

**How was it for me? : A grounded theory
exploration of growing up with Attention
Deficit Hyperactivity Disorder.**

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HOW WAS IT FOR ME? : A GROUNDED THEORY EXPLORATION OF GROWING UP WITH ATTENTION DEFICIT HYPERACTIVITY DISORDER.

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D. Clin. Psychol. Declaration of own work

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Date *25.7.05*

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Abstract

Attention Deficit Hyperactivity Disorder (ADHD) has been one of the most comprehensively studied of all childhood psychiatric conditions. However, most research has focussed on aetiology, diagnostic criteria, or treatment efficacy, and in such research the voices of adult professionals dominate, while the voices of the children remain silent. There has been little research into the everyday lived experiences of children diagnosed with ADHD. The present research is a grounded theory study, of the experiences of nine young adults (aged 14 – 18 yrs.) previously diagnosed and treated for ADHD. The aims of the study were to explore the experiences of adolescents diagnosed with ADHD, and to understand how personal meaning-making within the context of receiving diagnosis and treatment influenced beliefs about themselves and the world. Analysis of the adolescent's narratives revealed three themes. Firstly 'Exclusion', which occurred in relation to friendships and teacher relationships. Secondly 'Identity Conflict,' which described the conflict experienced between three possible perceptions of self as either 'normal', 'ill' or 'weird'. The third theme 'Overcoming' details the strategies adopted by adolescents for resolving exclusion and supporting their desired perception of a 'normal' self. The study concludes that regardless of aetiology, the felt experience of growing up with ADHD is not one of managing a medical condition, but of striving to overcome social difficulties and engage in normative adolescent developmental tasks.

1) Introduction, Stage One: Planning the journey

1.1 Chapter One – To ‘The Enchanted Forest’- An Explanation for the Journey

Preface

We cannot over emphasise the point that, as a matter of science, the notion that ADHD does not exist is simply wrong. All of the major medical associations and government health agencies recognise ADHD as a genuine disorder because the scientific evidence indicating it is so is overwhelming.

International Consensus Statement on ADHD January 2002, issued by 83 ADHD academics and professionals

*Writing as a special-needs teacher, I am quite sure that a lot of it is complete b. I get sick of being trashed by some little s*** who then tells me I cant punish him because his pill hasn't kicked in yet. When you give a kid a syndrome, you give him an excuse. I blame uppity parents looking for compensation, extra funding, a stick to beat teacher and an excuse for their kids obnoxious behaviour, and their inadequate parenting.*

Chatroom quote from anonymous teacher

My 8 yr. old daughter was recently diagnosed with ADHD. The healthcare practitioner immediately prescribed Concerta for her to take. My husband went and had the prescription filled while I went to the internet to do some research. After 4+ hours of research, I am absolutely outraged at what I have found. I immediately flushed the Concerta down the toilet and am now trying to calm myself down before I approach the healthcare person that prescribed this med. I am deeply shocked at what is happening to our children and I will NOT be a part of drugging my child because she is not acting "appropriately" in school. I refuse to label her as having a "diseased" brain and I would love to take this matter further to the attention of those in Washington. Something needs to be done to stop this!!! I am beside myself.

Internet posting from “A very concerned mother in North Carolina”.

Attention Deficit Hyperactivity Disorder (ADHD) is reported to affect between 6 - 11per cent of children, (Faraone *et al.*, 2003) and is a condition regarded as so detrimental to the well-being of the child that treatment with powerful psychotropic medication is recommended (National Institute of Mental Health, 2004). Yet it is also a condition that prior to the late 1980s was largely unknown to general society (Schmitz *et al.*, 2003). Since this time however, there have been ever increasing numbers of ADHD related articles appearing in both professional and lay media, (Schmitz *et al.*, 2003) and ADHD has come to be firmly embedded within society's collective consciousness. With terms such as ‘hyper’ entering common playground parlance. It is

a topic that continues to evoke controversy and heated debate as the above quotes illustrate, appearing on dedicated websites, women's magazines and mainstream news programmes.

Whilst the voices of physicians, psychologist, health professionals, teachers and parents are loud and strident in this debate, what struck me was the poignant silence of the central characters, the children. This study was born of my interest in understanding how children themselves have made sense of the experience of growing up with ADHD amidst this debate, and a desire to create a space for their voices to be heard. Consequently, the questions asked here were; what meaning does the experience have for young people and how is this experience woven into the ongoing developmental narrative of their lives?

In keeping with the narrative approach underlying this thesis, a classic childhood tale 'The Faraway Tree' by Enid Blyton was utilised as a structural metaphor for the study. The essence of the tale is; a small group of children discover a magical tree in the middle of an enchanted forest. At the very top of this tree through the clouds is the entrance to ever-changing magical lands. There are number of reasons for choosing this as a metaphorical vehicle. The prosaic – I happened to be reading it to my own children, and was struck again by how child centred the writing is and the absence of adult voices in this world. This thesis aims similarly to give primacy to the voices and experiences of the children involved. A second reason is that the story combines themes that mirror many aspects of this thesis. *An adventure into the unknown*, mirroring the 'discovery orientation' of qualitative study in an area where existing research is negligible. *The struggle to climb to the top* and gain a new perspective. Mirroring both the active nature of the researcher as participant and the aim of gaining a new perspective, which is both grounded in the data (woods) and rises above that, to see new possible structures and forms. *Finding new, surprising and ever-changing, lands* at the top of the tree. Reminding me, as the researcher, of a commitment to approach the subject with an open mind, to be led by the young people and to be willing to be surprised by the findings.

Finally, 'The Faraway Tree' conveys multiple stories within the framework of one major narrative. This thesis similarly aims to both, enable participants to voice their unique experiences, and to weave these together into a single narrative capturing the essence what it is like to grow up with ADHD.

Map of the journey's stages

Stages one and two: planning and preparation:

The thesis commences with a review of the three areas of knowledge, which were considered relevant in terms of initial orientation towards the research. Aiming to provide a context for the research and also an understanding of the entity labelled ADHD within this study. As it was initially thought participants views of ADHD and themselves would be shaped by the various different representations of ADHD available to them, through healthcare professionals, teachers, family and peers. These are reviewed first.

The second area of literature provides a review of ADHD outcomes in the context of normative development, providing a background for understanding participant's narratives from a developmental perspective.

A final strand reviews literature concerning development of the concept of 'self,' through childhood, as a primary interest in the current study was understanding the possible impact receiving a diagnosis and treatment for ADHD might have on how children viewed themselves and their lives.

Stage three- study implementation

Stage three describes the practical management of the study such as arrangements for obtaining necessary approvals and for recruiting and interviewing participants. Chapter 5 focuses on the process by which an appropriate methodology was selected and implemented along with a discussion regarding implications for study quality assurance.

Stage four – results

Stage four outlines the result of the analysis, describing the core and major sub-categories to emerge from the data, and how these are positioned with respect to existing literature. The latter part of stage four provides an overarching account of the experience of growing up with ADHD.

Stage five – discussion

The discussion outlines the limitations of the current study and suggests areas for future research.

Reason for the journey - Aims of the research

To explore the every day lived experiences of young adults, previously diagnosed and treated for ADHD.

To understand similarities and differences in how individuals construe the shared experience of receiving ADHD diagnosis and treatment.

To understand how personal meaning-making within the context of receiving ADHD diagnosis and treatment influences participant's beliefs about themselves and the world.

Significance

Recognising that the assumptions a researcher brings to qualitative analysis are important, and shape interactions with the data, the following section aims to explicitly outline my initial assumptions at the start of the study.

1) The first assumption was that the study might reveal possible connections between individual perceptions of experience, differential developmental trajectories and long-term outcomes. This assumption was based on the reflection that the experience of being diagnosed and treated for ADHD occurs within a highly individual and powerful social context; in that by the time a diagnosis is offered, the child will already have suffered by definition substantial difficulties academically, socially, at home and at school (World Health Organisation, 1996). Relationships with teachers, parents, siblings and peers are likely to be fraught and stretched to breaking point and the child may already feel themselves different or isolated.

2) The second assumption was, that the impact of receiving diagnosis and treatment at this point could have different consequences, depending on the meaning of the event for the individual child within the context of their specific social environment. This assumption was based on reflections from adult literature on coping with illness, where the meaning of the illness in terms of self and social context are highly influential in

directing subsequent behaviour (Fife, 1994). So that for example, where one child experiences a sense of relief, perhaps a feeling of ‘at last there is an explanation, the problem lies *out there*, it’s medical, I am not to blame.’ Another may experience diagnosis as merely confirming a sense that something is fundamentally wrong with them. In the former scenario one could speculate that a child may retain a positive self-image, and engage in behaviours associated with adaptive coping strategies, including for example better medication compliance. Whereas in the latter scenario it may lead to lower self-esteem, poorer coping strategies, feeling stigmatised, and possibly lowered expectations of the child, both by themselves and the adults around them. Same event therefore, but depending on individual meaning and context markedly different outcomes.

3) A third assumption was that ADHD diagnosis and treatment may also impact on a child’s developing sense of self as a result of the stage at which they tend to receive the diagnosis. Most children are diagnosed and treated for ADHD between the ages of 7 and early adolescence, a period that encompasses considerable transition in the development of a child’s sense of self. When they move from early to middle childhood views of self, which tend to be rather global and undifferentiated (Harter, 1990); to early adolescence, when they are struggling to redefine themselves, and embarking on the emotional transition towards independent adulthood (Houch, 1999). The impact of the voices of authority and wider society around them and consequently exposure to widely differing representation of ADHD, therefore during these adolescent years, was thought likely to be significant. However, no studies of these interactions and their impact on an adolescent’s developing sense of self within the context of ADHD diagnosis and treatment are known by the author to have been conducted to date. By exploring the experiences of young adults who were diagnosed and treated for ADHD as children and are now engaged developmentally in the process of forging an adult self identity, the present study will begin to address this gap in the current body of knowledge.

1.2 Chapter Two – Possible ADHD lands at the top of the ‘Faraway Tree’.

Context of the Issue I.

Introduction

This section provides a brief overview of ADHD and in particular the different ‘stories’ or understandings of ADHD that were thought may be influential in shaping participants views of themselves growing up with ADHD.

Why so many stories?

As a diagnostic construct, ADHD is used to describe a particular pattern of co-occurring behaviours. At its most basic level this can be summarised as developmentally inappropriate levels of inattention, impulsivity and hyperactivity. The current DSM-IV criteria for ADHD (American Psychiatric Association, 1994) (Appendix I) identify three possible categories of ADHD. 1) ADHD with mainly attentional problems but not hyperactive-impulsive problems. 2) ADHD with few attentional difficulties but mainly hyperactive-impulsive difficulties, and 3) children with significant problems on both lists. Whilst the inclusion of the term ‘disorder’ in the label, perhaps implies the existence of a single underlying problem, this has yet to be demonstrated. Further difficulties arise in that, firstly the behaviours typical of ADHD are quantitatively, but not qualitatively different to many ‘normal’ child behaviours, and secondly the same behavioural manifestation can arise as a result of many different pathways, and therefore cannot reliably be used to indicate causality. This has led to ADHD being somewhat tautological; because a child is inattentive, hyperactive and impulsive they are considered to have ADHD, and because they have ADHD they are seen as inattentive, hyperactive and impulsive.

These difficulties have led to ADHD being conceptualised in different ways, all of which are potentially available to the young adult or child who has an ADHD diagnosis, through their contact with various health and education professionals, the media and wider society. This section outlines the primary ways in which ADHD is currently differentially represented and understood. No attempt is made to argue the case for one representation having greater veracity than any other, as the aim was to become aware of the many ADHD ‘stories’ participants may have encountered, and to link these with

the possible self identity discourses they may promote and which could emerge from participants narratives. To aid clarity these are artificially presented separately, whilst accepting that stories often may overlap, and are not mutually exclusive.

ADHD and ‘the land of broken bodies’ – biological perspectives

The medical view assumes that the behaviours attributed to ADHD have an aetiology rooted in biological abnormality be it, genetic, biochemical or neurological. The condition is viewed therefore as due to factors inherent within the child and best treated by addressing the underlying organic deficit through medical means such as pharmacology. It is these stories of ADHD that participants were thought most likely to have encountered through contact with health professionals, and also from their parents as research suggests biological models are also those most often held by parents (Harborne *et al.*, 2004).

Its all in the genes - The Genetic Hypothesis

Support for a genetic component to ADHD comes from three areas of research. Firstly studies noting the higher prevalence of psychopathology within the families of those with ADHD; such that the offspring of a parent with ADHD carries a 57 per cent risk of also developing the condition (Biederman *et al.*, 1995). It is unlikely however that genetics provide the whole explanation as behaviours can also be transmitted in families through non-genetic means, for instance shared child-rearing practices (Hinshaw, 1994). Also, whilst shared environmental factors may contribute little variance (Barkley, 1997) non-shared environmental factors, such as differences in the way parents relate to individual children are significant, accounting for between 15-20 per cent of variance in ADHD behaviours (Silberg *et al.*, 1996).

It's my brain - Organic Deficit Hypotheses

Minimal Brain Damage

Here the assumption is that ADHD reflects some form of organic deficit, such as minimal brain damage (Strauss & Lehtinen, 1947). Neuroimaging studies have

attempted to demonstrate specific structural brain abnormalities associated with ADHD (Tannock, 1998) but have failed to obtain a consistent relationship. Zametkin *et al.*, (1990) found significant differences in the way the frontal cortex took up glucose during tasks requiring focussed attention, between adults with ADHD and a non ADHD control group, but the study was limited by the use of a small potentially biased adult sample and further studies in adolescents have only partially replicated Zametkin's findings (Cantwell, 1996).

In common with other childhood disorders there is a higher prevalence of factors leading to potential pre or peri-natal brain damage amongst ADHD groups compared with controls, for example maternal smoking or alcohol use, premature birth, or infant disease, (Barkley *et al.*, 1990). However this is not unique to ADHD being a common finding for other childhood disorders.

Neurotransmitter dysregulation

This hypothesis suggests there is an abnormality in neurotransmitter functioning, particularly dopamine, related to the D4 dopamine receptor gene (El-Faddagh *et al.*, 2004). Drug treatment with methylphenidate and dextroamphetamine target these systems and have been shown to be effective in improving symptom control, with the result that pharmacological treatment is currently recommended as the most effective intervention for ADHD. (Barkley, 2002; Jensen *et al.*, 2004a; Scottish Intercollegiate Guidelines Network, 2001)

Several criticisms of biological models have been made. Firstly, ADHD behaviours often show considerable situational variability suggesting significant environmental mediation. For example, symptoms have been shown to vary depending on setting and caregiver. Secondly, even when differences in diagnostic classification are controlled for, different prevalence rates between countries are still found. For example Iceland, Australia, Italy and Sweden all report lower prevalence rates than the US and 16 other non US populations, (Faraone *et al.*, 2003) implicating social and cultural factors.

Summary

The biological models briefly summarised here, position ADHD as a medical problem with an organic basis that can be treated pharmacologically. They therefore potentially position the child as a patient, and consequently improvement as being due to medication.

ADHD and 'the land of faulty thinking' – cognitive perspectives

Four theories are currently proposed which seek to explain ADHD as a form of cognitive impairment.

Inattention hypothesis

This hypothesis suggests individuals with ADHD have difficulty sustaining attention on a single task and screening out distracting stimuli. As a result their attentional focus changes frequently, which at a behavioural level appears as general hyperactivity and impulsivity (Douglas, 1983). Other studies however have shown that children with ADHD are objectively more active during sleep, when there are no demands on selective attention. Also that difficulties with selective attention are not gradual as predicted by this hypothesis but can often present immediately .

Hyperactivity hypothesis

This hypothesis argues the core problem in ADHD is a failure to inhibit excess motor activity, which manifests as impulsive and inattentive behaviour (Schachar, 1991). This hypothesis is strengthened by studies in which the amount of movement exhibited by ADHD children has been objectively rated and shown to be higher than controls. Also hyperactivity, unlike inattention and impulsivity, appears to be more unique to ADHD and to correlate with academic indices of attentional difficulty (Hinshaw, 1994; Taylor, 1994).

Impulsivity hypothesis

The contention of this hypothesis is that the core problem underlying ADHD is cognitive and behavioural impulsiveness or disinhibition. Although supported by some neuropsychological evidence suggesting children with ADHD have difficulty

withholding responses over time. Other studies have demonstrated that when social and motivational factors, such as the presence of the experimenter during tasks or altering the length of the experimental session are manipulated, differences between the ADHD group and control group can become non significant (Prior & Sanson, 1986; Sonuga-Barke, 2002; Sonuga-Barke *et al.*, 1992).

Behavioural Inhibition Model

The behavioural inhibition model views ADHD as a deficit in executive functioning (Barkley, 1997). In order to achieve behavioural inhibition there needs to be the capacity to: a) Mentally maintain internally represented information. b) Use internal speech for reflection and description in order for events to be contemplated before responding to them. c) Have sufficient affect self-regulation in order to sustain goal-directed behaviour when there are no contingent external rewards and d) have the ability to plan purposeful behaviours based on previous learning. Barkley, (1997) views ADHD as a failure of these executive functions to develop normally, with the result that the ADHD child is unable to minimise or suppress non-goal related sensory or motor behaviour.

Each of these cognitive explanations of ADHD attempt to demonstrate that the triad of symptoms can be best explained by specific deficits in cognitive processing. However, although children with ADHD have been shown clearly to perform poorly on general neuropsychological tests of attention, and response inhibition (Pennington & Ozonoff, 1996), the evidence base remains patchy and inconclusive (van den Meere, 1996) and as yet no neuropsychological test has been demonstrated as sufficiently robust that it can be used as a diagnostic tool.

Summary

Both the medical and cognitive ADHD discourses outlined above fundamentally locate a child's difficulties within the individual, assuming an individual organic based deficit. One implicit message for the child within these models therefore is, 'there is something wrong with you', or 'you are ill' and with that comes the possibility that such

representations would act to promote identity discourses around being ‘a patient,’ ‘defective’ or ‘recovered,’ whilst suppressing alternatives.

ADHD and ‘the land of others’ – a sociological perspective’.

Alternative understandings of ADHD focus on contextual social and dynamic explanations and a crude summary of these stories would be; ADHD is a cultural construct, reflecting society's labelling as defective essentially normal or adaptive child behaviours. Prevalent theories seek to explain two dimensions of this position. That is a) the processes by which one society but not another may choose to label and medicalise a behaviour, and b) the process by which individual social and dynamic contextual factors may interact to predispose a child to respond with inattentive, hyperactive or impulsive behaviour. ADHD in this story is less a difficulty located within a ‘broken’ child but rather one located within the wider context: cultural; historical; political; economic and social. These theories were considered also relevant to the current study, both through providing a wider perspective on what is called ADHD, and also because research suggested these representations were likely to be encountered by participants in exchanges with adults outside of family or healthcare settings (Harborne *et al.*, 2004).

ADHD as a social construct – macro influences

To date, no medical diagnostic test for ADHD has been developed and there is no physiological or biological marker indicative of organic pathology. Diagnosis is made instead through the collection of observations of a child's behaviour at home, school and in the clinic, often using some form of rating scale. However, this process is inherently subjective and cultural, with cultural values playing a significant role in determining how rating scales are completed and viewed. A particularly important point, given that the behaviours being rated are essentially those that every child does, the only difference being the perceived frequency, or level of developmental appropriateness. Mann (1992), for instance showed that when mental health professionals from four different countries; Japan, China, Indonesia and the USA rated identical standardised videotape vignettes of four 8 year old boys. Raters from China

and Indonesia gave significantly higher scores for hyperactive-disruptive behaviours than those from the US or Japan, with the explanation that the result reflected differences in cultural standards for appropriate childhood behaviour. This raises the question of what processes in western industrialised societies, predominantly the USA and the UK, are driving the identification of this particular group of behaviours as signifying a medical problem in growing numbers of children. Psychosocial explanations claim part of the answer lies within the power structures and discourses currently utilised in our society. In this section macro influences, such as; the cultural power vested in medicine, business and the media, which act in a top down manner are briefly considered. Then in the following section micro, or bottom up, influences reflecting the context of individuals in society are reviewed.

