficult. Runswick-Cole and Ryan (2019) contend that western society condemns the existence of childhood disability, blaming mothers who are perceived as ‘responsible’ for producing children who place present and future burdens upon society. They go on to state that society implicitly believes that mothers of disabled children have ‘failed’ in their task to avoid disability in their children “at all costs” (Runswick-Cole & Ryan, 2019: 203).

Consequently, mothers of disabled children are forced to take responsibility as advocates and activists for their children, seeking recognition of their worth and humanity whilst pursuing appropriate education and provision (Runswick-Cole & Ryan, 2019). The good-bad mother binary becomes increasingly problematic for mothers of children with ‘deviant’ or atypical behaviour such as ADHD, given that behaviour is a constant reflection of the mothers parenting choices, fuelling ‘bad-mother’ narratives (Wilder, Koro-Ljungberg, & Bussing, 2009). Finally, given ADHD’s status as a hidden disability, mothers of children with ADHD must fight even harder to protect their self-concept as the cause of their children’s difficulties is not as immediately obvious as it may be if their child had a visible illness (Cronin, 2004). Within this study, one of the ways in which mothers explored the twists and turns of mothering self-concept was through the subplot of the “Good, Heroic or Valiant Mother”.

### 8.1.1. The Good, Heroic or Valiant Mother

#### **Debbie 934-944**

*All a mother wants is for her kids to be happy*

When utilising this subplot, participants presented positive conceptualisations of themselves as mothers, giving examples of their good and valorous deeds. Mothers narrated themselves as figures who fight for their children against the antagonistic forces of “The System” [Ch7.1], positioning themselves as a heroic and valiant counterforce. Mothers utilising this subplot also give examples of ‘Good’ mothering, demonstrating how they fulfil the ‘Good’ mother ideal in contemporary society. The ‘Good’ Mother is presented as self-sacrificing, prioritising the needs and wellbeing of her children above all else, whilst being unafraid to fight to have those needs met:

**Jane 1458-1463**

*I'm at the point of reading legislation and pulling things together. I know I'm going to have to fight for her, I'm not prepared to give in. I think a lot of parents would give in, but I don't. So many children let down by the school system and by the health service system. You have to have the fight. If this was for me, I would have given in a long time ago, a long long time ago. **But because it for my kids, there is no length I won't take.** I will just keep going and going and going*

**Pam 247-251**

*I will do everything I can and I feel I will have to fight, I'm getting the sense I'm going to have to be his advocate. I don't think anybody is going to do that for him. **I'm his mum** so I'll do that. He might not like all the things, but I'm going to do what I can and do what I can at home, I'm going to get a trampoline and stuff!*

These passages show how mothers present themselves as strong forces of good for their children. The willingness to do “*everything I can*” and there being “*no length I won't take*” indicate a desire and acceptance of doing anything required of them as mothers to ensure the needs of their children are met. Brock (2017) describes this framing as mother as ‘modern-day saint’, whose willingness to do anything for the child indicates evidence of being a good mother. However, there is also a clear tone of conflict within the passages, as fighting becomes an accepted part of the motherhood role. This is echoed within Thomas’ (2020: 461) work, where he describes mothers as “responsible for fighting on the frontline” for their children. For Sharon, the frontline in which she can ‘prove’ her heroic motherhood is school:

**Sharon 270-271**

*I'm understanding, intuitive. Proactive. I've stormed into that school and stormed out when I felt they weren't listening!*

Sharon's statement gives interesting insights into usage of this subplot. She begins by listing virtues she exhibits, framing herself as a ‘Good’ mother before demonstrating her valiant defence of her son via conflict. Sharon's storming into the school could be perceived by a listener as unnecessary aggression, however, by pre-emptively describing her ‘Good’

mothering traits, Sharon is able to temper these potential criticisms and justify her behaviour. There was evidence across other transcripts of mothers wishing to present themselves as 'Good'. Jane uses her desirability as a childminder to 'prove' her positive maternal traits:

**Jane 229-231:**

*I never, ever have parented negatively, and in childcare, I didn't either. A lot of people wanted me to care for their kids, so I knew that I was doing something right.*

Overall, mothers attempted to present themselves as "Good, Heroic, or Valiant" across the diagnostic journey. It was insufficient for mothers simply to demonstrate their 'intensive mothering' (Hays, 1998) capacity, for they described a need to go above and beyond the "Good" mother ideal. Examples of "Heroic" and "Valiant" deeds were used to present mothers as defenders of their children, combatting the damaging forces of "The System" and a wider society which perceived themselves and their children as burdens. This subplot encapsulates attempts from mothers of ADHD children to challenge the common framing of themselves as 'failed parents' (Eaton et al, 2016). It captures the variety of ways in which mothers attempt to prove their capacity to reach the good mother ideal within their narratives. For those who failed to meet these practically unattainable standards, the subplot was used to present mothers as either 'good enough', a conceptualisation often used by mothers to protect their self-concept (Pedersen, 2016), or as 'determined' and 'courageous' in the face of the diagnostic journey. The antithesis to this subplot is explored in the following section: personified in the subplot "The Guilty, Broken, or Fragile Mother".

### 8.1.2. The Guilty, Broken, or Fragile Mother

Unfortunately, mothers were more likely to describe negative conceptualisations of their mothering identity, typified in the subplot "The Guilty, Broken, or Fragile Mother". Typically embodied by their 'failure' to fulfil 'good' mothering requirements, mothers utilised this subplot to describe their negative, often deeply upsetting, self-conception as a mother across the diagnostic journey. Mothers described being broken down by the daily challenges associated with their children's ADHD alongside the overwhelming guilt and stress exerted upon them by "The System" [See Ch 7.1]. Mothers told stories of high levels of blame and shame both self-directed and from others. Pre-diagnostically, mothers described experience

significant guilt and shame, questioning their mothering ability in the face of their children's difficulties:

**Rachel 218-220**

*I had less of a bond with her when compared with the others. I would always question myself. I don't know why but I would always question myself.*

**Rachel 1013-1015**

*I've always questioned myself, thinking if I had of done this a different way or if we had of ...if I had of done that, would things be different? It's just one of those things that I **had beat myself up** for, for years.*

**Debbie 84-87**

*As a mum you just **blame yourself for everything**, and a mum with ADHD you blame yourself even more. I thought, why did I not fight CAMHS more, why did I not? I knew they were talking rubbish when I walked out of that room 3 years ago. Why did I let them do that?*

The above examples demonstrate how mothers portray themselves as blameworthy and guilty due to their parental choices prior to diagnosis. Debbie blames herself for not pushing for diagnosis more when her daughter was previously assessed for ADHD, whereas Rachel questions her parenting choices in the context of the current diagnostic journey. Rachel's concern about feeling less of a bond with her ADHD daughter compared to her non-ADHD children is common, as Kroegar (2018) suggests that parents of children with ADHD and non-ADHD children often felt less close to their diagnosed children. Rachel's difficulty bonding with her daughter leads to constant questioning of her mothering ability, fuelling self-admonishment within her story. ADHD assessment itself was also described by mothers as guilt inducing:

**Jane 881-885**

*He was asking things like "had I potentially been too obsessively clingy as a parent to fulfil other needs" and things like that? I don't feel I have. I was able to give examples quite easily because I've had her older sister. I think as a parent going through it, if it was the first time, you get really guilty when they ask questions like that. It's a really not nice experience as a parent, because they do make you feel like you're inadequate*

### Pam 393-396

*It felt like the finger was being pointed at me. They would say things such as “is there something going on at home”? Ooh he struggles with emotional resilience... It’s just the finger pointing at you, something must be going on at home, but I never thought there was.*

Jane and Pam’s experiences are indicative of common sentiments across the mother participants. Mothers gave examples of professionals directly and indirectly questioning their parenting ability, blaming them for their children’s behaviour instead of accepting the potential that their children may have ADHD. Mother-blame from others is prevalent across ADHD research, though most findings emphasise mother blame from other mothers (Singh, 2004; Blum, 2007). Mothers within this study primarily felt blame directed towards them by medical professionals tasked with their children’s assessment. Young et al’s (2021) damning consensus statement on the state of UK ADHD provision outlined this issue as a major barrier faced by parents of children on the ADHD diagnostic journey. They found that professionals often “overemphasized the role of adverse home environments, and/or the perception of poor parenting” (Young et al, 2021: 5), echoing Pam and Jane’s experiences above. Seeking ADHD diagnosis has been described as a parental “crusade to attain normalisation” (Ryan & Runswick-Cole, 2008: 205), and a means for mothers to re-contextualise themselves as ‘Good’ (Wilder, Koro-Ljungberg & Bussing, 2009). However, professionals across the ADHD assessment pathway often have unhelpful and negative attitudes around ADHD, seeing parental help-seeking as a desire to ‘shift blame’ (Tatlow-Golden et al, 2016), leading to increased feelings of parental blame and dismissal (Klasen & Goodman, 2000; Young et al, 2021). Stories of blame and shame are typical in the culture of parent blame experienced by parents of children with hidden difficulties (Cronin, 2004; Broomhead, 2013). Interestingly, Cronin’s (2004: 84) work on mothering a child with hidden impairments found that mothers of children with cystic fibrosis were generally “optimistic and able to focus on their children’s successes”. In contrast, mothers of ADHD children experienced life being “sucked away”, experiencing higher levels of depression and withdrawal from society. It appears that although there are some similarities to other hidden disabilities, parental experience of the ADHD journey is particularly negative.

Mothering stories of guilt also included intense narratives of self-blame, presented here by Debbie, where ADHD’s heritability and her own diagnosis led to the devastating belief that she had “*given*” her children ADHD:

### **Debbie 606-611**

*I don't like it. I've given it to my kids. I don't like talking about it I'll probably start crying. You fucking know what I mean, to think as a mother that you've passed that on to your children is destroying, it's awful. I can't cope. Cause now I look at them and their lives and I think, I know it's fucked up to say but **I've done that** to them. I've given them that. Obviously, I had no idea I had it when I had kids, maybe I wouldn't have. They have to live with their life challenges now. I've passed this hideous thing onto them. So, I think that's a problem of why I don't love it **because the guilt of being a mum** and thinking, I've done that to them.*

### **Debbie 1027-1032**

*As a mum it's not good, because you give that to your children. That's what I've given my kids, to live with that. I gave them the gift of life and a load of ADHD with it. It's not a nice feeling...If I knew I had ADHD and would have passed it on to my kids, I'm not sure I would have even had kids. And I feel really bad saying it because it's like saying people with ADHD can't be happy. Its fucking hard.*

The above passages display the deeply complex interplay between biological models of ADHD and the sociology of mothering blame within contemporary society. For many parents, biological models of ADHD allow for reduction in parental blame as the 'problem' can be understood in bio-medical terms (Singh, 2004). This "biological repertoire" (Brunton et al, 2014: 245) goes some distance to absolve parents of blame attributed towards their parenting ability due to their children having a medical problem (Conrad & Potter, 2000; Young et al, 2021). However, bio- and neurological conceptions of ADHD have paved the way for a differing avenue of parental self-blame: 'faulty genetic inheritance'. For Debbie, ADHD's heritability implicates her as blameworthy for "*giving*" her children ADHD, even though she was not aware of her own ADHD at the time. This additional mothering responsibility represents the double-edged sword of ADHD's medicalisation (Runswick-Cole & Ryan, 2019), and is present in fathers' narratives of their children's ADHD related problems where their genes are considered "*problematic*" (Brunton et al, 2014: 246).

Other parental stories utilising this subplot include feelings of intense emotional anguish and upset. The most poignant example being when mother's spoke of being "Broken" within stories describing a loss of identity due to the overwhelming burnout and exhaustion associated with the diagnostic journey. This plot usage was prominent within Jane and Debbie's final interviews:

### **Jane 1409-1415**

*I can't be Jane because I have to be their mum. I have to be their advocate. I have to be their everything so I can't be Jane and that affects my health. From a parent's point of view. You have to get so far down that downward spiral to break, no matter how strong you are, it doesn't matter what you've gone through how strong you are or what evidence you provide, what you say, what you do, it doesn't matter*

These final excerpts display the significant mothering 'work' (Singh, 2016) required of parents seeking ADHD diagnosis. For Jane, her identity is so personified by her mothering role that she can no longer "be Jane". Her identity has been eroded away by the needs of her son and the difficulty of the diagnostic journey, losing her individuality. Debbie also experienced an eroding of her previous identity, the burdens of the diagnostic journey led to her taking time off sick even though she is a "really strong person":

### **Debbie 1308-1311**

*I ended up going off sick from work to be honest. The system broke me, it finished and destroyed me. And I'm a really strong person but I just thought I can't. It was because I was going through a tribunal with her brother's educational plan and everything. So literally all my time was spent trying to get services for the kids and the support they needed. Trying to get my daughter help with her GCSE's. It was horrendous to be honest.*

Parental experiences of exhaustion are well documented within ADHD literature (Cocoran et al, 2017a) and popular media such as the ADHD magazine ADDitude which recently published an article on the 'exhaustion problem in extreme parenting' (Burger, 2021). However, this study adds to existing literature by evidencing how high levels of parental exhaustion and stress can be attributed to the diagnostic journey itself, and the labyrinthine elements of the assessment pathway, and not just the general experience of living with a child with ADHD as seen in other studies (Leitch et al, 2019). At some point, all mothers engaged with the subplot of the "Guilty, Broken, and Fragile Mother" to demonstrate the emotional difficulties associated with mothering identity alongside the ADHD diagnostic journey, a finding supported by previous work (Malacrida, 2001; Wilder, 2009; Runswick-Cole & Ryan, 2019). However, for some mothers, the following subplot [The Informed or Insider Mother] provided protection against damaging "Guilty, Broken, and Fragile" mothering conceptualisations.

### 8.1.3. The Informed or Insider Mother

The final subplot exclusively related to mothers is “The Informed or Insider Mother”. This subplot enabled participants to tell stories of their well-informed positions on ADHD and above average knowledge of ADHD research, processes, and policy. “The Informed or Insider Mother” embodies a professional mothering identity (Davies, 2018), as healthcare related professional experience allows them to use ‘insider’ status to gain preferential treatment or bypass barriers across the diagnostic journey. The position of ‘informed’ mother was narrated as desirable due to its capacity to reduce emotional distress during the diagnostic process and allow mothers to have realistic expectations. In its simplest iteration, some mothers declared themselves ‘informed’ due to their having previously traversed the diagnostic journey with a different child as seen in Jane’s statements:

#### **Jane 770-778**

*If I didn’t already have her sister, if I didn’t have some knowledge, it would have been very, very daunting...I’ve done some research and things, I did have a bit more knowledge than probably most mums in that situation.*

#### **Jane 945-6**

*So being in a second child situation of going through the assessment process does make it a little bit easier.*

Jane’s application of the “Informed Mother” subplot demonstrates how she perceives the diagnostic journey as less daunting due to her increased knowledge compared to “most mums.” However, other mothers presented themselves as “Informed” when justifying the decision to seek private diagnosis to avoid long waits and perceived negatives of NHS assessment.

#### **Pam 158-162**

*We did consider the NHS route. But my concern is the waiting list. I just can’t wait. I feel like he’s waited long enough, and we need to know now. I also feel like I’m more guaranteed a better service if I go privately, so I would know for sure. For me, I want the best for him, and I can’t wait 2-3 years and not get the best quality. I feel private will be a better-quality service. **I’ve sourced the best top-quality guy** I have every confidence in*

### **Sharon 126-131**

*Why did I choose to go private? Okay, I used to work in the local CYPS, and I wouldn't have my son go. I've always gone private. I've always gone private when I've looked for help understanding him because I've worked in it. If I could choose who he saw and when he saw them, I would have no hesitation going through the NHS. But I'm not having him passed around by multiple clinicians, which was my experience when I worked there for these kids. To be no further forward in months or even years' time.*

Pam explains how she “sourced the best top-quality guy,” indirectly indicating that she has the knowledge and skills required to make an informed decision regarding assessment pathways. Sharon is much more overt when she declares that she has “worked in it” and is informed enough to know that her son would be “passed around”. Both mums use their perceived “Informed” status to justify their decisions to seek private diagnosis. Parents opting for private assessment has increased in recent years due to the perceived and actual barriers to diagnosis and treatment within the NHS, reduced trust in ADHD services, and increased willingness to pay (Young et al, 2021). The “Informed Mother” recognises this trend, “Subverting the System [7.1.4] for her children’s needs.

The subplot of the “Informed Mother” has additional use as a defensive measure against negative self-concepts found within the “Guilty, Broken, or Fragile Mother” subplot. Debbie, faced with repeated experiences of blame pointed towards her by professionals, frames herself as “Informed” in a protective manner below:

### **Debbie 377-382**

*In terms of like, information, **I think I do probably know more than him** but what he could teach us, he could really help us, he sees all these other parents, he could give us such insight and ideas into things we could never know for ourselves. **I'm not a stupid parent, I'm resourceful and I'm quite motivated.** But I know a lot of people would be very beaten down by bringing up a child with all those issues and would they have the energy to sit and google all these things and learn about them themselves so what happens to their families?*

### **Debbie 1541-1543**

*I know more about ADHD than they do, if I wanted any therapy for her, I'd pay for it and probably get better therapy anyway.*

The desire for parents to self-identify as knowledgeable regarding their children's diagnosis/disability is common. Madden and Sim's (2016) exploration of parental narratives concerning their children's fibromyalgia diagnosis discusses the parental 'expert self'. Although parents in Madden and Sim's study (2016) were keen to learn all they could post-diagnosis, a finding echoed within this subplot, many already considered themselves to be knowledgeable 'expert selves' going through the motions of the diagnostic journey. The concept of "mother as expert" was also present within Brock's (2017: 89) thesis, where parents described a requirement to immerse themselves and acquire expert knowledge regarding their children's diagnosis additional to typical caregiving responsibilities.

The findings within this subplot challenge Hays (1998) intensive mothering concept, which argues that mothers must be guided by expert advice (Pederson, 2016). "Informed Mothers" accept the requirement to follow expert advice, but also administer their own terms to the process, prioritising private diagnosis over standard NHS care due to their 'knowledge' of issues. "Informed or Insider Mothers" use 'superior knowledge claims' obtained from articles, books and journals as seen in other studies (Gwernan-Jones et al, 2015; Davies, A, 2014; 2018), whilst also drawing upon relevant professional healthcare experience and knowledge not typically available to most parents. The only mother not to present herself as already "Informed" was Rachel, who still described the position as desirable:

### **Rachel 303-306**

*I would like to know more in depth. I'll **educate myself**. There're books at the library, stuff you can read and whatever. I've always said once I get that diagnosis, I want to go on the parenting course that's right for what she's got.*

Where the "Informed" portion of this subplot focusses on parental desire to be knowledgeable regarding ADHD, the "Insider Mother" includes stories where mothers are portrayed as "Insiders" within "The System." The "Insider Mother" often has an awareness of the inner workings of the assessment process, typically due to having experience working within healthcare or having a personal relationship with the professionals involved. The "Insider Mother" is distinct from Goffman's (1956) backstage actors, as these mothers were

not necessarily in collusion with other 'actors' (in this case medical professionals) but were using their "Insider" status to gain favourable outcomes in both combative and friendly ways. This subplot was particularly apparent in the stories of parents who had experience working within CYPS (Cath, Sharon, and Phil) and introduces the overlap between the mother and father related subplots.

Cath explored how her "Insider" knowledge allowed her to expedite medication reviews since she knew that call handlers would be "scared" by words such as "coroner and stroke".

### **Cath 668-675:**

*I think it's been really really helpful for them, the knowledge and education that I've had has been massively helpful for them. Even just the things like being able to ring CYPS and say if you don't give my child a follow up appointment when they die of a stroke, I will tell the coroner that the call handler said they would have to wait 3 months. And they go "ooh I'll sort it". You shouldn't have to do that. Actually, **what other parent would know to say that?** "I will tell the coroner this." It should never have been said in the first place but that did help, because I had that knowledge, **I can scare this call handler with the words like coroner and stroke, and "your responsibility". That helps.***

When reflecting on her position as an "Informed and Insider Mother", Cath is grateful for the ability to actively influence the diagnostic journey due to her knowledge, whilst lamenting the challenges that non-insider parents face. As an "Insider Mother", Cath is aware of the privileged position she holds within the context of the journey:

### **Cath 1526-1535**

*I think it's tricky, not just being a parent, but I think when you're a parent that knows how the systems work and you still can't navigate round it? When you work in a similar service, and you're coming up against blocks, we're lucky that we know how the policies and procedures work, and what should be happening and what isn't happening, but if you're Joe Bloggs on the street, and you've potentially got a neurodevelopmental disorder, and, you know, like I say, I've had tears and snots and all the rest of it, **how somebody who doesn't have that knowledge and have that training does it!***

Sharon's position as an "Insider Mother" is different, using her position as justification for pursuing private assessment and avoiding typical diagnostic processes entirely. However, Sharon also explores how this position may cloud her judgement into being overly critical:

#### **Sharon 143-145**

*I know that there is some good stuff there. And if I could ring up and say that my son would be seen by them within the next three months, then I would. But if I had to leave it all the chance, no way would I put him through that. Awful*

#### **Sharon 404-408**

*Maybe I'm against things that could be really helpful for him. Maybe mainstream CAMHS is what he needs. A local therapist who hopefully could attend to everything. Rather than just going for an ADHD assessment and just getting an ADHD diagnosis. I need to see the report and think about it*

The subplot of "The Informed and Insider Mother" appears to be a novel concept within ADHD research. Although there is evidence of parents wishing to become informed and knowledgeable about ADHD to support their children (Cocoran et al, 2017a; Davies, 2018), there are very few examples in the wider literature of parents with professional healthcare knowledge of ADHD utilising this knowledge for favourable outcomes. Dockerty and Dockerty's (2008) reflective paper on being health professionals and NICU parents described their occupational healthcare experience as helpful and hindering. Like Sharon, they expressed difficulties between ensuring the healthcare their child received was consistent with the highest quality of up-to-date evidence, whilst maintaining their position as "passenger seat parents" (Dockerty & Dockerty, 2008: 295). They, like Cath and Phil (discussed in the following section), found that once their professional position was discovered, interactions with professionals changed and staff became either more willing to facilitate their additional demands, or uncomfortable dealing with healthcare professional patients.

A further example of 'Insider' parents was present in the stories of South African medical doctors who were parents of deaf children (Birdsey & Joseph, 2021). Their experience is a "plurality of perspective" (Birdsey & Joseph, 2021: 3) in which the lived experience of illness through their children allowed them to recognise significant gaps in knowledge, perceptions,

and expertise in medical professionals. First-hand lived experience of deafness within the family allowed participants to achieve greater levels of appreciation of their own limited understanding as doctors, whilst pushing them to greater levels of advocacy for deafness in their professional and personal lives. However, participants in Birdsey and Joseph's study (2021) did not give examples of using their professional position to influence their children's healthcare journey and instead focussed on the impact on their own professional practice following their child's disability experience. For mothers within the current study, their "Insider" status was predominantly described as a benefit in ensuring care provision for their child, or as a double-edged sword which could colour their perceptions of their children's needs due to being overly aware of potential problems.

The subplot of the "Informed or Insider" parent is of further interest as it is the only subplot regarding parental identity shared between mothers and the only father participant. Where mothers presented themselves in various contexts (Good, Heroic Valiant, Guilty, Broken, Informed, or Insider), it is noteworthy that Phil exclusively utilised the plot of the "Informed or Insider Father" when exploring his parental identity.

#### 8.1.4. The Informed and Insider Father

As Phil's son was assessed within the typical NHS diagnostic process, his utilisation of the "Insider" parent subplot is similar to Cath's as he describes influencing professional's' behaviour. Phil explores his capability to use his privileged position to send "*gentle*" reminders with his NHS email, implying that professionals able to see his NHS status may be more supportive:

**Phil 225-235.**

*I just dropped a gentle email, because obviously I work in the trust. So, it's there to be able to drop in and I have sent stuff, paperwork we have filled in, I have scanned it in and sent across anyway because it's a secure way of doing it. So, I thought, "If I just drop an email, just to, not so much hurry things along, but just find out where we are".*

Phil's "Insider" awareness also presented emotional benefits, allowing him to have realistic expectations of timelines and processes:

### **Phil 1313-1317**

*I think knowing how the system works you don't set yourself unrealistic expectations. You don't think after you've put a referral in, you'll know what's happening next week, you don't think you'll go to GP and get a prescription straight away. It's not that way at all and I've been there and met parents in that same thought process, so I think having the insight into all of that, we didn't set ourselves unrealistic expectations.*

Phil's "Insider" knowledge was also presented in a way similar to Sharon, as he presented this awareness as a potential negative due to his being aware of what can go wrong. However, where Sharon chose to avoid this risk altogether through private assessment, Phil uses his "Insider" position to have candid conversations with the consultant and care-coordinator to avoid problems:

### **Phil 1338-1342**

*It's complicated knowing what can go wrong, and you want to make sure that that route doesn't get taken. I'm quite fortunate that the consultant, I know. His care co-ordinator, I know. So, it feels like I can have them conversations. You've already got a bit of rapport before. But at the same time, you have to make sure you differentiate between the fact that you're now a service USER in the service*

When considering the literature, it is unsurprising that the sole father within this study presented their parental identity in significantly different terms when compared with mothers. Fathers are typically subjected to blame and shame at significantly lower frequency than mothers, as fathers who undertake simple parental responsibilities are often praised as 'exceptional' for doing what is expected of mothers (Pedersen, 2016). Phil's position as primary caregiver in his sons ADHD diagnostic journey is atypical, since fathers engage less in medical assessments and ADHD research (Singh, 2003; Joseph et al, 2019). Phil's involvement presents an example of contemporary- or new-fatherhood, where fathers are more involved in childcare and health provision than ever before (Randles, 2018). Evidence suggests that within "highly educated, white, heterosexual dual-earner couples with children" (Dush, Yavorsky & Schoppe-Sullivan, 2017: 519) such as Phil and his wife, women continue to do significantly more childcare, further demonstrating Phil's atypicality in this demographic group. Although fathers are often more critical of medical conceptions of ADHD, defending against diagnosis, medicalisation, and medicating their children's behaviours (Singh, 2003; Osbold, Helene, & Hilde, 2019), Phil's position as an "Insider Father" may have influenced his more accepting attitude of ADHD diagnosis and medication. However, like other fathers who commonly prioritise children's outcomes such as academic performance over perceived barriers to support (Fabiano & Caserta, 2018), Phil's narrative focussed on his son's

educational outcomes as the primary justification for commencing the diagnostic journey and eventual medication use.

Overall, the plot of “The Mother” was a significant and overarching plot across every parental narrative. The presentation of “The Mother”, and the impact of that presentation, was a major contributor to the positive or negative experience of the overall diagnostic journey. The shifting sense of identity experienced by mothers such as Debbie (oscillating between the Good and the Guilty Mother) and Pam’s complete character inversion (from Guilty Mother to Good Mother following diagnosis) is captured within the plot. The development of the “Informed or Insider” subplots, and the unique challenges faced by parents who may have greater knowledge of the machinations of the diagnostic process presents novel findings and an interesting area for future research. Echoing previous research, the gender of the parent played a significant role in parental self-conceptualisation, and subsequent plot usage. Phil’s unidimensional self-conception and lack of engagement in other parental identity subplots further evidences significant gender differences in parental experience across the ADHD diagnostic journey. Although not within the remit of this study, further research could explore the ADHD diagnostic journey’s impact on the experiences of parents who identify as trans, non-binary, and other gender identities.

# 9. Medication, Disability, and Difference [Plots 6 & 7]

## 9.1. Plot 6: Narratives Regarding Medication

Given the most common treatment for ADHD is stimulant medication, and its controversial status and “sensationalist reporting” within media representations (Cocoran et al, 2017b: 338), it is unsurprising parental narratives heavily featured medication as a prominent plot. Parents engage with this plot when discussing the decision to start, not start, or continue to utilise stimulant medication for their child. The parental decision of whether to commence medication treatment can be understood as part of a long series of decisions within a complex process (Charach et al, 2006).

### 9.1.1. Positive Narratives Regarding Medication

The subplot of “Positive Narratives Regarding Medication” highlights how most parents discussed ADHD medication in broadly positive terms. These positive stories and portrayals are used by parents to evidence and justify their decision to pursue and/or begin medication treatment for their child. Cath, Jane, and Sharon’s early accounts of medication are framed by personal experience, as each of these mothers were effectively medicated with stimulant medication for their own ADHD. The perceived benefits for themselves were presented as a useful tool in the decision-making process:

#### **Jane 474**

*So, I have the same medication as her sister. We have the same medication, so we know that that is our concentrating medication. We **know** that.*

#### **Sharon 116-121**

*I never thought that I would have started thinking about medication at this stage... but if **he can have this pill where everything is better**, and I'm getting it for myself, and if it's going to help me why should he not be helped as well?*

**Cath 863-865**

*When I've got my medication in me, I'm less likely to be impulsive. I'm less likely to feel those intense emotions. I can deal with and process things in a different way. I bear that in mind for him as well.*

These examples show how parents consider their own positive experience of ADHD medication to evidence its potential positive impact for their children. For Jane, Sharon, and Cath, medication is a positive tool in managing some of the challenging experiences of their own lives, and they present medication as a way in which one can effectively engage with the wider world. However, for Debbie, her own negative personal experience of medication is counteracted by her son's positive experience, influencing her position regarding her newly diagnosed daughter's medication choices:

**Debbie 480-483**

*Medication is an option for her, isn't it? That's going to be her choice whether or not she wants to try that, might change her life. I don't know, I don't take it, as you can probably tell. I didn't like it when I tried it. My son does, he has his medication. Not in the holidays but at school he does, it's got a purpose, it works for people.*

The despondent tone of Debbie's use of this subplot reveals the range of emotions parents face when exploring their children's medication use. For Debbie, the gratitude that it is effective for her son, the sadness that it wasn't useful for her, and the hopefulness that it may work for her daughter all factor into her decision-making process. Her statement "*as you can probably tell*" further indicates that Debbie believes her ADHD symptoms are so apparent within the interview that others would be able to determine her treatment status and potentially pass judgement. Previous studies have found that parents contemplating the decision to medicate their children often focus on what they feel is best for their child (Charach et al, 2006), and previous or current indications of a positive impact are a key motivator in continued medication use (Ahmed et al, 2013). For parents within this study, previous successful pharmacological treatment of themselves or siblings are described as relevant to medication related decisions. This additional comfort in recommending and pursuing stimulant medication following previous use corroborates with findings from Flood et al (2019), who found that parental experience of ADHD medication often develops from

one of doubt and fear, to one of increased confidence and autonomy as time and usage continues. Given the subplot “Informed or Insider Parents” [8.1.3/4], a further contributing factor to positive parental portrayals of ADHD medication is the professional awareness and knowledge held by some participants. This was apparent in Phil’s narrative where, instead of talking about his personal life, he draws upon his professional experience within CYPS to frame the decision-making process not as ‘whether’ to start medication, but ‘how’ to start it most effectively:

**Phil 627-635**

*We are going to go down the medication route. It is just how that is done initially and how we do it over a longer period. Because we are keen to help him out at school but don’t really want to give him it on a weekend or during the holidays. We want him to see it as a benefit to him at school. I know some of the drugs have changed since I came out of CYPS but initially I think it is going to be a medication that is given seven days a week. Then look at how that works, and basically as time goes on reduce it so it is just Monday to Friday.*

Charach et al (2006) argue that for professionals, the decision to commence stimulant medication seems simple when considering the overwhelming evidence of efficacy and safety. Given that stimulant medication is a recommended NICE guidelines intervention (NICE, 2018), professional advice typically includes medication as a primary treatment recommendation. This study echoes Charach et al’s (2006) findings that parental considerations of medication use are of increased complexity when compared to professionals. Interestingly, Phil’s use of the subplot of “Positive Narratives Regarding Medication” shares more in common with Charach et al’s ‘professionals’ than with the other parents, as his exploration of medication includes less of the tension inherent within the other narratives. For Phil, the decision to medicate his son is a simple professional one and not a deeply personal one since medication is both expected and necessary to ensure academic performance. Phil’s previous expert clinical position within healthcare plays a significant role in his sensemaking processes in relation to medication and the development of his medication narrative.

In a similar vein, Sharon presents medication as positive not because of its current impact, but because it may reduce the chance of her son utilising illicit drugs in the future. Sharon

also states that the age of commencement of medication is important as her son may have been less likely to agree to its use had he been older:

**Sharon 601-605**

*I think I got him at the age when I have a bit of influence. And it's all before he goes experimenting with drugs and what not, and getting what he needs from that, which he will have done. So now he's on medication and will be able to kind of teach him that, he absolutely can't be taking any other drugs whilst he's taking this. But actually, people that do take a lot of those drugs take them instead of the medication. They wouldn't need those drugs if they had the medication*

Sharon's story highlights a further complexity in the parental decision-making process regarding ADHD medication, the child's comfort levels. The findings from this study corroborate with previous studies, where evidence suggests that parents seeking medication for older children have additional difficulties due to older children being potentially more vocal and resistant regarding their treatment (Ahmed et al, 2013). However, Sharon's position as an "Informed or Insider Mother" is evident as she argues that ADHD medication will *reduce* the risk of her son using illicit substances in the future. This is contrary to findings from other studies, where a primary parental concern regarding ADHD medication is a fear of increased risk of substance abuse problems due to normalisation of stimulant use (Ahmed et al, 2013; Cocoran et al, 2017b). Sharon's understanding that effective stimulant treatment for ADHD reduces future illicit drug use is justified, as numerous meta-analyses and follow up- studies have found that medicated individuals with ADHD are less likely to become addicted than those unmedicated (Wilens et al, 2003; Wilens et al, 2008; Humphreys, Eng, & Lee, 2013). This finding supports discussion in the previous section on "Informed or Insider Mothers" [8.1.3] as previous awareness and knowledge of ADHD evidently plays a significant mitigating role in reducing parental anxieties regarding medication.

### 9.1.2. Stories of Trepidation

Where Phil, Cath, Sharon, Debbie, and Jane were able to draw upon their personal experiences of medication, Rachel and Pam's narratives were filled with a greater sense of trepidation and lack of surety. The subplot "Stories of Trepidation" captures medication

related narratives containing parental anxieties and fears as can be seen in Rachel's excerpts:

**Rachel 337-341**

*I don't know what this medication is going to do to her and hopefully there is light at the end of the tunnel do you know what I mean? And it's for the best for her and for us. I can finally have that little happy family that everybody has always wanted, and I've never had. And then there's no more arguing, no more bitchiness*

**Rachel 720-723**

*I was told that it would obviously help her concentration. I just want her to get that chance to see what it is like from other people's perspective. She needs to concentrate at school more and stuff like that. So, for me it's been a long time coming because I want her to **feel like everybody else.***

Rachel's narratives regarding medication are filled with doubt and uncertainty, a finding echoed within the wider literature (Cocoran et al, 2017b). Rachel describes her hope that the medication will allow her to "have that little happy family" and have her daughter "see what it is like from other people's perspective". ADHD medication is often perceived by parents as an effective tool for managing social relationships (Brinkman et al, 2009; Khan et al, 2022), however, there is limited evidence that stimulant medication improves outcomes such as social skills and relations (Molina et al, 2009; Dalsgaard, Nielsen & Simonsen, 2014). For Rachel, ADHD medication is perceived as a tool with which she can normalise her child to fit into the family unit, whilst also supporting her schooling. Rachel draws upon parenting repertoires witnessed elsewhere, in which medication is seen as "doing right by the child" to maximise their potential to achieve (Davies, 2018: 118).

For Pam, her engagement with this plot and subplot included a reflection during the interview, where she expressed concerns about side effects and seemed to develop her position in real time, utilising the storytelling process as decision-making:

**Pam 598-613**

*I wouldn't want to give him medication anyway. But I've been reflecting, and I've been chatting with one of my friends whose little boy is about to go through the assessment, and she made me think sometimes you have to weigh it up because if you don't medicate there could be harms in terms of their confidence and self-esteem and achievement in school. So, I'm not going to rule it out and I think that the minute*

*for us I'm going to try strategies first...One of my concerns is that he is small of stature, he's small like me and **I have heard that there are some concerns in that it can stunt your growth. It affects sleep.** I know there's going to be side effects but there are things that worry me, so I think for us the right thing to do is to go down that route but keep it in the back*

Pam's use of "Stories of Trepidation" is typical of findings across the wider literature when compared with the narratives found in the "informed" parental narratives previously discussed. The complexity of medication decisions for parents of children on the ADHD diagnostic journey is clear within the above passage, where Pam explores an understanding that not medicating may harm her son due to the impact of ADHD on his life, whilst also weighing this up against fears regarding potential side effects. Parental fears around ADHD side effects are common, particularly regarding appetite suppression (Bull and Whelan, 2006), weight loss (Hansen & Hansen, 2006), and sleep disturbance (Ahmed et al, 2013). Concerns have also been raised in previous research about the 'zombification' of children on high dose stimulants and an eroding of personality (Charach et al, 2006; dosReis & Myers, 2009). The fear of 'zombification' was explored by Phil, who presented this as one of his wife's fears:

**Phil 714-719**

*[Medication] is a concern for my wife, because if you go back to when Ritalin first came about, and kids were... What shall we say? I wouldn't say zombified is the right word, but it changed their personalities and everything very dramatically. So that is obviously a fear, because he is a bit of a cheeky chappie and you don't want to lose that, because that is very much part of who he is.*

The "zombie effect" (Perugi et al, 2019: 8) of ADHD medication is clinically considered evidence of an overly high dose, leading to a reduction in spontaneity, reactivity, and empathy. However, for parents uninitiated in psychiatric language and awareness, fears of 'zombification' due to medication are common (Muellar et al, 2012; Lu et al, 2022) and influence on decision making (Flood et al, 2019). The reality of adverse medication side effects (Faraone et al, 2021) and parental fears (Muellar et al, 2012) assist us in understanding parental trepidation regarding ADHD medication commencement. All parents within this study accepted the potential benefits of stimulant medication for their children and, outside of the above fears regarding negative side effects, presented medication in

generally positive terms. However, Pam did allude to the explicitly anti-medication position of her husband, which may play a role in her desire to try other strategies first:

**Pam 613-615**

*My husband is very anti-medication. But I wouldn't rule it out if it's going to be helpful, who knows you can't in the future, it depends how it goes.*

Pam's statement that her husband is "very anti-medication" reflects a suggested societal difference in the conceptualisation of ADHD medication between mothers and fathers. Fathers have been found to be more critical and less accepting of stimulant medication for treating their children with ADHD (Hansen & Hansen, 2006), whereas mothers are more accepting of its use (Cocoran et al, 2017b) and often emphatically behind medication (Clarke and Lang, 2012). However, in families with typical structures in which the mother performs the majority of the caregiving role, fathers have been described as either "reluctant believers", who accept the medications usefulness but question its necessity, or "tolerant-nonbelievers", who may disagree with the medicalisation of their child but who are largely absent from the medication decision making process (Singh, 2003: 314). Pam's statement that she "wouldn't rule it out if it's going to be helpful" can be considered evidence of her fulfilling the "mother as advocate" role (Brock, 2017: 101), who fights for provision to support their child against *any and all* opposition, including her husband's reluctance.

### 9.1.3. Framing ADHD Medication: ADHD and Physical illness

The "Narratives Regarding Medication" also explored the framing of ADHD medication in a wider social and medical context. Parents were aware of the distinction made between ADHD medication and medication utilised for physical illnesses, and their narratives included reflections and challenges to this disparity. Parents felt that ADHD medication was perceived as culturally and socially less legitimate than medication for physical conditions, leading to an increased pressure to justify their decision to use medication and have it accepted by others. This conceptual disconnect between utilising medication for a physical condition when compared with ADHD was explored by Pam, who acknowledged it, and Cath, who rejected it:

**Pam 615-618**

*I think about the stigma about it, I think this stigma about putting your kids on a medication.*

*Interviewer: Would be different if it was a physical illness?*

*Pam: Exactly, you wouldn't think twice. He is on an inhaler for asthma.*

Pam's passage demonstrates the unfortunate position of parents on the ADHD diagnostic journey, as they consider the stigma of medicating their children whilst also accepting that this stigma is not apparent with other widely accepted physical illnesses such as asthma.

Cath, who has specific knowledge on ADHD medication itself, takes this further:

**Cath 392-399**

*It's a big thing, we see it very much as it's almost like having diabetes. Your body doesn't make insulin, so you take it, or having a thyroid disorder. You don't make enough thyroxine, you take it for that time period. You have an increased dopamine level for that time period. That's all it is. You've just got more dopamine. You can use it for certain tasks, but it won't be there all the time so it's what else you have to do as well... One of the things I've always said about why I enjoy working with ADHD as it's the only disorder where you can change someone's life within 20 minutes of giving them an instant release medication. All three of us have said **it's like putting on glasses**.*

There appears to be limited discussion in the wider literature regarding the parental desire to recontextualize ADHD medication as akin to medication for physical conditions. This is perhaps surprising given that stigma plays a pivotal role in the parental decision to discontinue medication (Honkasilta & Vehkakoski, 2019; Khan et al, 2022; Paidipati, 2022; Spencer, 2021). The process of likening ADHD medication to that of medication for physical illness and the conceptual boundary work between 'physical' and 'mental' illness appears to be useful for parents who are stuck in the paradoxical position of being blamed for their children's ADHD related behaviours, but also shamed for their decision to administer stimulants to reduce those behaviours (Ghosh et al, 2016). One potential remedy to this contradictory societal position experienced by parents is to normalise ADHD medication within lay discourse, allowing for effective treatment to be utilised without negative social repercussions. However, normalisation of medication use is seldom a comfortable process since, it requires an implicit acceptance of biomedical understandings of their children's experience, and acknowledgement of some form of neurochemical imbalance or deficit

requiring chemical alteration. On a fundamental level, parents utilising ADHD medication must, to some degree, accept a biological understanding of ADHD to have hope for its effectiveness, and justification of its use (Stewart, 2017). Therefore, contrary to Conrad's (1992) assertion that stimulant medication is utilised by parents and society as a form of social control against deviancy, parents hoping to use, and I would argue recontextualise, ADHD stimulants are aiming for a view of medication as 'agency' as opposed to control over their children (Stewart, 2017: 89). Negative media portrayals of ADHD medication also play a significant role in parental acceptance of its use, especially when they include narratives linking these medications to illicit drugs such as methamphetamine (Charach et al, 2006). In the face of criticisms arguing that parents are giving their children drugs akin to methamphetamine and cocaine, it appears understandable why parents would wish to have their children's medication be reconceptualised as more like thyroxine or insulin.

#### 9.1.4. Medication Isn't Always the Answer

The final subplot within "Narratives Regarding Medication" was unique to Debbie and is worth exploration. Within Debbie's story, she presented herself as a mother on the brink of mental collapse. Debbi was fighting with all her strength for diagnosis to be made as soon as possible so that her daughter could start medication in time for her GCSE's, believing that medication was required for her daughter to have any chance of success. Unfortunately, the medication did not have the desired effect, leading to a period of reflection and a disruption of her narrative:

##### **Debbie 779-783**

*She started on Concerta, a low dose which didn't make any difference. She went up a dose and that didn't make a difference. Now she's on 36mg and she only started it yesterday and she said she's never been so tired in her entire life and can't keep her eyes open. So, even though it's not my place, I think I might ring CAHMS and say it's probably best if she just leaves the medication for now, I'm not sure if it's the right time to be messing around with it. **It's a hard decision to make.***

This final section from Debbie gives further insights into the turbulent and emotional rollercoaster regarding parental experiences and narratives around medication. Although Debbie's story is dominated by her fighting for what she thought her daughter needed, it is

noteworthy that the lack of medication efficacy erodes her confidence in decision making, evidenced by her stating that it is “*not my place*” to make medication decisions. Hansen and Hansen (2006) describe this experience as the parental “balancing act”, as parents weigh up the improvements in academic performance against side effects. This is clear within Debbie’s excerpt, as the lack of benefit is outweighed by her daughter’s extreme tiredness. Debbie and her daughter’s decision to cease medication use is immediately followed by the statement “*it’s a hard decision to make*”, supporting Hansen and Hansen’s (2006: 1277) argument that the parental decision to terminate medication is often followed with second-guessing and “inner turmoil”.

As with many studies exploring parents and ADHD, (Bull & Wheelan, 2006; Charach et al, 2014; Cocoran et al, 2017b; Singh, 2004; Singh, 2005; Taylor & Antshel, 2021) discussion regarding medication featured heavily within parental narratives. For most parental participants, the plot of “Narratives Regarding Medication” included the presentation of medication as a useful tool in allowing them to support their children and improve their children’s ability to function within society. This finding is shared with other studies, where medication use is presented by parents as useful for the pragmatic management and immediate resolution of their children’s difficulties (dosReis et al, 2007; dosReis & Myers, 2009; Khan et al, 2022), with focus primarily being on improvement in academic performance and social experience (Ahmed et al, 2013; Flood, 2019). For others, this plot included the agonising balancing of the risks and benefits of medicating their children with stimulants, the fear of future addiction, and the potential stigmatising experiences that may follow. The plot of “Narratives Regarding Medication” also captures a seemingly underrepresented phenomenon within ADHD literature; a strong parental desire to normalise, legitimise, and justify ADHD stimulant medication use by likening it to more societally acceptable forms of medical treatment for children, such as insulin and inhalers. This recontextualisation represents a strategy available to parents to challenge the unfair and unreasonable stigma and blame felt when utilising stimulant medication and demonstrates a desire for ADHD treatment to become societally acceptable. Medication dilemmas represent one ‘balancing act’ (Hansen & Hansen, 2006) parents on the diagnostic journey must perform. The final plot will explore a further balancing act for parents: “The Balancing Act Between Disability and Difference”.

## 9.2. Plot 7: The Balancing Act Between Disability and Difference

Chapter 2.2 [The Theoretical Tension Between Paradigms of ADHD] outlined the ongoing tension between two dominant conceptual paradigms of ADHD, specifically the neurobiological medical disorder model versus a model of neurodiversity. The neurobiological conceptualisation of ADHD positions those with ADHD as medically deficient, disordered, and disabled (APA, 2015), and those diagnosed are considered patients with a medical ‘problem’ requiring treatment (Conrad, 2007). Those with ADHD, therefore, require medical intervention to receive a diagnosis and treatment to allow them to function in civilised society, as without such support they ‘suffer’ from a “very profound disturbance in one’s brain’s capacity” due to “the most impairing outpatient disorder we see” (Barkley, 2011: 42). The neurodiversity paradigm challenges this understanding, identifying individuals with ADHD and other neurodevelopmental disorders, such as ASD, Dyslexia, and others, as simply different. These different individuals are often characterised as ‘neuroatypical’ or ‘neurodivergent’ due to their altered sensory, cognitive, or affectual functioning when compared to the predominant “neurotype”, characterised as the neurotypical (Rosqvist, Chown, & Stenning, 2020). A model of neurodiversity argues that the disadvantages faced by neuroatypical individuals is primarily related to systemic and environmental barriers and prejudices placed upon them by a neurotypical society, and that neurodiverse individuals are not inherently disabled, but environmentally so (Shields & Beversdorf, 2019). This theoretical context proves vital in making sense of plot 7 “The Balancing Act Between Disability and Difference”, with which parents attempt to make sense of these conflicting epistemic positions across the diagnostic journey in their own unique ways. This plot is utilised by parents to reflect on their children’s strengths and difficulties, develop and employ the most appropriate language to understand their children and their specific needs, and to explore, challenge, and find equilibrium between the seemingly competing concepts of disability and difference.