The Cultural Power of Medicine and ADHD

Within our culture, medicine and those who practice it, are perceived as holding a great deal of power, authority and status (Boyle, 2002). This gives medicine the power of a 'master narrative' that is one which functions as a cultural standard used by authority figures in the 'management of sense making' (Thorne & McLean, 2003). Radcliffe and Timimi (2004) state that in the case of ADHD medicine has reified a diagnostic label into a causal entity through this mechanism. Citing the International Consensus Statement quoted at the start of this thesis being a good example of doctors using their powerful status to claim veracity and position ADHD as a medical condition (Barkley, 2002). This marginalizes other views by positioning them as uninformed and/or unscientific. Social perspectives point to this exercise of cultural power, along with other drivers such as economics, as potentially accounting for the apparent increases in ADHD. For example the pharmaceutical industry, which financially benefits each time a child is diagnosed and invests heavily in strategies to promote awareness of ADHD. These representations portray ADHD as something that is false and imposed upon young people. If participants encountered this representation therefore and construed it as valid it could potentially change the meaning of being diagnosed and treated, from one of a patient receiving help, to a victim being exploited.

The Cultural Power of the Media and ADHD

Representations of ADHD in the media may also play a role in shaping participants views of ADHD. From 1990 onwards, biological causes for ADHD have been cited more frequently than any other (Schmitz *et al.*, 2003). This appears to have been precipitated by the results of Zametkin *et al.*, (1990) brain imaging studies which were widely publicised in lay press, complete with striking false colour photographs of the brain, and statements such as '*...in more than 20 years of intense scientific scrutiny, no one was able to find the key [to the cause of ADHD]. Until now. In a landmark study that could help put to rest decades of confusion and controversy...[scientists have] traced ADHD for the first time to a specific metabolic abnormality in the brain.* Time (Nov, 26th 1990)

Hand in hand with portraying biology as the cause of ADHD, the most frequent treatment cited in general media sources is medication. However whereas in the medical journals there is a professional consensus for the role of medication (Barkley, 2002; Jensen *et al.*, 2004a, 2004b; Scottish Intercollegiate Guidelines Network, 2001) lay press representations of medication since 1988 have remained consistently ambivalent (Schmitz *et al.*, 2003). On the one hand presenting Ritalin as '*one of the raving successes in psychiatry...a pill that allows children and a growing number of others to focus their minds*' and on the other as a stimulant that '*may be causing some hidden havoc to their child [and is a] quick fix, for children forced to live in an impatient culture*' (Newsweek, Mar 18, 1996)

These popular representations of ADHD were again anticipated as being potentially important in shaping participant's perceptions of both ADHD and themselves. Possibly strengthening biological deficit messages, but at the same time creating a fear of medication

ADHD as a social construct – micro influences

These stories reflected views of ADHD, which unlike some of the strong uni-directional social perspectives above, seek to explain ADHD as being situated not within the child but in the interaction between the child and their environment. In terms of the present

study it was anticipated that participants may be aware of some of these theories through their parents. Previous studies have suggested that parents are very aware of non-biological explanations for ADHD, particularly those associated with poor parenting, which were often negatively perceived and a source of dispute between families and other adults (Harborne *et al.*, 2004).

I can't cope -Changing demands on children and families

In these theories ADHD is the behavioural manifestation of difficulties a child has in meeting the demands of our modern industrialised society. For instance the demand that by the age of 4 or 5 a child is able to enter a formal education system; with its requirements for compliance, concentration, sitting still, listening and verbally reflecting on activities. Unlike macro influences, which are uni-directional, these are integrative views, where both biology and social factors are seen as exerting ongoing bi-directional effects, causative and perpetuating. Here ADHD arises from a combination of lack of 'fit' between a child's capabilities and the demands of their environment. In this light Block, (1977) views ADHD as simply the pathologising of children who are unable to meet environmental demands.

How successful a child is in meeting such demands may depend on many factors. Such as, developmental maturity, physical health, social skills, and the absence of emotional difficulties associated with family circumstances. Success or failure in coping also has an ongoing impact on a child's perceived sense of competence, mastery and self-esteem, and consequently their behaviour.

Predominant theories in this story often focus on possible connections between ADHD and insecure attachment relationships, poor parenting or trauma.

It's my parents - ADHD as a response to attachment or parenting difficulties, or trauma.

The story of ADHD as an attachment disorder arises from the observation that many children who have experienced attachment bonding breaks or trauma display the same patterns of disordered behaviours as children diagnosed with ADHD, (Golding, 2004).

Two theories of ADHD as an attachment disorder have been proposed. Ladnier & Massanari (2000) take an aetiological perspective suggesting that a child with a poor attachment history will have difficulties with self regulation due to not having received appropriate limit setting, guidance or discipline which lead to difficulties internalising rules for self-government. Lack of a consistent responsive carer also means that the child struggles to learn self-soothing skills and becomes chronically hyperaroused. Constant autonomic arousal, they suggest, interferes with the child's ability to learn and access alternative cognitive strategies that could allow them to stop and consider the possible consequences of their actions. The combination of poor self-regulation, and chronic hyperarousal then leads to behaviour that appears hyperactive, impulsive and inattentive.

A second view of ADHD as an attachment disorder is proposed by Golding (2004), who views ADHD type behaviour as an adaptive attempt to deal with carers who are unresponsive, unpredictable or inconsistently available. Children in this situation understandably experience considerable anxiety, which leads to exaggerated attempts to secure carer attention and increase feelings of security. These efforts manifest themselves as displays of extreme negative affect, or becoming loud, restless and hyperactive. All patterns of behaviour also associated with ADHD. The child's inattentive, hyperactive, attention seeking behaviours are understandable functionally therefore as strategies to gain the attention of carers who are or are expected to be inconsistently available and responsive (Clarke *et al.*, 2002).

Summary

In conclusion, macro sociological perspectives seek to explain ADHD as a consequence of existing cultural and economic power structures that function to (re)categorise specific child behaviours as illness, consequently initiating the appropriate societal actions of seeking expert medical diagnosis and medication. For someone who is diagnosed with ADHD, acceptance of these sociological representations, may communicate ideas of exploitation, and potentially promote self identity discourses based on being a victim or exploited over other possibilities such as for example that of being a patient as discussed previously.

Micro influences alternatively, represent ADHD as occurring as a result of adverse events such as trauma or most often attachment difficulties, which reduce a child's ability to successfully meet the demands of contemporary industrialised, individualistic western society. Although direct exposure to these representations of ADHD may be less common for young people, as they are given primacy neither in medical journals nor lay press. Evidence from studies of parent experiences suggests that these stories are prevalent in the form of perceived parent, usually mother, blame (Harborne *et al.*, 2004). For the young adult with ADHD the message communicated by these discourses may be of a self characterised as a 'victim' or 'misunderstood child' over other possible self identities.

Summary of ADHD biological versus sociological stories

The varied stories of ADHD represented here reflect ADHD as ranging from a biological deficit located within the child, to something that is entirely socially constructed. It was considered likely that young adults living with a diagnosis of ADHD would be exposed to both of these extremes, and probably all shades in between. The question was how do they make sense of this debate in their own lives at a time when they are also attempting to grow-up and forge a coherent identity?

1.3 Chapter Three – Climbing the 'Faraway Tree' (or Children's development of 'self'). Context of the Issue II

Introduction

This study aimed to explore the experience of growing up with ADHD in our current society, and to understand how this may impact on the process of creating an integrated self, as reflected in their autobiographical narratives. This chapter provides an overview of ADHD in the context of child development. Secondly this chapter provides a review of literature concerning the development of autobiographical memory and construction of 'self'.

ADHD and 'the land of growing up' - a developmental perspective

The course of ADHD

ADHD was initially thought to be a condition confined to childhood, with children becoming less distractible, impulsive and hyperactive as their teenage years ensued (Mendelson *et al.*, 1971). However in the last 15 years research following up adolescents and adults with ADHD has led researchers such as Barkley (2004) to re-conceptualise ADHD as a chronic disorder. One that carries significant risk for a whole range of later difficulties such as increased; drug and alcohol use, antisocial behaviour, self-esteem problems and poor academic outcomes (Brown & Borden, 1986). Despite the almost unanimous agreement that childhood ADHD is clearly associated with negative developmental outcomes. The statement that this makes ADHD automatically a chronic disorder in adults has been questioned by others, such as Adenbach (1995). As it may be that it is not ADHD itself but rather the impact ADHD symptoms exert on normal developmental processes, such as parent-child relationships, peer relationships, and academic performance, that account for the negative outcomes.

Two approaches have been taken to try and establish whether ADHD is a chronic continuous condition or one that remits with maturity. The first approach uses diagnostic retention criteria and simply looks at what percentage of children still fulfil diagnostic criteria as adults. This approach has provided a mixed set of results, with the percentage of children quoted as still meeting diagnostic criteria by adulthood ranging from essentially zero (Hill & Schoener, 1996) to 90per cent if sub-threshold levels of ADHD symptomatology are included (Biederman *et al.*, 2000). However as these studies used different criteria both at the diagnostic stage and crucially at the stage of defining 'diagnosis' at follow-up they are difficult to meaningfully compare and tell us little about the developmental course of ADHD.

A second approach focussed upon following the natural history of the individual symptoms over time in individuals, using repeated measures and continuous scales rather than 'all or nothing' diagnostic cut-offs. In a study of 106 ADHD youths aged 8-15 years, Hart, (1995) reported that hyperactive-impulsive symptoms significantly declined with increasing age, whereas inattentiveness did not, and the main factor

predicting whether ADHD persisted was the presence of co-morbid conduct disorder. A similar finding with regard to declining symptoms was reported by Biederman (2000) who found a decline in inattentive symptom levels as well as hyperactivity-impulsivity, although compared to controls the ADHD youths were still more hyperactive, impulsive and inattentive.

The general conclusions to date are that all symptoms, but particularly hyperactivity-impulsiveness are likely to decline with age in most children diagnosed with ADHD. However despite this decline, behaviour does not become 'normal' and significant differences between ADHD diagnosed youth and the control groups persists. For a small minority symptoms appear not to decline but rather worsen leading to serious psychiatric and anti-social difficulties. This has led to calls for more research into individual symptom variation and also research into how symptom presentation varies across the developmental spectrum from childhood to adulthood (Willoughby, 2003).

Impact of ADHD on development

Although it is known that ADHD is associated with negative developmental outcomes, the lack of prospective longitudinal research has limited knowledge of the mechanisms by which risk is increased. It is not known for example to what extent the coercive parenting style often observed in parents of ADHD children is as a result of the child's difficult behaviour or the cause of it. As mentioned above however, it is probable that ADHD negatively impacts upon a number areas that are important for good psychological adaptation and social outcomes in later life, and these are reviewed below. Although these are presented separately, each impacts on the other, with the presence of one risk factor increasing the probability of another.

ADHD and parent-child relationships

There is a wealth of literature demonstrating that difficulties in parent-child relationships and insecure attachment are risk factors for later poor psychological adaptation in later life (Bretherton & Walters, 1985). Children diagnosed with ADHD are frequently described by their parents as having been, temperamental, colicky or difficult to settle as babies, factors that by themselves can interfere with establishing

good parent-child relationships. Families where a child has been diagnosed with ADHD also tend to have higher levels of parental mental health difficulties, and report experiencing greater levels of stress and feelings of incompetence (Edwards *et al.*, 1995; Faraone *et al.*, 1995,) which makes parenting even more challenging. These difficulties whether causal, a consequence of managing a challenging child, or bi-directional, are also likely to impact on the style of parenting adopted by parents. Parents of children with ADHD have been observed to be less responsive and use coercive styles more frequently in interactions with their child (Edwards *et al.*, 1995). These styles of parenting are more likely to foster insecure attachment with its attendant risks for the future. As noted earlier this has led some to propose that ADHD is essentially a form of attachment disorder (Golding, 2004).

ADHD and Peer relationships

Poor parent-child relationships continue to impact on development throughout childhood, as insecure children also tend to have more difficulties forming friendships and to be less popular with peers (Erhardt & Hinshaw, 1994). If there has not been good parental modelling of social skills they may also be less socially skilled than peers, a problem that is exacerbated if they are then also rejected by peers, and denied the opportunity to practice. Poor peer relationships and peer rejection are some of the strongest predictors of poor psychological and social outcomes (Cowen *et al.*, 1973) (Berndt & Savin-Williams, 1993; Bierman, 1987) and children with ADHD have a particularly high risk of rejection (Erhardt & Hinshaw, 1994) especially if they have concurrent difficulties with aggression. Aggression and early rejection by peers is also closely linked with dropping out of school and delinquency.

ADHD and School attainment.

ADHD symptoms interfere with school attainment directly in that being inattentive, impulsive and hyperactive makes it difficult to learn. Difficulties at school often become evident early in a child's scholastic career and negative early school experiences tend to go on to have a negative cumulative effect. Leading to more failure and poor attainment (Pellegrini & Horvat, 1995) unless appropriate intervention is provided. However the impact of ADHD and failing at school may also have other

effects which serve to increase the risk of subsequent psychopathology. Frequent exposure to failure has been associated with the development of negative attributional styles, resulting in less persistence on tasks. Less persistence results in more failure experiences and reduced learning. This process has been demonstrated in a study by Lufi and Parish-Plass, (1995), who found that children with ADHD do indeed show less task persistence. Experiencing repeated social and academic failure also has implications for the development of 'self' reducing the likelihood of developing the resilience that goes with having a robust sense of yourself as competent, effective and with some control over whether your endeavours are successful or not.

In conclusion, whether ADHD causes all of these associated difficulties or arises as a result of encountering them, what is clear is that they act to significantly interfere with normative development and predispose children to adverse long term outcomes.

Treatment outcomes for ADHD

Treatment interventions for ADHD have sought to reduce symptoms and thereby normalise the developmental trajectory. Two main forms of intervention have been evaluated, pharmacological and psychosocial. A brief review of the outcomes to date for both types of intervention is outlined in this section.

Medical Intervention Outcomes

Treatment with psychostimulants have been shown to be effective in improving symptom control for between 60-90 per cent of children with ADHD. With the result that pharmacological treatment is currently recommended as the most effective intervention for ADHD (Barkley *et al.*, 2002; Jensen *et al.*, 2004a, 2004b; Scottish Intercollegiate Guidelines Network, 2001). However many of these studies have been relatively short randomised controlled trials, which although well controlled and sufficiently powered, still provide only short term efficacy and safety data and it is unclear how these short term results relate to long-term outcomes. There is no evidence to date for instance that medication improves academic performance, or social problem solving, (Hinshaw *et al.*, 1984a, 1984b). Although many children benefit in the short

term from stimulant medication this needs to be weighed against potential side effects such as growth suppression, sleep disturbance, lethargy and withdrawal.

Potential psychological effects mediated by medication have not been investigated to the same extent as physical side effects, although it has been suggested that medication may have subtle psychological effects, for example on self perception and attributions.

Several researchers (Brown & Borden, 1989; Henker, 1980; O'Leary, 1980; Whalen *et al.*, 1979; Whalen *et al.*, 1991), for instance have speculated from case studies that stimulant medication may undermine perceived self efficacy through learned helplessness (Abramson, 1978). Where positive changes are attributed to medication and not to the effort or ability of the individual. However, this view has been challenged by the results of three studies, which aimed to test the hypothesis empirically. The results of these studies suggested, that boys receiving psychostimulant medication were *not* more likely to attribute success on tasks to medication (Ialongo, 1994; Milich *et al.*, 1991; Milich *et al.*, 1989). The relationship between perceptions of self-efficacy and receiving ADHD treatment however may be complex and idiosyncratic, and to date there have been no large long- term studies evaluating connections between treatment attributions, self-efficacy beliefs and therapeutic outcomes.

Psychological intervention outcomes

The main areas of psychological intervention have been based on self-instructional training, behavioural parent training, or some combination of both.

Self instructional training is based on Meichenbaum and Goodman's (1971) self-instruction approach plus a response cost procedure (Kendall & Braswell, 1982; Kendall & Finch, 1978; Kendall & Wilcox, 1980). The results of these studies suggest that compared to controls between 75per cent and 90per cent of school age children show improvements at school, though not necessarily at home. Behavioural parent training has been evaluated for pre-school children (Pisterman *et al.*, 1992), school age (Anastopoulos *et al.*, 1993) and adolescents (Barkley *et al.*, 1992). The results of these suggest behavioural parent training is effective for between 65 – 73 per cent of cases with children under 12 years, but less effective for adolescents, with only 20per cent

showing clinically significant gains. Studies using interventions in combination appear to yield further improvements compared with single component packages for reducing home problems, but not for school based problems, self-esteem or improved attention (Carr, 2000).

The largest randomised trial of treatment outcomes for ADHD was sponsored by the National Institute of Mental Health (National Institute of Mental Health, 2004) and involved 579 children with ADHD aged between 7 and 10 years of age. They were randomised to receive either high dose stimulant medication (MED), a behavioural intervention including parent training, a school based programme and an eight day intensive treatment program based on Pelham's (2000) Summer Treatment program (STP) approach (BEH). A third group (COMB) were randomised to combined treatment and received both the behavioural intervention and low dose medication, and finally a community control group (CC) were randomised to standard community care. The initial findings were that the COMB and MED groups both showed significantly more improvement than the BEH or CC groups, with no difference between COMB and MED. Reanalysis by Conners & Epstein, *et al.*, (2001) however suggested that the combination condition provided a 12 per cent increased success rate over medication alone, with the medication component being at a lower dose, than for the MED alone group. The failure of the BEH intervention to demonstrate improvements compared to controls has been suggested as arising from a number of confounding variables. Firstly, that while medication was individually tailored, the behavioural intervention was not, and secondly, concerns were raised that the BEH interventions were not incorporated adequately. A concern supported by the finding that moderate to large effects were found at three of the study sites while small to large negative effects were found at the other three sites (Hoza, 2001; Swanson *et al.*, 2001).

One area that is developmentally important, but has received little attention in terms of intervention, is peer rejection. Despite evidence that children with ADHD are at high risk of peer rejection (Smith & Williams, 2001) and that peer rejection is one of the most consistent predictors of poor psychological adjustment (Cowen *et al.*, 1973) (Berndt & Savin-Williams, 1993; Bierman, 1987) relatively little research has been carried out directly seeking to improve social skills and facilitate social inclusion. In a

systematic review of psychological interventions for ADHD carried out by Carr (2000) only one (Frankel *et al.*, 1997) evaluated a social skills intervention for children with ADHD. This study demonstrated that 84-86per cent of treated children improved compared with controls. Whether these findings can be replicated however or translate into long-term gains is as yet unknown.

In conclusion there is good evidence that interventions combining low dose stimulants and multi-component psychological interventions are effective. However there is a paucity of large-scale longitudinal studies to assess outcomes in terms of sustained benefit and whether these interventions lead to the anticipated reductions in risk of poor social outcomes, such as drug and alcohol use or antisocial behaviour. Although peer relations have been identified as particularly problematic for children with ADHD and peer rejection is an identified risk factor, few interventions to address this have been evaluated.

ADHD and ‘the land of children’ – a child’s perspective

Whilst there have been studies concerning specific aspects of children experiences, such as self esteem, and self attributions, naturalistic studies of how children experience growing up with an ADHD diagnosis are few. Where children’s own words and views are published, they are generally purposefully utilised as specific examples to vividly illustrate an author’s particular stance, as opposed to being valid subject matter in their own right. For instance, the story of Thomas in ‘Stop Medicating, Start Parenting’ (Stein, 2004). Only two published studies (Kendall *et al.*, 2003; Krueger & Kendall, 2001), and one unpublished study (Harborne, 2002) were found by the author, which directly sought to explore and analyse children’s experiences. All three studies were qualitative exploratory grounded theory analyses of semi-structured interviews with young people diagnosed with ADHD. In the first study, Kendall *et al.*, (2003) interviewed 39 children (26 boys, 13 girls, mean age 11, range 6 – 17yrs) and identified six categories; problems, meaning and identity, pills, Mom, causes, and ethnicity. They concluded that children were aware that they had problems and saw the problem as theirs, rather than imagination or something placed on them unreasonably. Kendall *et al.*, (2003) concluded: *‘The idea that ADHD is a bogus disorder smacks of ignorance and naivete among those who do not live with its sequelae...the findings from this study*

indicate that ADHD exists [and] the continual debate about the authenticity of ADHD only further victimises families.'