### 9.2.1. Initial Rejection of Disability

During interviews, most parents initially rejected the use of terms such as ‘disability’ or ‘disabled’ when discussing ADHD. Disability related language proved uncomfortable, as parents were quick to challenge these terms, opting for more preferential terms such as “different”, “having strengths and difficulties”, or “neurodiverse”. Parents were asked what

sense they made of ADHD being potentially classed as a registered disability under the UK government's Equality Act (2010), and whether they understood their children in these terms. In all parental narratives, there was an initial reluctance or rejection of the language of disability as can be seen in the following response by Pam:

**Pam 213-225**

*I don't like that at all actually. I don't view him as having a disability. Definitely not. He's just as capable as any of his classmates, it's just that he struggles with different things a bit more or differently. Maybe it's just difference. He's not disadvantaged you just need a different approach. We've managed, we have adapted to him. Yeah, I wouldn't say he's got a disability. I don't like that. I think it's **really negative**. It's saying if you're different then your disadvantaged. Yeah, I don't like the term. I think maybe the world is wrong not him.*

Pam's immediate adverse reaction to the word, and implied framing of her child as, 'disabled' was typical across the parental narratives. Although Pam's position on disability becomes more nuanced in future interviews, this immediate early negative reaction displays a powerful parental desire to avoid the framing of their child as disabled. This response appears common within the sociological literature, where having a disabled child represents a socially undesirable thing, to be avoided by parents "at all costs" (Ryan and Runswick-Cole, 2008: 202). Ryan and Runswick-Cole argue that parents must "crusade to attain normalisation" (2008: 203) to avoid this undesirable outcome as accepting that your child is disabled leads to an "othering" of oneself and one's children, potentially fuelling 'bad mother' narratives as explored in Chapter 7 [The Mother]. Thomas (2020) builds on this, stating that parents resist disability terms to avoid the 'grim imagined' future of their children, and inevitable societal hostility and indifference. As Pam states, the label of disabled is "*really negative*" and regardless of its definition, she "*dislikes*" the term. Although the concept and language of disability has seen much development and added nuance within disability studies (Goodley, 2011), and recent critical reflection within neurodiversity literature (Rosqvist, Chown & Stenning, 2020), parents within this study often framed disability in simpler terms. For Pam, her child is "*definitely not*" disabled, even though she accepts he is "*disadvantaged*" and "*struggles differently*" to other children unless given an individualised approach. This linguistic distinction is of interest as, like Pam, many parents appeared to describe their children and ADHD's impact in terms almost identical to commonly accepted

definitions of disability. For instance, two major UK documents of disability legislation, the Equality Act (2010) and Disability Discrimination Act [DDA] (1995), define disability as:

*“A physical or mental impairment which has a substantial and long-term adverse effect on your ability to carry out normal day to day activities”*

However, it is important to note that this definition has come under significant criticism by disability scholars (Goodley, 2011). The medical model definition of disability has been argued to ignore the role played by society in excluding those labelled as ‘disabled’, and the contribution of the non-disabled majority in creating social environments where the disabling aspect of impairment is magnified (Barnes, 1991; Anastasiou & Kauffman, 2013). The above definition has also been criticised for making room to allow “further inequality” (Byrne, 2018, 14), by prioritising inherent bodily dysfunction and allowing for differential translations of the subjective terms of what constitutes ‘ability’ and ‘normal’ (Woodhams & Corby, 2003). Nonetheless, this wording is currently used as the legal definition of what constitutes disability within the UK and guides many health and social care processes such as application for financial aid and additional social provision. For advocates of the social model of disability, in which the disabling impact of societies’ response to individuals with ‘impairments’ is prioritised, the below definition exists:

*Impairment: The functional limitation within the individual caused by physical, mental, or sensory impairment.*

*Disability: The loss or limitation of opportunities to take part in society on an equal level with others due to social and environmental barriers*

(Barnes, 1991; 1999).

The social model of disability presents an alternative understanding of disability, in which the ‘reality of disability’ is brought to attention, devoid of medical obfuscation (Swain et al, 2003). It allows for the real problems of disability: “the social barriers, discrimination and exclusion, societal stigma, lack of access to resources, and poor perception of the disabled person” (Swain et al, 2003: 24) to be the focal point. Although Barnes’ definition is more commonly utilised in disability orientated and sociological literature, it is not without criticism (Anastasiou & Kauffman, 2013). With concerns being raised that the social model of disability represents an extreme form of cultural determinism (Anastasiou & Kauffman, 2013: 12), in which the lived bodily experience of many people with disabilities is denied.

The scope of this thesis does not include a thorough and nuanced discussion on the merits of the various definitions or theories of disability but is instead interested in the way in which various models of disability are utilised within parental narratives. Nonetheless, it is clear

from the findings that parents' **initial** reactions to the language of disability in relation to their children's ADHD do not consider academic or nuanced definitions, but deep-seated fears and concerns regarding the words 'disability' and 'disabled'. The most salient instance of this can be found in Rachel's response:

**Rachel 355-366**

*It's not as if she's got learning disabilities, she's got learning **difficulties**. That's how she is. That's how I've always seen it, that she has difficulties*

*Interviewer: Do you see her as disabled?*

*Rachel: Nah. **I see her as having disabilities, but I don't see her as disabled.** Cause to me, a disabled person has a lot more stuff wrong with them than what she has, you know like wheelchair or not being able to walk or whatever.*

*Interviewer: So, is disability physical?*

*Rachel: Yeah, but that's just me, I don't see the mental side or the other side of disabilities. But you would think with me being a carer I see like loads of people with disabilities and difficulties. I feel offended when someone says she's got disabilities. But I know, but it's like **DIFF**iculties for her to get over and once we get past those difficulties.*

Rachel's utilisation and understanding of the term disability as being only relevant to individuals with a physical condition proves problematic since, it leads to a contradictory position in which her daughter has "disabilities" but is not "disabled". She goes as far as to say she would be "offended if someone said her daughter had disabilities", even though this is exactly what she asserted moments before. This seemingly paradoxical position shows the significant reluctance of some parents to utilise the term "disabled". As Lupton (2012: 103) argues, parents do not always "absorb the dominant discourses passively and without question", so although there is evidence that her daughter is likely to have difficulties across her life span by nature of her ADHD (Barkley, 2015), Rachel is hopeful that her daughter will "get over and past those difficulties". Rachel and Pam's reluctance to class their child as disabled is perhaps unsurprising, given that disability has been argued to be commonly associated with ideas of significant impairment, social rejection, and a lowering of social worth (Thomas, 2020). Davis et al's (2003: 194) deconstruction of UK social policy on disability argues that medical perspectives on disability at that time assumed that disabled

children will: “live a life of suffering, depend on others to live a fruitful life, and burden the state via support costs”. The findings of this thesis suggest that the terms ‘disability’ and ‘disabled’ continue to be an *initially* undesirable term for parents to use regarding their ADHD diagnosed children. However, although parents rejected the language of disability at the outset, as discussion on the topic continued and the diagnostic journey progressed, a complete rejection of the language of disability became problematic for parents who were seeking medical diagnosis and treatment for their children’s differences. This often led to a cautious acceptance of the language of disability captured in the following subplot.

### 9.2.2. Tentative Acceptance of Disability Language

As the parental journey progressed and further interviews were conducted, a trend emerged within the parental narratives in which previous outright rejection of the language of disability was abandoned for a developing acceptance of its use. Further discussion on the concept of disability indicated that many parents are forced to re-evaluate their disregarding of disability language in light of the problematic reality that ADHD was experienced as disabling in their children’s lives, and that their child faced additional difficulties compared to other children. The following passage from Debbie illuminates the challenges that a complete rejection of the language of disability incurs:

#### **Debbie 967-972**

*I don’t want to use the word disabled because I don’t know if it is that. It is a “Dis”-advantage. What does disabled even mean, you say that word but then you really start to think about it what does it mean? “Dis” ...abled. So that means you’re not able? What does Dis mean? Less. Less abled. Well maybe you are disabled then. They are less able aren’t they. I’m less able. I’m less. My brain doesn’t work like I wish it would and It doesn’t work like my friends do so maybe I am disabled? I don’t know.*

For Debbie, accepting that ADHD may be seen as a disability for her children also meant that she would then need to reflect on her own ADHD and whether she should see herself as disabled. Moses (2010) argues that many parents have a general perception that families with disabilities, especially in relation to psychological and neurological diagnoses, are devalued in society. This is apparent in Debbie’s narrative, as she states that she and her

children are “less able”, and that she is fundamentally “less” as a person. Although some have argued that the medicalisation of ADHD has led to experiences of validation and legitimisation for parents (Klasen, 2000; Moses, 2010), these findings suggest that an acceptance of medicalisation, deficit, and difficulty may be followed by a potentially uncomfortable appraisal of their views on disability. Cath explores this point further as she discusses acceptance of disability and stigma:

**Cath 350-356**

*It's something that I've found really really tricky. Applying for jobs, ticking the box that says you have a registered disability. It's really really tricky. Cause to me, we're just us. It's just the way we are. But it's recognising that actually, **it is a disability in some ways**, and I will need help and they will need help In certain areas. The stigma puts you off it. People will say “we'll it is just naughty boys”.*

The above excerpt exemplifies a prevalent use of the plot of the ‘Balancing Act Between Disability and Difference’ and the oscillations between the two dominant paradigms of ADHD. Cath expresses an understanding of the usefulness of medical conceptualisations of ADHD in seeking support and ensuring reasonable adjustments at work and at school in accordance with the Equality Act (2010). Cath acknowledges that she and her children are disabled “in some ways”, whilst simultaneously wishing to frame herself and her family as “just us, the way we are”. This desire to be “just us”, and the consistent use of the term neurodiversity and neuroatypical throughout Cath’s overall narrative. It also indicates preference towards non-medical understandings of ADHD and models of neurodiversity and difference in the face of the systemic enforcement of disability language in legal documentation. Pam also explored this issue, stating that:

**Pam 747-749**

*I don't like the word disability, but sometimes you have to put on a piece of paper and tick that box if you want to get support*

The “Tentative Acceptance of Disability Language” becomes salient when discussing state benefits such as Disability Living Allowance [DLA] or when parents discussed their requests for additional support in the classroom due to their children having special educational needs [SEN]. Although the foundations of ableism are challenged within a neurodiversity paradigm (Tan, 2018), and parents can understand their children as ‘different’ but needing support, the experience of “ticking the box” to declare their children had a disability, or the applying for **Disability** Living Allowance, was emotionally and epistemologically problematic as parents

are forced to describe their children in disability language terms they prefer to avoid. Thomas (2020) describes the process of applying for DLA for children as a form of violence enacted on parents, who are forced to exaggerate their children's impairments and contemplate worst-case scenario days simply to have their own, and their children's, challenges legitimised. This issue is present across disability studies, with Davis et al (2003) arguing that parents of children with difficulties must overemphasise their children's impairments to access resources, whilst being forced through a system of inordinate testing. It is felt to be a practical impossibility for parents of children on the ADHD diagnostic journey to avoid disability terminology within their children's lives, regardless of their own theoretical position. I argue this is akin to Jenk's (2005) 'parental paradoxical position', in which individuals with disabilities and their families are required to first have their difficulties emphasised and accepted, and accommodations made, prior to true acceptance and celebration of their difference and strengths. Given the difficulties experienced by parents of legitimising their children's ADHD diagnosis and healthcare needs discussed throughout this thesis, the contemporary societal ADHD landscape appears to force parents to engage with, if not accept, the language of disability, deficit, and disorder, to receive the bare minimum of appropriate health and social care provision. The findings of this study suggest that little has changed for some parents experiencing these difficulties when compared to the experience of parents two decades ago (Davis et al, 2003).

There appears to be limited empirical evidence exploring the subjective use of disability language within the ADHD population, however, within the adjacent field of autism research there are many useful insights on the use of disability terminology and its impact on parents and autistic individuals. Rasmussen et al (2020, 5) found that parents of children recently diagnosed with autism also expressed a desire to avoid disability language, with hopes that their children not "see themselves as disabled". Similarly, Jones et al's (2015) exploration of adolescent sensemaking post autism diagnosis found that there was confusion regarding whether autism is "automatically classified" as a disability, and many of the participants did not identify with the disability label or community. Selman et al's (2018: 793) study on the experiences of Somali parents living in the UK with autistic children had similar and relevant findings. Parents in their study described the language of disability as highly sensitive and felt that there was no language to utilise between a "normal, and a mentally sick person". Parents in Selman et al's (2018: 789) study also engaged in a "complex negotiation of autism as a diagnosis", in which they would resist the negative labels of sick, ill, and disabled, and utilise their own language of "different or delayed". The preference to refer to autism as a 'difference' and not a 'disability' has been argued to be a way for parents of autistic children to view their difference as a "wonderful variation of humanity" (Singh, 2016:

1111); a conceptualisation shared by the parents of children with ADHD within the present study. Many similarities exist between the experience of parents on the ADHD diagnostic journey and those on the ASD diagnostic journey regarding the rejection of disability language and its applicability to their children. The statement by Jones' et al (2015: 1501) that "the term disability carries such stigma that individuals do not wish to identify within the label or culture" is equally applicable to parents within the current study. However, unlike the aforementioned studies, parents on the ADHD diagnostic journey described a tentative, and arguably culturally and societally enforced, acceptance of the language of disability. This is due in part to a system predicated on a medical model of difficulty, deficit, and disability, but also due to a recognition that their children experience objective difficulties in addition to those without ADHD and not wholly due to social and environmental barriers.

There was however one exception to the "Tentative Acceptance of Disability Language" within parental narratives. For Jane, the language of disability was not only inappropriate, but completely non-sensical. Jane considered ADHD as a gift and the next stage of human evolution currently being stifled by a stagnant society:

**Jane 544-559**

*I don't care, right, I may be breaking all of the rules, but I feel honestly that it is the new evolution. I don't even know if this is acceptable. I believe that the neurological disorders are the equivalent of human thumbs. You know like Darwin? I think they are like the superheroes of society. People in the world label it as a 'disability', but I completely disagree with that. It's wrong. It's completely wrong. It's like one day, neurodiversity is going to take over. That's my inside, honest opinion. I love it. I think it's amazing.*

**Jane 594-600**

*The world is wrong. It's stagnant. Society is stagnant and that's what's wrong. Society is not open-minded enough, and it's proven in primary schools. They preach 'unique child', but they can't live it.*

The language of disability is anathema to Jane, who utilises a fully positive view of ADHD. This wholly positive conceptualisation, in which children are often labelled as 'indigo children' across the literature has developed into a cultural movement (Carroll & Tober, 1999; Lench, Levine, & Whalen, 2013; Singler, 2015, 2017). The parents of 'indigo' children have been found to view societal negative reactions to their children's behaviour as evidence of an inability to accept the child's advanced knowledge (Lench, Levine, & Whalen, 2013) and

thus, place the responsibility to change on society, not the child or family. This position seemed in conflict with the lived experience of the diagnostic journey, as Jane felt forced to apply for SEN provision and DLA for her daughter due to “*societies failings*”. This conflict gives some insight into the significant emotional distress experienced throughout her journey, and her significantly biographically disruptive experience discussed in Chapter 10.

### 9.2.3. Non-Medical Paradigms and a Search for a Balanced View

A common strategy employed by parents attempting to combat and/or find balance with the disability narrative of their child involved engagement with alternative models of disability. In a process akin to Brock’s “negotiating normality” (2017: 109), where the concepts of “normal, disabled, and different” are adjusted through contrary theories and understandings, parents within this study presented a desire to have a ‘balanced’ view of their children, captured in the subplot “Non-Medical Paradigms and a Search for a Balanced View”. This involved acknowledgement of disability narratives, followed by a counter-conceptualisation of the child in which their differences and strengths are celebrated, and their difficulties are acknowledged and supported. Across the participant group, parental narratives included deliberation on potential counter paradigms to the medical model of ‘disability and deficit’, and a leaning towards non-medical, strength-based approaches. Although not always explicitly named, parents often gravitated to conceptualisations of ADHD consistent with the social model of disability as they presented their children’s difficulties as forms of ‘oppression’ (Abberley, 1987) existing due to societal issues (Landsman, 2005: 132; Shakespeare, 2006), which culminated in exclusion from typical life (Oliver, 1996; Anastasiou & Kauffman, 2013). Parental understandings of ADHD as neurodiversity, where ADHD is considered as a benefit and strength for their children is also included within this subplot. Parental engagement in non-medical approaches to ADHD and the focus on their children’s ADHD given strengths often appeared to be a defensive response to the problematic language and experience of disability terminology previously discussed. This process can be seen within Phil’s statement below:

#### **Phil 849-866**

*I think there is a large element of people, and I am one of these people, that see it as something special. It is **not** a disability. Yes, it prevents you from doing some things, but it also allows you to do other things. He has got an immense amount of endurance, fitness wise. Would he have that if he didn’t have ADHD? Probably not.*

*We don't class as having a disabled son. We have just got a son that is a little bit more special in some areas. And that is really what it is.*

Within Phil's utilisation of the "The Balancing Act Between Disability and Difference" he rejects the term disability, preferring to focus on what he perceives are the great strengths bestowed upon his son due to ADHD, namely increased endurance. Phil's statement that ADHD has benefited his son with higher levels of energy is consistent with findings across the literature. Sedgewick, Merwood and Asherson (2018: 245) observed that individuals with ADHD often describe an "abundance of energy", and Mahdi et al's (2017: 1225) international study of ability and disability in ADHD found that ADHD granted an increased energy level and "ability to engage with physical exercise". Phil's desire to prioritise this aspect of ADHD during a portion of the discussion exploring disability indicated a clear conceptual preference. Pam takes a similar approach, though instead of focusing on her son's strengths, she engages with a social model of disability and explores how the structure of society and school leads to his difficulties being more pronounced:

**Pam 530-536**

*It's like being at a disadvantage. But then if I think about it like that in this society he is. At school the way that they teach him doesn't play to his strengths. It highlights where he struggles. So, then you could say well he is disadvantaged and it's not his fault. I don't like the label. It's a difference.*

Pam's belief that school environments are not well suited for children with ADHD, countering the common argument that it is the child with ADHD who is not well suited for school environments, gives some insight into one of the factors driving her use of this subplot. The parental perception that the origin of the problem is situated in school is present in numerous studies on parental experience and ADHD (Carpenter & Austin, 2008; Watson, 2011). During the 2021 ADHD Foundation conference, comedian Angela Barnes argued that children with ADHD often feel like "chameleons" forced to sit on the "patchwork quilt" that is school. The parental desire to engage with strength focussed conceptualisations of their ADHD children, and the preferred use of language terms such as "different" and "neurodiverse," created theoretically problematic territory for many parents when coupled with the "Tentative Acceptance of Disability Language" [Ch. 9.2.2]. The space between these conflicting positions was narrated by parents as confusing, unstable, and amorphous, as

complete acceptance of either side was not fully satisfying at describing the sense they make of their children. Sharon describes this phenomenon:

**Sharon 315-321**

*I don't necessarily think that neurodiversity always has to be a disability. But again, it's very much dependent on the people and the environment around you. I do feel disabled. When I see my colleagues just being able to just get on with their day from start to finish. I do feel disabled. But now I know it's because my brain doesn't produce as much of a certain chemical as theirs.*

Using her own experience as an example, Sharon's statement exemplifies both models of ADHD and disability previously discussed. She holds a medical understanding of ADHD by presenting objective biological evidence of impairment in the statement "*my brain doesn't produce as much of a certain chemical as theirs*", whilst simultaneously arguing that the experience of disability is "*very much dependent on the people and the environment around you*", a position implicit in the social model of disability. However, a further crucial point is that Sharon "*feels disabled*". For Sharon, it is impossible to deny the embodied experience of difference and difficulty, regardless of conceptual preference of ADHD and disability language. This phenomenon may be understood using Shakespeare's alternative model of disability, where he argues for a discarding of a "'strong' social model which has outlived its usefulness" (Shakespeare, 2002: 9) alongside an acceptance that disability should not be solely reduced to the realms of medical problem (Shakespeare, 2014). Shakespeare (2002; 2014) argues that disability may not always be important in the construction of the self, but also that strategic identification with disability language may be beneficial at different times for the individual with additional needs. Shakespeare's model allows those with impairments to simultaneously hold a belief that society is predominantly to blame for their disabling experience, whilst also accepting the lived experience of bodily limitation and difference personified in Sharon's statement "*I feel disabled*".

#### 9.2.4. Conclusion

Fundamentally, this plot personifies the experience of parents on the ADHD diagnostic journey as they attempt to make sense of the confusing and contradictory concepts of disability and difference. Many parents oscillate between a variety of differing and conflicting

conceptions of ADHD across the spectrum of disability and difference, in a process which, I argue is best described as a “Balancing Act Between Disability and Difference”. Parents draw upon medical models of ADHD to aid in understanding impairment, whilst viscerally rejecting the framing of their child as disabled or having a disability. However, as the diagnostic journey progresses, parents feel coerced into tacit acceptance of disability language due to the experience of societal violence and discrimination in the form of narrow definitions of disability within education, health, and social care. The framing of ADHD within disability terms was felt to be a necessary requirement by parents to accessing practical, educational, occupational, and financial support, and was consistent with evidence that their children were disadvantaged. Parents are drawn to social and strength-based models of disability and neurodiversity, though these prove problematic in the face of the ADHD lived experience where environmental factors are not seen as fully responsible, and the language of neurodiversity discounts the experience of impairment. Contemporary disability models such as those presented by Shakespeare (2002; 2014) may be of use to parents throughout this process, though limited exposure to this and other alternative models means that parents perform their own theoretical illness work in balancing their position on the emotive subject of disability. For Jane, the one parent whose narrative had limited engagement in the balancing act argued within this plot, a complete rejection of medical models and a wholehearted embrace of “*neurodiversity as superpower*” allowed for a fully positive framing of her children, but also led to significant anger and negativity towards society. Cath succinctly summarises the typical parental experience of “The Balancing Act Between Disability and Difference”:

**Cath 1898-1899**

*Understanding that it's a disability but that it comes with positives, it's a massive thing to get your head around, huge thing to get your head around*

Thus far, Chapters 6-9 have explored the primary findings of this study in relation to the narrative plots utilised by parents in the construction, and telling, of their story regarding the experience on the ADHD diagnostic journey. The following chapter will discuss the relevance of these findings within wider sociological and ADHD related theory.

# 10. Discussion

## 10.1. Introduction

This discussion chapter fulfils a dual purpose. The first part of this chapter begins with an analytical discussion of the overall development and structure of the parental diagnostic journey narrative, linking to findings and analysis present within Chapters 6-9. This discussion explores the sequential and chronological nature of many of the narrative plots and their relationship to the 'typical' parental diagnostic journey. It also deliberates on the inherent tension present when attempting to order and make sense of the often messy and non-ordered data of complex lived experiences. The second part of this chapter discusses the multiple forms of 'illness work' (Corbin & Strauss, 1985) parents are required to engage in across the ADHD diagnostic journey and explores how parents make use of narrative plots to perform and make sense of this work.

Due to scant discussion in the wider academic evidence base of illness sociology regarding parents of children with ADHD and 'illness work', this chapter draws upon literature related to parents of children with other chronic conditions and/or hidden disabilities such as autism (Singh, 2016; Rasmussen et al, 2020), developmental co-ordination disorder (Novak et al, 2011), physical health conditions such as cystic fibrosis (Cronin, 2004) and studies including multiple diagnoses (Kish et al, 2018; Tabatabai, 2019). However, although there are significant similarities present between the lived experience of parents and ADHD and parents and other conditions, this chapter also makes the case that a distinct sub-discipline of ADHD social science is a required and important step forward in understanding the specific experience of this group. Section 10.4 [Justifying the Need for a Social Science of ADHD] argues that the parental experience of the ADHD diagnostic journey is unique within the field of illness sociology and discusses the distinctive elements of what makes ADHD different to other chronic conditions and hidden disabilities. Finally, the chapter sets out the elements of a nascent concept of a social science of ADHD, laying the foundations for future development in a field I propose as fertile ground for further sociological discussion.

## 10.2. Development and Structure of the Diagnostic Journey Narrative

During data analysis an interesting concept emerged. Parental development and deployment of the diagnostic journey narratives included an element of temporal and chronological ordering, whilst also consisting of the disordered complexity typical of narrative data. When analysing the overall use and presentation of narrative plots, a correlation was found between the practical processes of seeking and receiving a diagnosis of ADHD, and a potential underlying story framework. This was specifically relevant when considering four of the seven plots (There was a Problem, The Diagnosis, The System and Narratives Regarding Medication). However, the final three plots (The Mother, The Fight and The Balancing Act Between Disability and Difference) did not exist within this underlying structural framework as these plots were utilised by all parents at multiple and differing times across their journey with minimal consistency and structure.

### 10.2.1. Four Temporally Structured Plots

The parental construction and delivery of the ADHD diagnostic journey narrative was individual whilst also sharing considerable structural similarities, especially regarding order and timing of plot usage. Although there were many differences in experience in terms of the practical aspects of the diagnostic journey itself across parental participants (such as different waiting times, multiple referrals to different teams, and private assessment as opposed to NHS assessment), all parental ADHD diagnostic journeys followed this general and loose structure:

- The child presents with a difficulty
- Parental recognition and acceptance that a referral to mental health services was necessary, often including engagement with system of education
- Engagement with the system of healthcare
- A period of waiting for assessment
- Acceptance of the child onto an ADHD specific assessment pathway
- The child undergoes ADHD assessment
- The parent(s) attend an ADHD diagnostic meeting in which a diagnosis is either given or not

- A post-diagnostic discussion regarding medication and other treatment/support options
- A post-diagnostic period of living

Given that the process of assessment and diagnosis of children for ADHD is by necessity broadly structured in comparable ways regardless of location, this structure leads to most parents interacting with similar issues and experiences at approximately consistent times across that journey. I argue that awareness of this broadly similar structure of experiences is helpful in understanding the commonalities in plot timing and usage and is a useful heuristic in explaining why parents utilise certain plots at specific times.