The Kendall *et al.*, (2003) study has a number of strengths, such as having enough participants to achieve saturation, and also includes both genders and a mix of ethnic backgrounds. However, a number of potential limitations may also be identified. The authors adopted a strong positivist philosophical orientation, which was implicit rather than explicit. This was evident in their conclusions, which claimed that the children's stories provided evidence of a corresponding 'truth' *out there*; the factual existence of ADHD. As the reader it was difficult to see the process by which the authors conclusions emerged from, and were grounded in, the study categories as the categories simply described the substantial and significant difficulties the children were struggling with in their day to day life. In a second similar study Krueger and Kenall, (2001) interviewed 11 adolescents aged 13 – 19 years and focussed on how participants viewed and described themselves. The results of this study were reported in the form of two tentative hypotheses. One, that adolescents with ADHD defined themselves in terms of their ADHD traits and symptoms and did not view themselves as distinct from the disorder; a process labelled ADHD-defined self and two, that adolescent responses and outcomes to ADHD had apparent gender-related patterns and differences. The participants were reported as refusing to see the ADHD as a disability or illness separate to themselves, but rather as viewing the symptoms as parts of their own identity and thus *'justifying and explaining poor behaviours...as if defending their right to exist'*. Boys in particular were reported as being unable to *'internalize and integrate [problematic behaviour] into their definition of self as a failed self, but rather [saw themselves] as an unappreciated and/or misunderstood self. They saw themselves as being smarter, braver, more daring, or individualistic.'* This was linked to resultant behaviours where boys either isolated themselves or were aggressively assertive. Girls similarly absorbed the symptoms as part of their identity but were reported as being more sensitive to feedback from others creating a sense of inadequacy, leading to feelings of hopelessness, self-hatred and hurt. Krueger *et al.*, (2001) concluded that *'the neurobiological aetiology of the disorder, which indicates major deficits in the development of normal inhibition, [and] major impairments in self regulation and*

perception' interferes with the process of developing empathy through its effects on early interpersonal relationships. And as a result, the boys fail to develop '*a strong and cohesive perception of self as adequate and separate*'. Potential criticisms of Krueger *et al.*, (2001) are again the implicit rather than explicit positivist orientation and the taken for granted assumption of ADHD as unquestionably a neuro-developmental causal condition. This closes down alternative explanations and possible meanings of the reported experiences and again it is unclear how the hypotheses were emergent from the data as opposed to being imposed upon it. In addition, there is an assumption that the children describe themselves in this way because they have ADHD without reference to general gender differences in psychopathology. The finding that boys more frequently display externalising behaviour whereas girls more frequently demonstrate internalising disorders is well documented and not confined to ADHD.

In terms of development of 'self' Krueger *et al.*, (2001) draw connections between the children's apparent difficulties in reporting a temporally continuous self and impulsive ADHD behaviours. However this would seem to ignore evidence from studies of autobiographical memory formation, which suggest that it is only in adolescence that this process normally begins to occur anyway, (McAdam, 2003) and therefore it cannot be concluded that their failure to demonstrate temporal continuity is necessarily related to ADHD. A third study, an unpublished thesis, (Harborne, 2002) interviewed 9 children (aged 8 – 11 years) and their parents. The study focussed almost entirely on parents experiences but interviews with the children also revealed three categories, 'external battles: bullying' 'internal battles: ritalin' and 'adjustment'. Bullying is self explanatory, the battle over Ritalin reflected the dilemma felt by children who wanted to take Ritalin because it made them good, but didn't like taking tablets because of side effects. The adjustment category concerned control, with many of the children describing how they felt they had some control over their symptoms. The study concluded that children's understanding of ADHD reflected a more social and integrative stance rather than purely medical. This study was limited by small participant numbers, and from the perspective of comparison with the present study, the minimal focus on the children's experiences.

Summary

Despite limitations these studies demonstrated that children and adolescents are able to provide meaningful rich and detailed accounts of ADHD related experiences during interviews, which was encouraging for the present study. Also given the similar methodologies employed they provide an important comparative context for the current interviews, to assess how far the findings of this study may be generalised.

ADHD and ‘the land of Who am I?’

In this second part of exploring growing up, the literature concerning self and autobiographical narrative are considered. Providing a context for the narratives given by participants about life growing up with ADHD, particularly in terms of what it means for beliefs about themselves and the development of self identity.

The notion of ‘Self’ *‘is a surprisingly quirky idea – intuitively obvious to common sense, yet notoriously evasive to definition by the fastidious philosopher’* (Bruner, 2003). Consequently diverse ways of understanding; what constitutes a “self,” how best to study it, and even whether such a thing exists at all (Gergen, 1984) have arisen. In psychology traditionally, self and identify have been conceptualised as a closely related set of cognitive structures (Marcia *et al.*, 1993), such as self-esteem, self-efficacy beliefs, and self perception; collectively termed ‘self concept’, which form a relatively stable, generalised set of beliefs characteristic of an individual. This self concept or self schema is envisioned as an interpretative framework that enables processing of personal experience and acts as guide for future behaviour. However, this implicit acceptance of ‘self’ as a stable concept has been criticised for failing to take into account the dynamic influences of development, culture and context, as determinants of a persons particular self concept at a singular time and place. For instance, Wells (1992) found that young professional women’s current on-going self-esteem was higher when they were at work or engaged in leisure activities than when they were at home caring for children.

Alternative theories of “self” hold that there is no such thing as an intuitively obvious “self” to be known in the first place. Instead positing that we are constantly in a

dynamic process of constructing and reconstructing a self to meet the demands of the various situations we encounter, (Bruner, 2003; Gergen, 1984). This is an ongoing process guided by our recall of the past and our also our hopes or desires for the future, and it becomes manifest in the stories we tell to others and ourselves about our lives. These latter theories were considered particularly relevant to the present study and are outlined in more detail below.

Autobiographical Memory and the Narrative Self

Each of us has a coherent story or narrative of 'me,' embedded in our own personal socio-cultural framework: a framework, which has culturally prescribed ways of organising events. Who we are is created through this autobiographical narrative.

How individuals recount their histories – what they emphasize and omit, their stance as protagonists or victims, the relationship the story establishes between teller and audience – all shape what individuals can claim of their own lives. Personal stories are not merely a way of telling someone (or oneself) about one's life; they are the means by which identities may be fashioned (Rosenwald & Ochberg, 1992)

The development of a narrative self.

The ability to form an autobiographical narrative is theorised to be dependent initially upon the linguistic and social environment a young child experiences. Nelson (2003) suggests that the kinds of narrative discourse parents and children engage upon from 1-7 years regarding the past, present and future acts as a linguistic scaffold which assists the child in understanding differences between 'my' experience, 'your' experience and 'our' experience. So that they are able to move from the experiencing 'I' characteristic of the two year old with no past or future to stories of 'me,' which do have a past or future, and finally to stories of 'us in the world' at around 7. It is at this point, when the story becomes set into a cultural framework complete with incidents and meanings for the self and the child draws distinctions between rules and roles for different settings (school/home/playground) and times (babyhood/adulthood), that true autobiographical memory comes into existence. How successfully a child navigates this transition has also been linked unsurprisingly to attachment (Reese & Farrant, 2003), as it has been

consistently observed that differing attachment styles correlate with different styles of story telling. For example when children were followed up at age ten/eleven and asked to tell an autobiographical story about their lives, secure children responded with stories that were more coherent, more complete in terms of actual memories, more reflexive and more self-aware. In contrast the stories of insecure children were less coherent and detailed (Main, 1991).

Further significant developments in autobiographical competence and the construction of self occur during late adolescence. Erikson (1963) classically identified this period as being fundamentally concerned with the formation of identity – when the ‘I’ (re)configures the ‘me’ into a coherent integrated personal ideology which carries its own beliefs, values and life plans. To achieve this the various different, potentially conflicting roles and relationships, past and present need to be pulled together in a way that they can be seen as different facets of the same unified identity. In adolescence the young person begins to realise that they are, have been or could be, many things and experience a need to integrate this into a single unified whole. This process is precipitated by cognitive development with the emergence of the higher levels of abstraction and formal operational thought. Abilities, which are necessary to be able to integrate memories thematically, temporally, causally and biographically, and so begin to articulate a coherent and meaningful life story. Before this time people can and do tell stories about themselves but they lack the continuity of linking how ‘I went from this to that’ or why ‘this experience led to that’ (McAdam, 2003).

The narrative self and culture

Culture has been shown to influence how we process stimuli, reason about causes of events and how we describe ourselves (Fiske *et al.*, 1998). It’s impact therefore on how we construct a personal narrative is also significant. From the earliest days cultural norms will shape what and how caregivers share information with a child, and children’s stories are replete with master narratives for that culture. For example, in individualistic cultures such as America, stories and self narratives typically emphasise individuality, self-expression and personal uniqueness. Whereas more collectivist/interdependent societies, typical of East Asia, Africa, Latin America and

southern Europe in which group harmony and shared identity is highly valued tend to have narratives which focus on interpersonal connectedness, social obligation and conformity (Markus *et al.*, 1997). Such cultural differences have also been reflected in the way that parents and children reminisce with individualistic cultures generally engaging in reminiscence more often, and with greater elaboration. The children from these cultures also tend to have earlier first memories and when recounting events provide longer more detailed accounts. As adults they regard their store of personal memories as essential to 'who they are'. It is through these different styles of early social interaction the embryonic cultural self is created.

Summary

This body of evidence suggests that participants in the currently study would be at a developmental stage intimately concerned with actively creating a narrative self which incorporates their ADHD experiences. It also suggests that they will have been culturally socialised into being able to reminisce and that such reminiscence would be likely to focus on themes of individuality.

ADHD and 'the land of the researcher'

In attempting to review the various representations of ADHD, during the orientation phase, a number of issues were reflected upon in a reflexive journal. The polarity of the ADHD debate struck me almost immediately when the very first question posed by two psychiatry colleagues was 'are you a believer or a non believer?' Although ostensibly just a figure of speech, the religious association in choice of words and the function of the question in demanding I state my position before discussion continued had a powerful impact. 'Believer' suggested to me ideas of belonging to a shared faith community who 'sing from the same hymn sheet' and of possible exclusion of those who don't share that faith. 'Believer' also carries connotations of 'faith' i.e. a view held that is not dependent upon the existence of physical proof and of 'evangelicalism' to convert others to the same belief system. Indeed, I was aware of feeling 'converted' as I read the medical literature, felt the allure of 'scientific fact' and also observed the

humanity and passion of medical colleagues committed to helping these young people. Yet as I attempted to summarise and represent the divergent views of ADHD the alternative theories were also compelling, particularly chiming with some of my own clinical experiences where children were being considered for an ADHD diagnosis but psychological formulation provided a better account of how the behaviours may have arisen and were being maintained. Recognising that my own stance towards ADHD cannot help but influence how I summarised the different stories, and also how I viewed and interacted with the data, despite efforts to bracket off assumptions, it was important to try to reflect upon my own opinions. I found myself at the end of the orientation phase of reviewing the literature more confused, rather than less, finding merit in each perspective. And that perhaps became the point, to accept ambiguity and view each representation pragmatically as a lens through which the children's experiences could be understood. Asking what happens if you look at it through this lens versus that one, but mainly to ask what happens when you look back up through the lens from the perspective of those being examined.

Conclusions from literature review

The literature review encompassed three topics that were considered relevant to the present study. The first section provided an overview of the different understandings or stories of ADHD available to participants and reflected on the implicit messages of those for participant's views of ADHD and themselves. While some representations may promote identities congruent with being ill or a patient, others promote identities congruent with being a victim or misunderstood. The second section outlined research on ADHD and development in order to provide a developmental context for participant's narratives, and also a review the few studies previously conducted exploring ADHD from children's perspectives. ADHD was shown to be a threat to achieving normative developmental tasks, such as peer affiliation and scholastic achievement. The third topic covered the development of self identity through autobiographical narrative which again provided a context for hearing participant's narratives. This suggested that participants in the present study would be able to provide narrative accounts and that developmentally these narratives would be from a stage

where participants were actively seeking to construct an integrated identity for themselves.

2) Introduction, Stage Two: Preparation for the Journey

2.1 Chapter Four – The ‘Enchanted Forest’, whose reality? A Theoretical Framework

Selecting a starting point – a philosophical decision

To answer the questions posed in this study about how young adults perceive being diagnosed and treated for ADHD, a qualitative research methodology will be utilised. The use of such an approach over quantitative methodologies carries both philosophical and methodological implications.

The difference between qualitative and quantitative approaches to research centres on the philosophical concept that there are two ways of being in and interpreting the world. Firstly, there is the idea of the ‘real’ world, which actually exists physically and can therefore be quantified, measured and reduced to theories and laws. This is the quantitative positivist paradigm, and from it flow research methodologies, which control and manipulate events in order to deductively discover relationships and laws. Constructivist approaches however argue that this kind of ontological reality, of somehow being able to view things as they really are in the world, is irrelevant as all knowledge of the world is gained through perception, which is an act of interpretation. What is important therefore is an epistemological reality, that is, the way the world is perceived and interpreted by individuals. From this stance flow the inductive qualitative methodologies, which emphasise understanding human behaviour by studying phenomena in their natural setting and attempting to make sense of them.

Traditionally, quantitative research paradigms have been regarded as the most powerful means of creating knowledge and understanding (Charmaz, 2000). However, their ability to define or explain complex human phenomena, which cannot easily be measured and quantified such as human values, culture and relationships has been

limited (Streubert & Carpenter, 1999). In recent years particularly within the social sciences newer qualitative research methodologies, such as grounded theory (Glaser & Strauss, 1967) have been developed to address this need. In these approaches the researcher seeks to explore all dimensions of human experience in order to discover the meanings individuals ascribe to their experiences. This is carried out by exploring the subject through the experiences of people in their everyday lives. Bits of information are collected and pieced together to build a mosaic of the experience being studied, with the full picture only emerging at the end, in effect an inductive bottom-up approach to knowledge generation (LoBiondo-Wood *et al.*, 1994). In contrast quantitative researchers start with the whole picture and explore pieces of it by testing one relationship with another, a top-down deductive approach (LoBiondo-Wood *et al.*, 1994).

These differences tend to push the purpose of the research towards different ends. With quantitative approaches being deemed more useful when there is an already an established body of research in the area, the phenomena are easily quantified, and the study is seeking to test a theory. Qualitative approaches in contrast may be more useful for exploration in an area where existing knowledge is scarce, the phenomena of interest are complex and the aim is theory generation (Morse, 1996).

Two qualitative methodologies were considered potentially for the present study, Grounded Theory, (Glaser & Strauss, 1967) and Interpretative Phenomenological Analysis (IPA), (Smith, 1996). Both are briefly reviewed below along with the rationale for selecting grounded theory over IPA.

Principles of Grounded Theory

Grounded theory was first introduced by Glaser and Strauss in 1967 (Glaser & Strauss, 1967), and since then it has become the most widely known and established of the qualitative methodologies. Glaser and Strauss (1967) described the aim of grounded theory as *“the discovery of theory from data systematically obtained from social research.”* Therefore the researcher does not start with a preconceived hypothesis, gather data and then analyse it, as in quantitative studies, but instead conducts data collection and analysis concurrently with the initial analysis dictating the direction of

subsequent sampling, a process known as theoretical sampling. As the theory is generated directly from the data and not some a priori source, it is said to 'emerge' from the data and consequently be 'grounded' in it.

During initial analysis, the data, often from interviews, is coded line by line to summarize meaning and generate descriptive codes. A first level analysis then seeks to identify initial categories by asking questions of the data, such as: who, what, where, when? What is the purpose, action, process, or consequences of the actions being described? Relationships between categories are tentatively identified and this information then informs the next interview where the preliminary hypotheses and concepts can be explored further to identify similarities and differences through constant comparison. As more data is obtained the categories are fleshed out and related to each other in order to generate a conceptual model, which may describe a core category, basic social process or hypothesis. This in turn stimulates further data collection and analysis in an ongoing iterative process. The process is considered complete, or 'saturated', when further sampling and analysis ceases to add any new information.

Throughout the process the researcher monitors their reflexive thoughts as they interact with participants and the data. A system of memos is also used to capture ongoing ideas, hunches and tentative conceptual linkages, providing a record of the process of theory generation within the study. Typically the results of a grounded theory study are presented in the form of a model, theory, story or some combination of these formats (Strauss & Corbin, 1998) and quality standards relate to the coherence of the categories and theory and to how well the theory works as an explanation for the phenomenon.

Principles of Interpretative Phenomenological Analysis (IPA).

A more recent form of qualitative methodology, IPA was introduced by Smith in 1996, (Smith, 1996). It shares many similarities with grounded theory in that both methods seek to understand and represent participants experiences of the world, typically draw upon interview data from which to identify key issues and themes, and can use similar techniques within the text analysis for this process (Dallos & Vetere, 2005). IPA has gained rapid acceptance amongst psychologists, psychotherapy researchers and

particularly health professionals (Dallos & Vetere, 2005) with its focus on reflecting participant experiences providing valuable insight into for instance how service users experience services. However, subtle differences also exist. IPA is underpinned by constructionist principles whereby meaning is generated between the researcher and participant and the researcher therefore actively brings to bear links with existing theory from the earliest stage in analysis. Thus in IPA, coding proceeds by using a two margin approach where one side of the text summarises, content, meaning, key issues while on the other the researcher notes associated theory, reactions, links with clinical experience and so on.

Grounded theory in contrast seeks to stay close to the data and delay any interpretative activity until the latter stages of analysis when hypotheses have emerged. A further difference lies in the primary aim of the methodology. IPA studies seek first and foremost to represent participant points of view and connect them with current literature, and are less concerned with theory generation. Grounded theory studies whilst seeking to represent participant views also aim to go beyond this and also develop a theoretical model of the phenomenon being investigated.

Rational for selection of Grounded Theory.

With respect to the present study both IPA and grounded theory were potentially appropriate methodologies, however grounded theory was selected based on the following rationale.

Firstly, the present study will be presented to an audience generally more familiar with traditional quantitative paradigms than qualitative, and grounded theory as the more widely established method was considered more likely than IPA to find acceptance within this audience as it is already extensively used in published studies, and has established procedures and quality standards (Strauss & Corbin, 1998). Secondly, the study is set within a context of also being required to fulfil the academic standards of a Doctoral level degree. IPA is less ambitious than grounded theory in its aims regarding theory generation, and therefore in terms both of meeting the academic standards for the present study and meeting the aim of generating a theoretical model, it was felt IPA posed the risk of being insufficiently analytical. Two further important advantages of

grounded theory were also taken into consideration. One, the requirement to delay the interpretative analysis minimised the risk of the researcher imposing preconceived ideas or concepts prematurely and thus closing down sensitivity to other interpretations that may exist within the text. And two, the three previous studies of children's experiences had also been carried out using grounded theory. This suggested grounded theory was a suitable methodology for exploring children's views, and in addition using a similar methodology in the present study would enable more meaningful comparisons to be drawn between the present study and previous literature.

The main limitation of using grounded theory was that the present study was limited in scope for conducting theoretical sampling, both due to time constraints and limited access to participants. However, within accepted grounded theory methodology this limitation may be partially overcome through the use of theoretical sampling within interviews, where the emergent theory dictates the direction of the interview questions rather than the selection of participants (Strauss & Corbin, 1998). The resulting theory however is then acknowledged as being more limited in scope and the risk of failing to reach saturation is increased (Strauss & Corbin, 1998). On balance it was considered that the methodological strengths and utility of grounded theory suggested it was the most appropriate methodology for the present study.

3) Methodology, Stage Three: Searching

3.1 Chapter Five – Exploring the Enchanted Forest. The Search for information

Study Design

The study used a qualitative design with 9 young adults, aged between 14 – 18 years previously diagnosed and treated for ADHD taking part in individual semi-structured interviews. Interviews were transcribed and analysed using the principles of Grounded Theory (Strauss & Corbin, 1998).

Study Procedure

A pilot interview was conducted prior to the commencement of the study with a young male (14 years) who was in the process of being assessed for attention deficit

hyperactivity disorder and had also been referred to the author's clinic. The interview was used to familiarise myself with the subject matter and interview process, particularly with a view to assessing out how participants of this age and with this diagnosis might cope with an unstructured lengthy interview. Based on this interview it appeared that participants could describe their experiences and cope with a research interview of that duration.

Potential participants were identified through discussion with psychiatrists providing routine ADHD treatment in the area and also through presentations carried out by the author to parents at an ADHD support group meeting. An information sheet and letter inviting adolescents to participate (Appendices VII & VIII) was provided and permission gained for the author to contact the young person directly. Prior to participating the researcher arranged a meeting with the participant in order to provide a full explanation of the study covering all the elements within the information leaflet and consent form. At this meeting participants were given every opportunity to clarify any point and further time to reflect if appropriate. It was emphasised that the participant was at liberty to withdraw consent at any time. If the young person consented to participate a written consent form was signed and dated by them and the researcher. (Appendix IX)

For participants under 16 years of age the pre-study meeting was conducted in the presence of the young person's parent or guardian who also provided written consent.

As a grounded theory study aims to allow a theory to develop as a result of data collection and analysis; the sample of who is to be included within the study is not usually pre-determined (Morse, 1996) and instead a process of purposeful theoretical sampling is carried out as described above (Strauss & Corbin, 1998). In the present study however practical constraints on resources prohibited open-ended recruitment therefore pragmatic sampling was carried out of available participants and a recruitment maximum of 10 participants was set.

Finding new companions, the sample

Inclusion/Exclusion criteria for the study.

Participants meeting the following criteria were considered eligible for inclusion in the study:

Young adults aged between 14 – 18 years who:

Had previously been diagnosed and treated for ADHD.

Were willing and able to attend the research interview.

Were willing and able to give informed written consent. (For participants aged under 16yrs, the informed written consent of a parent or guardian was also required)

Exclusion criteria: any participant unable to meet the above criteria.

Appendix II provides demographic details and contextual information for the 9 participants recruited to the study.

Interview procedure

In keeping with the principles of Grounded Theory, data collection and analysis were conducted concurrently with the emergent themes informing the direction of subsequent interviews. All participants were however asked to talk about their general experience of growing up, from being at primary school to the present day. From these general descriptions interviewees were prompted to elaborate through prompts such as ‘can you say a bit more about that’ and also to provide illustrative examples of what they were describing whenever possible by asking ‘can you give me an example of that’. The aim was to gain detailed information and to also to try to encourage exploration of what the experience meant for that person and how they understood it with prompts such as ‘What did you make of that?’

Interviews lasted on average 1hr 10 minutes (range 55mins - 1hr 35mins) and were held either in the NHS building where the participant normally attended for treatment or in the participants home, depending on participant preference.

Interviews were digitally recorded and transcribed verbatim into a word document, in preparation for analysis. Any identifying information was removed and the interviews assigned an identification code number.

Ethical Considerations.

Ethical approval for the study was obtained through the Tayside Regional Ethics Committee as participants were eligible for the study due to being or having been patients within the Trust. (Appendices IV & VI)

The study was also informed by the guidelines set out in the British Psychological Society Code of Conduct, Ethical Principles and Guidelines (British Psychological Society, 2000).

The ethical implications of interviewing adolescents who may have experienced difficulties which were upsetting or saddening to talk about was also considered. It was decided that if an adolescent became upset, the interview would be stopped and sources of adult support available to them would be discussed. The participant would then be encouraged to access these supports and given advice if necessary on how to do so. The need for this however did not occur during any interview. A second ethical issue concerned confidentiality in the event of an adolescent raising concerns about abuse. At the start of the interview participants were informed that the contents of the interview would be confidential, unless they raised an issue that caused the researcher serious concern for their or any other child's welfare. In such an event they were advised that the researcher would have to discuss the concern with the study supervisor, but that this would not be done without telling them first. No participants raised issues, which required this action to be taken during the course of the study.

Data analysis – discovering new lands

Immersion

Following initial transcription, the first stage of data analysis was a period of 'immersion,' where the interviews were listened to and transcripts read repeatedly until

a sense of thorough knowing and familiarisation with the data was obtained. This point was recognised when little new information was felt to be suggesting itself, just from listening and reading.

Open coding

The next stage was to open code the data, according to the principles of Grounded Theory (Charmaz, 2000; Strauss & Corbin, 1998). During open coding each section of data, was examined and labelled with a code that described and summarised the data. The data section was a word, phrase, line or sentence, as the intention was to capture each meaning unit in order to identify and code the main idea or concept it contained. During the initial pair of interviews coding was conducted at a fine grained level in order to identify and generate as many codes as possible, as a result each piece of data had several codes attached to it (Morse, 1996). This process was managed using QSR Nvivo software for qualitative research.

Grouping

A process of constant comparison was also conducted, during which each piece of data was compared with every other piece of data so that those found to be conceptually similar could be grouped under the same code. As the comparative analysis continued, data and codes were grouped together into more abstract concepts referred to as categories. This process continued as further interviews were analysed, with the categories and the codes within being repeatedly examined until a satisfactory fit of all the data into categories and sub-categories was obtained.

The process of open coding and comparative analysis resulted in a coding framework, which also acted as a conceptual guide for subsequent interviews.

As categories emerged the next stage attempted to develop the properties and dimensions of each category (Strauss & Corbin, 1998). 'Properties' referring to the specific characteristics of the category, such as place, and 'Dimensions' describing how these properties varied. For example in the present study the category 'friendship exclusion' had properties of 'school based' and 'shared interests' with dimensions of 'acceptance vs rejection' To facilitate this process and ensure a close connection with

the data was maintained, all text associated with each code was printed out and manually displayed so that whole categories could be scanned and codes manually moved back and forth as questions were asked of the categories such as 'How does this code/category link with that one?' To illustrate this process for instance, each incident of 'peer rejection' was systematically compared between interviews for similarities and differences, which provided dimensions of rejection such as 'physical bullying' to 'passive hostile toleration'. Then these were systematically compared with all instances where 'peer inclusion' to flesh out the opposite dimension. Findings were then used to reorganise the codes in Nvivo and the text search facility of Nvivo used to go back into the interviews and re-interrogate them for further illustrative instances based on the new findings and ideas. There was a constant iterative flow therefore between the levels of analysis and data.

Axial Coding and Selective Coding

During this phase linkages and connections between the categories were looked for; how they related to each other for example contextually or in terms of meanings. In contrast, to the open coding phase where data were fractured and broken down, during axial coding the data are reassembled with the aim of providing a more precise and complete explanation of the phenomena showing how the categories relate to each other, for instance in terms of context, process or meaning. In the final stage of selective coding, categories were integrated to create the core category, which captured and described the fundamental experience of growing up with ADHD. Again this stage involved both manual manipulation of paper based displays of text and also using Nvivo to aid structuring and managing the results, as well as keeping track of the study process and concept development.

Interpretation

The final stage of analysis interpreted the results in terms of implications for understanding how young people perceived the process of growing up with ADHD, and how this interacted with their beliefs about self and world. The core category and main themes emerging from the study were used to describe how the experience was construed by young people and discussed in the context of existing literature.

The researcher's position

Within qualitative approaches the researcher is an integral part of the research process, someone whose presence and interactions with the data are explicitly acknowledged (Charmaz, 2000). The process of coding for instance reflects not only what is in the data but also the personal understanding of the data brought to it by the researcher. In this study interactions with the data were documented through both the keeping of a reflexive journal and the use of memos during data analysis. The reflexive journal was used to enable me to explore personal thoughts and observations relevant to the study such as the emotional impact of interviews, and connections between the study and other aspects of my life, such as previously working in the drug industry.

During the analysis there was also an ongoing process of 'memoing' which followed the guidelines suggested by Glaser and Strauss (Glaser & Strauss, 1967) Whereby hunches, ideas, speculative hypotheses, coding ideas, conceptual relationships, closure of categories and personal reflections were documented to form a computer based 'paper trail' for the study. These memos acted as an information source informing the coding process particularly during the later stages of grouping, linking and interpreting.

Issues of rigor, reliability and validity

Reliability and validity are terms associated with the evaluation of quantitative research and it has been argued that the methods used to do this are inappropriate to apply to qualitative studies (Lincoln, 1985). Instead, the term 'trustworthiness' is often used to describe methods used to establish the rigor of qualitative research (Schwandt, 2000). Four terms are used to describe activities that establish the trustworthiness of a qualitative study: credibility; dependability; confirmability and transferability (Lincoln, 1985; Schwandt, 2000).

Within the current study it was attempted to meet these requirements through the use of a detailed audit trail comprising memos, process notes and a personal journal as detailed above, demonstrating the way in which the study progressed and how conclusions were arrived at. Credibility may also be assessed through the responses of participants and readers to the study when they ask themselves '*Do the findings of the study make sense?... (is this)...an authentic portrait of what we were looking at?*' (Miles, 1994)

therefore it is planned to share results with colleagues who work with children and adolescents diagnosed with ADHD and also with participants and families prior to publication. Unfortunately time constraints prevent this occurring in advance of the present submission however.

In addition to the above measures, Appendix III contains a summary of code frequencies across all interviews along with details of any text not accounted for within the final model, which it is hoped will aid credibility by enabling readers to review the density of concepts categorised within the study. Appendix IV also contains sample interview excerpts and Nvivo generated code reports illustrating the process of construction from text to category.

4) Results, Stage Four – Discovery

4.1 Chapter Six – Finding new lands up the Faraway Tree – Analysis and Interpretation

Analysis of participant stories to develop core category

Overview

This study explored the everyday lived experiences of young adults growing up, with a diagnosis of ADHD. From the grounded theory analysis of participant's interviews, a central phenomenon of 'felt exclusion' emerged, which described the many ways in which the adolescents felt themselves to be excluded from important aspects of social experience. They felt excluded from three domains of experience: friendship, positive

relationships with teachers, and feeling themselves to be ‘normal’¹. This core category of ‘felt exclusion’ was richly connected with all other major categories, and drives the interpretative analysis forming the heart of the model outlined in chapter 7. In the final model proposed here, the experience of having ADHD is construed primarily as a social condition and the story of the adolescents is presented as one of struggling to overcome exclusion and regain or establish a desired self identity of being ‘normal’.

In order to outline how this understanding of the experience of growing up with ADHD emerged; the following section provides an outline of the 3 major descriptive sub categories; Exclusion, Identity Conflict, and Overcoming, which were derived from the interviews, along with illustrative examples cited from the data. Quotes were selected on the basis of their clarity to illustrate the category, and do not seek to quantitatively represent participant contribution. Quotes are identified with participants through codes (e.g., (4) for participant No. 4, (3) for No. 3, and so on).

Description of Major Sub-Category 1: Exclusion

Exclusion: From Friendship

Overview

...I tried not to throw myself into making friends so quickly but I ended up throwing myself into making friends quickly because then I didn't really have many friends at all, and I was really wanting to have friendly people to spend time and stuff like that.... It wasn't the most important thing in the world but... to me, it really was.(7)

The first and most powerful theme to emerge from the data concerned friendships. Friends, the importance of friends, and difficulties with friends dominated the text of all the interviews, with other characters such family, occupying comparatively minor roles.

¹ The term ‘Normal’ as used here reflects the common sense understanding usage expressed by participants, where to be ‘normal’ meant being the same as other non-ADHD peers. ‘Normal’ was the term most often voiced by participants in this context.

Given the age of the participants this was an important finding in itself, suggesting that participants were engaging in on time developmental tasks regarding individuation and the process of moving from being a child in a family to an adult in society.

The Friendship theme comprises two elements. The first described the importance and value placed on friendship by participants, and included descriptions of the sadness and frustration experienced in the face of exclusion. Conversely when friendships were made these were cited as turning points and associated with feelings of great happiness. A second element described the sense of social exclusion experienced by these adolescents resulting from the difficulties they encountered attempting to form friendships. These difficulties had both internal and external dimensions with internal dimensions relating to individual abilities such as social skills competence, and external dimensions relating to experiences of physical isolation and social rejection precipitated by the actions of others.

The importance and value of friends

The importance of friendship was illustrated by the lengths participants would go to, when trying to engage peers, even in the face of rejection.

I always tried so hard to make friends, even if they didn't want to be friends. I still persisted on with it. You know, even if they totally threw it in my face or whatever, I'd still keep trying ... (7)

Another participant described a similar manner in which the need to form a friendship resulted in him continuing to attempt to engage others even when they were hostile. The desire to have friends was so important that the usual criteria of friendships such as reciprocity were over ridden enabling non-friends to be reclassified as friends.

...like when I'm in school I've got friends but they are not really my friends. It's just...I like them and that makes them friends... but they don't...it doesn't matter if they don't want to be my friends they are still my friends and I just try and speak to them...[if]...they start like calling me names and everything I don't like it but it's attention and I still feel like they are my friends, know what I mean? It's quite hard. (3)

The value of friendship was also expressed in the positive feelings described when a friendship was formed

I met most of my friends in the second year top group English class, the three of us sat together at the front and erm we were all into the same kind of things ...you know people that were actually prepared to put up with me as a person and not just slag me till I left...It was actually quite good...yeah really the turning point in a way.(1)

In addition to being a source of happiness, friendships were described as providing other benefits such as safety as indicated by this young boy who was being attacked by someone who didn't realise he had friends with him.

...because he jumped me one and he tried to hit me...he never knew I had tons of people with me and he jumped out of this bush and tried to hit me and everyone ran after him...(4)

For one participant the combination of wanting friendship and safety also underpinned his involvement in offending behaviour, even though it brought significant other disadvantages.

...in a wee place like xxxx it's like the young boys stick together and there's older ones, and it's like, you really want respect round there like, you want the older ones' respect and that, so you're like...you've been brought up to stick together and not back out of things and that... and you just want to like prove that you can like be a part of it...[because] if they respect you like 'Oh he's quite good he sticks up for himself', you'll have them sticking up for you if you ever...so you kind of want that. You get into a bit of trouble doing it...but I'd prefer having the wee bit of trouble and them being by my side if I needed them, if you know what I mean.(9)

Difficulty forming friendships

Internal dimensions: Social skills, social understanding and social naiveté.

Participants described three areas in which they perceived themselves as less competent than peers with respect to social skills or abilities. The first was knowing how to interact with peers in ways that would elicit reciprocity rather than hostility. As indicated earlier all participants were highly motivated and actively engaging in attempts to form friendships. When comparing this desire to make friends with the behaviours participants cited most often as problematic, either for themselves or others, it was striking how many of them were social in origin and intention.

I know I'm annoying somebody like, I'm trying to get attention from somebody but it them gets like negative attention and it just gets out of hand basically. Like because if they dinnae speak to me at the start right, then you've got to get their, I feel I've

got to get their attention in another way. If that sometimes doesn't work you've just like, got to like start pushing them or calling them names and everything and just try and get their attention. I don't want to do that but if it's the only way of getting their attention it's the only think I can do.(2).

Some of the behaviour attributed to ADHD occurred therefore because no other strategy was perceived to be available, as in this case. In another example the aim was again social; to try and create a favourable social impression but as before knowledge of how to achieve this was lacking.

I found it extremely hard to make friends because I was acting like such an idiot...showing off, I'm just showing off. I'm trying to be smart... I act stupid in front of them and they don't want anybody like that(3)

Participants were painfully aware of the rejecting responses such behaviour elicited in others, expressing sadness and frustration.

I'd get a bit too, you know, wooh, a bit too fun loving sort of thing, and they'd back off a bit and I'd be like no, let's go and play again and they'd be...you know, I just couldn't take no for an answer sort of thing(7)

Three of the older participants also provided additional meta-cognitive reflections on their social difficulties. For instance they were able to reflect on previous difficulties in understanding other's social behaviour and connect this with problems making friends, or being mistakenly led into activities that were not to their benefit. These reflections suggested two further related categories: poor social understanding and social naivety. Participant 1 for example, reflected...

I had very little appreciation of if someone meant something deadly seriously or if they were just joking about. Although it shouldn't really be, I don't know maybe its just me. A lot of like common conceptions about things...I didn't really get what everyone else thought(1)

Participant 7 also narrated an incident typifying problems of social naivete, where poor social understanding made her vulnerable to being led by others into behaving in a way that created conflict with her teacher.

Em...well one incident in one of my primary schools was I was playing with this boy and a couple of his other friends and he said bark like a dog and chase us for a joke, and I though Oh Fun! You know, they're trying to make friends with me, so I thought ok, so I did that and then they went back to the teacher and said I was chasing them barking like a dog...they didn't say they asked me to do that, that was

the big difference. And I was like, oh, I thought I was making friends here sort of thing and then I was just a bit... well I wasn't too sure, you know(7).

Whilst younger participants narrated similar incidents of being led by others, this participant was additionally able to reflect that it happened because she found the boys behaviours and intentions confusing to understand. She was also able to reflect upon how she thought at the time when she had mistakenly interpreted their requests as friendly in intention and her thoughts about the incident now. The presence of such meta-cognitive reflections also suggested that on-time adolescent cognitive development was occurring in this respect.

External dimensions: Isolation and rejection

Participants described frequently encountering exclusion that was both social and physical. These acted as significant barriers to the formation of friendships. Social exclusion occurred through processes involving rejection and isolation.

Rejection by others, ranged from the active hostility of bullying, which was described by the majority of participants, to a more passive avoidant type of rejection where the young person was refused admission to a group or activity. Bullying typically involved name-calling, although for the female participants physical abuse also occurred.

I get called Scabbers...you know that rat in Harry Potter? I used to get hit quite a lot.(8)

I used to get bullied, but never really in a very violent way, just kind of slagging off way.(1)

Passive rejection, where they found themselves avoided or included on sufferance, was even more common, and often based on the reputation the young person had, rather than on the basis of how they were behaving at that point in time.

people kept pushing me away if I was to do stuff. If I was told to be put in a group they, people in that group, would start moaning because they thought I wasn't quite bright.(3)

It's been hard cos if...as I said if you do something wrong you're stuck with it so they know what you're like so you can't change it, so to make a new friend with someone... it was hard very hard for me.(6)

The process whereby reputation alone led to exclusion was eloquently described by participant 8 who said...

Aye, well like, I mean like reputation wise. Like if no-one's heard of me, fair enough they'll give me a go but it's like, there was a guy just moved here, his gran told him [to] stay away from me. She didn't know me, she just knew my reputation.(9)

Isolation occurred through physical exclusion, most commonly through exclusion from class activities, either temporarily or in the course of formal school exclusion.

There used to be this screen thing and I used to be put behind it all the time. It was like a screen thing and it was put to separate me and... from all my mates and that because we used to muck about in the class and they just separated us.(4)

I used to have to spend a fairly high percentage of my lunchtimes inside and breaks doing work. (1)

The category of physical exclusion here related specifically to barriers in creating friendships, however physical exclusion also overlapped with a number of other categories, such as contributing to poor teacher relationships though perceived unfairness and also to exacerbating feelings of being different from non ADHD peers. These aspects of exclusion are discussed in the following sections.

Though barriers to forming friendships dominated interviews, participants also provided insight into the conditions under which friendships could be facilitated. The most common naturally occurring facilitator of friendship was a shared interest in sports and for the two participants who reported least exclusion the link between sport and friends was a consistent theme.

I liked rugby and that, I played, I play rugby. With the academy, I sometimes play up there and... I like skateboarding and that. That's what I usually do normally with my friends.(4)

Energetic I would be...I used to play for the school and I would be wanting to go out every night an play football with my friends... they've got time for me.(3)

More often however overcoming social exclusion was a difficult process and the various strategies employed to try and achieve this are described in category 3 'Overcoming'.

Exclusion: At school, 'always in trouble'

Overview

I got in trouble all the time just you know ADHD symptoms. (1)

The second theme to emerge strongly in the Exclusion category was 'always being in trouble', particularly being in trouble with teachers, which was referred to by all participants. This category comprised of three themes. The first identified 'areas of conflict', in which participants described situations where teachers usually became angry with them. The second concerned the perception of 'inequity' or injustice experienced by the adolescents when they felt that teachers were being hypervigilant and looking for misbehaviour and therefore likely to discipline them more than non-ADHD peers for similar transgressions. Inequity was related to a further sub category of 'escalation,' which described ways in which the response of teachers were perceived as escalating difficulties, leading to more trouble and further physical isolation as described in Category 1. These three themes interacted negatively, so that an increase in any one led to a further worsening of the relationship between the adolescent and teacher, contributing to their 'felt exclusion' from having good relationships with teachers.

Teacher conflict.

The first theme identified by participants was teachers becoming angry at their behaviour, such as talking or shouting in class, being cheeky, ignoring them or being unable to settle down.

I just spoke too much. (1).