All parents engaged with the plot “There was a Problem” at the outset within their narratives. Parents would tell a story in which they would present a “problem” they became aware of within their child’s life and would deploy evidence to argue that this problem required parental intervention. Although some parents contended that the “problem” was apparent in early infancy due to their child being ‘different’, the “problem” was usually evident within the context of academic difficulties. The presenting of a “problem” became the primary justification for the commencement of the diagnostic journey, and it is therefore logical that all parents would begin their narratives by ‘starting from the start’. As Jutel states, “people go to the doctor to find out what is wrong” (2009: 293), a declaration no less true for parents on the ADHD diagnostic journey.

Following an acknowledgement of a “problem”, parental narratives would typically involve an explanation of the process of searching for a solution. For parents within this study, this typically took the form of information gathering and a quest to increase understanding. This quest, referred to in autism focussed research by Singh (2016: 1110) as the parental “diagnostic quest”, then became the prominent topic for all parents during the first interview (prior to their child’s official ADHD diagnosis). At this stage parents engaged heavily with two major plots: ‘The Diagnosis’ and ‘The System’. Engagement with these two plots at this time is understandable, as parents seeking awareness and understanding of their children’s “problems” required them to engage with the overarching systems of education and healthcare and had culminated in their current situation as a parent on a specific ADHD diagnostic pathway. The plot of “The Diagnosis” played a major role within parental narratives, featuring across all interviews, but was always utilised early within each narrative. As each child was already accepted on a specific ADHD assessment pathway at the time of the first interview, engagement with the plot of “The Diagnosis” was used by parents to further justify and explain their hopes regarding the journey. “The Diagnosis” exemplifies the

parental portrayal of the usefulness of diagnosis in increasing understanding for themselves, as well as specific perceived benefits associated with ADHD diagnosis. The plot includes parental assertions that diagnosis is *necessary* to understand their children and their needs better, whilst also allowing their children to be better understood by society more generally. Diagnosis was also presented as a necessary requirement within the current educational system to accessing effective and appropriate support for their children's needs. Finally, the plot of "The Diagnosis" included the maelstrom of positive and negative parental emotions associated with the possibility of their children being diagnosed with ADHD. As parents were living through the reality of this uncertainty during the time at which the first interviews were conducted, parental engagement with the plot of "The Diagnosis" at this time was both a recounting of previous experience, but also a narration of their current experience, a further understandable explanation as to why the early timing of this plot usage was shared across all participants. Parental narratives would often return to and reengage with the plot of "The Diagnosis"; however, this re-engagement also typically occurred following specific temporal experiences across the journey. For instance, following the final diagnostic meeting in which their children were diagnosed with ADHD, parents would re-engage with the plot of "The Diagnosis" to explore the actual experience in comparison to their expected experience presented earlier in their journey.

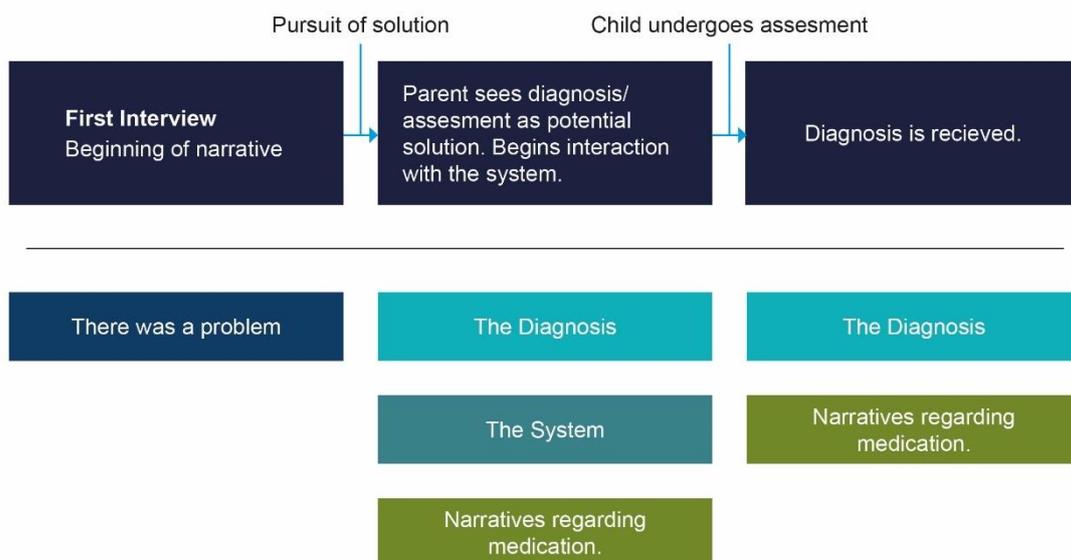
As stated, parental engagement with the plot of "The Diagnosis" often occurred in tandem with the plot of "The System". This is perhaps unsurprising as medical diagnosis requires engagement with a system of healthcare. Given parental experience of the healthcare system is rife with difficulties or unpleasant and distressing experiences, one would expect parental narratives to include their experience of that system alongside their conceptualisations of diagnosis. Unfortunately, plot 3 [The System] demonstrates how common these challenging experiences are for parents on the ADHD diagnostic journey when interacting with the mental healthcare system. The plot of "The System" was utilised by parents to explore their contact with, and experience of, working within the complex interlocking networks present within the healthcare system, and to a lesser extent the school system. From multiple referral pathways, a variety of diagnostic teams, incorrect information about how to refer, and long waiting lists, "The System" was used by parents to explain their past and current frustrations at having to work within the confines of the system, and their belief that the system was fundamentally broken and unnecessarily confusing to navigate. This plot also explores how parents forced to engage in this broken system led to a situation in which the system breaks you, unless you have the knowledge, ability, and confidence as a parent to subvert said system. Parental engagement with and deployment of "The System" at this early stage in their overarching narrative is akin to that of "The Diagnosis", as parental

stories related to this plot were either used to explain previous negative experiences or to explore their current reality. As parental narratives began with a presenting of “The Problem” and the solution (“The Diagnosis”), engagement with the plot of “The System” was often used shortly afterwards as further justification for their current existence on the ADHD diagnostic journey. For parents such as Sharon, Debbie and Pam, the presentation of previous negative experiences with, or beliefs held about the ineffectiveness of, CYPS and the current NHS system was used as justification for their pursuing a private diagnosis as a means of subverting the system. For other parental participants, engagement with this plot was used to narrate their current everyday experience and was returned to at multiple times across the diagnostic journey, typically following a negative related experience such as a lack of communication, incorrect information being given, or long waiting times.

The final plot point with a consistent pattern of use was “Narratives Regarding Medication”. As stimulant medication is generally considered to be the most effective (Faraone et al, 2021) and commonly used treatment for ADHD (Cocoran et al, 2017b), it was of no surprise to the author to find that parental narratives featured discussions and explorations of ADHD medication use. “Narratives Regarding Medication” describes the variety of ways in which parents conceptualised ADHD medication, and their portrayal of the decision-making process in relation to its usage and usefulness for their children. One way in which this plot occurred in parental narratives was to explore positive stories regarding medication, in which they utilised examples of ADHD medication’s effectiveness for themselves as parents or for the child’s siblings. This plot was also used by parents to present stories of trepidation and fear around medication use, or in Debbie’s case, to present the unexpected and upsetting reality that medication wasn’t the answer. Finally, “Narratives Regarding Medication” describes a desire by some parents to recontextualise ADHD medication, presenting it as comparable to medication for physical illness such as insulin or thyroxine. Even with the variety of ways in which this plot was used, parental engagement with the plot of “Narratives Regarding Medication” typically occurred at similar points throughout the diagnostic journey. For many parents, initial engagement with the plot of “Narratives Regarding Medication” occurred shortly after engagement with the above plot points of “The Diagnosis” and “The System” [see figure 2 below]. The reason for this seems logical, as parents were aware that their children were on a specific ADHD diagnostic assessment pathway and would have been informed that the end of this pathway would culminate in a diagnosis of ADHD either being given or not given. This would then typically be followed by a consequent decision on whether to begin pharmacological treatment. This was particularly important for parents on the NHS diagnostic pathway as children who did not begin medication treatment post-diagnosis would be discharged from CYPS and contact with mental health services would be

ended. For children who did commence medication treatment, they would then be transferred to a medication titration and monitoring service within CYPS, which would include regular visits to a clinic, potentially for years into the future. This systemic restriction led to parents being put in a potentially uncomfortable position, where medication use is presented as the simplest way in which continued healthcare support could be gained, whilst non-commencement of medication would lead to parents and children being discharged from mental health services and as described by one parent, “*abandoned*”. This systemic process means that parents are forced to consider their position on ADHD medication use early within their diagnostic journey, giving some explanation as to why this plot was typically present shortly after parental discussion of “The Diagnosis”. Furthermore, there was a consistent temporal usage of the plot of “Narratives Regarding Medication” following the child receiving a diagnosis of ADHD, as parents at this stage in the diagnostic process were on the figurative precipice and were now required to answer the question “To medicate, or not to medicate”? The salience of ADHD medication at this stage in the parental diagnostic journey meant that all parents engaged with this plot at this time, and the construction of their diagnostic narrative was directed into this typical structure by the external influence of the practicalities of the diagnostic journey. Figure 2 below illustrates temporal plot use at specific moments on the diagnostic journey.

Figure 2: Temporal Plots



### 10.2.2. Three Non-temporal Plots

The first non-temporal plot point is “The Fight”. Although there was some degree of consistency across all parental narratives in the temporal usage of this plot, there was also a great degree of difference and non-conformity. As discussed in Chapter 7.2 [The Fight], parental discourses regularly and repeatedly included stories of conflict and fighting to portray their diagnostic journey experience. Parental stories engaging with this plot were often non-specific as they display a general impression of adversity, a perpetual feeling of dehumanization, and the requirement to fight regular exhausting battles. Parental engagement with “The Fight” took on many forms, limiting its ability to fit within a consistent or typical journey structure. For some, “The Fight” was used to portray their everyday lived experience of ADHD and its impact on their lives, whether it be Phil’s focus on his son’s disruptive symptoms and the ensuing inter-familial conflict, Rachel’s harrowing stories of violence and aggression, or Sharon’s general experience of challenge and difficulty. These examples were highly individual and, given the variability in **when** parents had these experiences, did not present a consistent pattern or shared form across the narratives. However, the dominant portrayal of “The Fight” was regarding the diagnostic journey itself. For parents who opted for NHS assessment, the “The Fight” became prominent and useful in the construction of their narratives when they spoke of their experience of the often-frustrating practical limitations inherent within the system. However, there was no archetypical example of when “The Fight” was most salient across the parental journeys, as parents complained of battle and adversity throughout the entirety of the diagnostic process. Parents who opted for a private diagnosis also experienced these difficulties, though often these experiences were presented as driving forces for their decision to ‘go private’. “The Fight” was not only present in every parental narrative but was also present in every single interview. This universal and pervasive plot personifies the shared yet individual complexity of parental experience across the diagnostic journey, as there was no consistent way to determine the timing or form of its usage.

The plot of “The Mother” was another non-structured and non-temporal plot point utilised by all parental participants. As explored in section 8.2, “The Mother” exemplifies the participant storied presentation of the role and concept of the ‘mother’ character, and to a smaller extent the father, alongside the perceived role of mother’s within society. The use of this plot fell into four total subplots: ‘The Good, Heroic, or Valiant Mother’, ‘The Guilty, Broken, or Fragile mother’, ‘The Informed or Insider Mother’, and ‘The Informed or Insider Father’. As there was only one male participant, it was difficult to determine whether the subplot of the “Informed Father” is transferable to the wider ADHD father population, or whether there may exist a

more structured element to the father subplot if additional fathers were recruited. However, for Phil, his engagement with his identity as a parent was significantly different when compared to the mother participants, as he exclusively conceptualised his position as a father in the context of the 'informed parent'. Furthermore, Phil's exploration of his role as a father only occurred when prompted during the interview and did not appear spontaneously within his narrative as was witnessed in all interviews with mothers. It appeared that, at least for Phil, his parental self-concept was of less significance compared to that of the mothers.

The mother related subplots were used by participants to explore the various conceptualisations of themselves as mothers. In the context of the development and the structure of the parental narratives, usage of "The Mother" was inconsistent yet pervasive across the participant group. Parental discussion on what it meant to be a "good", "guilty", or "informed" mother could occur at any time and there was an overwhelming feeling that these concerns and fears were omnipresent for mothers on the ADHD diagnostic journey. At every stage along the journey, mothers were required to confront how their decisions and behaviour past, present, and future related to their position as a 'mother'. For some, their status as parents of children on the ADHD assessment waiting lists led to a recontextualising of their past behaviour. For instance, Debbie explores her guilt at not having fought harder for diagnosis for her daughter in years past "*Why did I not fight CAHMS more?*", whilst Sharon extols her previous parenting tenacity "*I've stormed into that school when I felt they weren't listening*".

The diagnostic journey was presented by mothers as antagonistic and invalidating, with finger pointing and mother-blame from strangers, family, and professionals a commonplace experience. This ever-present threat to mothering self-concept leads to a situation where mothers on the ADHD diagnostic journey do not have the privilege to determine how and when they will engage with the plot of "The Mother" but, are instead forced to engage with this plot at any and many points across their journey to construct a useful narrative. The subplot of the "Good, Heroic, or Valiant Mother" was presented as both preferable in terms of their presentation in society, but also as necessary in ensuring that their children achieved the best possible support and care. However, the diagnostic journey itself was described as instrumental and responsible for their negative self-concept within the "Guilty, Broken, or Fragile Mother" subplot. Finally, the relatively novel and interesting subplot of the "Informed or Insider Mother" illuminated a mothering desire to be knowledgeable and aware of ADHD and the diagnostic journey itself. This was presented as a preferable position for mothers to hold, as it allowed them to minimise and combat some challenges associated with other plots. The parental requirement to perform the requisite parental narrative "work" in this way will be explored in the following chapter.

The final non-temporal plot to be discussed is the “Balancing Act between Disability and Difference”. Chapter 9.2 analysed parental engagement with, and the storied exploration of, the ongoing theoretical and conceptual tension inherent between the dominant discourses on ADHD and the implications of this tension on parental perception of their children. This tension, discussed in Chapter 2.2, relates to the argued incompatibility between a bio-medical disease conceptualisation of ADHD, and a social model of neurodiversity and difference. This was made particularly salient for parents when exploring the concept and language of disability. Parents engaging in this plot described a conceptual and linguistic ‘balancing act’, in which they would present a desire to reject the use of the language and concept of disability in understanding their children, whilst also accepting the lived reality of the impairing and potentially disabling experiences faced due to the symptoms of ADHD. Furthermore, parents also explored the cognitive dissonance and discomfort experienced due to the paradoxical position of refuting the labelling of their children as ‘disabled’, whilst also acknowledging the Equality Act definition of disability, their children’s inclusion on SEN registers, and the receipt or pursual of **Disability** Living Allowance. Parents stated a desire to find a more balanced and nuanced view of their children in relation to disability, engaging in non-medical paradigms where their children’s difficulties are acknowledged and supported, and their strengths are celebrated. As with the other non-temporally structured plots, parental engagement with the “Balancing Act Between Disability and Difference” was highly individual and occurred in almost all interviews and at non-specific times. This reality makes it challenging to include this plot within a structured framework, as the practical diagnostic processes do not correlate with plot usage. Parental engagement with this plot would often be sparked during the interviews when a parent remembered a comment made by a professional or person within their family, or when the discussion delved into the challenges and difficulties faced by their children. This plot was also prevalent when some parents were discussing their own diagnosis of ADHD and their lived experience of disability and difference, which was often followed by musings on the applicability of their experience and self-concept for their children, a form of parental illness work which is explored in the following section [11.3].

Figure 3: Non-Temporal Plots



This section has discussed the structure and development of narratives exploring the parental experience of the ADHD diagnostic journey. This thesis has applied the concept of the parental narrative plot as a story device used by parents to make sense of, and present, their experience in storied form. I have argued that the typical diagnostic assessment process of ADHD, and the relative degree of temporal consistency in the order in which parents experience each step of this process, presents a framework which parents utilise to develop a consistent story structure in relation to four major plots. This chronological structure allows some degree of accuracy in predicting how parents on the ADHD diagnostic journey may portray their experience and gives insights into the timing of potential challenges and barriers across that journey. I have also presented the argument that the use of plots across the parental diagnostic journey of ADHD is not fully structured or consistent, as three plots were found to be both non-temporal in their usage and variable in the extent of their appearance within the parental narrative construction. These conclusions represent an original contribution to knowledge explored in Chapter 11.2 [Original Contributions and Implications]. The following section will transition from the structural considerations of the parental diagnostic narrative into an exploration of how the parental experience of the ADHD diagnostic journey, and specifically the various plots presented within this thesis, can be understood within the sociological context of illness work.

## 10.3. Illness 'Work' Across the Parental ADHD Diagnostic Journey

### 10.3.1. Introduction

During analysis, there emerged an overarching concept that encapsulates the lived experiences and stories of parents of children on the ADHD diagnostic journey: Parental illness work. Parental stories were dominated by examples of tasks, expectations, problems, barriers, and requirements directly related to the ADHD diagnostic journey; a phenomenon identified as 'illness work' (Corbin & Strauss, 1985). The narrative plots discussed in Chapters 6-9 enable us to understand the ways in which parents present the varying and overwhelming forms of illness work that they must undertake throughout this journey. This section explores and analyses the differing forms of illness work presented by parents, and an argument made for the uniqueness of ADHD within the field of illness work.

## What is illness work?

Since the concept's coining and the identification of three main types of work faced by sufferers of chronic illness (Corbin & Strauss, 1985: 224), the notion of illness work has been developed and applied to many contexts. In the home, the process of managing chronic illness includes 'illness work' (work related directly to the illness such as diagnostic work and symptom management), 'everyday life work' (the typical roles and responsibilities of living everyday life such as cooking and cleaning), and 'biographical work' (developing and maintaining identity in the face of chronic illness) (Corbin & Strauss, 1988; Williams, 2000). The experiences of parents are 'entangled' in the biographies of their children (Bray et al, 2014); therefore, childhood illness is likely to have a direct impact on the parent additional to the typical 'labour' of caregiving (Kittay, 2011). Although it can be argued that all parents face these experiences, for those parenting a child with a disability or chronic condition such as ADHD, these experiences are magnified (Green et al, 2013). Due to limited discussion regarding parents of children with ADHD and illness work within wider sociological debate, this section draws upon literature related to parents of children with other chronic conditions and/or hidden disabilities such as autism (Singh, 2016; Rasmussen et al, 2020), DCD (Novak et al, 2011), mental illnesses (Pejlert, 2001), physical health conditions such as cystic fibrosis (Cronin, 2004) and studies including multiple diagnoses (Tabatabai, 2019).

### 10.3.2. The Diagnostic Quest

A major form of illness work with which parents on the ADHD diagnostic journey engage includes 'diagnosis work' (Corbin & Strauss, 1988), or work related to the process and challenges of seeking, fighting for, justifying, and receiving a diagnosis of ADHD. Diagnosis work requires significant effort from parents across the entirety of the diagnostic journey and can be equated to the 'diagnostic quest' discussed in autism research (Singh, 2016). The plot of "There was a Problem" represents the beginnings of parental diagnostic work, as parents become aware of a potential 'problem' and begin an investigative process of monitoring and seeking confirmation of this problem. Increased parental engagement and involvement in education was common within the participant group, as ADHD symptom related academic difficulties required parents to communicate with teachers at increased rates, or to scaffold and support their children's education through increased emotional support, greater parental involvement with homework, and greater degrees of 'at-home'

education such as reading practice. Although this additional parental effort could appear to be evidence of parents simply supporting their children and may not seem immediately relevant to the diagnostic quest, on further inspection this process is often a form of strategic parenting work (Singh, 2016) to make others aware of the 'problem' their children are facing. Cohen's (2009) claim that parental complaints about behaviour and impairment indicate an implicit suggestion from parents that their children have/may have ADHD is of relevance. The requirement that their children's additional needs be seen within a medical context, and not as evidence of poor parental ability as is often the case (Carr-Fanning & McGuckin, 2018), presents one aspect of the aforementioned diagnostic work.

Following on from the preliminary effort of recognising, monitoring, and confirming their children's ADHD type behaviour, parents on the ADHD diagnostic journey are forced to engage in a slew of challenges. The process of gaining access and inclusion onto a specific ADHD diagnostic pathway is itself considerable illness work performed by parents. As the plots of "The Fight" and "The Diagnosis" demonstrate, parents of children exhibiting ADHD symptoms often have concerns rejected by schools, within families, and by medical professionals. Therefore, like Singh's (2016) parents of autistic children, the requirement to stand up to this rejection, fight for their concerns to be seen as legitimate by others, and to find a medical professional willing to listen constitutes a significant form of illness work. This work often exerts a physical and emotional toll on parents of children with ADHD, who describe a constant state of conflict and battle.

King and Bearman (2011) and Mazumdar et al's (2013) studies explored how higher levels of parental education and access to 'neighbourhood level diagnostic resources' are associated with an increased chance of autism diagnosis. This, Singh (2016) argues, indicates that parental social and cultural capital has a direct relationship with the success of the diagnostic quest, with 'higher capital' parents being able to confirm diagnosis more easily. It is interesting that higher levels of community-level resources increased prevalence of autism diagnosis, as this finding is directly opposed to similar studies within ADHD, where incidence rates were found to be highest among the most deprived patients (Hire et al, 2015). I would suggest that these findings could present evidence that the diagnosis of ADHD is less desirable than that of autism when related to parental social and cultural capital. Kazda et al's (2021) systematic scoping review on overdiagnosis and ADHD goes further, arguing that the social, psychological, and academic 'harms' of the diagnostic label of ADHD may be greater than the benefit for those with milder ADHD symptoms. These arguments are of interest, as parents of children with suspected ADHD within this study describe making expensive accommodations such as moving to 'better areas', or as three parents chose to do, paying for private assessment. Furthermore, parents undergoing

private assessment repeatedly expressed their regret, guilt, and concern for those unable to do so, as they perceived private assessment as more thorough, effective, and validating. These findings suggest that parents on the ADHD diagnostic journey see additional financial resources as beneficial to their desired journey outcomes, and exploration into the role and impact of social and cultural capital on the parental experience of ADHD is a potential area for future research. The belief that financial resources are beneficial in increasing the likelihood of receiving an ADHD diagnosis, whether objectively true or not, culminates in parents performing additional, often expensive, illness work such as paying for private assessment, moving home, or paying for private tutelage.

Once their child has been accepted onto an ADHD assessment pathway, illness work continues. The plot of “The System” relates to the many practical challenges faced by parents as they are required to engage in typical diagnostic work as outlined by Strauss and Corbin (1988) such as attending appointments, reading information leaflets, and filling in questionnaires. However, for parents in the current study, the stories and plot engagement regarding this typical work was often narrated as judgemental and inflexible [The Parent Must Work Within the Confines of the System], purposefully ineffective [The System is Broken], and emotionally destructive [The System Breaks You]. Parents engaging with healthcare systems for their children expect to attend appointments, however, for parents of children with ADHD, lack of flexibility in appointment times, and the perceived thoughtlessness of impractical appointment times and geographic location for working parents can be conceived as additional illness work. For parents, it is not simply a matter of attending a healthcare appointment. They must engage with further work by negotiating with employers for time off, requesting flexible working hours, reducing their overall working hours, or as Jane and many other parents of children with ADHD are required to do, leave employment entirely to support their children (Cocoran et al, 2017a). These issues are not unique to ADHD, as parents of children with other chronic conditions such as Type 1 diabetes, asthma, and eczema have also been found to have lower participation within the workforce and/or more insecure employment (Kish, Newcombe, & Haslam, 2017). It is clear that chronic childhood illness, alongside limited employer support and unsupportive employer attitudes (George et al, 2008), has a major negative impact on parental employment (Kish, Newcombe, & Haslam, 2017). The findings of this study add to this discussion, as I argue that it is not only the experience of living with childhood chronic illness that impacts on employment, but also the required parental work throughout the ADHD diagnostic journey itself.

Throughout the experiences and interaction with “The System”, parents of children on the ADHD diagnostic journey are often required to “*prove*” that they are not blameworthy for their

children's current difficulties by attending multi-week parenting courses and making practical changes at home prior to clinical assessments. The implicit, and often explicit, communication that parents are in some way to blame for their children's ADHD related difficulties requires parents to perform as a 'good parent' by not presenting as overly emotional, or challenging the status quo beyond the acceptable, further adding to the perceived work burden. Unlike parents of children with physical conditions where objective biological tests can be completed to confirm suspicions, parents of children with ADHD describe a painful duality of experience. Debbie, Jane, and Pam all described a situation in which they were experiencing emotional pain and anxiety because of the difficulties that their children were facing, whilst also feeling that they cannot fully present this emotional anguish to professionals for fear of being perceived as 'overly emotional' or as 'anxious, histrionic mothers'. Jane recounted an experience in which a medical professional early in her son's diagnostic journey told her that he was likely behaving that way "*because she was an overly anxious mother*". However, once her son received a diagnosis of ADHD she reflected on this moment as evidence that mothers must hide their lived emotional experience and perform as objective automatons. The apparent necessity to hide or at least manage emotional pain throughout ADHD assessment, to avoid being perceived as an unreliable source of information, is perhaps one of the more insidious forms of parental work throughout the diagnostic quest.

Once diagnosis is given, the diagnostic quest continues as parents seek ADHD related resources such as information on ADHD, academic and social support, financial assistance such as DLA, and information on prospective treatment options. This work takes many shapes as parents acquire and mobilise potential illness related resources similar to Bury's (1982) resource acquisition. All parents described a desire to develop their ADHD knowledge, "filling in" (Corbin and Strauss, 1988: 30) their information gaps by reading books and articles or watching ADHD related content online. Although parents of autistic children have been found to attend autism advocacy groups and parental support networks during this time (Singh, 2016), parents of children with ADHD described little to no access to these types of supportive resources due to their non-existence in the area. Pam described the lack of peer related support as isolating and anxiety provoking but promised to begin a local ADHD support network of her own, adding considerably to her illness workload. Parents on the ADHD diagnostic journey proclaim an almost complete lack of support post-diagnosis, forcing them to proactively and assertively seek out what they "*could get*". Although parents may not be the patient themselves, they must personify the 'activated' and 'motivated' patient (Wyke et al, 2013; Entwistle et al, 2018; Franklin et al; 2019: 14) to

manage the collection of resources and pursue relevant and useful ADHD related knowledge.

Within healthcare, unless a child commenced on a medication regime, parents describe being “*cast off*” and “*set-adrift*” as they are offered no alternative treatment or support. Parents express feelings of anger and frustration at the unfairness of diagnostic inconsistency, as those whose children are diagnosed with autism are offered a five-week autism awareness course whilst ADHD parents must “*fend for themselves*”. It has been argued that within typical illness encounters, self-management is “marginalised in favour of medical instruction” (Ong et al, 2014: 232) as medical professionals dictate and prescribe the most effective treatment options (Stevensen et al, 2003). However, the apparent lack of non-medication related support leads parents to work towards achieving the desirable position of ‘Informed Parent’ [8.1.3], where they would “*know what to do*”, could challenge the system, and self-manage their children. Other researchers have presented similar findings, with post-diagnostic information being declared by parents to be dissatisfying, overly technical, and non-specific to their child (Ahmed et al, 2014). Parental efforts towards becoming ‘informed’ evidences a form of ‘evidence-based activism (Rabeharisoa, Moreira, & Akrich, 2014), in which parents contest systemic and institutional problems with greater authority. Parents work towards becoming “credentialed experts” as well as “experientially informed” (Rabeharisoa, Moreira, & Akrich, 2014: 119) to seek supportive solutions for their children and destabilise existing understandings and narratives of ADHD.

Within education, many parents feel they exist in a state of perpetual potential conflict as they battle for their children’s needs to be met. Echoing previous research (Wolpert & Clare, 2004; Carr-Fanning & McGuckin, 2018), parents experience a constant need to convince educational professionals of their children’s additional needs both pre- and post-diagnosis. Once an ADHD diagnosis is confirmed, work transitions from pursuing, justifying, and legitimising their children’s ADHD, to fighting for effective academic provision. More than half of the parental participants gave examples of reading legal policy and legislation to seek provision more effectively for their children at school, a process which Debbie points to as the reason for her “*emotional break down*”. Parental ‘evidence-based activism’ (Rabeharisoa, Moreira, & Akrich, 2014) at school was described as particularly important towards the end of the diagnostic journey, as timely and effective educational provision was perceived as one of the most important and influential factors in improving their children’s future prospects. Although there were some examples of schools incorporating adjustments and learning interventions without parental prompting, these were rare, with the typical experience requiring parents to seek help proactively and persistently. The unfortunate

reality for parents on the ADHD diagnostic journey is that the 'diagnostic quest' related work does not dissolve once a diagnosis is given, it changes.

### 10.3.3. Biographical Work

The following two sections build on the discussion of illness narratives presented in chapter 4 [Illness Narratives], alongside the discussion and analysis within Chapters 8 ["The Mother"] and 9 ["Narratives Regarding Medication" and "The Balancing Act Between Disability and Difference"], to demonstrate how parents of children on the ADHD diagnostic journey perform a variety of biographical illness work. Both this and the following section are related to biographical illness work; however, there is an important distinction between the two. This section will explore the self-biographical illness work (Corbin & Strauss, 1988) that parents on the ADHD diagnostic journey perform to maintain and define a stable biographical identity in response to childhood ADHD. The focus, therefore, will be on the biographical work performed by the parent exclusively in relation to their own self-biography. It will argue that sociological discussion regarding chronic illnesses' impact on biography is not only applicable to parents of children with a pre-existing diagnosis of ADHD as discussed elsewhere (Singh, 2004; Bray, Kirk, & Callery, 2014), but is also useful in understanding the impact of the diagnostic journey itself on parental biographical narratives.

Where the following section discusses the biographical work in relation to parental biography, Chapter 10.3.5 explores the distinct parental work of recontextualising the biography of the child in the face of chronic illness. Singh's (2016) study of parenting work and autism trajectories of care talked of re-contextualising the possibilities for the future of the child. However, I argue that plots such as "The Balancing Act Between Disability and Difference" evidence that parents must reconsider future possibilities, whilst also engaging in biographical work which recontextualises the identity and personhood of the child **throughout** the diagnostic journey.

### 10.3.4. Self-Biographical Illness Work

The impact of chronic illness on personal biographies has seen much sociological discussion since Bury's (1982) seminal work on illness as biographical disruption. Chapter 4 [Illness Narratives] outlined the development and application of these theories over the last forty

years, and the elaborations on this concept such as: narrative reconstruction (Williams, 2000), biographical flow (Faircloth et al, 2004), biographical continuity (Ong et al, 2011) and biographical illumination (Tan, 2018). Although these theories were originally developed to understand the biographical impact of personal illness, they are increasingly used to aid understanding of the impact of childhood illness on parental biographies (Bray, Kirk, & Callery, 2014; Rasmussen et al, 2020). However, these studies have typically explored the parental experience of ADHD and ASD diagnosis retrospectively, asking parents to reflect on their experiences of diagnosis and examine the biographical impact. As timing, context, and circumstance play a role in the level of normalisation and problematisation of life altering events (Williams, 2000), these retrospective stories are told by parents at the latter stages of their children's diagnostic journey, potentially altering the perception of and retelling of their earlier experiences. Rasmussen et al (2020: 7) accept these limitations, calling for a longitudinal project to explore parental biographical work not just within the family, but also within "societies' institutional spheres". The findings of the current project not only substantiate the conclusions presented by Rasmussen et al (2020) that their parent-biographical spectrum model is beneficial for diagnoses other than ASD, but also further develop the discussion of parental self-biographical work in two significant ways. In the first instance, the findings of this study evidence that parental interaction with 'societies institutional spheres' (typified as 'systems' within Plot 3: "The System") across the timespan of the diagnostic journey has a direct and significant impact on parental biographies. These interactions require parents to perform additional biographical work outside of the family biographical work previously explored. Moreover, this project contributes to wider debates by presenting evidence that parents perform self-biographical work in response to the diagnostic journey itself, and not only in response to diagnosis.

Perhaps the most expected form of parental self-biographical illness work which emerged from the data was in response to a confirmed diagnosis of ADHD. Parents describe their children's ADHD diagnosis as legitimising, allowing them to re-establish their credibility as parents by having a tangible reason for their challenging everyday experiences. For most parents, ADHD diagnosis reduced feelings of guilt and shame brought on by the belief that they were ineffective or poor parents, a conclusion echoed in other studies (Gwernan-Jones et al, 2015). The realisation that their children had difficulties which were additional to the 'typical' child allowed parents to recontextualise their self-biography from that of a 'parent of a child with educational and/or behavioural difficulties' to that of the 'parent of a child with additional needs and/or a medical condition'. The receiving of ADHD diagnosis also allowed parents, in this case specifically mothers, to reflect on experiences across the diagnostic journey which were damaging to their self-concept (such as being blamed for their children's

behaviour or being told that they were overreacting to their children's difficulties) and reconstruct (Williams, 2000) their biography to a more positive one. This was particularly evident in the subplot 'The Emotional Impact of Diagnosis', personified in the following statements:

**Pam 385**

*I actually feel really good about myself now, we've been doing all right*

**Pam 843**

*People take you seriously, you're not just a neurotic mother.*

**Rachel 152**

*It was everything I wanted to hear so that I knew I wasn't going mad*

ADHD diagnosis allows some parents to reconstruct their personal narrative, transitioning from a critical and negative self-concept to one more positive. These findings are directly comparable to the biographical cohesion evident in studies exploring parents of children diagnosed with autism (Rasmussen et al, 2020), where re-narration of the 'self' from inadequate parent to supportive parent was experienced as a beneficial form of illness work. For parents such as Cath and Phil, biographical work at this time took on a different form. As they already conceptualised their children as neurodiverse and commenced the diagnostic journey expecting an ADHD diagnosis with a high degree of confidence due to their previous clinical experience in the area, the self-biographical work was experienced as a confirmation and continuation of their previous expectations. This ready acceptance of diagnosis and non-disruptive biographical work can be understood as examples closely related to biographical flow (Faircloth et al, 2004) or continuity (Ong et al, 2011). Although this may still be conceptualised as an example of biographical cohesion (Rasmussen et al, 2020), the absence of a pre-existing negative parental self-concept and the confidence in the presence of ADHD reduced the need for parental re-narration and can be better understood as parental biographical reinforcement work.

However, parental biographical work following ADHD diagnosis was not always a positive experience. For Debbie, confirmation of her daughter's ADHD diagnosis created two significant forms of biographical work. The first form of work was similar to that already discussed but with a different outcome. As Debbie's daughter had undergone an inconclusive ADHD assessment previously, the confirmation of an ADHD diagnosis led to an *increase* in feelings of shame and blame. For Debbie, diagnosis was 'proof' of her previous inadequacies as a parent, as she explained how she should have "*fought harder*" and "*not*

*given up*” during the previous assessment. Debbie engaged in post-diagnostic biographical work in which she re-narrated her past behaviour as evidence of her failings as a mother, a clear example of parental biographical disruption in the face of childhood diagnosis. This finding is particularly interesting, as this form of biographical disruption appears different to that typically discussed within the sociological literature. Biographical disruption is characteristically exemplified as disruption in the face of diagnosis (Bury, 1982), and has been argued to be relevant to parents whose identity is disrupted by childhood diagnoses which they had not considered (Rasmussen, 2020). Unlike examples of parental biographical disruption explored elsewhere, where it is the diagnosis of an illness that is disruptive due to the implications of its presence and the perceived assault on the selfhood of the child, Debbie’s story indicates that childhood diagnosis can also be biographically disruptive for parents, when perceived as evidence of parental inadequacy who have previously expected and pursued diagnosis. This finding may be of benefit to future researchers hoping to understand the experience of parents of children diagnosed with illnesses in which they have prior knowledge or experience and is likely transferable to other similar conditions. Table 1 below demonstrates each of the parental participant’s biographical response to their children’s diagnosis.

Table 1 Biographical Impact in Response to ADHD Diagnosis

Parent	Biographical Impact in Response to ADHD Diagnosis	Potential Reason Why
Jane	Disruptive	The lack of a diagnosis appears disruptive given Jane's firm conviction that her daughter has ADHD.
Debbie	Both Disruptive and Cohesive	Confirmation of a diagnosis proved Debbie's belief that her daughter has ADHD correct. However, it also evidences that she did not 'fight hard enough' in the first assessment.
Pam	Cohesive	The diagnosis recontextualised Pam's sons' difficulties by giving a justified medical reason for their existence.
Sharon	Both Disruptive and Cohesive	Sharon's healthcare background and personal diagnosis allowed her to draw upon her experience and feel confident in her conviction that her son has ADHD. However, the confirmation of a diagnosis also led her to worry about the future given that she was "aware" of the potential risks.
Cath	Cohesive	Cath's healthcare background, her personal diagnosis, and eldest son's ADHD diagnosis allowed for a high degree of confidence in her belief that her son has ADHD.
Rachel	Cohesive	The confirmation of a diagnosis was "everything" for mum as it allowed her to utilise medical understandings of ADHD to adjust her perception of her daughter.
Phil	Neither Disruptive nor Cohesive	Phil's high degree of confidence in his belief that his son has ADHD allowed for a more ambivalent approach to the diagnosis as it signified a minor barrier in his pursuit of treatment (medication).

The second form of self-biographical illness work parents engage with following their child's diagnosis can be conceptualised as 'ADHD self-diagnostic biographical work'. This work was relevant for parents who had a diagnosis of ADHD themselves, and was present in Debbie, Sharon, Cath, and Jane's narratives. For parents with a personal ADHD diagnosis, their children's diagnostic journey presented a series of interesting biographical moments within which the parent must explore the relationship between ADHD and themselves, often reconstructing their own story. Witnessing and assessing their children's ADHD related difficulties forced parents to consider ADHD's impact on their own lives and reflect on their own sense of selfhood. Parents begin asking questions of themselves such as: "*Do I have these same difficulties?*", "*if I had been diagnosed earlier would my life have been better?*", and "*am I disabled?*". This parental example of illness work is remarkably similar to typical examples of biographical disruption (Bury, 1982) and reconstruction (Williams, 2000), as parental responses to their children's diagnosis appear comparable to a parent receiving a diagnosis themselves. In the process of recontextualising the child throughout the ADHD diagnostic journey (to be discussed in Chapter 11.3.7), parents with a personal diagnosis describe having to compare how they see their own ADHD with how they see their children's ADHD. Debbie and Sharon both explored how they perceive their own ADHD in exclusively negative terms, portraying it as an antagonistic force or entity which needed to be overcome. However, they both spoke of a desire for their children to see their own ADHD as both beneficial and challenging, a position in conflict with their own conceptualisations. The development of a self-biography in which this dissonance became tenable exemplifies the type of biographical work argued here. Debbie and Sharon present their self-concept in relation to ADHD as an artefact of the past, developed due to a lack of information on the diagnosis within a society experienced by older generations. This self-biographical illness work allowed them to hold the seemingly contradictory positions of seeing their own ADHD as a disruptive force, whilst concurrently hoping that their children see their own ADHD in a more balanced way. For Jane, her assertions that both of her daughters' ADHD makes them "*special*", "*gifted*", and "*superheroes*" also had the added benefit of allowing Jane to confirm her own ADHD as evidence of her personal uniqueness. I argue that these examples of ADHD self-diagnostic biographical illness work present unique and interesting developments to the sociology of diagnosis and sociological discussion on illness' impact on biography. Furthermore, given the high level of heritability of ADHD diagnosis (55% likelihood of a child fulfilling the diagnostic criteria if at least one parent has a diagnosis (Barkley, 2015)), I suggest that this finding presents an interesting and exciting area for future study and exploration, within ADHD and other similar heritable diagnoses such as autism. Table 2 outlines each parent's ADHD 'self-diagnostic' biographical response.

Table 2: ADHD "Self-diagnostic" Biographical Response

Parent	ADHD "self-diagnostic" biographical response	Potential Reason Why
Sharon	Disruptive	Her son's diagnosis led to a period of reflection in which Sharon lamented how ADHD has presented many difficulties and barriers in her own life. Sharon described how she would gladly take a pill which removed her own ADHD but would hate for her son to feel the same way.
Debbie	Disruptive	Debbie's daughter's diagnosis forced Debbie to reflect on her own concept of ADHD and disability, reframing herself as "less-able". Debbie's framing of her own ADHD as her "biggest nemesis" meant that she was forced to confront this nemesis once her daughter was diagnosed.
Jane	Cohesive	Jane's daughter not getting a diagnosis was a matter of great frustration for Jane as she strongly associates with being neurodiverse and already having another daughter with ADHD. The lack of a diagnosis solidified Jane's belief in her own ADHD and the high likelihood that her daughter does have ADHD as she was able to explain this discrepancy as CAMH's incompetence.
Cath	Cohesive	Cath strongly identifies herself and her family with the label of ADHD and neurodiversity. Her son's diagnosis allowed for a comfortable integration and affirmation of her own ADHD related strengths and difficulties and further evidence of her 'neurodiverse family'.

The longitudinal nature of this project, and the novel area of exploration being the overall diagnostic journey, illuminated a form of illness work previously uninterred in prior research on ADHD and similar conditions. Interview one was typically undertaken prior to a diagnosis being given, which allowed for examples of parental biographical illness work to emerge in response to the process of referral, the experience of waiting lists, and most significantly the interactions with the systems of healthcare and education ("The System"). This illness work

became particularly prevalent for mothers who were attempting to withstand ‘The System’s’ assault on their self-perceived mothering role (“The Mother”). As explored in Chapters 7 and 8, parents, most prominently mothers, on the ADHD diagnostic journey experience a slew of implicit and explicit attacks on their parenting ability. Questions are regularly raised regarding their parenting capacity and the impact of their parenting choices on their children’s behaviour. These attacks were narrated as being present across the entirety of the journey and were felt to be more consistent and targeted prior to an ADHD diagnosis being confirmed. Mothers in particular spoke of having ‘fingers pointed’ at them for their children’s difficulties, being blamed for their children’s ADHD behaviours, and being questioned on whether they believed themselves to be “*overly neurotic*” or “*obsessively clingy*”. These questions were felt by mothers to be used to invalidate their concerns regarding ADHD and place the onus of responsibility on their perceived emotional and behavioural weaknesses and delegitimise requests for ADHD assessment. In the face of such an onslaught, I argue that mothers must perform further self-biographical illness work not only in response to the presence of illness or following medical diagnosis, but in response to the processes across the illness journey itself.

The confrontational and blame-laden interactions with professionals across the systems of education and healthcare force parents not only to perform the practical diagnostic quest illness work [Ch 10.3.2], but also to reconstruct and adapt their personal biography. At this stage it is useful to consider Rasmussen et al’s (2020) parental biographical spectrum model, and its framework for including disruptive, cohesive, both disruptive and cohesive, and neither disruptive nor cohesive biographical experiences. I propose that the self-biographical illness work in response to parental interactions with ‘the system’, and the construction and adaption of a mothering self-identity (“The Mother”) fit within the confines of their model. For parents such as Pam, interactions with ‘the system’ are relayed as biographically disruptive, as she described how these attacks on her parenting ability led her to question and doubt her mothering self-concept. Pam’s tearfulness and visible emotional distress as she states that she “*thinks she is a good mum*” after describing a healthcare professional questioning whether she is “*overly neurotic*” evidences the disruptive impact of these experiences on parental biographies. Although the eventual diagnosis was a cohesive biographical experience for Pam, the necessity to defend and reinforce her mothering identity prior to diagnosis demonstrates this additional biographical illness work. In Chapter 7.1.3 [The System Breaks You], Debbie’s breakdown and self-described “*destruction*” in the face of the demands of ‘The System’ was evidenced in the plot of “The System Breaks You”. However, this moment also represents parental biographical disruption, as Debbie explains how she thought she was strong enough to manage these parental demands but

'failed'. Debbie's experience of revising her mothering self-concept from one prioritising strength and heroism to one in which she acknowledges her self-defined 'failure' represents a further example of disruptive parental self-biographical illness work. However, for parents who have more validating interactions with 'the system' and who experience fewer direct attacks on their parental identity, the pre-diagnostic portion of the diagnostic journey can be a biographically cohesive experience. Cath, whose expertise around ADHD allowed her to position and conceptualise herself as an "Informed or Insider Mother", experienced very little blame directed at her from healthcare professionals. This appears to be in part due to professionals' ready acceptance of her professional expertise, but also because of her confidence in challenging bad healthcare practices and her medically informed language usage. These factors allowed Cath to reinforce and strengthen her own mothering biographical self-concept, and maintain her identity as a knowledgeable, informed, and clinically professional mother of a child with suspected ADHD. Table 3 highlights the individual parental biographical responses to the diagnostic journey itself alongside potential explanations.

Table 3: Biographical Impact in Response to Diagnostic Journey

Parent	Biographical Impact in Response to Diagnostic Journey	Potential Reason Why
Phil	Neither Cohesive nor Disruptive	<p>Potentially influenced by Phil's position as an "Informed Father" and as the only father in the group, Phil's biographical experience of the ADHD diagnostic journey was unique within the sample. There was limited emotional conflict within Phil's story as the journey was presented as simply a series of goalposts and steps towards the expected outcome of his sons ADHD diagnosis and the commencement of stimulant medication. The diagnostic journey was narrated as a necessary step towards Phil getting support for his sons' education.</p> <p>Although the diagnostic journey was presented as difficult and emotional due to systemic failures within the system, his healthcare experience allowed Phil to prepare for and expect these difficulties in a way which did not disrupt his biographical position. "The Diagnosis" of ADHD for his son was comfortably integrated into Phil's pre-existing narrative for his son but was not presented as particularly disruptive or cohesive.</p>

Parent	Biographical Impact in Response to Diagnostic Journey	Potential Reason Why
Pam	Cohesive	<p>Pam's story is one of significant biographical cohesion. Through the power of "Diagnosis", Pam's narrative completely shifts from a mother on the brink of emotional collapse and breakdown, to an empowered, hopeful, informed, and strong mother.</p> <p>Prior to assessment, Pam's story is dominated by uncertainty, worry, and concerns around complete emotional collapse. Pam presents herself as a mum desperate to help and understand her son even if the answer is that she is a "bad mother". However, once assessment began and a diagnosis of ADHD is given, Pam's narrative completely flips into one that is filled with positivity, hope, proactivity, and determination. "The Diagnosis" is a formative, biographically cohesive experience that allows Pam to understand her son and reconstruct her mothering identity to being a "Good Mother" to a child</p>
Cath	Cohesive	<p>Cath's "Informed and Insider" position allowed her to consistently "Subvert The System" to achieve the outcomes she desired. Although Cath experienced difficulties and "Fights" throughout the journey, she was confident in her ability to overcome these by utilising her professional experience. Cath's conceptualisations of her family as the <i>"weird and wonderful neurodiverse family"</i> allowed for a seamless integration of her son's ADHD diagnosis into the overall narrative.</p> <p>Although the process was less illuminating as it was for Pam, Cath's journey was cohesive and relatively problem free when compared with other parents.</p>
Jane	Disruptive	<p>Jane explores how "The System", have let both her and her daughter down by not meeting her daughters needs by diagnosing ADHD. Jane presents the diagnosis of ADHD as the primary way of accessing support for her daughter. She regularly expounds that society is the problem and that "The System" does not allow for her children to flourish.</p> <p>Mum regularly presents herself as the "Informed Mother" who is more knowledgeable than the professionals responsible throughout the diagnostic journey. Jane's story is one dominated by the plots of "The Fight" and "The System" as she experiences significant disruption to her own and her daughters' narratives due to the significant challenge of pursuing a diagnosis.</p>

Parent	Biographical Impact in Response to Diagnostic Journey	Potential Reason Why
Rachel	Both Disruptive and Cohesive	<p>Rachel's overall story is one of great emotional difficulty, challenge, turbulence, and waiting. Although her daughters ADHD diagnosis was biographically cohesive, the journey itself was experienced as constant disruption and strife. Rachel experienced long waiting times with limited or no communication with CAMHS.</p> <p>The diagnostic process was often likened to being '<i>lost at sea</i>', as Rachel described limited support and communication from professionals and a perpetual state of anxiety and concern for her daughter. Rachel's diagnostic journey was significantly disrupted by the Covid-19 pandemic and lockdown, as her daughter's assessment was postponed for over a year.</p>
Debbie	Both Cohesive and Disruptive	<p>Debbie's 'Quest' for a diagnosis was a quest for cohesion. Previous inconclusive ADHD assessments and multiple experiences of being shamed and blamed as a mother throughout the journey were significantly biographically disruptive. Whereas the diagnosis of ADHD was a cohesive experience, the disruption of her own biography as a mother was primarily due to "The System" in which she had to seek "The Diagnosis".</p> <p>Debbie always expected the diagnosis of ADHD, in part due to her own diagnosis and the diagnosis of her youngest son. However, although the diagnosis of ADHD was a cohesive and expected experience (remove for Debbie's view of her daughter), the additional diagnosis of dyslexia and autism were biographically disruptive as they were unexpected additions. Debbie's focus on the ADHD diagnosis led to her being "blindsided" when confronted with additional diagnoses.</p>
Sharon	Both Disruptive and Cohesive	<p>Sharon expected her son to be diagnosed with ADHD, declaring that her previous experience working within CAMHS allowed her to know what to expect. This was a biographically cohesive experience for mum given her expectations. However, during the diagnostic journey professionals also considered a diagnosis of autism, which was experienced as significantly biographically disruptive to mum as she saw autism as a "less hopeful" diagnosis.</p> <p>This unexpected additional diagnosis, alongside school reports demonstrating her son's significant difficulties were emotionally upsetting for mum and felt by Sharon to be evidence of her being a "bad mum", causing disruption.</p>

### 10.3.5. Child Biographical Work and Recontextualizing the Child

A further form of biographical illness work relates to how parents contextualise and view their *children* in response to the ADHD diagnostic journey. Modified from similar findings in Singh's (2016) study of parents of children diagnosed with ASD, recontextualising the child is often necessary for parents whose "self-understanding and the possibilities for understanding and supporting their children" (Rasmussen et al, 2020: 6) is "under assault" by diagnosis or illness (Bury, 1991: 453). This parental work is exemplified in the plots "The Diagnosis", "Narratives Regarding Medication", and "The Balancing Act Between Disability and Difference".