It's like always chat, chat, chat, chat, chat... if someone said a wee funny joke I just couldn't stop laughing...or when I was told to do something I wouldn't do it. (8)

Answering back, that kind of cheeky, I would answer people back. That's a bit of a bad thing I've got just now. I'm answering people back when I shouldn't. (3)

She's like sit down and be quiet for the whole period, but I can't do it(9)

These behaviours were typically referred to as being hyper, loud or cheeky though the relationship between 'being hyper' and ADHD was rarely vocalised directly. So that

while all participants described experiencing these kinds of teacher conflict only two (8 and 5) directly attributed these behaviours to ADHD...

I was always hyperactive. Leading to the ADHD I was always off the moon, I was as high as a kite.(8)

Others couched such behaviour in terms that implied a sense of personal ownership and gave explanations which suggested they struggled to see these behaviours as any different to the behaviour of others, or saw them arising as a consequence of how teachers treated them. These explanations resulted in the two further closely related categories of 'inequity' and 'escalation' emerging.

Inequity and escalation

Participants described feeling excluded from the normal rules applied to other pupils, whom they perceived as being allowed greater freedom.

...they're basically making me stick to rules when everyone else within reason can do what they want. I mean other folk can talk in the class but I cant because I'm too noisy or whatever but they're allowed to.(2)

So, for participants, part of the explanation for being in trouble so often, lay in their belief that stricter rules were applied to them. Consequently even when they were behaving in a similar manner to non-ADHD peers they were more likely to be reprimanded.

we were all throwing rubbers at her head when she turned round and I kept on taking the blame for it...I just always got the blame.(4)

Teachers were also perceived as being hypervigilant and looking for ways to be critical of the adolescent.

I knew he'd be watching me, expecting me to get into trouble...they're really wanting me to...well I feel they're wanting me to, like get annoyed, so they can send me out.(9).

This form of hypervigilance led not only to the young person being in trouble more often but also to perceptions of not being liked by the teacher or of not being believed when it was their word against that of another pupil. These relationship dynamics then interacted with the previous category of 'Exclusion' so that a typical scenario from the

adolescent's perspective might be, being encouraged to do something silly by others, or being ridiculed and retaliating. Then when a teacher intervenes being unfairly blamed. Being in trouble so often then leads to gaining a reputation, further hypervigilance and more severe punishments being issued such as physical exclusion by the teacher.

Two participants reported that situations like this were responsible for difficulties escalating, because they would feel angry at the injustice and begin to argue with the teacher.

most of them... [teachers]... they didn't like talking, you have to sit in silence and I can't do that so I'd get into trouble for talking... they'd send me out and I'd get into trouble, get... phone my mum and dad to get me and take me home.(3)

I get into trouble because I'll talk, they'll shout and I'll raise my voice back and that's me out.(9)

The most common feeling expressed in association with these episodes was of feeling stuck or disempowered, angry and frustrated. Which generalised into a dislike of authority and school more globally. Verbal abuse is a frequent complaint voiced by teachers in connection with children who have ADHD, from the perspective of the young person however this behaviour can be understood as a social response in the context of a poor relationship with their teacher.

Summary of Category 1: Exclusion

The first category to emerge from the data was Exclusion, which occurred in the context of peer relationships, and teacher relationships. All participants spoke of the difficulties they had encountered in making friends and how important this aspect of life was to them, overshadowing as it did all other concerns. Participants reported being subjected to bullying and being excluded from social activities with peers, either because peers rejected or avoided them or because they were physically excluded from activities by teachers. Whilst younger participants narrated events as isolated incidents the 16 and 17 year olds theorised that they occurred as a result of difficulties they had in understanding social interactions.

Teacher relationships also emerged as a significant source of difficulty with all participants speaking of feeling that they were always in trouble. Being in trouble was

closely linked to feelings of inequity; being watched more closely, having stricter rules, not being listened to and being unfairly blamed in comparison with non-ADHD peers. Responding negatively to this perceived injustice exacerbated relationship difficulties increasing the risk of further exclusion.

Description of Major Sub-Category 2: Identity Conflict

Overview

I had no clue...how much people knew or were going to think they [someone with ADHD] were strange. Is he just a weirdo or is there something actually wrong with them.(1)

Whilst none of the participants disagreed with being given a diagnosis of ADHD, their accounts revealed an ongoing struggle to reconcile subjective perceptions of being 'normal' with the day to day difficulties they had in making friends and succeeding at school, which were not shared by their peers. Three possible identity positions were identified in the narratives 'normal' which was the word most often used when describing themselves as being just the same as everyone else, 'weirdo or strange' and 'ill.' The second category to emerge from this study 'Identity Conflict' describes the tension between these identities as the adolescents attempted to understand their difficulties and engage with the normative adolescent task of negotiating a coherent positive self-identity.

Identity Conflict: Being normal

Overview

The first theme to emerge within the 'Identity Conflict' category describes how subjectively participants felt themselves to be just the same as their non-ADHD peers or 'normal' despite having problems. Setting the scene for this difficulty was the finding that ADHD lacked an experiential reality for participants; it was not something they could feel in their bodies, and thus they could only infer its presence from events and what others said. This lack of a felt reality to ADHD was reflected in how participants described the diagnosis process, and their descriptions of what they understood ADHD

to be, which were thin and sparse even when directly asked about. In contrast, participants presented rich spontaneous evidence to support their subjective perception of being normal. For instance describing how problem behaviours could be controlled and providing explanations for why such behaviours occurred.

ADHD doesn't feel real

When discussing being diagnosed with ADHD all of the participants reported recalling scant details of the process, regarding it as just something that happened a long time ago.

Em...I didn't know much about when I was diagnosed, I didn't know. In fact I don't remember any of that. Being diagnosed with it until I was a little bit older, that I'd got ADHD.(8)

Where any details of the diagnosis process were remembered they were truncated in terms of people, place and time.

I'm really not sure how...the er school nurse came here and spoke to people and eventually they gave me Ritalin.(1)

When more detail was sought, the next response was invariably a statement of not really remembering or saying someone else would know better.

I think, from memory, remember I told you about that teacher from primary school. I think it was her, I'm not sure, I would have to ask my mum after see if she knows.(4)

In response to questions asking participants about their understanding of what ADHD was. Four were unable to provide any answers or just repeated that it stood for 'Hyper' (1,2,5 & 6). Two (3 & 7) mentioned that it was to do with your brain, with participant 7 providing the most detailed explanation offered by any participant.

Well my mum sort of said... the little thing up here [points to head] isn't connecting with other parts in your body and that's the way I always remembered it and though oh ok, simple thing (7)

Though all participants described having problems concentrating only two (4 & 9) explicitly described ADHD in terms of a concentration disorder.

Well they just explained what it was and that, and what happens like, what ADHD is like, like what it actually does like, stops you concentrating I can't concentrate. Just explained things like that to me, and then started talking about Ritalin...(9)

This lack of a felt reality to ADHD was perhaps best described by one participant when they said:

when you tell other people 'I've got ADHD', they say what's that. It's like you can't explain it to them, you can't explain it to them because you feel normal... you feel like any other person. Like just as I say, you do your school work, blah blah, blah, you go home and it's just the same as that like. You're just like any other person(2)

Having neither a subjective felt reality, nor a theoretical understanding suggested ADHD was an empty concept for participants. A term they used to potentially contain any or all problems they may have. For instance one participant had a co-morbid diagnosis of dyslexia and described difficulties reading and writing as a symptom of their ADHD, another with co-morbid depression described feeling down and crying as part of their ADHD.

Closely linked to the notion of ADHD as lacking any felt reality, was the shock and surprise expressed by participants who remembered how they felt after being diagnosed.

Em...just a bit of a shock cos I never knew that there was anything wrong, I just thought I was different.(6)

Am I 'normal'?

Feeling normal, despite having problems, and the desire to be perceived as the same as everyone else, were frequently reoccurring themes throughout the narratives.

I just, as I say feel myself as a normal person because I'm basically human like. I know I've got problems, I know my behaviour can sometimes be not very good but there's lots of people with other problems but they are still a person, they are still people....I want to be treated like any other person and I just, I feel normal but by the way I'm being like ruled about and treated I don't feel normal.(2)

In order to emphasise this normality, participants engaged in a number of different strategies such as providing explanations for their behaviour, or evaluating their behaviour in ways that supported an identity or presentation of themselves as 'normal'.

The most common strategy of this type was attributing behaviour as a response to situational factors such as feeling bored, restless, or stuck.

It's the theory that I don't like, I used to be getting all 9s [a good mark for achieving behavioural targets in class] cos I was good, but then you could tell in the theory class I'd be getting 1s, and that, and it's all because I don't enjoy doing it, so I'm like fidgety and that, I'll graffiti and that.(9)

Or positioning the behaviours as an understandable response to provocation from others.

Because we had a different teacher people would get sly remarks into me and I used to take that, I used to give attention to that and I would start moaning and getting into trouble for disrupting the class.(3)

Another way of explaining the behaviour was to see it as just part of their character and reflective of qualities that are often viewed as desirable, such as being enthusiastic, and energetic.

I'm like everyone else, you know, I'm just a bit more energetic!(7)

I just loved it because I was always full of ideas, enthusiasm...I would describe myself as loads, full of ideas, good imagination.(8)

Where it was not possible to provide a situational or character based explanation, behaviour was (re)evaluated in ways that served to minimise severity.

A final strategy for explaining behaviour in a way that retained a self identity consistent with being normal was to emphasise the extent to which behaviour was under conscious control. This strategy appeared in the narratives of 6 participants and ranged from knowing they could set limits on behaviour, to stating that they had some choice in whether to behave in ways that got them into trouble or not.

Sometimes I think about going a bit further like breaking glass or something or hurting myself or hitting my mum. I mean I know I would never do that... there is no way I could ever do that to mum.(3)

I could be quieter if I wanted to, but I don't. I just...let myself be as loud as, you know, I want to be or whatever but I could just stop being loud and get my head down and work, but I didn't.(7)

By providing explanations for behaviour that were social, situational or character based and emphasising conscious control, participants were able to position themselves as 'normal' and resist the alternative positions of being 'ill' or 'weird'. Positions of themselves, which they perceived as being held by others

Identity Conflict: Difference

Overview

The second theme to emerge within Identity Conflict, has the opposing stance of 'difference' and described areas where participants did perceive themselves as different, or perceived others as viewing them as different from non-ADHD peers. Whereas participants themselves moved between all three positions; 'normal' 'weird' or 'ill,' they saw others as only viewing them as either 'weird' or 'ill,' and rarely 'normal.' The final theme in this category reflected the active nature of the adolescents struggle to make sense of these opposing positions. Questioning their diagnosis, and questioning the evidence for or against each position.

Being different

I don't know if I see myself as different, no I do in fact, I don't know if that's got to do more with other people or me being paranoid.(1)

The above quote captures the dilemma felt by participants as they tried to work out if or how they were the same or different from others. Some areas of consensus existed with for instance all participants described having difficulties with concentration. Though not all linked this directly with ADHD.

I wasn't concentrating a lot.(5)

One participant commented that until he was told he had ADHD he didn't realise that he couldn't concentrate, he had just thought he was bored.

Participants perceived being unable to concentrate as marking them out as different in a number of ways such as needing medicine, needing extra teacher attention, and needing additional practical support at school. Each of which, even when seen as helpful, also contributed to making them feel different.

people were saying where are you going and at first I was just saying I'm just going away to get something and they'd say oh are you going to get your mental pill...calling me a mental idiot.(3).

However, with regard to other behaviours that were predominantly social, participants oscillated, wrestling between viewing those behaviours as either 'normal' responses as described above, or as indicative of being either ill or weird.

Am I a 'weirdo' or am I 'ill'?

...to what extent are people going to think that's a load of shite he is just using excuses for being a little muppet basically. And... erm... to what extent they would accept it and say look he's obviously going to go daft if you wind him up he cant really help himself.(1)

The central struggle for participants was what do these differences mean, and feeling caught between two options; that it meant either they were 'a weirdo'(1), or that they were ill, but with neither of these according with the felt sense they had of being normal. Consequently all three positions were evident in the narratives at different points as participants struggled to resolve this dilemma. However the positions were present to different degrees and varied depending upon whose view was being presented. When talking about their own perceptions, participants tended to present differences as indicative of illness, but when talking about how they thought others perceived them the tendency was to present difference in terms of being thought strange or weird in some way. Representations of themselves as ill occurred mostly when they described poor concentration over which they perceived having little control and where improvement tended to be attributed to medication.

I sometimes get a wee bit hyper and that if I've not had them [ritalin], I get a wee bit... It's not like hyper, it's like I can't concentrate and that.(3)

Social behaviours on the other hand were more likely to be explained in the ways described above as being an understandable response to situational factors. The narratives indicated that although 'illness' was a stance adopted at times, adoption of it was often ambivalent, recognising both advantages and disadvantages. For some it was helpful to take this position as it lessened feelings of blame...

I felt vindicated in a certain way [after diagnosis] because I knew the other people didn't lose their tempers as badly as I did and they could get their work done...people will think well that's why he did that.(1)

...and gave access to additional supports they found genuinely helpful, as described in the later category 'Overcoming.'

But for others it exacerbated feelings of exclusion and difference.

I don't want to be the boy who goes away and takes these tablets to help him concentrate...they would think oh he's got to take tablets to help keep himself concentrated, he's a bit of a freak.(3)

Perceiving themselves as somehow strange, naughty or a misfit in some way, whilst sometimes stated as their own view of themselves, was more often described in the context of reflecting how they thought others viewed them. This movement between the positions of normal, ill/weird, again portrayed the struggle to work out what these difficulties meant in terms of identity.

Older participants engaged in greater levels of introspection about whether they should be viewing themselves in the same way as they felt others did, and if not, trying to work out how to make decisions about who they were.

I don't really think I can pass judgement on myself because for so long people just thought I was a bloody weirdo.(1)

In the struggle to answer such questions participants appeared to be engaged in a process of questioning or weighing up the evidence for each of the three identity positions; normal, weirdo, or ill.

...to what extent is that not my responsibility, not my fault anymore. How much of that... and then on the other hand you know... to an extent thinking I've been ill all these years kind of...(1)

Evidence for being different came from a combination of what others said and an acknowledgement of having problems that were difficult to control.

Like I don't know how to control, well I do know, but it's hard.(2)

For six participants it also came from the finding that when they took medication it noticeably helped.

...well after that I knew fine well without a doubt that I had ADHD and no matter what anyone said you know to the contrary I knew fine well that I had a problem, the drugs were effective treatment.(1)

But on the other hand, evidence for being neither ill, nor weird, came from their felt sense of being normal, and from being able to account for their difficulties in non-biological ways as outlined above.

Summary of Category 2: Identity Conflict

While none of the adolescents in this study disagreed with having a diagnosis of ADHD, and all indicated that they believed they had difficulties non-ADHD peers did not, incorporating ADHD into a sense of identity was problematic. Particularly, since ADHD itself had no experiential reality for participants. What participants described instead was, having a subjective perception of being 'normal' or just like their peers, but having this subjective normality conflicting with the reality of day to day difficulties and their perception of how others saw them, which was as either 'ill' or 'weird' but rarely 'normal.'

Whilst participants narratives mainly reflected feeling 'normal', descriptions of themselves also moved at times between the other two identity positions of 'ill' or 'weird', reflecting their ongoing struggle to resolve this tension. The central dilemma for them appeared to become one of finding some way to integrate difficulties so that a normal identity could to be maintained and collusion with the ill/weird identities perceived as being promoted by others avoided.

Strategies to achieve this formed the third major sub-category, Overcoming.

Description of Major Sub-Category 3: Overcoming

Overview

Seven participants in this study described themselves as having largely overcome their ADHD or problems, and were optimistic about their futures. One felt that his difficulties were becoming worse and one was uncertain about change. Both these latter participants described feeling pessimistic about the future, which contrasted sharply with the optimism of the others. This section outlines the themes that emerged around

‘overcoming.’ The first theme describes overcoming social difficulties and encompasses a range of internal and external strategies. Internal social strategies being those initiated and managed by the adolescent, such as fitting in, positive positioning of self, and managing social interactions. Whereas, external social strategies were those based upon the actions and responses of others, such as whether they were perceived as accepting and understanding.

A second theme describes how other practical supports were considered helpful or unhelpful, such as medication and access to learning support services.

A final theme of ‘resolving’ reflected differences in how participants perceived the destination they had arrived at in terms of resolving who they were. With the data suggesting that participants engaged in different resolving tasks depending on developmental level. While for younger participants resolving mainly seemed to be about simply fitting in, for older participants resolving was about finding a role in a group and achieving an integrated ‘normal’ identity.

Collectively these strategies form the third main category entitled ‘Overcoming.’

Overcoming Exclusion: Internal Strategies

Participants used two internal strategies to overcome social exclusion, the most strongly represented strategy was fitting in, that is finding a peer group they could identify with and establishing a place for themselves within it. The second strategy described ways in which participants positioned themselves positively compared with peers.

Fitting in

For two participants, as described earlier, sport provided access to a natural peer group in which quite literally ADHD and its problems ceased to exist. In a sports context participants described being interested and highly motivated, therefore concentration ceased to be problematic, and their energy and enthusiasm were also assets rather than hindrances. These participants also described experiencing lower levels of social exclusion in general compared with the other adolescents. For the majority however fitting in was a more difficult process, involving both active searching and active

conformity. Searching took the form of finding ways to identify with a target social group, for instance one participant associated Ritalin with street drugs thus lending credibility to claims of membership with a group whose social structure was based on listening to particular music and using soft drugs.

...its almost like, its I don't know, like people probably taking amphetamines would...like..then in 3rd year someone introduced me to marijuana and er I got into started listening to music...buying CDs and stuff and hanging round with people...(1)

Searching also took the form of identifying a valuable social role in a group that the participant could successfully meet. Two participants took this route with one identifying a role for herself as a carer in the learning support unit and the other identifying a leadership role as 'top dog' in a gang where he felt his ADHD helped by giving him strength and a short temper.

...well some kids in learning support,... they have mental disabilities and stuff like that, and the other kids in school, they'd give them a lot of grief because of that, and I just thought that was such a shame because I went through school like that....if they used to be really upset, I would sit down and talk to them. The teachers didn't do much they'd be, sit down, don't cry, more than help. So I used to sit down and talk to them and, you used to see it afterwards they say thanks for that....It made me feel really good afterwards to help someone... and even some of the teachers were like, you know, you've' helped us out a lot here..(7)

When I first moved [W] bullied me and that's when I turned round and [got into] a fight and I won, then he was like Oh right...now me and W are best mates... Me and W are what you could call top dog, the kind of ones that everyone is scared of. It's cos we've both got the same tempers and we've both got like short fuses.(9)

As well as finding a peer group, participants also had to conform in order to maintain a place, conforming took two distinct forms and appeared to differ by age. When younger, conformity involved doing what others said regardless of whether it was in their interest or not. This type of conformity overlapped with social naiveté as described earlier, where the desire to have friends led to participants acting in ways that ended up getting them into more trouble.

there was a display on the table, like birds displayed and there was eggs and everything...so I just done it for a joke because there was this person beside me who was telling me to just do it, just do it, it will be alright, and I thought, aye...(2)

For older participant's conforming was described as a more consciously thought out process in which the pros and cons were weighed up.

I used to be more cheery and that...my HA teacher just said that I've stopped saying 'hi' and than, he wants to get back to when I was saying Hi to him in the hall like...now I just walk past him. It's more like... you think they'll take the mick, the mates'll take the mick, or someone'll take the mick if you say hi to a teacher outside. So I stopped it and then that just kind of ruined the relationship I had with him, plus I was trying to show off and they were like, what you doing now? Who are you trying to impress and that, and I just got in more trouble and that.(9)

Positive positioning of self

This strategy was closely connected with seeking to present a self-identity that was congruent with being normal as described in both the categories of 'Exclusion' and 'Identity Conflict.' As seen earlier, participants attempted to position themselves as being just the same as peers by explaining and evaluating problematic behaviours in ways that enabled them to be understood as normal responses to situations. In addition to this, participants also described positioning themselves positively in relation to others. This was either by elevating their own status and referring to specific abilities in which they felt they were more competent or powerful than peers..

Standard grades are nothing, I passed 4 1s and 4 2s,...it was like you know pathetically easy.(1)

[I am what] you could call top dog.(9)

..or by lowering the value of others in relation to themselves; by dismissing their legitimacy or authority, or by highlighting ways in which they could be viewed as worse than the participant.