The plot of "The Diagnosis" exemplifies how parents on the ADHD diagnostic journey see diagnosis as a beneficial tool to improve understanding of their children and as a steer to instigating effective support. A diagnosis represents a vital puzzle piece in explaining their children's atypical behaviour, allowing Debbie to learn "*what is making her [daughter] tick*", and to re-evaluate her daughter from just a "*scatty ditsy girl*" to a girl with additional needs. Hamed et al (2015) personify this process when they state that ADHD diagnosis allows the individual to become a 'person who has a problem', not a 'problem person'. Given that parents were typically aware of their children's differences at an early age [Plot 1: There Was A Problem], the concept of biographical flow is of relevance, as those already aware of health issues may more readily accept additional health concerns (Faircloth et al, 2004). This was evidenced within Phil, Cath, Sharon, Jane, and Debbie's stories, as these parents held firm convictions that there was a previous problem and a strong belief that their children had ADHD prior to diagnosis. Parents who had stronger pre-diagnostic belief of their children's ADHD experienced limited disruption in how they conceptualised their children post-diagnosis. These parents describe a more flowing, cohesive experience and ready acceptance of the diagnosis as it confirmed their pre-existing illness narrative for their children. For parents who described limited levels of pre-diagnostic conviction that their children had ADHD, such as Pam and Rachel, the receipt of a diagnosis was more akin to Tan's (2018) biographical illumination. For these parents, ADHD diagnosis created an enriching and empowering recontextualising of their children, allowing them to reconstruct their perception of their children from the distressing 'abnormal neurotypical child' to the preferable 'normal neuroatypical child'. The delivery of an ADHD diagnosis enabled parents to engage in biographically cohesive illness work where they recontextualise and/or solidify their prior understandings of their children in relation to ADHD.

Parents also perform post-diagnostic illness work in which they imagine and construct futures for their now medically diagnosed children. These futures can be optimistic in nature, as parents describe diagnosis as important in allowing educators to understand their children better. This accurately reflects reality given that teachers have been found to adjust their perception of poor behaviour from children diagnosed with ADHD, recontextualising it as valid due to a medical condition (Moore, Arnell, & Ford, 2017), or viewing it as more 'reasonable' given the diagnosis (Rogalin & Nencini, 2015). However, the construction of these new and imagined futures also included the emergence of additional parental fears and concerns as ADHD diagnosis created a potential conduit through which their children could be stigmatised and discriminated against. The reconstruction (Williams, 2000) of these potential futures for their children, and the parental acknowledgement that their children will face unexpected future dilemmas, such as disclosing their diagnosis to friends, employers, and academic institutions, demonstrates further child recontextualisation work relatively unexplored within the wider ADHD literature.

### **Disability, Difference, and Personhood**

Parental engagement in child biographical illness work is also apparent when considering Plot 7 [The Balancing Act Between Disability and Difference]. Across the diagnostic journey, parental oscillation between medical and social models of disability and ADHD, and the search for a balanced multi-modal view of their children, reveals further work. Given the benefits of increased understanding, biographical cohesion and continuity, the opening of treatment pathways, and the reductions in blame following medical diagnosis as discussed above, a medical model of ADHD is presented by parents as undeniably useful. However, the implications of a fully medical model proved problematic for parents who wished to celebrate the individuality and personhood of their children beyond the confines of illness classification. Parents rejected the presentation of **all** their children's differences as evidence of medical symptomology, opting for counter conceptualisations in which difficulties were acknowledged but differences and neurodiverse strengths were celebrated. This process of patients challenging dominant medical discourse embodies general trends in illness sociology, where illness and disability 'negotiations' are becoming increasingly common in the face of "medical claims to knowledge" which "sit uneasily with patient demands for co-operation" and individualism (Barnes & Mercer, 2010: 58). Chapter 9.2.1 [Initial Rejection of Disability] explores how initially, parents unanimously rejected the use of disability language and the viewing of their children as disabled. However, Chapters 9.2.2 [Tentative Acceptance of Disability Language] and 9.2.3 [Non-Medical Paradigms and a Search for a Balanced View] evidence how complete rejection of disability language proves untenable for parents wishing to utilise the benefits associated with medical models of ADHD. Parents

describe feeling compelled to accept the objectively evidenced and lived reality of neurocognitive difficulties faced by their children. They also describe the practical challenges of rejecting disability language, especially when they are required to ‘tick the box’ confirming that their child is ‘disabled’, or ‘has a disability’, when accessing or applying for educational and social support such as DLA and classroom assistance. The theoretical insecurity of being stuck between these contrary epistemological conceptualisations of ADHD and disability requires parents to engage in a ‘balancing act’ of illness work. Parents seek an understanding of their children which utilises the beneficial elements associated with a medical model, whilst also allowing for social and strength-based models to encapsulate the positives of their children’s neurodiversity. A major benefit of the longitudinal nature of this project was being able to observe and study this process in real time, and to analyse how parental performance of this work adapted across the journey. The apparent preference towards models of neurodiversity and neuro-atypicality represents parental desire for their children to exist outside of the confines of the individualising perspective of medical disability (Turowetz, 2015), and to seek “neurobiological citizenship” (Brownlow & O’Dell, 2013: 106) for their children. Chapter 2.9 [A Note on Terminology] discussed the inconsistencies and variability in language regarding ADHD, and the linguistic challenges faced by parents who can choose to refer to their children’s ADHD as a: disorder or neurodevelopmental disorder (APA, 2015; WHO, 2018), an impairment, disease, disability, illness or injury (Ortega, 2009), a psychiatric/medical problem (Conrad, 2007), a cognitive disability or learning difficulty (Lassinantti & Almqvist, 2021), a neurobiological disorder, injury, or personality trait (Scavarda & Cascio, 2022), as a superpower (Lench, Levine, & Whalen, 2013) or simply a difference. Although parents on the ADHD diagnostic journey navigate between and across this smorgasbord of terminology, all parents felt that the paradigm of neurodiversity most comfortably allowed for their positive opinions of their children to flourish and allow them to see their children as part of the wider neuroatypical world, seeking Brownlow and O’Dell’s (2013) neurobiological citizenship. Jane went a step further, proposing a language alteration by coining the term “*DIFFability*” in an attempt to capture the *difference* and *ability* of her children, whilst also alluding to the concept of disability. This presents a clear example of the inadequacy and unsuitability of typically used illness vocabulary for parents of children with ADHD.

However, dominant biomedical understandings of ADHD continue to prove beneficial in the parental process of recontextualisation of self and child, but problematic in its denial of children’s individualism. The process of biographically recontextualising the child with regard to disability and ADHD provides an interesting area for future exploration, especially as non-medical paradigms such as the neurodiversity movement become increasingly prevalent in

wider society. A study in which parents on the ADHD diagnostic journey were presented with a variety of differing social models of disability, such as Shakespeare's alternative model of disability (2002; 2014), alongside contrasting medical models such as Jensen's (1997) ADHD as a disorder of adaptation, and Barkley's (2015) conceptualisation of ADHD as purely biological disorder, would be particularly useful in helping understand parental preferences regarding options across the 'balancing act'. This may give insights into whether specific information and resources on these models would be beneficial for parents on the journey.

The final form of parental child story work is regarding medication. Parents on the ADHD diagnostic journey perform a plethora of work in relation to medication, including information gathering to make medication commencement decisions [8.1.3 & 8.1.4 Informed or Insider Mother/Father], reconstructing and adapting the portrayal of ADHD medication from psychiatric drug to physical medication [9.1.3 Framing ADHD Medication: ADHD and Physical Illness], and constructing a cohesive narrative of personhood, responsibility, and identity for their children. Focus will be on the latter two forms of parental work, recontextualising the child and recontextualising ADHD medication. Parents on the ADHD diagnostic journey must consider, or at least engage in healthcare conversations about, their children being prescribed stimulant medication such as methylphenidate given its status as an efficacious and conventional treatment for ADHD (Faraone et al, 2021). There was considerable discussion and contemplation within the parental narratives towards medication use both pre- and post-diagnostically, a finding building upon Cocoran et al's (2017b) claim that parents are typically ambivalent about medication use post-diagnosis. Although there was some medication related trepidation within Rachel and Pam's stories, most parents expected and hoped to commence medication as soon as possible, unlike parents in Brinkman et al's (2009: 584) study who saw medication as a "last resort".

Given parental engagement with both medical and social models of disability and illness as discussed in the previous section, the framing of ADHD medication becomes additional work in which parents consider whether medication treatment fits within their conceptualisation of ADHD and their children. There exists a tension between the desire to see ADHD as simply a neurodiverse difference, and the commencement of medication regimes aimed at reducing problematic symptomology and improving academic performance. Parents also express an awareness of the societal stigma associated with medicating their children with ADHD medication, a concern well-founded given the wide array of evidence of stigmatising views towards stimulants, in particular Ritalin (Koro-Ljungberg & Bussing, 2009; Mueller et al, 2012; Cocoran et al, 2017b; Masuch et al, 2018). To pre-emptively combat this stigma, Cath, Phil, Sharon, and Pam all attempt to reframe the discourse on ADHD medication by

presenting it as biological ‘correction’ via re-establishing dopamine balance; adjusting its status to a necessary medical treatment akin to insulin for diabetes and thyroxine for low thyroid function. This position is strongly associated with a medical model of ADHD, in which parents implicitly accept a biological deficit in their child’s ability to function at a normative standard and aim to ameliorate this ‘medical’ issue with pharmacology. Parental engagement with these counter-stigma medication narratives were typically included in the stories of parents with healthcare related professional backgrounds and were absent from the narratives of non-healthcare parents, a finding echoing Birdsey and Joseph (2021) who argue that parents can utilise their medical perspective to adjust their choices and experience. Medically ‘informed’ status allowed for deeper engagement in this parental work, as parents draw upon the language of medicine to present a counterargument more palatable than the dominant societal discourse, reframing medication from a form of social control against deviancy (Conrad, 1992), to agency over illness (Stewart, 2017).

The recontextualising of ADHD medication and the presenting of the treatment as ‘biological need’ represents a further negotiation with medicine (Barnes & Mercer, 2010), and proves vital in the wider child-related biographical work. Given that some have argued that ADHD medication represents a method of social control and the ‘drugging’ of unwanted behaviours (Conrad, 1992; Conrad & Potter, 2004), the framing of ADHD medication as synonymous with medication for physical illness allows parents to conceptualise their children as ‘typically ill’, and not deviant. This relatively unexplored form of parental illness work is of particular interest given changes witnessed within the wider discussion of stimulant medication usage and ADHD. Comstock (2015: 15) explored how individuals taking ADHD medication justified their actions in online forums by framing the treatment as “self-investment”. He argues that ADHD medication can no longer be viewed as merely “prosthetic enhancement” (Conrad & Potter, 2004), but as a form of self-actualisation in which one is able to produce a “self-disciplined and productive identity” (Comstock, 2015: 17). Parents commonly acknowledge that symptom improvement outweighs medication’s potential ‘cost’ (Wong et al, 2018), with many declaring that medication is crucial in managing ADHD (Bull & Whelan, 2006; Brinkman et al, 2009). However, unlike most research regarding parents and ADHD medication, where the focus is on assessing effectiveness, adherence, medication decision-making, and parental opinion (Cocoran et al, 2017a; Wong et al, 2018), the current study further develops sociological discussion by positing that parents on the diagnostic journey must perform two distinct forms of medication related illness work. Parental illness work includes attempts to reconstruct the framing of ADHD medication, recontextualising it as a necessary physical illness treatment. The second form of illness work relates to the child

biographical recontextualisation in the face of medication, where parents must consider whether the use of medication alters their own notion of their children's identity.

## 10.4. Justifying the Need for a Social Science of ADHD

Thus far, this chapter has developed sociological discussion of parental illness work and ADHD by detailing three main components of parental illness work across the ADHD diagnostic journey: 'The Diagnostic Quest' [11.3.2], 'Self-Biographical Illness Work' [11.3.4] and 'Child Biographical Work and Recontextualising the Child' [11.3.5]. This section will conclude the discussion by presenting a series of justifications of how the diagnosis of ADHD holds a unique and interesting niche within illness sociology, alongside arguments for the development of a specific social science of ADHD. This section will not attempt to present an exhaustive or fully developed model due to limitations in the scope of the current project but will present a starting point for future research activity. I present here justifications of the unique position of parents and ADHD within sociological discourse:

### **1. ADHD problematises medical classification, language, and biological objectivity**

As explored throughout this thesis [Ch 2.9. Ch.9.2. Ch.11.3.5] medical, educational, and lay discourse of ADHD is often beset with linguistic challenges and complications in classification. A lack of cohesive terminology to define and refer to ADHD proves counterproductive in developing a universal shared understanding of the phenomena. Within medicine and psychiatry, ADHD has been argued to have no clear distinction between diagnosis and non-diagnosis (Stevens et al, 2018), and its highly heterogeneous presentation has led to many adjustments in its diagnostic symptom criteria and its 'disease' classification (APA, 1968; 1980; 1987; 1994; 2013; WHO, 1991; 2018). Unlike physical disease in which quantifiable evidence of illness can be obtained via clinical measurements such as blood and urine tests, the absence of these options, alongside a lack of cohesion in illness terminology, make ADHD unique from biologically quantifiable diagnoses. This distinction also exists between ADHD and learning/genetic disorders such as Down's Syndrome, where genetic testing gives definitive evidence of genetic abnormality (Diamandopoulos & Green, 2018).

## **2. ADHD is a hidden ‘illness’**

Given that there are no visible physical illness indicators ADHD is typically invisible to others, leading to illness related behaviours such as increased impulsivity, inattention, and hyperactivity to be misconstrued as childhood misbehaviour (Blum, 2015; Singh, 2016). The hidden element of ADHD presents additional problems for those with, and the parents of children diagnosed with, ADHD. Unseen, invisible, or hidden (Matthews & Harrington, 2000; Kundrat & Nussbaum, 2003) illnesses are often problematic for sufferers as misunderstandings arise when illness related behaviour is mistaken for moral deficiency (Goffman, 1968; Freidson, 1970). Similar to those with other hidden illnesses such as fibromyalgia and chronic fatigue syndrome (Åsbring & Närvänen, 2002), individuals with ADHD must choose whether to disclose their ADHD status or risk threats to their “social and moral credibility” (Sim & Madden, 2008: 65); a difficulty compounded by the stigma related to the ADHD diagnosis itself. ADHD’s invisibility also impacts parents who experience an increased need to legitimise their child’s atypical behaviour and to validate their challenging caregiving experiences through medicalisation (McIntyre & Hennessy, 2012).

## **3. The parental experience of ADHD is unique when compared to other hidden illnesses**

Although experiences are shared between parents of those with ADHD and other hidden/invisible illnesses, Cronin’s (2004) paper presented evidence that parents of children with ADHD experience significantly greater levels of frustration and depression when compared to parents of children with other hidden illnesses such as cystic fibrosis. The ADHD parental experience includes greater levels of chaos and higher variability in daily caregiving tasks. Though there are difficulties associated with the invisible nature of a diagnosis, once diagnosed many invisible conditions present parents with a clear trajectory of care in which they have well-defined tasks and procedures, and an awareness of the typical trajectory of care (Cronin, 2004). However, Cronin argues that for parents of ADHD this clarity is often absent. The findings of the present study substantiate these assertions, as parents experience an absence of structure and clarity in their illness related caregiving role post-diagnosis and a lack of medical support outside of medication prescriptions. Furthermore, where other hidden conditions such as fibromyalgia syndrome are often conceptualised as uncontrollable external forces invading the body (Madden & Sim, 2016), the “Balancing Act Between Disability and Difference” and the neurodiversity paradigm display how parents of children with ADHD

often do not make distinctions between the condition and their child, preferring models where their children's needs are conceptualised outside of the medical sphere.

#### **4. Parents are commonly blamed for their children's illness related behaviours**

Parents of children with ADHD are commonly blamed and shamed for their children's ADHD related behaviour both pre- and post-diagnostically. Although there is evidence that some professionals such as teaching staff alter their perception of children's behaviour once made aware of the diagnosis (Rogalin & Necini, 2015; Moore, Arnell, & Ford; 2017), parents continue to describe implicit and explicit blaming and shaming for their children's ADHD related behaviour which continues even when others are aware of the diagnosis (Peters & Jackson, 2008; DosReis et al, 2010; Carr-Fanning & McGuckin, 2018). Given that ADHD's symptoms often present as atypical or 'deviant' (Conrad, 1992) behaviour, Parer (2010: 6) suggests that there exists an inherent contradiction in the notion that ADHD is a physiological developmental condition, but also that children in society must learn to "behave and control themselves", demonstrating an additional nuance to ADHD as a diagnosis.

#### **5. Many parents of children with ADHD have ADHD themselves**

There is a significant body of evidence demonstrating ADHD's high degree of heritability (Barkley, 2015; Uchida et al, 2020). Furthermore, not only does parental ADHD increase the risk of the child having ADHD, but also the "type and severity" of childhood ADHD is "significantly correlated with the severity of their parents' symptoms" (Barkley, 2015: 358). Uchida et al's (2020) meta-analysis on the subject suggests a risk of 40% of a child being diagnosed with ADHD when at least one parent is already diagnosed. However, given the significant challenges faced across the ADHD diagnostic journey for both patients and parents when it comes to receiving a diagnosis, this may not reflect the true number. The findings of this study suggest that parental ADHD was a significant factor in shaping the parental narrative and in the experience of parental work, making it an important consideration in any future sociological exploration. ADHD fills a relatively niche place within parental illness sociology as it is uncommon in many of the chronic conditions explored across the literature to have both parent and child diagnosed with the same condition concurrently.

#### **6. Parents feel blamed and shamed for 'giving' their children ADHD due to high heritability**

Following from the above, the heritable element of ADHD can lead to parental feelings of blame and shame for 'giving' their children ADHD. Parents with ADHD who adopt a

biomedical conceptualisation of the diagnosis experience a double-edged sword, in which they attain absolution of blame regarding their parental ability (Brunton et al, 2014), but feel responsible for problematic or faulty genes (Runswick-Cole & Ryan, 2019).

### **7. ADHD medication is often stigmatised and vilified**

Unlike learning disabilities and other neurodevelopmental disorders, ADHD is unique in that medication is a primary treatment option. However, damaging and poorly evidenced media portrayals of ADHD medication have paved the way for stimulants to continue to be stigmatised and vilified within society (DosReis et al, 2010; Mueller et al, 2012; Lebowitz, 2016), placing parents in a moral dilemma of 'social condemnation' when considering medicating their children (Davies, 2018). The decision to commence stimulant medication is often experienced by parents as vastly different to the experience of parents of children with less contentious medication choices, such as diabetic children commencing insulin therapy. Regarding diabetes, not medicating would be tantamount to child abuse, however, the parental decision to begin the evidence-based first-line treatment for ADHD has been likened to drugging children into 'zombies' (Perugi et al, 2019). As stated by one mother "I feel damned if I do give him the pills and damned if I don't" (Taylor et al, 2006: 120). Parental work attempting to re-narrate ADHD medication as comparable to medication for physical illness indicates a unique challenge not typically faced by parents of children prescribed medication for a medical condition.

### **8. The diagnosis of ADHD is contested and stigmatised in lay discourse**

As explored throughout this thesis, it is common for parents and patients diagnosed with ADHD to experience stigma due to the belief that ADHD is a contested and contentious diagnosis (McIntyre & Hennessy, 2012; Tyler & Slater, 2018). Unlike many other medical diagnoses, a plethora of books continue to be written and sold in bookstores across the country which query the validity of ADHD as a phenomenon. Although many may not read these books and be exposed to the potentially more nuanced arguments than their titles suggest, the visibility of books such as "ADHD does not exist" (Saul, 2014) and "A disease called childhood" (Wedge, 2015) continue to alter the public perception of a diagnosis recognised as a medical disorder by the major medical groups WHO (2018), NICE (2021), APA (2015), and the NHS (2021). However, even given the position of these major medical groups, evidence suggests that medical practitioners, such as 22% of GP's, continue to question the reality of ADHD as a true medical disorder (ADHD Foundation, 2018). The regularity and frequency in which parents express having to

defend the reality of their children’s medically diagnosed condition demonstrates a further atypical difficulty faced by parents.

## **9. Linguistic barriers not present in other neurodevelopmental diagnoses**

Individuals diagnosed with ADHD are presented with a linguistic difference when compared with other neurodevelopmental conditions. The language of personhood and identity has shifted considerably within the neurodiversity movement, and terms such as “person with autism” are no longer preferable due to the implication that autism is something bad (Silverman, 2008). The National Autistic Society states in their “dos and don’ts” that you should avoid saying “has autism/person with autism”, but you should instead say the person “is autistic” (National Autistic Society, 2022). This linguistic choice is available to those with other neurodevelopmental conditions as one can label oneself: autistic, dyspraxic, and dyslexic. There is however no equivalent linguistic choice for those with a diagnosis of ADHD (Ortega, 2009). ADHD specific charities give no guidance in their advice on terminology (Green, 2022), and if one were to say they were “ADHD” or an “ADHD’er”, two of those letters are words with negative connotations (Disorder/Deficit). Individuals with ADHD do not have a word related to the diagnosis with which to personify their personhood and identity, forcing them to self-describe as “having ADHD”.

## **10. Other neurodevelopmental disorders and learning disabilities do not have medication as a treatment option**

For most learning disabilities and neurodevelopmental disorders, medication is not offered as a standard treatment option. Although medication such as antipsychotics and antidepressants may be used to treat some of the difficulties that autistic people may face, medication should not be used for the “management of the core features of autism” (NICE, 2021). ADHD, and Tourette’s syndrome, are unique in this group of medical conditions as medication is the most common medical treatment delivered (Barkley, 2015). This is an important distinction given that medication features so heavily in the parental experience of ADHD (Cocoran et al, 2017b), and was a major plot within the development of parental narratives throughout the diagnostic journey [Narratives Regarding Medication]. Researchers grouping participants with ADHD alongside participants with other neurodevelopmental disorders should be aware of this distinction due to the significant influence of medication on illness journeys and narratives.

## **11. Neurodiversity and other adaptive paradigms are often absent in other illness narratives**

Jensen et al's (1997) paper presenting ADHD as an adaptive evolutionary response to hunter-gatherer environments demonstrates an important aspect of ADHD discussion absent from other illnesses and diseases typically studied in sociology: that ADHD does not need to be fixed or treated. The radical neurodiversity perspective argues that efforts to understand the pathophysiology of ADHD and autism is of secondary importance when compared to efforts in changing societal attitudes towards neuroatypical individuals (Sonuga-Barke & Thapar, 2021). An adaptive and positive paradigm towards illness, and rejection of further development in understanding pathology, is absent from many other illnesses in which more effective treatment options and improved prognoses are prioritised and sought. People living with rheumatoid arthritis, cancer, and other debilitating long-term diseases do not typically draw from adaptive paradigms in which their having the disease is a positive strength and important part of their identity, evidenced further by the need to reconstruct (Williams, 2000) identity in the face of the biographical disruption of the illness (Bury, 1982). Furthermore, unlike illnesses such as heart disease or arthritis, those with ADHD do not typically experience a "slow deterioration" (Faircloth et al, 2004) but are more likely to experience steady improvement as skills are learned (Singh, 2016).

## **12. ADHD is often missing or excluded from neurodiversity discussion and literature**

My final argument regarding why the development of a specific social science of ADHD would be a useful development within the sociology of ADHD is that historically, ADHD has been missing or excluded from the literature of neurodiversity. Ortega (2018) argues how the neurodiversity movement has been dominated by autistic people, a position I echo. In exploring literature on neurodiversity for this thesis, I noticed the continued exclusion of ADHD from neurodiversity literature. As an example, when using a computerised search function in the contemporary and excellent book 'Neurodiversity Studies: A New Critical Paradigm' (Rosqvist, Chown, & Stenning, 2020), the term autism is utilised 168 times, whilst the term ADHD, and other permutations, is used only eight times (With four of those occurring in the introductory paragraph to the book and the index). In the first chapter of Baker's (2011) book regarding 'Why Public Policy Matters for Neurodiversity', ADHD is included on three occasions, whilst autism occurs 33 times. I present these findings not as a rigorous or valid analysis but, given that ADHD is estimated to be five times (0.6-1.6% versus 3-5%) more common than autism

(Polanczyk et al, 2007; Russell et al, 2014), this discrepancy is particularly interesting and would be a useful area for future research into the extent of this mismatch in representation.

## 10.5. Concluding Thoughts

This chapter has presented a detailed discussion of three major findings from this research project exploring the needs and experiences of parents across the ADHD diagnostic journey. First, the development and structure of the parental diagnostic journey narrative was shown to adhere to a loosely chronological and sequential framework, where both temporal- and non-temporal narrative plots were utilised by parents at different times, often in response to experiences across the diagnostic journey. This was followed by a detailed argument about how the ADHD diagnostic journey can be conceptualised as an array of illness work, personified in: The Diagnostic Quest [11.3.2], Self-Biographical Illness Work [11.3.4], and Child Biographically Work and Recontextualising the Child [11.3.5]. The chapter concluded with the presentation of a series of considerations and arguments justifying the need for a bespoke and specific social science of ADHD, where ADHD is no longer thoughtlessly incorporated alongside other chronic conditions and diagnoses without due care and attention given to the unique and novel differences of ADHD when compared with other diagnoses.

# 11. Conclusion

## 11.1. Research Questions and Main Findings of the Study

The purpose of this study was to address a significant gap in the literature regarding the changing parental experience of the ADHD diagnostic journey. The project explored this process within the context of illness sociology, contributing to the sociological discussion of parents and ADHD. The research was designed to answer the following research questions:

- 1- What stories do parents tell regarding this journey?
- 2- What are the parental needs and experiences across the ADHD diagnostic journey?
- 3- Do these needs and experiences change across the journey and, if so, how?
- 4- How do parents make sense of the ADHD diagnostic journey?

This thesis has utilised a narrative approach to explore the lived and storied needs and experiences of parents as they traverse across the ADHD diagnostic journey with their children. It has taken an adapted sociocultural narrative analysis methodology (Grbich, 2013; Jones & Mistry, 2019) with which the concept of the narrative 'plot' was developed and used to make sense of the construction and delivery of parental narratives. Using longitudinal serial interviews, I was able to study these parental experiences at the temporally significant time periods of pre-diagnosis, diagnosis, and post-diagnosis, witnessing meaningful changes that occur for parents as they travel across the journey. The thesis draws upon theoretical literature within illness sociology, whilst acknowledging the limited inclusion of ADHD as a diagnosis within this field of study.

In response to all four research questions, seven major narrative plots emerged from the data evidencing how parents tell stories of their needs and experiences. The seven plots, explored in depth in Chapters 6-9, demonstrate the most prevalent and impactful of these experiences and assist us in understanding the difficulties and joys which parents face. A summary of the plots are as follows:

Figure 4: Plots and Plot Summary

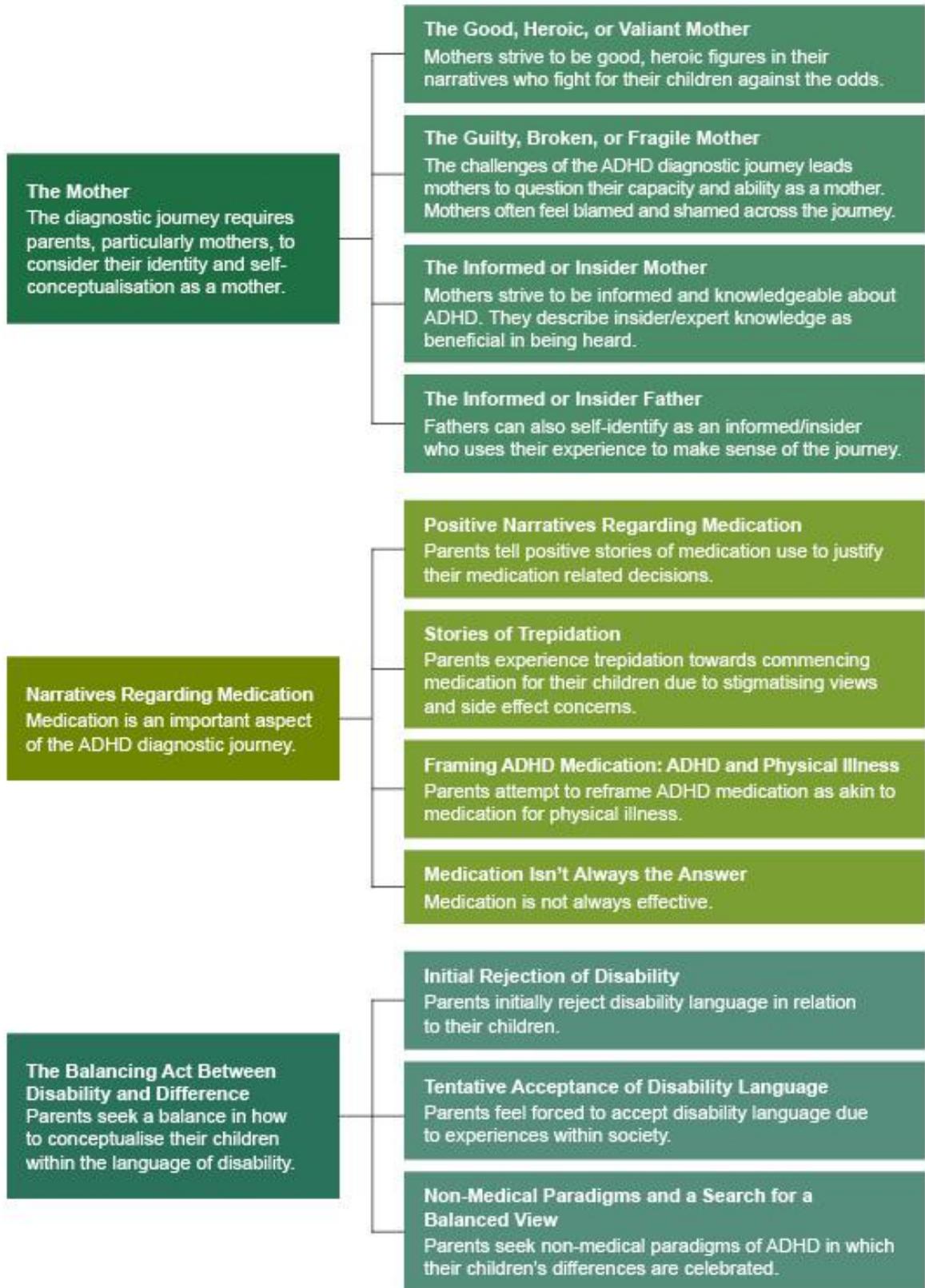
### Plot and Explanation

### Subplot and Explanation



**Plot and Explanation**

**Subplot and Explanation**



Additional to the development of the above plots, this thesis has demonstrated how parental use of these plots within their narratives follow a loosely chronological and temporal structure [Ch 11.2: Development and Structure of the Diagnostic Journey Narrative]. Four major plots (There Was a Problem, The Diagnosis, The System, and Narratives Regarding Medication) were found to be associated with specific moments or experiences across all parental narratives, whilst the three other plots (The Mother, The Fight, and The Balancing Act Between Disability and Difference) were not found to exist within this structured framework. The moderately consistent practical processes of the assessment pathway give some explanation as to why four of these plots were temporally structured and consistent in usage. This finding is useful for healthcare professionals and those supporting parents across the ADHD diagnostic journey as the relative temporal consistency of plot use allows those working with parents to prepare for these experiences. The temporal structure could enable professionals to have validating and supportive conversations with parents regarding the experiences of other parents at that stage of the journey, for instance giving information about how other parents feel about a childhood ADHD diagnosis prior to a diagnosis being given. The non-temporal structure of three plots is also a useful finding for those working with and supporting parents on the ADHD diagnostic journey as it grants greater awareness into the deeply individual experience and non-conformity of the journey. This finding demonstrates how universal or generic processes of support and information giving across the diagnostic journey may be less effective at supporting parents in relation to these plots as the timing of these parental experiences can vary significantly. It may be beneficial for parents if professionals are prepared to have nuanced discussions regarding disability and difference throughout the ADHD diagnostic journey, given the unpredictability of its importance and relevance in parental narratives. My findings do not present evidence regarding what is the most effective way to utilise knowledge of the temporal and non-temporal structure of parental plot usage but do present an interesting area for future inquiry.

From a wider sociological perspective, I have argued that the experiences of parents across the ADHD diagnostic journey can be conceptualised as significant illness work (Corbin & Strauss, 1988). My findings and conclusions concur with similar studies investigating the experience of parents of autistic children (Singh, 2016), in which illness work is divided into practical diagnostic work and biographical work. I have evidenced how parents must engage on a 'Diagnostic Quest [11.3.2], upon which they must recognise their children's additional needs, seek diagnosis, engage with the complexities and failings of 'the system', fight for their children's needs and selfhood to be understood, and acquire educational and social resources. I have also demonstrated how parents engage in two distinct forms of biographical work: 'Self-Biographical Illness Work' [11.3.4] and 'Child Biographical Illness

Work and Recontextualising the Child' [11.3.5]. The former prioritises the personal and individual biographical response of the parent, utilising a spectrum model of biographical cohesion and disruption (Rasmussen et al, 2020). This biographical impact was multifaceted, experienced both in response to the ADHD diagnosis and the diagnostic journey itself, as well as involving a "self-diagnostic" biographical response for parents with a diagnosis of ADHD themselves. Parental re-contextualisation of their children, alongside other child biographical work, was also evidenced. The findings presented explore how the diagnosis of ADHD allows parents to recontextualise their children from a 'naughty typical child' to a 'normal atypical one', enabling them to explore their children's identity and personhood within the remit of disability language and neurodiversity.

The final finding of this study calls for the development of a social science of ADHD [11.4], in which the unique and nuanced position of ADHD as a medical phenomenon or illness classification is explored in greater depth. I have argued that there are elements to the ADHD diagnosis and the experience of parents of children with ADHD that are distinct in important and theoretically relevant ways. I have presented a series of arguments justifying this position and demonstrated how a social science approach to ADHD could be developed.

## 11.2. Original Contribution and Implications

This section explores the original contributions to knowledge presented within this thesis alongside the potential implications of these findings in both clinical and academic settings. The original contributions to knowledge are presented within the context of two key bodies of literature: Sociological literature regarding illness narratives and illness work, and literature regarding ADHD and parents.

### 11.2.1. Contribution to Illness Sociology and ADHD

This thesis provides multiple novel contributions within the field of illness sociology and ADHD. It is the first study to prioritise an illness sociology perspective for parents of children with ADHD in both a pre-diagnostic and post-diagnostic manner. Given the practical challenges of recruiting participants without a confirmed diagnosis in studies focussed on illness narratives, this study presents unique insights into the benefits of such an approach where possible. The theoretical benefits of this approach are particularly apparent when

analysing the difference in the expected biographical response which parents narrate prior to diagnosis, and the actuality of that biographical response post-diagnosis. The evidence presented within this thesis also indicates that the pre-diagnostic illness experience differs from the post-diagnostic experience. This offers an interesting area for future study in which the differences and similarities in pre- and post-diagnostic ADHD illness experience, and consequent effect on biography, could be explored further. Alternatively, this approach could be utilised to explore other conditions and illnesses.

This study employed the theoretical and analytical tools of parenting work and biographical illness work utilised within autism studies (Singh, 2016; Rasmussen et al, 2020) and applied them in a novel manner to an ADHD context where these theoretical approaches are scarce. The thesis builds upon Singh's (2016) approach to parental illness work in US families with an existing diagnosis of autism and applies this sociological perspective to a UK based ADHD context. This thesis furthers the scope of Singh's approach by including the wider diagnostic journey and not limiting the area of study to the post-diagnostic period. The thesis offers unique insights postulating that the parental experience of the ADHD diagnostic journey presents parents with a variety of challenging illness work. I have explored how the concept of diagnosis work (Corbin & Strauss, 1988) and the ensuing diagnostic quest (Singh, 2016) are representative of the protracted and prolonged challenges faced by parents of children who traverse the ADHD diagnostic journey, and how ADHD parental diagnostic work shares similarities to other conditions whilst also exhibiting significant differences. This conclusion, alongside the presentation of Self-biographical Illness Work [11.3.4] and Child biographical Work and Recontextualising the Child [11.3.5] as integral elements in understanding the parental experience of the ADHD diagnostic journey, provides further development in the field ADHD and illness narratives. This has been achieved by elaborating on previous work within which these concepts are alluded to but not fully explored (Cocoran et al, 2017a).

A further contribution presented by this project is in the development and transferable usage of Rasmussen et al's (2020) biographical spectrum model of disruption and cohesion. This project demonstrates evidence that their model, originally created to enrich understanding of the parental biographical response to autism diagnosis, is equally valid and theoretically relevant when applied to ADHD. The effectiveness of this model to an ADHD context is perhaps unsurprising, given the similarities explored throughout the thesis regarding the many shared elements of parents of children with ADHD and autism, including but not limited to: arguments positing the conditions as outside of medical language but as maladaptation to one's environment (Turowetz, 2015), the framing of the diagnoses within the context of a neurodiversity paradigm (Singer, 2016), the growing trend in parental desire

to renegotiate the diagnoses and seek biological citizenship (Brownlow & O'Dell, 2013), and the lack of medical objectivity and quantifiability in diagnosis (APA, 2015). Moreover, this project furthers the scope of Rasmussen et al's (2020) parental biographical spectrum model, evidencing how it is also a beneficial analytical tool in understanding how parents with a personal diagnosis of ADHD may experience a self-biographically disruptive or cohesive experience in response to their children's ADHD diagnosis. To my knowledge this is the first study to shed light on this phenomenon, in which a child's diagnosis of ADHD leads parents with the same diagnosis to experience a biographically cohesive or disruptive experience in a similar manner to if the parent had been diagnosed themselves. This finding provides a fascinating area for further inquiry and may be transferable to other heritable conditions in which parent and child are likely to have the same diagnosis at the same time. The final contribution in relation to Rasmussen et al's (2020) parental spectrum model of disruption is in the original application of the model outside of a solely diagnostic context. Table 3 within Chapter 11.3.4 [Parental Biographical Illness Work] reveals how the overall diagnostic journey itself can be experienced by parents as biographically cohesive, disruptive, neither, or both, and how the spectrum model is useful in analysing the overall diagnostic quest and not only the confirmation of a diagnosis. The successful application of a spectrum model of disruption and cohesion provides future researchers opportunities to explore how experiences outside of the diagnostic moment, such as invalidating conversations with professionals or the influence of parental conviction and belief in the presence of a problem, can impact parental biographical response.

The final original contribution this thesis provides to wider sociological discussion is presented in Chapter 11.4 [Justifying in the Need for a Social Science of ADHD], within which evidence is presented arguing for the development of a social science of ADHD. Although individuals with ADHD are often included in sociological illness studies alongside participants with physical illnesses (Cronin, 2004), mental illnesses such as depression (Jeneva et al, 2013), and other hidden/invisible disabilities (Tabatabai, 2019), the proposed development of a social science of ADHD represents a necessary step forward in the theoretical framing and inclusion of ADHD within wider illness related sociology. A social science of ADHD would be particularly beneficial in teasing out and understanding the stark variance in findings found in work such as Cronin (2004), where the experience of parents of children with ADHD was significantly different to the experiences of parents of children with other hidden disabilities. Section 11.4 presents a potential framework of this model and provides researchers with a series of considerations to explore prior to inclusion of ADHD within sociological illness research. Further development of this model into a robust social science of ADHD presents an exciting area for future discussion and would assist in the

justification of including ADHD alongside other similar conditions and in answering potential variance in response when compared to other diagnoses.

### 11.2.2. Contribution to Research Regarding ADHD and Parents

As discussed in Chapter 3 [Literature Review Part 1: Parents and ADHD], existing qualitative literature on the parental experience of ADHD is typically limited to studies where parents reflect on their experience *after* their children have received a diagnosis (Cocoran et al, 2017a). These studies often explore the experience of *having* a child with ADHD (Mcintyre & Hennessy, 2012) or the parental experience of their children's ADHD diagnosis *after* the diagnosis has been given and integrated into their everyday life (Harborne, Wolpert & Clare, 2004; Ghosh et al, 2016; Carr-Fanning & McGuckin, 2018). Furthermore, although many of these studies explored the parental experience of diagnosis, none have focussed on the overall parental experience of the diagnostic journey itself. The limited exploration of the parental experience pre-diagnosis, alongside a paucity of longitudinal projects on the parental experience of ADHD, allowed for the development of two significant contributions.

First, the longitudinal nature of this thesis allowed for deeper exploration into the changing nature of the parental experience across the journey. Three serial interviews across a two-year period enabled evidence to emerge of the transformative experiences, varied use of narrative plots at different times, and shifting parental sensemaking across the journey. This thesis presents evidence of significant changes in parental self-concept and parental conceptualisations of the child in response not only to the diagnosis of ADHD, but also to experiences on the diagnostic journey. For instance, a non-longitudinal or single interview project may not have illuminated the process of change explored by Pam, who identified in interview one as a 'guilty, bad mother' who questioned her mothering capacity, whereas in interview two she detailed the transformative power of diagnosis and her changing self-conceptualisation to the 'good' mother with a neurodiverse child. Furthermore, as this project interviewed parents very close to the date of their children's diagnosis (in some cases within days), this project was able to explore the parental sensemaking process of diagnosis without the potentially influencing factor of time and familiarity with a diagnosis.

Secondly, as this project was interested in all aspects of the diagnostic experience, the thesis is able contribute further evidence of the numerous challenges parents face across the journey. The findings corroborate previous research in which parents describe the process of ADHD diagnosis as a series of "hoops and hurdles" (Rowland, 2016: 183), long

waiting times (Fridman et al, 2017; Thevathasan et al, 2022), and professional dismissal (Harborne, Wolpert and Clare, 2004; DosReis et al, 2010). The thesis adds to this discussion via the plot of “The System” by corroborating prior findings indicating that pursuing a diagnosis is a laborious, emotionally challenging, and overly complex experience. The subplot of “Subverting the System” provides a novel contribution in this area, evidencing how parental dissatisfaction with the diagnostic experience may alter parental decision-making and behaviour to counteract these challenges. This project provides insights into how parents respond and combat the ever-increasing challenges and pressures in accessing support for ADHD (ADHD Foundation, 2017), and how behaviours such as seeking private assessment, writing letters to MPs, and using their professional status to gain preferential treatment are conceptualised by parents as necessary measures in subverting a failing system.

As explored throughout the thesis, the theoretical tension between the contrasting paradigms of ‘ADHD as neurodevelopmental disorder’ and ‘ADHD as neurodiversity’ continues to be an area of significant debate. Where recent papers have explored the benefits and challenges of integrating both concepts from a clinical and scientific perspective (Béliard et al, 2019; Sonuga-Barke and Thapar, 2021), this thesis presents further evidence of the growing trend towards parental engagement in non-medical models of disability (Singh, 2016). “The Balancing Act Between Disability and Difference” [Ch 9.2] provides exciting developments in the academic discourse regarding parental conceptualisations of ADHD and disability. Where much work has explored how parents deploy neurological and medical models of ADHD to understand their experiences and alleviate blame (Ghosh et al, 2016; Horton-Salway & Davies, 2018), this thesis provides an alternative perspective as to how and why parents may oscillate between a variety of differing and conflicting conceptualisations of ADHD across the diagnostic journey. The notion of a ‘balancing act’ along the spectrum of disability and difference presented within this thesis is a new and useful representation of the parental experience, and could provide academics, clinicians, and other parents with a concept to explain the theoretical dissonance of holding contradictory conceptualisations of ADHD. The rejection of the language of disability, the forced use of this language within healthcare and education, and the parental desire to find a balanced conceptualisation of their children and ADHD, may be used to justify providing parents with information of contemporary models of disability developed in response to this theoretical instability.

### 11.2.3. Other Contributions

The follow section will outline a series of smaller but relevant contributions to the field of ADHD and parents presented within this thesis:

#### **Informed and Insider Mothers**

This thesis adds interesting insights into the role and concept of the mother within an ADHD context. Previous work claiming that ADHD mothers often self-identify as blameworthy or good (Davies, 2014) or that mothers are responsible for the majority of ADHD caring tasks (Singh, 2004) is supported within the plot of “The Mother”. This project also supports arguments indicating that father’s responses to ADHD diagnosis often differ from that of mothers (Singh, 2003), evidenced by the only father within the study not engaging with self-conceptualisations of ‘guilty’ or ‘good’ parent. Although there has been much discussion regarding the desire for mothers to become ‘informed’ or ‘expert mothers’ following medical diagnosis of their children (Brock, 2017), the additional perspective of ‘insider’ parents presented within this thesis appears to be a novel finding. The ‘insider parent’, who uses their expertise and professional position within healthcare to influence their journey and conceptualisations of ADHD, has not previously been present within an ADHD context. This finding contributes to wider discussion on the altered experience of ‘professional patients’ (Dockerty and Dockerty, 2008) by demonstrating how the ‘plurality of perspective’ (Birdsey and Joseph, 2021) and insider status is deployed by parents to positively impact their diagnostic journey experience.

#### **ADHD Diagnosis as a Balm for Parental Blame**

Within the wider ADHD qualitative literature there continues to be debate regarding the benefits of an ADHD diagnosis for parents (Gray, 2008), with some scholars arguing that the harms of a diagnosis may outweigh the benefits for those with milder ADHD symptoms (Kazda et al, 2021). This study contributes by presenting further evidence of the blame exonerating impact of diagnosis for parents, alongside the multiple perceived benefits in understanding and resource acquisition granted via the ADHD label [6.2: The Diagnosis].

#### **Pre-diagnostic Parental Awareness**

The findings of this project also contradict findings presented by Pajo and Cohen (2013), who suggested that parents are often unaware or unconcerned with any problem prior to school years. The subplot of a “Problem in Early Infancy” is in direct contrast to this statement, as parents expressed significant concerns and awareness of their children being

‘different’ or having a ‘problem’ at a very early age. Evidence of this early awareness is also present in McIntyre and Hennessy’s study (2012: 77), where one parent described challenges at a “very young age” as their child exhibited an extreme need for attention.

### 11.3. Impact on Policy and Practice

This thesis presents multiple opportunities to positively impact on ADHD policy and practice. The dissemination of the study findings to CYPS teams and organisations performing ADHD assessments offers an exciting opportunity to positively impact clinical practice and patient experience. Within the UK, ADHD continues to be under-identified, under-diagnosed, and under-treated, partly due to poor funding, systemic failures, long waiting lists, and professionals unskilled or unconfident in supporting ADHD patients (Young et al, 2021). The reality of these significant and macro-level systemic challenges is that the impact of a study on parental experience on practice is likely to be modest.