Dismissing legitimacy or authority most often occurred either in the context of explaining a misdemeanour "*I think I bit some girl in the first week. She was an idiot anyway*"(1) or in response to a teacher.

Well everyone's saying blah, blah, blah, the teachers and it makes you feel put down and everything if they're basically, Because you're being ruled and you don't do it properly they are telling you off an that you're doing it wrong and you feel put down by that.(2)

Whereas peers were more likely to be positioned as being worse in terms of either their behaviour or medical need.

As I say I've got more mature but some people haven't. I mean I know myself I'm a better person because I've ignored what they've said and I've matured a lot more and they are just acting like stupid idiots.(3)

there was this girl that used to be there she had to take these white capsule things about that long...I was like, I'm lucky I've only got 2.(4)

Another strategy for dismissing others was to ignore or avoid them altogether. This was particularly helpful in situations where peers were being abusive or rejecting as it both acted as a defence, enabling them to protect a positive sense of self, and on a practical level it also enabled them to avoid further trouble.

I'm beginning to feel what other people think about me doesn't really matter because I could go round saying what I think about them but it would just go round and round and round(2)

Nowadays I learn to just ignore whatever they say. I mean I know what I really am and it really doesn't matter what they think.(3)

For the two participants who were less successful in overcoming exclusion the need to protect themselves by dismissing others appeared also in a more extreme form of wishing for actual physical escape.

I love the countryside, because there's like nobody up there...I just get to run wild...so I can do whatever I want, within reason.(2)

I don't want to be here....I want to get away from this place...don't want, see people, other people, you know.(5)

Overcoming Exclusion: External Facilitators

The second theme in 'Overcoming' described how participants viewed external factors as helpful or unhelpful in terms of helping them on a day to day basis. Three themes contributed to this section; the effect of medication, the response of teachers, and access to practical support.

Medication

Eight of the participants described feeling that medication was beneficial to them, of whom four stated that they definitely needed it as they would be far worse off without medication. The remaining ninth participant described how others had seen positive changes in him but he was not so sure himself.

Medication was perceived to help primarily by enabling the adolescents to concentrate better in class and “*keep on track*”(1) though for one it also reduced the desire to misbehave.

...like I'm actually wanting to work...I can actually do my work and I'm not wanting to get into trouble or that, I'm wanting to get something done like.(9)

The effect for this participant was strong enough that he would choose to not take medication at weekends so that he would be up for mucking about with friends.

Well aye, I'm like, I like taking it like, on weekends and that, I don't because I'm like in the mood for mucking about with my pals but when I take it, I'm no' really in the mood for doing much. I'm just ... kind of tired, I'm like bored and that, but I dinnae want to go out and muck about because you think you'll get in trouble, but when I'm not on it, I'm like, like what are you wanting to dae and that?(9)

An additional benefit of medication for another participant was that he felt it normalised his position in the class because he no longer required the teacher to keep coming over to him. Something that he valued highly as it assisted him in feeling ‘normal’ or the same as his peers.

Three participants described feeling calmer and more tolerant in situations that they would have reacted badly to previously, which was helpful in enabling them to avoid conflict.

On bad days when I wasn't on my tablets I wouldn't care how she felt because that's just the way I am on that kind of day.(3)

I go hyper. Sort of hard to take...they calm me doon.(5)

Although most reported benefits from medication, limitations were also described some of which appeared highly idiosyncratic, for instance whilst medication helped participant No3 care more about others feelings, participant No1 reported it “*stopped*

me caring so much about what other people think”(1). One of the areas of consensus however was that although all felt medication helped concentration, the majority also felt it was of limited help socially.

...that’s something the pills don’t do anything for, if you are pushed too far you’re pushed too far and you are going to snap anyway.(1)

On some days I felt like it didn’t help at all, when I went out of my way to annoy people or whatever...I was just pushing past it [the medication] and going out of my way to be annoying.(7)

Perhaps unsurprisingly, given that medication was mainly viewed as aiding concentration rather than helping socially, medication was regarded by several participants as really only necessary for school or when studying, and therefore not required at weekends, holidays or after leaving school.

I’ll need to always take them when I’m at college because I’m wanting to be a mechanic so I’m needing as much information as I can.’(3).

I’m staying on it until I’m 16 and then I get the choice to stay on it or go off it and I’m gonnae say I’ll go off it like, I dinnae really think I need it that much when I’ve left school. It’s mainly just for school.(9)

Understanding and acceptance by teachers.

Although all participants described conflict with teachers as a frequently occurring difficulty they also described, particularly post diagnosis, occasionally having teacher relationships that were characterised by understanding, tolerance and acceptance. When these occurred they were highly valued by participants and seen as significant factors in enabling them to overcome school difficulties. Familiarity was also felt to be important and so for one participant it was helpful to have had the same teacher for two years at primary, by contrast temporary teachers were often seen as problematic.

it did make it better because there were a few teachers in there who didn’t know who I was and they were just thinking what is he like and all that but because these teachers knew me and had experienced what I was like they found it was quite easy for me to work because they know how I could cope in work and all that. It was quite good.(3)

Teachers who resisted automatic exclusion and were willing to talk instead were particularly valued, and from the adolescents perspective one of the benefits of

diagnosis was that some teachers moved from an attitude of automatic blame and exclusion to greater understanding and talking.

Well some of the teachers... would just be you know, like, go outside. my maths teacher Mr M, he'd just say go outside, take five minutes. I didn't really personally like being chucked out of the class, it was much nicer to have the teacher talk to you.(7)

the teachers started to lighten up a wee bit..yeah the teachers were a lot kinder then. Mrs E, oh she was fantastic.(8)

Access to practical support.

A final external facilitator in overcoming school difficulties was the provision of additional support at school, which was provided for six participants. Support was mainly in the form of attending the support for learning bases, where the teachers were perceived as more positive and understanding. One participant who in the rest of his narrative described almost relentlessly poor teacher relationships stated

there was a support for learning base up there and the teachers there were really good. They put support into all my classes, just to help me concentrate and to get used to the place better and just to make sure I was doing what I was supposed to be doing. It was quite helpful and they still are.(2)

Other helpful interventions noted were working in a small groups, and receiving specific tuition for areas of particular difficulty.

She's like a tutor, every Friday night like just to help me and I do quite a lot of work with her and that.(4)

These narratives suggested that participants valued the interventions and assistance offered, even while recognising potential downsides such as highlighting that they were different. Of most value to participants was the reduction in conflict with teachers that diagnosis and medication could bring, through both changes in behaviour and changes in teacher's attitudes towards their behaviour. A finding that further highlights the role of social factors in either exacerbating or attenuating difficulties attributed to ADHD.

Overcoming and Resolving

The final theme within the category of 'overcoming' was 'resolving'. This reflected how participants perceived their current position, and also how they saw their future. Of the nine participants, seven considered their difficulties resolved in that either they felt the problems were now completely in the past or that residual difficulties were now more manageable and had ceased to be problematic. For younger participants, resolution appeared based on whether they had successfully found friends and were managing to do their schoolwork. For the three older participants however there was a return to the question of identity with resolution appearing to be when they had achieved some way of integrating past difficulties with a self identity of being normal. Two themes characterised 'Resolving' firstly 'I'm fine now, I've matured' where participants described how although they had had problems in the past they were much better now that they had grown up a bit. Secondly, 'acceptance and integration' where an integrated identity was being sought that encompassed past difficulties within a self-identity of being normal.

Fine now

I think it was worse when I was younger, and I think it's sort of lessened out, em... now that I've grown up...it's like I forget it's there, sort of thing. I've just grown to live with it. Its like you don't even know it's there.(7)

The majority of participants, (seven) considered that their problems were now either resolved or very much better, and the main explanation give for this improvement was maturity or simply having grown up.

I'm going to have to start studying for exams soon but I've matured a lot more and that is it, I've just matured and I know what silly things I've not to do that I wouldn't have known in primary school.(3)

With maturity they perceived having gained greater knowledge of how to behave, and also an ability to think of the consequences of actions for themselves which enabled them to resist, for instance, violent retaliation in the face of provocation.

In first year, someone kept calling me names...I wanted to punch him in the face. If I was at primary and that happened I probably would have, but now I just realise its

just a name...just ignore it and I walked away and just... felt happy with myself that I never did anything that I would have regretted.(6)

Along with this view of why improvement happened was a reflection on, past behaviour, which was in retrospect, now seen as correspondingly childish or immature.

I'm much happier now than I was when I was younger. I mean, I've grown up a lot more. I feel I have anyway. When I was younger I was just much more childish, I mean...now I feel that I've actually grown up more, I feel a difference. But sometimes... you know, I get a bit over childish, it's like oh it's [the ADHD] still there [laughs].(7).

Acceptance and Integration

I think its for energy, I've always been an energetic person, so...it's got its positives and negatives. Goods and bads(7)

For the three oldest participants a further stage of resolving appeared to occur in which they were able to review the past and see their difficulties as having carried both disadvantages and advantages, as an integrated part of a positive 'normal' identity. So for one participant whose desired positive self identity was to be a hard man leading the local gang ADHD carried advantages in enabling him to access powerful feelings of anger during fights.

I've always had a short fuse...always had a temper but I kind of know how to use it if you know what I mean like...I've used my ADHD and that in school to try and get out of things and that....I use it like if I was fighting, there is just something about being angry when you've got to fight...I suppose you could say you're stronger or harder when you are angry.(9)

For another it meant accepting who they were and ceasing to place as much store on trying to win the approval of others at any cost.

In primary I tried to fit in a bit more, you know tried to calm down and realise you know this is not going to work, I'm just me and then in high school, I thought I'm just going to be me, and I was just me and...I made friends that way because I wasn't you know, trying to hide it.(7)

And similarly participant 1 described this stage as one of valuing his uniqueness being happy to accept who he was and no longer feeling that he had to change in order to fit in.

...its not really so much that I had a willingness to fit in as, almost to say... bugger them... I'm going to hand around with who I want and er you know people with similar ideas, sense of humour....my friends will actually think of it as funny or something but erm its just acceptance really I suppose.(1)

Summary of Category 3: Overcoming

The category 'overcoming' outlines the various ways in which participants described overcoming difficulties. For seven participants this was largely a successful journey with each narrating a story in which gradually they were able to overcome the difficulties of; friendship exclusion, being in trouble all the time, and feeling that their identity choices were limited to a choice of either being ill or weird. These difficulties were overcome through strategies that the adolescents brought to bear themselves such as actively seeking a peer group and employing tactics that enabled them to fit in by conforming. Also actively defending an identity of 'normal' by explaining problematic behaviours as mainly situational responses to difficult social conditions, and by evaluating themselves positively in comparison to others. Overcoming was also aided by external supports provided by others. The most important of which was medication, which enabled them to concentrate at school and thereby helped them to establish better relationships with teachers. The second most helpful external support was provided by teachers who were perceived as understanding and willing to talk; as opposed to blame and exclude. A final source of valued input was in access to additional educational support such as a learning support base. The last theme in overcoming 'Resolving' described how participants understood the journey to arrive at this point, with most reflecting that their past behaviour had been connected with immaturity and childishness. Consequently much of the resolution of their difficulties was seen as being a result of growing up. For older participants a final stage of resolution emerged, which suggested an integration of both positives and negatives of their experiences into a coherent whole 'normal' self identity.

4.2 Chapter seven – Narrating the story

The Emergent Core Category – or main story-line

The question at the end of the descriptive analysis was, so how does this all fit together to describe growing up with ADHD from the perspective of the child and adolescent. In this section a central narrative, or core category, is derived which seeks, as richly and inclusively as possible to describe the typical story of the young people speaking here. To assist in pulling this together a fictional narrator ‘John’ captures and condenses the essential story line that emerged from this group.

John’s story – a semi fictional account.

It was okay when I first started school, but then everybody else seemed to make friends and I got left out. I don’t know why. I tried and tried to join in but somehow it kept going wrong, they bullied me and tried to avoid me. It was really hard and made me feel sad and angry. Sometimes I honestly thought they did want to be my friend like when they asked me to join them in some mischief. But when we were caught it was always me that got into trouble, I got all the blame and they would get off. Speaking of trouble, I was always in trouble with the teachers, moan moan moan that’s all they ever did, either I was being blamed for something or they were shouting at me for not getting on with my work. I just used to get bored so easily and there were always interesting things going on like conversations I wanted to join in, or sometimes I was just really excited and enthusiastic about what we were doing. Whatever the reason it usually ended up with me in trouble and being put out the class. It was so unfair, I was always getting the blame and they just wouldn’t listen to my side, I used to get so angry with them. It seemed like it was okay for everyone else to do stuff, but not me.

I can’t remember how the ADHD thing happened very well but I think the teacher spoke to Mum and that’s how I ended up getting pills, I didn’t like taking them especially when I was called names like ‘mental boy’ but they did help. I was able to do my work without getting as distracted. But the pills don’t make you behave. I could still be loud and make trouble when I wanted. Being told I had ADHD was a real shock though, I had no idea there was anything wrong with me. I thought I was just a bit loud or easily bored. But the tablets worked so I suppose that means I must have been ill,

doesn't it? But, I didn't feel ill. I know other people think I'm a weirdo or, you know, mad, strange or whatever, but that's not how it feels to me. It's strange I can't quite work it out. I want to just feel normal, but that's not how they see me.

It's different outside school, I play rugby and football, I'm quite good at football actually. I've got so much energy I always want to be outside playing all the time, and I've got friends there too, that's really good. Primary school was bad, being stuck with the same people all the time, when they all thought I was a weirdo. High school was better, lots more people and a fresh start with folk who didn't know me. I was able to find other people that I liked, with the same interests as me. That was a real turning point when things got much better. I also got some extra help at school through the learning support unit. That was good the teachers there were really nice, not shouty. Thinking back about it all, I think things just got better as I grew up. I stopped doing as many daft things as I got older and knew better. I was able to use the ADHD sometimes you know, like when I wanted to get out the class I would make myself angry and the teacher would say 'Go for a walk,' so it wasn't all bad. Now that school is finished I think things will be fine. I'm going to stop the pills, they were just to help me concentrate at school. Though I suppose I might need them again if I get a job that's really boring! I'm fine now though, I'm really happy I've finally found a way to fit in, now that I've grown up I can just be myself.

The Core Category – Felt exclusion

From the grounded theory analysis of the transcripts, the core category or central phenomenon to emerge was one of 'felt exclusion.' This encompassed the powerful feelings expressed about being excluded from friendship, excluded from good relationships with teachers and also being excluded from feeling that they were normal or just like their peers. Felt exclusion therefore incorporated Sub Category 1: Exclusion and also Sub Category 2: Identity Conflict. The other Sub Category to emerge from the study was Overcoming which was also closely linked to 'felt exclusion' as it reflected the strategies and tactics utilised by adolescents to overcome the problems of exclusion. Such as finding ways to 'fit in' and maintain a positive self identity of being 'normal.'

As 'felt exclusion' was able to contain all of the major sub categories, properties and dimensions this was considered to fulfil the requirements of a core category as defined by Strauss & Corbin (1998), and used as the heart of the tentative theoretical model constructed below.

The experience of having ADHD – A theoretical social model

Overview

A possible model of the experience of growing up with ADHD as a social condition is presented in Figure. 1. The creation of a theoretical model was in order to have an analytical tool to explore the phenomenon further and ask questions about the relationship between the various descriptive categories. Reviewing the categories it appeared that some were causal in that they lead to feelings of exclusion, whereas others best represented the various strategies and tactics used by participants to overcome exclusion. In addition the categories suggested shaping factors that influenced when and how these strategies were used. For instance, older participants adopted some strategies more often than younger ones, suggesting maturity may be a shaping factor. Following on from understanding the strategies, were categories that represented the consequences of either successfully or unsuccessfully overcoming exclusion. Each of these elements of the model will be discussed and related to existing theories of ADHD where applicable.

ADHD as a social condition

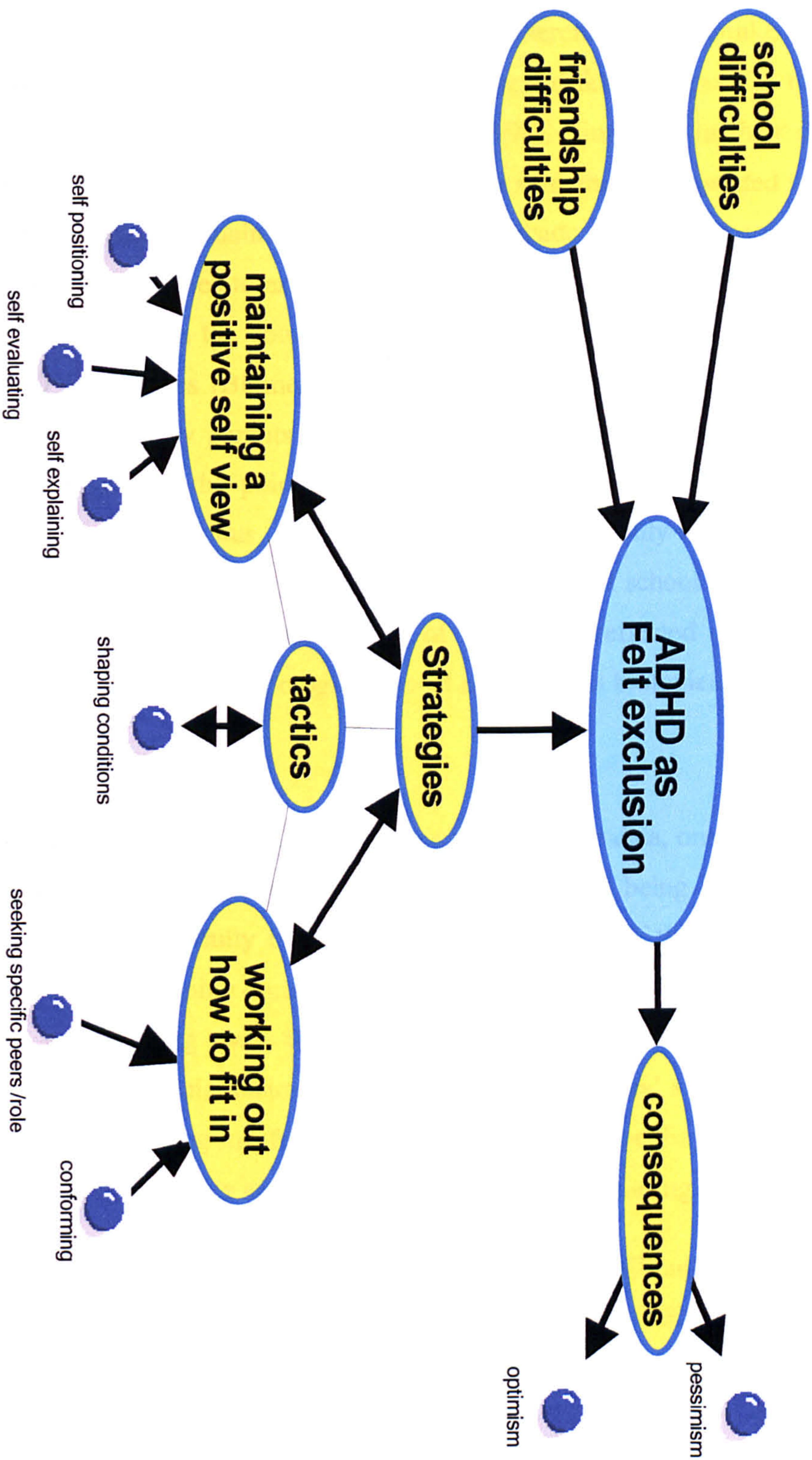
The central proposition of the model presented here is that ADHD, while it may or may not be biological in aetiology, from the perspective of those suffering from ADHD is experienced as a social condition.