#### 11.3.1. Impact on Practice

Chapter 7 [The System] demonstrates the challenging and emotionally damaging experiences of parents as they interact with the systems of healthcare and education. The subplot of “The Parent Must Work Within the Confines of The System” highlights how inconsiderate and ineffective practical administrative practices during the ADHD diagnostic journey are negatively experienced by parents. Increasing clinician awareness of this subplot could allow professionals to be cognizant of the effective of these seemingly minor administrative decisions and to present alternatives better suited to parental wellbeing, such as consideration towards parental employment and the inclusion of fathers.

“The Balancing Act Between Disability and Difference” also has the potential to positively impact mental health practice. Improving clinician awareness of the nuanced complexity regarding ADHD and disability language is likely to have a direct positive impact on the parental experience of the ADHD diagnostic journey. Considering this subplot, clinicians may be able to initiate conversations regarding disability and the framing of ADHD, potentially by presenting parents with the advantages and limitations of both neurobiological and neurodiversity models. Developing professional awareness of the disability ‘balancing act’ parents perform could enable professionals to highlight and reflect on these considerations

throughout the journey, potentially reducing emotional distress. This consideration becomes particularly salient when discussing the pursuit of disability support and financial assistance as it presents an opportunity to reduce stigma and present parents with disability language which is useful to them and their children.

### 11.3.2. Impact on Policy

Prior to submission, the seven plot findings exploring the parental experience of the ADHD diagnostic journey were peer reviewed in 2022 via conference presentation in two specific ADHD conferences: 'The ADHD Foundation - Neurodiversity: A New Paradigm' and 'The ADHD Foundation and ADHD Ireland: ADHD and Enabling Opportunities'. The audience of these conferences were professionals directly involved in the care and support of ADHD families such as: educators, healthcare professionals, business owners, and academics. The dissemination of the study findings in these environs has the potential to impact on policy by adjusting the perspective of professionals regarding the parental experience of the ADHD diagnostic journey. Both conference presentations also gave a call to action, challenging the dominant medical discourse of ADHD by highlighting the parental preference to a nuanced, multi-modal conceptualisation of ADHD.

Furthermore, the author is currently in the process of working with the Royal College of Nursing [RCN] to adapt their neurodiversity guidance once it was recognised during the reading for this thesis that no specific ADHD resources were available in their neurodiversity reading list (RCN, 2022). The wide reach of the RCN guidance to all nurses provides an excellent opportunity to impact on both nursing policy and practice by using their neurodiversity guidance as a platform to disseminate the study findings.

## 11.4. Limitations

### **Sample**

The sample size (N=7) prohibits transferability of the findings to a wider variety of parents of children on the diagnostic journey when considering demographic homogeneity.

Nonetheless, the sample size was appropriate given the requirements of a narrative methodology and the parameters of a doctoral thesis. Furthermore, all participants lived and had their children's ADHD assessment occur in the North-East region of England, reducing

the transferability of the findings to UK regions or other countries which may have different assessment processes. One potential strength of this project in this regard is that participants were spread across four separate local authorities and consequently, four different CAMHS/CYPS teams and two distinct NHS mental health trusts, reducing homogeneity in assessment and likeliness of results being influenced by one or two prominent diagnosticians as may occur if all participants were from one clinical team.

Overall, the sample was mostly homogenous, with all participants being white, heterosexual, and the biological parents of their children. The absence of parents from diverse minority groups is limiting as findings are unlikely to reflect the additional intersectional challenges faced by these groups such as: racial bias and the dual stigma of racial diversity and ADHD (Emmanuel et al, 2022; Paidipati et al, 2022); the experience of stigmatisation and victimisation of ADHD children of same-sex parents (Sullins, 2015), and the currently unknown and relatively unexplored (Conway et al, 2022) experiences of trans and non-binary parents. Furthermore, as all participants were the biological parents of their children, results may not reflect alternative perspectives regarding ADHD and heritability that foster and/or adoptive parents may hold. However, I have intentionally avoided implying that my sample is representative of a typical population of parents of children with ADHD, especially given the high proportion of the sample being employed or having experience working in health and social care professions. The high proportion of participants with health and social care professional backgrounds is likely to have brought forth findings which may not have emerged in a sample more representative of the general parent ADHD population, especially when considering the subplot of "Informed or Insider Mothers/Fathers". Nonetheless, the participant sample presented both interesting and unexpected research findings. This atypical participant sample was heavily influenced by challenges across the recruitment process, as recruitment was significantly impacted by CYPS services not giving out information regarding the project as previously agreed during the ethics process, alongside the devastating impact of the Covid-19 pandemic and consequent UK lockdown. The former challenge led to most participants being recruited through ADHD charities and via social media, with only one participant included through NHS services.

This project also only included one father within the sample, presenting a further limitation. The challenges of recruiting fathers in ADHD studies are well documented (Singh, 2003; 2004; Cocoran et al, 2017a), and the lack of father representation mimics this trend. Attempts were made to ameliorate this discrepancy as each mother participant was asked whether the child's father would also like to be involved in the project, either separately or together, with none wishing to do so. It appears that focussed and specific recruitment targeting may be the most effective way to ensure more fathers are included in research on

ADHD, as evidenced in Singh's seminal work (2003). A project specifically exploring the narratives and sensemaking processes of fathers on the ADHD diagnostic journey provides a starting point for future research.

### **Narrative as an approach to ADHD and parents**

This project explored the needs and experiences of parents across the ADHD diagnostic journey through a sociocultural narrative lens. As the focus of the sociocultural approach includes broad cultural narratives and their perceived influences on individuals via participant story (McAlpine, 2016), these stories may be absent of information which the participant does not wish others to know, or which they are unaware of themselves. This potential limitation may well be minimised within this project as the focus was not on objective experience, but parental interpretations of experiences. Furthermore, multiple interviews with the same participant enabled greater development of a trusting relationship in which participants often felt comfortable to share more intimate and personal details not shared in only one interview. Having multiple participants also allowed for the emergence of overarching and shared narratives, which granted a more varied representation of experience (McAlpine, 2016). This project has prioritised the spoken word and the story in the construction of identity and has not included other forms of data such as non-verbal narration, art, music, or other communication of sensemaking and experience. The inclusion of more varied forms of narrative data may have strengthened the findings, enhancing 'thickness' (Denham & Onwuegbuzie, 2013) of the data by allowing participants to explore their experience and sensemaking in ways potentially more meaningful to themselves than spoken word. Like many researchers and activists attempting to better the lives of parents and children with 'disabilities' or differences (Runswick-Cole & Ryan, 2019), I have put my faith in the power of the narrative as a catalyst for change. However, it can be argued overly optimistic to hope that the telling of stories in isolation is adequate in bringing significant societal or cultural change without effective action. Nonetheless, this project aimed to give voice to a societal group whose voices often go unheard or ignored. I argue that effective action cannot be undertaken if one does not first know the story and experience indicating the need for it.

Although other methodological approaches may have ameliorated some of these issues, they present with additional problems. An ethnographic approach, in which the researcher was present during the giving of a diagnosis or during the interactions with CYPS professionals may have provided additional and interesting insights into the difference between the experience as narrated and the experience as witnessed by an observer.

However, this approach would likely miss the deeply personal and emotional elements of the parental experience gained via the building of a trusting relationship across multiple interviews.

Atkinson's (2017) critique of narrative reductionism bears some relevance to this project, as he may consider it narrative 'butterfly collecting' of a new medical problem. His argument that narrative research needs a disciplined renewal and that it is no longer enough to "conduct interviews, identify themes, and reproduce extracts whilst celebrating the expression of story" (Atkinson, 2017: 203) is important. I acknowledge that this thesis privileges the illness narrative, however, whereas Atkinson argues that the discursive function of narrative reconstruction has progressed little since Williams (1984) I point towards the development and application of the spectrum model of parental disruption and cohesion utilised and modified within this thesis as evidence of progress. In response to the potential criticism of narrative "butterfly collecting", I accept that this project does not attempt to synthetically explore how narratives are constructed via functional or rhetorical devices as Atkinson would prefer, but I contend that the value of understanding the story of differing illness experiences is an intrinsically worthwhile endeavour in improving the lives and experiences of those who embody it.

### **Hiding the interviewer**

Concerns have been raised regarding projects utilising semi-structured interviews in which the questions put forward by the researcher are absent in the data analysis (Potter and Hepburn, 2012). These questions, alongside other potentially influencing communications such as agreement responses of "uh uh" and "mmm" are said to reveal to participants that they are giving 'good' and useful responses to the researcher. My response to these potential criticisms is similar to those brought forward by Davies (2014) in her narrative-based project of parents and ADHD. I, like Davies (2014), gave much thought and consideration to the potential impact of my questions on the production of the answers during the process of data analysis, being mindful of any potential influence or bias towards certain types of response. Furthermore, many participants would speak for 10 to 15 minutes after a single question was asked, often covering topics orthogonal or beyond the scope of the original question but still relevant to the study aims. In these situations, it was deemed inappropriate to include the original question within the excerpt.

Furthermore, Davies (2014) and I also share expertise from our previous professions, as counsellor and mental health nurse respectively, and are trained to develop therapeutic and

comfortable environments for discourse whilst limiting the influence of our own positions on participant/patient responses. As this project was concerned with parental stories and sensemaking processes more generally, the inclusion of the minutiae of each interaction and analysis of the impact of each micro-communication (such as head nodding or utterances) would prove both cumbersome and distracting to the projects aims and was thus discounted from analysis.

## 11.5. Recommendations For Future Study

This thesis has presented potential areas for future study throughout; however, the following proposals represent my strongest recommendations for development:

### **1. Parental Self-Biographical Illness Work Following Their Children's Diagnosis**

The evidence of parents with a diagnosis of ADHD experiencing additional self-biographical illness work in response to their children's diagnosis presented in section 11.3.4 [Self-Biographical Illness Work] proves an exciting potential area for further research. Future study could build on this unexpected finding by exclusively focusing on this experience, determining the influencing factors on parental narrative construction. There is also potential for exploration to include other hereditary conditions and neurodevelopmental differences such as autism, examining whether the prognosis of the diagnosis impacts on parental re-experience of disruption and/or cohesion.

### **2. The Balancing Act Between Disability And Difference**

Further research into the theoretical and linguistic 'balancing act' of disability and difference parents traverse on the ADHD diagnostic journey would be beneficial in determining what influences parental preferences and decision-making. I propose that a study in which parents are presented with a series of models of disability and ADHD such as Jensen (1997), Shakespeare (2002), and Barkley (2015), would be useful in determining whether the theoretical work presented within these models is helpful to parents, and whether awareness of these models alters parent preference in conceptualising ADHD in relation to disability language.

### **3. Further Development of A Social Science Of ADHD**

My final major recommendation for further study is regarding the development of a specific and nuanced social science of ADHD. It is hoped that the beginning of this model outlined in section 10.4 [Justifying the Need for a Social Science of ADHD], will provide further research with a framework to develop a valid and rigorous social science of ADHD. Using this framework, researchers could ensure that ADHD would no longer be idly included in illness studies without prior theoretical consideration of its unique and potentially problematic differences as a medical and social label.

## **11.6. Concluding Remarks**

I would like to conclude this thesis by returning to a statement made within the introductory chapter. The aim of this research was not to make epistemological or theoretical claims about ADHD as a medical diagnosis or as a sociological construct, but to understand the narratives of parents. In seeking to understand the needs and experiences of parents across the ADHD diagnostic journey, I hope this thesis has portrayed the highs and lows experienced by parents, and the often arduous and challenging illness work they must perform.

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# 13. Appendix A: Participant Information Sheet

Understanding the needs and experiences of parents whose children are on the ADHD diagnostic Journey: A longitudinal Study.

## **Participant Information Sheet**

You are being invited to take part in this research study. Before you decide, it is important for you to read this leaflet so you understand why the study is being carried out and what it will involve.

Reading this leaflet, discussing it with others or asking any questions you might have will help you decide whether or not you would like to take part.

### **What is the purpose of the Study?**

This is a PhD research project interested in understanding what it is like to be the parent of a child who is currently on the Attention Deficit Hyperactivity Disorder (ADHD) journey.

#### **ADHD journey?**

The ADHD journey is any part of the diagnostic process of ADHD. This includes if your child has been referred for an assessment for suspected ADHD, is on the waiting list, is currently having an assessment, or has already been diagnosed with ADHD.

This study hopes to improve understanding of what it is like to be a parent of a child who is on this journey. I am interested in what your needs and experiences are, and how these needs and experiences change over time.

### **Why have I been invited?**

You have been invited to take part in this study as you are the parent of a child who is currently beginning the ADHD diagnostic process or has recently been given a diagnosis of ADHD. To be included in this study you must:

Have a child who has recently been referred for assessment of ADHD.

Or

Have a child who has recently received a diagnosis of ADHD.

English speaker

Live in North-East of England

### **Do I have to take part?**

No. Taking part in a research study is completely up to you. This information sheet has been given to you to help you make the decision to take part or not. If you do take part within this study, you will be free to leave at any time and will not need to give a reason for leaving. Deciding not to take part, or deciding to leave mid-way through the study will have no effect on your child's health and social care.

### **What will happen if I take part?**

If you agree to take part with this research project, you will be asked to take part in three interviews over a period of up to two years. These interviews can take place within the family home, in the location that you were recruited for this research project, or through an digital telecommunication platform such as Skype, whichever you prefer. The interview will be informal and will be arranged for a day and time that suits you best.

With your permission, during the interviews your voice will be recorded. You will be asked a short series of questions about what it is like to be the parent of a child on the ADHD diagnostic journey. The interview will be for up to 1 hour long. You are welcome to complete the interviews individually, or with both parents.

This interview will then be repeated on two occasions from 6 month to 1 year apart. Meaning a total of three interviews over up to two years

After three interviews, you will be invited to attend a focus group with other parents who have been participants within the study. The focus group will be at a local community centre that will be conveniently located or through a digital medium such as Microsoft Skype and will last approximately 1-2 hours. Within this group, the discussion will be around sharing what our experience has been over the last 2 years, and sharing stories about being a parent of a child on the ADHD diagnostic journey.

### **What are the possible disadvantages of taking part?**

As this research is regarding your experience of being a parent, you may experience some emotional discomfort during the interviews. The principal researcher is a trained mental health nurse and will make sure that the interviews are as informal and comfortable as possible. Everything that we talk about will be confidential and you will be free to leave the project at any time. At the end of each interview and at the end of the focus group there will be a debrief period where we can discuss any difficulties regarding the interview with the voice recorder turned off.

### **What are the possible benefits of taking part?**

By taking part in this study you will be able to get your voice heard, and will be able to talk about your needs and experiences and the benefits and difficulties of being the parent of a child who is on this journey.

You may find the interview sessions helpful and your involvement in the focus group may allow you to connect with and share stories with other parents who are in a similar position to yourself.

### **Will my taking part in this study be kept confidential and anonymous?**

Yes. Your name will not be written on any of the data that is collected. Any written information relating to yourself or anyone who you may talk about will be anonymised and a pseudonym will be used. Your name will not be written on the recorded interviews or on the typed up versions of our discussions. In the final written thesis of this study your name will not appear, and any quotes used in relation to yourself or anyone identified by you will be anonymised. The consent form you have signed will be stored separately from your other data. The data collected from you in this study will be confidential. The only exception to this confidentiality is if, during the interview, I feel that you or others may be harmed if information is not shared, or if there is a safeguarding concern. This is because I have a duty of care to the public as a registered nurse under the Nursing and Midwifery Council (NMC). If confidentiality was broken for this reason, you would be informed of the situation in full.

As this study uses a small sample size, measures will be taken to ensure that any risk of identifiable data is reduced, this may include changing minor details unrelated to analysis.

*Northumbria University is the sponsor for this study based in the United Kingdom. We will be using information from you in order to undertake this study and will act as the data controller for this study. This means that we are responsible for looking after your information and using it properly. We will keep identifiable information about you for 1 years after the study has finished and non-identifiable information for 3 years after the end of the study.*

*Your rights to access, change or move your information are limited, as we need to manage your information in specific ways in order for the research to be reliable and accurate. If you withdraw from the study, we will keep the information about you that we have already obtained. To safeguard your rights, we will use the minimum personally-identifiable information possible.*

*Individuals from Northumbria University and regulatory organisations may look at your research records to check the accuracy of the research study.*

*You can find out more about how we use your information by Contacting Tom Nicholson (Contact details at the bottom of this form.*

### **How will my data be stored?**

All paper data, including the questionnaires, the typed-up transcripts from your interview and your consent forms will be kept in locked storage. All electronic data: including the recordings from your interview, will be stored on the University U drive, which is password protected. All data will be stored in accordance with University guidelines and the Data Protection Act (2018).

### **What will happen to the results of the study?**

The general findings of this research will be reported within a doctoral thesis (PhD Project) which may also be submitted to a scientific journal or presented at a research conference, however the data will be anonymised and you or the data you have provided will not be personally identifiable, unless I have asked for your specific consent for this beforehand. I can provide you with a summary of the findings from the study if, at the end of the study. Your contact information will be kept on an encrypted PC within a locked university room. This information will be used at the end of the study to email you the study results.

### **Who is Organizing and Funding the Study?**

Northumbria University is the funder of this study, which is the PhD research project of Tom Nicholson (Graduate tutor of Mental Health Nursing)

### **Who has reviewed this study?**

Before this study could begin, ethical permission was obtained via the integrated research application system (IRAS), from Northumberland Tyne and Wear (NHS) Foundation trust, and Northumbria University. This PhD project is being supervised by Dr Richard Lee and Dr Michael Hill at Northumbria University.

The Faculty of Health and Life Sciences Research Ethics Committee at Northumbria University have reviewed the study in order to safeguard your interests and have granted approval to conduct the study.

### **Contact for further information:**

**Researcher email: [t.nicholson@northumbria.ac.uk](mailto:t.nicholson@northumbria.ac.uk)**

# 14. Appendix B: Consent Form

## CONSENT FOR TAKING PART IN A STUDY DISCUSSING A SENSITIVE SUBJECT AREA

**Project Title:** Understanding the needs and experiences of parents whose children are on the ADHD diagnostic journey: A longitudinal study.

**Principal Investigator:** Tom Nicholson

*please tick or initial  
where applicable*

I have carefully read and understood the Participant Information Sheet.

I have had an opportunity to ask questions and discuss this study and I have received satisfactory answers.

I understand I am free to withdraw from the study at any time, without having to give a reason for withdrawing, and without prejudice.

I agree to take part in this study.

I understand that by taking part in this study I will be talking about potentially sensitive and emotional topics. I accept that this is part of the research project.

I also consent to the retention of this data under the condition that any subsequent use also be restricted to research projects that have gained ethical approval from Northumbria University (This data will be non-identifiable).

Signature of participant..... Date.....

(NAME IN BLOCK LETTERS).....

Signature of researcher..... Date.....

(NAME IN BLOCK LETTERS).....

# 15. Appendix C: NICE Guideline

## NG87: Diagnosis of ADHD

### Identification and referral

1.2.3 Universal screening for ADHD should not be undertaken in nursery, primary and secondary schools. **[2008]**

1.2.4 When a child or young person with disordered conduct and suspected ADHD is referred to a school's special educational needs coordinator (SENCO), the SENCO, in addition to helping the child with their behaviour, should inform the parents about local parent-training/education programmes. **[2008, amended 2018]**

1.2.5 Referral from the community to secondary care may involve health, education and social care professionals (for example, GPs, paediatricians, educational psychologists, SENCOs, social workers) and care pathways can vary locally. The person making the referral to secondary care should inform the child or young person's GP. **[2008]**

1.2.6 When a child or young person presents in primary care with behavioural and/or attention problems suggestive of ADHD, primary care practitioners should determine the severity of the problems, how these affect the child or young person and the parents or carers, and the extent to which they pervade different domains and settings. **[2008]**

1.2.7 If the child or young person's behavioural and/or attention problems suggestive of ADHD are having an adverse impact on their development or family life, consider:

- a period of watchful waiting of up to 10 weeks
- offering parents or carers a referral to group-based ADHD-focused support (this should not wait for a formal diagnosis of ADHD).

If the behavioural and/or attention problems persist with at least moderate impairment, the child or young person should be referred to secondary care (that is, a child psychiatrist, paediatrician, or specialist ADHD CAMHS) for assessment. **[2008, amended 2018]**

1.2.8 If the child or young person's behavioural and/or attention problems are associated with severe impairment, referral should be made directly to secondary care (that is, a child psychiatrist, paediatrician, or specialist ADHD CAMHS) for assessment. **[2008]**

1.2.9 Primary care practitioners should not make the initial diagnosis or start medication in children or young people with suspected ADHD. **[2008]**

1.2.10 Adults presenting with symptoms of ADHD in primary care or general adult psychiatric services, who do not have a childhood diagnosis of ADHD, should be referred for assessment by a mental health specialist trained in the diagnosis and treatment of ADHD, where there is evidence of typical manifestations of ADHD (hyperactivity/impulsivity and/or inattention) that:

- began during childhood and have persisted throughout life
- are not explained by other psychiatric diagnoses (although there may be other coexisting psychiatric conditions)
- have resulted in or are associated with moderate or severe psychological, social and/or educational or occupational impairment. **[2008]**

1.2.11 Adults who have previously been treated for ADHD as children or young people and present with symptoms suggestive of continuing ADHD should be referred to general adult psychiatric services for assessment. The symptoms should be associated with at least moderate or severe psychological and/or social or educational or occupational impairment. **[2008]**

### 1.3 Diagnosis

1.3.1 A diagnosis of ADHD should only be made by a specialist psychiatrist, paediatrician or other appropriately qualified healthcare professional with training and expertise in the diagnosis of ADHD, on the basis of:

- a full clinical and psychosocial assessment of the person; this should include discussion about behaviour and symptoms in the different domains and settings of the person's everyday life **and**
- a full developmental and psychiatric history **and**
- observer reports and assessment of the person's mental state. **[2008]**

1.3.2 A diagnosis of ADHD should not be made solely on the basis of rating scale or observational data. However, rating scales such as the Conners' rating scales and the Strengths and Difficulties Questionnaire are valuable adjuncts, and observations (for example, at school) are useful when there is doubt about symptoms. **[2008]**

1.3.3 For a diagnosis of ADHD, symptoms of hyperactivity/impulsivity and/or inattention should:

- meet the diagnostic criteria in DSM-5 or ICD-10 (hyperkinetic disorder; but exclusion based on a pervasive developmental disorder or an uncertain time of onset is not recommended) **and**

- cause at least moderate psychological, social and/or educational or occupational impairment based on interview and/or direct observation in multiple settings **and**
- be pervasive, occurring in 2 or more important settings including social, familial, educational and/or occupational settings.

As part of the diagnostic process, include an assessment of the person's needs, coexisting conditions, social, familial and educational or occupational circumstances and physical health. For children and young people, there should also be an assessment of their parents' or carers' mental health. **[2008, amended 2018]**

1.3.4 ADHD should be considered in all age groups, with symptom criteria adjusted for age-appropriate changes in behaviour. **[2008]**

1.3.5 In determining the clinical significance of impairment resulting from the symptoms of ADHD in children and young people, their views should be taken into account wherever possible. **[2008]**

# 16. Appendix D: Interview Topic Guide

## Topic Guide for Interviews

*The core question represents the primary question to be asked in each interview. Additional questions may be asked based on the participant answers to the core questions and if conversation has slowed. The use of these questions is at the discretion of the interviewer and informed by analysis. Prompting statements may be used to illicit additional information and explore topics related to the research questions in greater detail.*

### **Part 1:**

Introductions. Overview of the interview process. Consent taking (10 Minutes)

- Introduce the project and the projects aims

### **Part 2:**

Core questions:

First question: Would it be possible for you to give me some background? Who you are and who is currently going through the ADHD assessment process?

### **Follow up questions:**

- What is it like as a parent to have a child on the ADHD diagnostic journey?
- How does it feel to be on this journey?
- What does ADHD mean for you?
- What do you feel that you need during this process?
- How does having your child on the ADHD diagnostic journey make you feel about yourself?

- [If private diagnosis was sought] Why did you choose to pursue diagnosis privately?

**Additional questions added after first stage analysis:**

- Do you see ADHD as a disability? What are your thoughts on the term in relation to ADHD?
- Has your perspective on ADHD changed since you began this journey?
- Was the feeling of receiving a diagnosis what you expected?
- Has the diagnosis given you what you want?
- How has the journey been?
- What are your thoughts regarding ADHD medication or other treatments at this stage?