Context

The model in Figure 1 begins with an overarching context of Healthcare and School. This reflected the finding that although participants in this study held a weak biological view of ADHD in that they accepted they had problems for which they saw a doctor and

Growing up with ADHD a theoretical model

Context Healthcare & School



took pills. ADHD as an entity only actually existed for them once they were in contact with healthcare professionals. This was indicated also by the shock expressed when a diagnosis was given. ADHD for them was therefore quite unlike a continuous felt biological problem which has an ongoing internal felt existence for the sufferer, as in for example epilepsy (Weinbren & Gill, 1998). Similarly, in their day to day lives ADHD was not a constant presence but rather something that existed within the context of certain social domains such as school. Outside of school, particularly when with friends ADHD ceased to exist in many cases. Of course an important caveat here is that this is purely from the young person's perspective alone. Research into the impact of ADHD on families (Blumenthal *et al.*, 2004; Harborne *et al.*, 2004) plus comments made to myself by parents indicated that for them ADHD was problematic out with school. However, the point presented here is that for the young person themselves ADHD was an nebulous, inconstant entity that tended only to exist for them following contact with healthcare professionals and in the face of school demands, both academic and social. Thus their understanding of ADHD as reflected in lived experience was closer to an integrated sociological model rather than a biological one.

Causal Factors

Two causal factors of felt exclusion emerged from the data, one was school difficulties; such as difficulty concentrating completing work and being in conflict with teachers. The other was difficulty in forming friendships. Both of these problems were usually described as beginning during the earliest years of primary school. From the narratives what was striking was the extent to which these difficulties were frequently underpinned by social factors, such as trying to gain peers' attention or trying to join in activities, but having insufficient social skills or understanding to manage this in a way that elicited acceptance and reciprocity. For example resorting to shouting, or pushing.

Conflict with teachers was also often based on difficulties conducting a social relationship. For instance not feeling listened to and feeling frustrated, but lacking sufficient social skills to manage the situation was what often led to further escalations in conflict.

Difficulty concentrating appeared superficially the least socially based problem, however difficulty concentrating per se was often perceived as less of a problem than the behaviours that followed on from feeling bored. Such as talking, shouting or interrupting others, which were social and had negative social consequences through creating greater conflict with teachers. It was only as children grew older that difficulty concentrating was seen as a problem in it's own right causing frustration when they were studying for exams or struggling to do work that the previous day had been fine.

In terms of fit with existing theories of ADHD, again there is perhaps a closer fit with integrative theories that advocate the problem as arising from a mismatch between the child's capability and situational demands. When discussing what they thought accounted for their problems one of the most frequently cited was '*I was just immature*'(3) and the most common reason given for resolution of their problems was consequently '*growing up*'(7) this accords with integrative theories such as those proposed by Block (1977) who points to the demands of formal schooling which require a child to be able to comply, concentrate, sit still, listen and verbally reflect. Developmental skills which substantial numbers of 4 or 5 year olds, in particular boys, may not yet have attained sufficiently. It was interesting in this respect that so many noted the onset of problems as being very early in primary school. A further link between immaturity and friendship difficulties may lie in a mismatch of friendship concepts. The nature of a friendship depends upon the developmental stage of a child. Whereas pre-school friendships are based on being momentary playmates, early school ones are based on assistance, (Selman & Jaquette, 1977) and difficulties in forming friendships have been suggested as occurring when individuals hold mismatched friendship concepts. If participants were indeed less mature than peers on entry to school part of their difficulties may be as a consequence of such a mismatch. As was evident in the narratives however, once these difficulties arose, they begot more problems and so had the capacity to become self-perpetuating. Being unpopular with peers led to further rejection based sometimes on reputation rather than actual behaviour, consequently more extreme behaviour would be elicited from the child in order to force social interaction, leading to more rejection. Similarly being in trouble frequently meant teachers became more watchful and from the participant's perspective,

less tolerant, again resulting in more frequent disciplinary exchanges. These self-perpetuating negative cycles have been observed in previous studies, with children who have high aggression combined with low social skills facing an increased risk of rejection, (Newcomb *et al.*, 1993). For six participants escaping from this cycle only began to occur with the move to high school where they could begin with a clean sheet and have access to new wider cohorts of potential friends.

The central phenomenon

The central phenomenon was 'felt exclusion' as described earlier where participants felt themselves to be excluded from three important domains of social experience. The first was exclusion from friendship, which dominated most of the narratives. Peer exclusion has not been included as a significant factor in previous theories of ADHD beyond noting that children with ADHD often tend to be unpopular with their classmates (Smith & Williams, 2001). However developmental psychopathology studies strongly suggest that acceptance by peers is an important factor in predicting later outcomes, with those who experience exclusion at an early stage, being at significantly greater risk of poor mental health in later years (Berndt & Savin-Williams, 1993; Bierman, 1987).

The second area of exclusion was from having good relationships with teachers. Teachers were a frequent source of complaint in the narratives, particularly in terms of unfair blame, hypervigilance and being forced to abide by stricter rules than peers. Where an understanding and supportive teacher was encountered they were highly valued by participants. Although no direct studies were found concerning teacher attributions in this respect. A study of how children judge popular and unpopular peers participating in exactly the same behaviour supports such a bias with greater latitude given to popular peers than unpopular (Hymel *et al.*, 1990) and it is possible similar mechanisms may operate in adult to child classroom interactions also.

The final area of exclusion related to feeling excluded from a sense of being 'normal' or the same as their peers. Again this was a prevalent concern appearing repeatedly across interviews. This finding suggested two things, the first was that the adolescents were engaging in on-time developmental tasks concerned with individuation and identity development. In common with other adolescents at this stage they were beginning to

address the question 'Who am I.' They were concerned with wanting to fitting in and not being different while at the same time not wishing to loose their individuality. For the older participants this question reflected the developmental task of attempting to create an integrated self where opposing characteristics such as having problems and being normal could co-exist harmoniously (Damon & Hart, 1988; Harter, 1990). Secondly, this finding suggested that being diagnosed with ADHD and encountering problems with school and friends was intimately connected with how they addressed the question of 'Who am I? Participants described feeling that their behaviour, in the views of others, marked them out as either ill or weird. These were views of themselves, which were both unwanted and incongruent with their own internal felt sense of being normal. As this study was of the personal subjective meaning making of individuals diagnosed with ADHD and the views of others were therefore not sought, it is not possible to say whether others actually held such dichotomous views, it is only possible to say that is how others were perceived.

In order to overcome exclusion therefore and complete the important developmental tasks of finding friends, overcoming school problems and developing an integrated normal self; participants engaged in several strategies, which form the next part of the model.

Strategies & tactics

As outlined in the descriptive section, participants used a number of strategies and tactics to overcome the various aspects of exclusion. The most important task described was finding friends and fitting in, which for those who did not have the natural arena of sports required a combination of active seeking for a group or role, and then conforming to that groups social mores. In essence this task was not so different to that of an adolescent who has not been diagnosed with ADHD, however a non-ADHD peer is likely to be more popular and socially skilled making this an easier process. For the group in this study there appeared to be a more conscious striving to locate and join a group, with previous unpopularity potentially narrowing the options available to them. As one commented there were the "*all American high school prefect types*"(1) who had always been popular and successful at school, and whom he felt would look down on

him. He clearly did not view himself as belonging with such a group even though academically he was achieving as well or better. Having reduced options seemed to push participants into selecting friends from other more marginalised groups, and once there, having to conform in order to maintain the friendships. This pattern may help to explain one of the findings in a study by Barkley & Fischer, *et al.*, (2004). They reported that adolescents with ADHD, compared with conduct disordered adolescents, were more likely to be involved in the social aspects of antisocial behaviour such as drug dealing, than actually using drugs. This may be understandable if it is seen as reflecting a need to belong to a peer group, rather than a desire to be antisocial or having a physical substance addiction.

The other main strategy was maintaining or constructing a self image that was congruent with their felt, and desired, experience of being normal. Here again although superficially accepting a biological explanation for ADHD. Participant's experiences were more congruent with social explanations, which enabled them to avoid the labels of being either 'ill' or 'weird'. This was done through tactics such as explaining their behaviour as being an understandable social response to provocation or injustice, or evaluating their behaviour in ways that minimised it's severity, or by finding favourable comparisons with others who were deemed to be inferior or worse off in some way. This finding is interesting, as the process of positive positioning found here may be similar to the finding that non depressed boys with ADHD overestimate their competence in the areas where they have the greatest deficits (Hoza *et al.*, 2004). This has led to a debate about whether such positive illusions are protective adaptations in the face of repeated adversity and therefore helpful or whether they act as an additional liability preventing the child from perceiving a need to address skills deficits. The present study suggests a protective function, in terms of self identity. However without long term data comparing outcomes for those with accurate versus inflated perceptions of competence this question is difficult to answer.

Shaping Factors

Shaping factors were conditions, which affected the strategies utilised by participants. The most important factor shaping strategies was maturity. The developmental literature

on ADHD suggests that whilst some have ongoing difficulties, in general hyperactivity and impulsivity tends to decline with age. This fits well with the subjective experience of participants in the present study who perceived that improvement had occurred simply as a result of them growing up. Natural adolescent development also includes increased meta-cognition and introspection (Elkind, 1974) which were both described by the older participants and this would also facilitate the ability to self reflect and navigate how to maintain a sense of 'normal' identity. A second shaping factor was being given medication which participants found valuable at school. Although medication did not help overcome exclusion directly it did help to reduce the frequency of conflict with teachers by helping them to stay on task and also by changing how teachers responded to them.

Consequences

The consequences of successfully finding a peer group and managing to establish friendships were an increase in optimism and a perception that their ADHD was no longer a problem. These participants talked about the future positively and looked forward to the next stage, and the apprehensions they expressed were similar to those of any adolescent thinking of college or starting work. For the older participants this was akin to achieving Harter's (1990) harmonious co-existence, where the past was integrated and organised in to a coherent self. They could see positives and negatives in their experiences, acknowledge difficulties and retain a comfortable sense of being normal.

This path contrasted with those who appeared unable to overcome exclusion, who expressed greater pessimism, frustration and disempowerment. They continued to struggle in all three domains of exclusion and were unable to utilise the strategies adopted by others, for instance they were less able to maintain a positive self view and more likely to now seek withdrawal from social engagements rather than fitting in.

Study in context of previous explorations of children's experiences.

It is useful to compare the results of the present study with those obtained in the three previous studies exploring children's perceptions of living with ADHD, conducted by, Kendall, Hatton et al., (2003), Harborne, (2002), and Krueger & Kendall, (2001). Table

1 provides an overview of similarities and differences between these and the present study.

As can be seen from Table 1 many of the categories revealed in the study by (Kendall *et al.*, 2003) were also present in the current study, in particular the categories relating to problems, pills and causes were descriptively very similar. The categories Mom and ethnicity however were not shared, probably reflecting the exclusively older and ethnically homogeneous population in the present study. Interesting areas of overlap occurred with respect to 'meaning and identity' and also 'illness versus normal'. Kendall *et al.*, (2003) concluded that the children adopted an ADHD identity seeing the ADHD as who they were rather than as symptoms they experienced. In the present study there was a similar sense of difficulty separating ADHD from self, but the interpretation offered here is that this was because ADHD lacked any felt experiential reality and therefore was unavailable to be separated from. In terms of 'illness versus normality' overlap occurred in that Kendall *et al.*, (2003) also reported '*ADHD did not become a real thing until legitimised and formalised through authority figures, usually physicians*' and similarly in the present study ADHD only came into being following contact with healthcare professionals. The Kendall *et al.*, (2003) study is purely descriptive however, and does not seek to create any overarching theory of the experience therefore the theoretical model developed here cannot be compared. The similarities in descriptive content suggest though that the findings of the present study may be representative of the wider population of children and adolescents diagnosed with ADHD.

| | Category | Shared with present study | |
|-------------------------------|---|---------------------------------|----|
| | | Yes | No |
| Kendall et al., (2003) | Problems | √ | |
| | Meaning and identity; Who I am vs what I suffer | Overlaps Identity conflict (ID) | |
| | Illness vs normal | Overlap ID. | |
| | Pills | √ | |
| | Causes | √ | |
| | Mom & ethnicity | | √ |
| | Harborne, (2002) | Bullying | √ |
| Ritalin | | √ | |
| Adjustment/control | | √ | |
| Krueger et al., (2001) | Unappreciated self | Overlap ID | |
| | Failing inadequate self | | √ |
| | Temporal continuity | | √ |
| | Self cohesion | | √ |
| | Esteem and empathy | | √ |
| | Empowerment | √ | |

Table 1. Summary of similarities and differences between emergent categories from previous studies and the present study.

The second related study by (Krueger & Kendall, 2001) elaborates on the issues of identity, gender and ADHD. Whilst again some of the descriptive content in the study was recognisably similar such as finding that the adolescents with ADHD often perceive themselves to be unappreciated and misunderstood compared with non ADHD peers, and engaged in positioning themselves as better than others, the interpretation was different. In the Krueger et al., (2001) study this was interpreted as indicative of poor insight and consequently a failure to recognise the true extent of their difficulties. In the present study this was interpreted more broadly as being both an understandable response to possible real iniquity and/or a strategy, which served to help them establish or retain a normal self identity and avoid the alternatives offered by others of being either 'ill' or 'weird'.

The third study by (Harborne, 2002) is more difficult to compare as the children's experiences were a minor part. Descriptively the accounts of bullying were similar and there was a similar recognition of medication being helpful. Control emerged in the Harbourne (2002) study as well as here with a similar finding that the children felt they did have some control over symptoms. As in the other studies there was no theoretical model of the children's experiences proposed and therefore this aspect could not be compared.

One area in which the present study is different to each of the preceding studies is in the prominence given to the role of friendships. This seems surprising given the degree of overlap in descriptive categories generally and it is unclear why friendship should emerge so centrally for the present group but not previous ones. However, given the evidence from studies of normative adolescent development, which highlight the importance of friends, its emergence here is not perhaps unexpected.

Summary

The present study generally fitted well with the findings from previous studies, in particular the common findings that the children all reported experiencing similar difficulties, and struggled with identity issues. The present study adds to the findings of previous studies through the emergence of friendship as an additional important category and by developing a tentative theory of the experience of growing up with

ADHD. The commonality with previous studies suggests that the present findings may be representative of the experiences of other children growing up with ADHD.

5) Discussion, Stage Five: Final Report

5.1 Chapter eight – reviewing the adventure or Revisiting the Purpose

Reviewing the original objectives

The original aims of this study were:

To explore the every day lived experiences of young adults, previously diagnosed and treated for ADHD.

The present study suggests that the every day lived experience of children and adolescents diagnosed with ADHD is one of struggling to overcome feeling excluded. Whilst the adults around them may focus on ADHD as a medical condition or a behavioural problem, for the adolescents themselves ADHD does not feel real. What they are concerned with is trying to make friends, stop being in trouble at school, and avoid being labelled as either ill or weird.

To understand similarities and differences in how individuals construe the shared experience of receiving ADHD diagnosis and treatment.

The data in the narratives on how receiving ADHD diagnosis and treatment was construed were limited, as few participants were able to remember much detail, beyond feeling shocked. From the information that did emerge there was a general consensus that medication was helpful, both in helping them to concentrate at school and in improving relationships with teachers. The overall paucity of emergent data around this aim was revealing in itself however, as it was surprising and highlighted the disparity between my own assumption that diagnosis and treatment would be perceived as a major turning point and the quite different priorities of the adolescents. Letting go of this prior assumption encouraged me to ask the question; what are *they* saying is the

problem? and, what are they telling me were the turning points? Questions, which brought the importance of friendship and exclusion back into focus.

To understand how personal meaning-making within the context of receiving ADHD diagnosis and treatment influences the young person's beliefs about themselves and the world.

The present study suggested that having an ADHD diagnosis, was woven into the narratives of how young people thought about who they were in complex ways. There was an ongoing struggle reflected in the narratives of trying to reconcile difference and sameness, of on the one hand accepting that they had this condition called ADHD, had problems and needed medicine, which worked. Yet on the other hand subjectively feeling themselves to be 'normal' and the same as their non-ADHD peers. The struggle was not just between internal representations, but also external as the adolescents viewed their perceptions of being normal to be different to the perceptions held by others about them; that they were either ill or weird.

The active nature of this struggle reflected the extent to which participants were engaging in on-time developmental tasks such as individuation and identity integration. Indicating the presence of cognitive changes typical of adolescent maturity, as it was clear they were actively engaging in a process of trying to address the question of who they were and how they fitted in with others.

As participants reflected on their experiences most believed that they had been immature for their age and that the improvements they experienced at high school progressed were largely due to simply growing up. For most participants the destination they had arrived at today was seeing their problems as mainly in the past, and leaving both the ADHD and need for ADHD medication behind when they left school. For those who had failed to overcome felt exclusion however, the developmental trajectory appeared different, leaving them feeling helpless, frustrated and pessimistic about change and the future.

Conclusions

This study explored the autobiographical narratives of nine young adults previously diagnosed and treated for ADHD. The study presents a theoretical model of the experience of growing up with ADHD suggesting that from the perspective of those affected, ADHD is not something that is felt as a medical condition, but something that is experienced as a social problem of feeling of left out or left behind. This does not imply acceptance or rejection of the view that ADHD may be biological in origin, but attempts to describe instead what is actually experienced by the child and adolescent on a day to day basis and how they manage this.

Felt exclusion emerged as the core category in the study, encompassing exclusion from friendship, good teacher relationships and from feeling 'normal.' Exclusion and receiving a diagnosis of ADHD created additional difficulties for adolescents growing up in terms of self-concept. As in addition to dealing with the kinds of identity questions shared by most adolescents, they were engaged in a struggle to establish or maintain an identity position of being normal, which was congruent with how they felt. Resisting the alternative identities they felt were offered by others, of either being 'ill' or 'weird.' To overcome felt exclusion adolescents engaged in various strategies to fit in, such as actively seeking and conforming to available peer groups. They also actively positioned themselves as 'being normal' and the same as non-ADHD peers, through the actions of explaining, and evaluating their behaviours as just part of their character or as an understandable in response to social situations. For the majority of participants who had successfully overcome exclusion, ADHD was considered to be largely resolved and they viewed the future with optimism. The small number of participants who were unable to overcome exclusion however still regarded ADHD as highly problematic and expressed greater pessimism about the future.

Limitations of the study

Whilst the present study suggests new avenues of understanding the experiences of young adults diagnosed and treated for ADHD, it is important to recognise a number of significant methodological limitations.

The sample:

Three particular limitations are evident with the sample. Firstly, in common with most qualitative research, the small sample size, secondly, the process of recruitment being driven by practical rather than theoretical considerations, and thirdly the lack of female representation in the sample.

The participants were drawn from a small section of the potential population of children with ADHD, and this raises the question of how representative they may be of the wider population. Seven of the nine participants were recruited through their regular psychiatrist or psychologist when attending for routine care, they were mainly regular attenders and therefore potentially more likely to be young adults who were perhaps accepting of their condition and the necessity of receiving psychiatric or psychological care. It is also not known how selective the process of colleagues suggesting participants was, as these participants may have been individuals the psychiatrist or psychologist felt would be the most willing and able to reflect upon their experiences, or even those for whom the service appeared to have been particularly successful. It is perhaps significant in this respect, that all nine participants approached, were very positive about healthcare professionals and immediately volunteered to participate, a tenth participant also volunteered but was unable to be interviewed for the study due to exams and holidays. It is not known therefore if those who were not suggested for invitation, would have expressed similar views.

As mentioned earlier, in qualitative research, prospective sampling is ideally used to continue recruiting participants until a point of saturation has been reached. In addition recruitment of serial participants is based upon seeking to follow up emergent issues from analysis. Whilst this process was followed in terms of the analysis informing the direction of interviews it was not possible to select different participants as only a limited number were available, nor was it possible to continue recruiting in an open-ended manner due to time constraints. It is recognised that a potential limitation of this study therefore may have been failure to reach true saturation point. It may have been more helpful for instance to specifically seek out participants who rejected the diagnosis or those attending non-medication based therapy to understand if different

representations of ADHD had been influential in those cases. Also within the present study different groups emerged that would have been helpful to follow up with more specific examples. For instance, there appeared to be a noticeable shift in meta-cognitive abilities between the older and younger participants with the older ones able to provide more in depth reflections on what having ADHD meant for who they were. As this was an aspect of particular interest in the present study, in retrospect, it may have been more useful to recruit from an exclusively older cohort. There also appeared to be distinct differences between a majority group who felt they had largely overcome ADHD and a minority group who were experiencing ongoing difficulties. For the purposes of a grounded theory study it would have been better to have actively recruited more participants from a single group and achieve saturation initially, then look for specific comparator examples.

A further limitation of the sample was gender bias. Only two females participated and although they shared many themes in common with the males, there were also suggestions of some differences. For instance females reported a higher level of physical bullying, and also expressed a desire for roles that were caring in a group, features not seen with the boys. However, with so few female participants it was not possible to assess whether these were idiosyncratic differences or representative of issues that were particularly important for girls diagnosed with ADHD.

Whilst these limitations suggest interesting avenues of further research, they weaken the present study and suggest that the theory generated should to be regarded as somewhat tentative at this stage.

Data Collection.

Issues also arose in relation to the process of data collection, primarily the difficulty of obtaining information from young adults with whom no prior rapport had been developed.

Whilst most of the participants spoke freely and easily requiring mostly just simple reflective prompts to elaborate and continue. One participant had been medicated prior to interview and although willing to talk, appeared tired and lethargic, tending to give

short often one-word answers, which were descriptively thin and contained less information from which to develop theory. In other instances, interviewees struggled to articulate issues that were important for them around traumatic experiences, either not having an emotional language to express themselves or carefully selecting what information to share and what to withhold. These difficulties suggest that it may have been helpful to arrange interviews prior to medication, and possibly also to offer a series of shorter interviews over a longer period of time. This would have given extra time for rapport to develop and for participants to become more familiar with the interview experience. Such approaches might have enabled a greater richness of information to be gathered.

Data Analysis.

As discussed earlier, it was planned to use an additional secondary coder who was an experienced clinical psychologist familiar with ADHD to carry out a credibility check by coding two samples of interviews and discussing areas of similarity and difference with the author, particularly in relation to theory development. Unfortunately a series of staff changes meant that the secondary coding was unable to be performed, prior to submission. However the theory as it developed was discussed through a peer forum and also with an academic supervisor familiar with working with children and families affected by ADHD and this was helpful in assessing the credibility of the study. A further check of the study's credibility is planned by seeking testimonial validity (Barker, 2003) where the study findings will be presented to participants to assess the extent to which the results accurately reflect their experiences. Although at the time of writing testimonial validity had not yet been carried out, it is proposed to conduct this procedure prior to submitting the report for publication.

Implications of the results

Clinical and research implications

A number of implications emerge from the study. Firstly it highlights that the need to prevent a child from experiencing exclusion at the earliest possible stage. Suggesting

that intervention should be carried out as soon as difficulties are detected regardless of whether a formal diagnosis of ADHD has been made or not.

In terms of social policy, whilst beyond the scope of an individual clinician, it may be useful to reconsider the age at which young children, particularly boys are placed into full time formal education. On an individual level it also makes sense to advise families of the merits of prolonging nursery provision and delaying school entry as late as possible for children who may be at risk of rejection. As it is unlikely that such families would come into contact with a clinical psychologist unless other significant difficulties were present, this advice may be best provided through consultation with other professionals working with nursery aged children.

Once at school it may be helpful for teachers to become aware of the social intention and function behind behaviours that otherwise may be labelled as indicative of ADHD, and for additional resources to be made available to coach at risk children in social skills. This study suggests that where teachers are able to communicate acceptance, willingness to listen and avoid exclusion, they are highly valued and perceived as helping the young person cope better at school, by reducing the likelihood of unhelpful escalation. It would again be helpful for such support to be available to both pupils and teachers whether or not a formal diagnosis has yet been made.

This study also suggested some practical ways in which inclusion and friendship may be facilitated. For friendships to develop the children and adolescents needed opportunity, proximity and familiarity with others, in the context of shared activities where their energy was an asset. Sport provided this naturally for some participants and they reported lower levels of exclusion generally, along with fewer troublesome symptoms. This does not imply any causal relationship as it may be that these participants had less severe difficulties and so were less excluded anyway. However, this finding does suggest that children with ADHD, or those displaying behaviours that may lead to an ADHD diagnosis being considered, would benefit from having as much opportunity as possible to interact with peers in an environment where difficulty concentrating or being energetic is not a problem. In this respect again at a social policy level it would be helpful to provide more funding for support groups and to promote particularly sports or

activity based youth groups that could provide such opportunities. For individuals as part of a therapeutic intervention it may also be helpful to encourage families to seek out these opportunities for their child.

Whilst further research is required to assess the impact of such social interventions on subsequent ADHD diagnosis rates or outcomes, what is known already about the risks of peer exclusion on future psychological well-being suggests that such interventions would be worthwhile implementing and evaluating. One hypothesis directly suggested by the present model is that if children with ADHD are able to overcome exclusion earlier, they may perceive a wider choice of potential peers groups to be available to them. If so this may reduce the likelihood of choosing to join more marginal groups such as those involved in antisocial behaviour. Longitudinal research is required however to investigate this further.

Although the results of the present study fit well with those of previous studies the role and importance of friendship emerged as a new category. Further research is required to establish if forming friendships is as important for other adolescents with ADHD in terms of perceiving themselves as overcoming ADHD. Also to separate out the relationship between symptom severity and exclusion as it may be that those who overcame exclusion had fewer symptoms to begin with. It may also be the case some with relatively mild symptoms for various reasons encountered rejection and then were denied opportunities to practice social skills, which led to further difficulties and ADHD symptoms appearing to become worse.

The conflict between being 'normal' 'ill' or 'weird' also emerged more strongly in the present study than previous ones, where although touched upon it was not explored further. Future research is necessary to find out if this struggle is common to all children growing up with ADHD and also to identify ways of helping them to negotiate this. One hypothesis may be that if they feel their 'normal' self identity to be validated by others, they may engage in less active positioning of themselves to counteract perceptions of being 'ill' or 'weird.' Previous research has indicated that ADHD boys overestimate competence in areas weakness creating an illusory self-concept (Hoza *et al.*, 2002) but they stated it was not known whether this reflected a conscious attempt to present

themselves favourably or an inaccurate perception of themselves. The present study suggests an element of the former may be more accurate as participants were acutely aware of difficulties, though the aim may be less impression management than a reflection of the struggle to form an integrated positive identity, this requires further evaluation.

The researcher's position

During the study issues were reflected upon through the use of a reflexive diary, post interview notes and the use of memos and Nvivo databites.

Although the study was carried out in a setting full of ADHD cues, for instance, the young people knew the study was related to ADHD, the interviews were often conducted in a place where they received treatment, and by someone (a psychologist) that they might associate with ADHD treatment. ADHD was not the subject uppermost in participant's minds, even when I specifically asked for further information. Instead it was issues around 'friendship,' that dominated the interviews. This backgrounding of ADHD surprised and initially frustrated me, as it was ADHD I wanted to discuss. However, this frustration also made me reflect on where the young people situated ADHD in their lives, compared to where the adults around them (including me) situated it. My assumption had been that diagnosis and treatment would be a huge event in their lives, positive or negative and that they would have strong feelings about coming for treatment. My assumption had also been that they would have encountered the various conflicting representations of ADHD that exist and would have been trying to make sense of those in terms of how they thought about themselves. However, this was not the case, indeed descriptions of interactions with healthcare professionals were almost entirely absent.

Their continued focus on friendships and trouble at school led to the realisation that ADHD only existed for them in relation to other people and their demands, such as the need to concentrate or the need to behave in a certain way. Out-with the presence of these demands, the felt presence of ADHD disappeared from view. This understanding then made sense of several participants' comments that they didn't feel they needed medication at weekends or during school holidays. It struck me here that the young

adults were expressing something that was very different about ADHD, in comparison to for instance other illnesses or disabilities such as epilepsy, where there is a continuous perceived permanence of condition separate to the self identity (Weinbren & Gill, 1998). In this study participants accepted they had something wrong; because they were aware of having problems at school and/or at home, or because someone told them they had it, or because they noticed a difference with medication. However, there did not seem to be a corresponding internal felt sense of having a disabling condition from which the self could be separated. This realisation was useful in shifting the framework from how was ADHD woven into their life narrative and self-identity to thinking about; how have these 'difficulties' been incorporated into their narratives. From such a standpoint it was possible then to see the interviews as narrating a process of overcoming exclusion and forging a self identity that could include and often utilise these problem experiences. As in for instance, one participant wanting to use her experiences to help others in a caring role, or another seeing his experiences as helping him secure 'top dog' position in a gang of youths.

The intensity of sadness as well as frustration expressed during interviews was also powerful and moving. This was expressed most often in relation to the struggles they encountered making and sustaining friendships. Almost all had experienced periods at school of feeling isolated and alone, and this led again to the observation that for them the primary issue was not one of finding a way to overcome or manage ADHD, but rather of trying to overcome a huge social hurdle. A factor which overrode almost all other considerations, pushing academic and family difficulties aside. There was great frustration poignantly expressed as just not knowing how to make friends' and sadness when attempts were either not reciprocated, or resulted in episodes of bullying. Hand in hand with this was a seam of deeply held frustration at perceived unfairness where they perceived harsher rules often being applied to them than others. Or when others, particularly authority figures, automatically assumed that they were to blame for events and incidents. Reflection on this led me to consider the extent to which these young persons often felt themselves to be judged and disempowered in their daily life and how this contributed to their common felt sense of being stuck, and also perhaps to them using novel strategies to find a place in a peer group. Those who expressed the most

optimism and positive movement appeared to be participants who had effected such a transmutation of their ADHD experience into something that enabled them to fulfil the developmental task of identity and peer group affiliation as mentioned above. Even if conceivably the strategies they might adopt take them to the fringes of society.

Concluding statement

The present study set out to explore the everyday lived experiences of those growing up with ADHD. The analysis suggested that whilst the adolescents accepted the diagnosis, valued the help of medication and were aware of experiencing difficulties that non-ADHD peers did not, their felt experience was not of having a medical condition, but of feeling excluded. Exclusion was reflected in their difficulties with peers and teachers, as well as views about themselves where they felt excluded from feeling that they were normal and the same as peers. The study describes various strategies that are adopted in order to try and overcome exclusion along with the consequences and the factors that shape how these strategies are used. The results of the study are discussed in terms of implications for future research and clinical intervention.

6) Appendices.

Appendix I: DSM-IV ADHD diagnosis criteria

DSM-IV Criteria for ADHD

A. Either (1) or (2):

(1) six (or more) of the following symptoms of inattention have persisted for at least 6 months to a degree that is maladaptive and inconsistent with developmental level:

Inattention

- (a) often fails to give close attention to details or makes careless mistakes in schoolwork, work or activities
- (b) often has difficulty sustaining attention in tasks or play activities
- (c) often does not seem to listen when spoken to directly
- (d) often does not follow through on instructions and fails to finish schoolwork, chores, or duties in the workplace (not due to oppositional behaviour or failure to understand instructions)
- (e) often has difficulty organising tasks and activities
- (f) often avoids, dislikes, or is reluctant to engage in tasks that requires sustained mental effort (such as schoolwork or homework)
- (g) often loses things necessary for tasks or activities (e.g., toys, school assignments, pencils, books)
- (h) is often easily distracted by extraneous stimuli
- (i) is often forgetful in daily activities

(2) six (or more) of the following symptoms of hyperactivity-impulsivity have persisted for at least 6 months to a degree that is maladaptive and inconsistent with developmental level

Hyperactivity

- (a) often fidgets with hands or feet or squirms in seat
- (b) often leaves seat in classroom or in other situations in which remaining seated is expected
- (c) often runs about or climbs excessively in situations in which it is inappropriate (in adolescents or adults, may be limited to subjective feelings of restlessness)
- (d) often has difficulty playing or engaging in leisure activities quietly
- (e) is often 'on the go' or often acts as if 'driven by a motor'
- (f) often talks excessively

Impulsivity

- (g) often blurts out answers before the questions have been completed
- (h) often has difficulty awaiting turn
- (i) often interrupts or intrudes on others (e.g., butts into conversations or games)

B. Some hyperactive-impulsive or inattentive symptoms that caused impairment were present before the age of 7 years

C. Some impairments from the symptoms is present in two or more settings (e.g., at school/work and at home)

D. Clear evidence of clinically significant impairment in social, academic or occupational functioning

E. The symptoms do not occur exclusively during the course of a Pervasive Developmental Disorder, Schizophrenia, or other Psychotic Disorder, and are not better accounted for by another mental disorder (e.g., Mood Disorder, Anxiety Disorder, Dissociative Disorder, or a Personality Disorder)

Appendix II: Participant Demography and Context

Participant demographics and contextual details.

| Participant code Number | Gender | Age | Current Stimulant Medication Yes/No | School / Work | Additional contextual information where provided |
|--------------------------------|---------------|------------|--|--|--|
| Participant No 1 | Male | 17 | Yes | Completed 6 th yr going on to University | Intact professional family. Urban area. |
| Participant No 2 | Male | 16 | Yes | 5 th year, sitting some exams. Desperate to leave school. | Intact family rural environment |
| Participant No 3 | Male | 15 | Yes | 4 th year, taking 7 standard grades expecting good passes. Hopes to become mechanic | Lives with Mother and brother. Urban area. |
| Participant No 4 | Male | 14 | Yes | 3 rd year. Dyslexia diagnosis - additional support provided. | Intact family, self employed business. Older sister. Rural area. |
| Participant No 5 | Male | 15 | Yes | 4 th year, no exams. At risk of formal exclusion. | Lives with mother, stepfather and baby sister. Urban area. |
| Participant No 6 | Male | 15 | No | 4 th year, taking 7 standard grades. | Intact professional family. Urban area. |
| Participant No 7 | Female | 17 | No | Left school – hoping to attend college | Lives with mother, rural area |
| Participant No 8 | Female | 14 | Yes | 3 rd year. Hoping to take exams next year – additional support provided. | Lives with mother. Urban area |
| Participant No 9 | Male | 16 | Yes | Left school, starting vocational course at college in autumn. | Lives with father. Rural area. |

Appendix III: Table of code frequencies,

| Summary of coding density | | | | | |
|--|-----------------------------|----------|--------------------------|--------------------------|----------|
| | No of passages coded | % | Node Area Total % | No of Inter-views | % |
| CAUSAL CONDITIONS | | | | | |
| Friendship difficulties | | | | | |
| Facilitators | 43 | 3 | 13 | 8 | 89 |
| Barriers | 156 | 10 | | 9 | 100 |
| School difficulties | | | | | |
| Teacher relationships | 84 | 5 | 7 | 9 | 100 |
| Academic failure | 28 | 2 | | 8 | 89 |
| FELT EXCLUSION | | | | | |
| From feeling normal | 83 | 5 | 11 | 9 | 100 |
| From friendships | 25 | 2 | | 8 | 89 |
| From good teacher rels | 60 | 4 | | 9 | 100 |
| STRATEGIES | | | | | |
| Fitting in | | | | | |
| Seeking specific peers | 25 | 2 | 8 | 5 | 56 |
| Conforming | 22 | 1 | | 5 | 56 |
| Seeking peer attention | 83 | 5 | | 9 | 100 |
| Seeking 'normal' self | | | | | |
| Explaining | 104 | 6 | 22 | 9 | 100 |
| Positioning | 114 | 7 | | 9 | 100 |
| Evaluating | 152 | 9 | | 9 | 100 |
| CONTEXT | | | | | |
| Healthcare | | | | | |
| Diagnosis process | 60 | 4 | 7 | 9 | 100 |
| Treatment process | 28 | 2 | | 9 | 100 |
| Understanding of ADHD | 12 | 1 | | 7 | 78 |
| School | | | | | |
| Primary | 9 | 1 | 2 | 4 | 44 |
| Secondary | 11 | 1 | | 5 | 56 |
| ACTIONS & INTERACTIONS | | | | | |
| Managing social exchanges | 46 | 3 | 5 | 8 | 89 |
| Finding positives in experiences | 27 | 2 | | 4 | 44 |
| Self management techniques | 12 | 1 | | 3 | 33 |
| SHAPING | | | | | |
| Impact of diagnosis & treatment | 37 | 2 | 10 | 8 | 89 |
| Developmental stage | 63 | 4 | | 6 | 67 |
| Interventions by others | 58 | 4 | | 9 | 100 |
| CONSEQUENCES | | | | | |
| Optimism | 35 | 2 | 3 | 8 | 89 |
| Pessimism | 17 | 1 | | 2 | 22 |
| TOTAL CODED TEXT | | | | | |
| UNCODED TEXT | | | | | |
| fragments eg, participant queries, or unrelated facts such as description of birthday cake & 'yeahs' | 214 | 13 | | 9 | 100 |

Appendix IV : Sample Interviews, category structure & node text printout

**Participant 1. Interview excerpt (middle of interview)
Talking about making friends at high school.**

3rd year someone introduced me to marijuana and er I got into started listening to music. Before that I'd just been like culturally, you know Listened to the music my dad played and stuff like that I didn't really have any...I wouldn't say I didn't have any culture but I hadn't really sat down and thought about it for ..bit far out..erm in 3rd year started buying CDs and stuff and started hanging round with people in the village and things like that and yeah social activities and things, and er...er started listening to music properly so like Pink Floyd, (pause) it was yeah really the turning point in a way, because before that I hadn't really had much of a social life at all. Erm the erm ritalin was, it enabled me to get on well in school, but I was still you know basically a weirdo because all that anyone had ever heard of me were these memories of primary school and I was just this little kid who hung around with all the geeks basically erm

You used the word weirdo there where did that come from

err urm don't know, its just my friends they're all like (pause) some of the people that you tend to meet make the impression that anything that doesn't comfort to exactly what they do is like, you know, strange in some way. That you know, people are really awkward, forceful often they'll 'personalise ' at things. Not sure it that's the right application of the word its just sounds you know the kind of person that its like leads from the front. I am the example follow me and the a lot of people like that.

I think when you first come to secondary actually, the kind of people, in [school] you are all in regi classes so you are not necessarily lumped tog with people who are your friends. Of course they have made it all completely daft and bugged it up now and regi is just bollocks. (*what's changed?*) they've mixed up the year groups. So previously you had regi class that was the people that you were in all of your classes with for most of 1st/2nd years. But erm now its lessons.. how to stop bullying or something but really it just means 1st years speak to 1st years there is a bench for each year and no one speaks to anyone else its really daft.

But they er,...I cant even remember what I was speaking about.

I was the mentioning you'd used the word weirdo and I was wondering about that

yeah the kind of people in 1st 2nd year you know the trouble makers the people who will take charge of the class and disrupt it and not let anyone get on with their work. And to and extent like after 1st /2nd because you were in classes that were more to do with ability they kind of loose I think to a certain extent their almost prestige almost. They are not special anymore they are just the dumb asses they always were but up until then no-one had realised but erm (pause) yeah so in 3rd 4th year that so I had friends, but its I was irresponsible because really in 3rd /4th you still have to stay at school and standard grades are nothing I passed 4 1 and 42s and this is completely off the record I went to the prelims stoned and pulled off the same trick it was like you know pathetically easy. And erm...I think to some extent 1s/snd was just a piss take but like still kind of behind in a way because that was when I got my social skill and my friends.

For like a couple of years before that just getting my head down and getting on with my work and stuff, and erm..er that its ...er ...kind of weird I don't know whether its been (pause) that people regard you less as a weirdo because when you are at the regi class groups then um someone s'like these trouble makers that those who, its kind of a bad stereotype, but there is one in ever class and its like these peoples their opinions kind of matter less because you don't have to put up with them every day. So I think that you can of course choose who you hang with more or less I mean youre in with people that think and I met most of my friends in the second year top group English class the 3 of us sat together at the front and erm we were all er into the same kind of things and kind of rubbed off on each other like he got me listening to Pink Floyd and I taught L stuff like just daft things like just pick up from other people, like you know, people that were actually prepared to put up with me as a person and not just slag me till I left. It was actually quite good..

Would you say a bit more about what you meant 'put up with you as a person'

well the to the extent that I can hang around with them every single night for a whole week and like that whole for like I don't know 4 years now, longer in fact but and er in that whole time not one of us has had a serious falling out with the other one. No serious fight or anything.

I was intrigued about the 'as a person' what that meant.

I don't know what it is that's eh..because I don't know a bit more socially aware erm things that I say as I mentioned earlier on are quite tactless sometimes in a funny way, but you know I erm try to do it..sometimes things come out with out meaning it as they do and erm you say something daft like that and erm I just became acutely aware of this and that erm. And...but...like most people I wouldn't even notice that I was being strange in the course of a conversation doing something that someone else would consider strange and then they would go over and say hes a bloody weirdo, but my friends will actually think of it as funny or something but erm its just acceptance really I suppose. Is erm...this is erm...strangeness most of the other ADHD kids that you used to meet because we all got the second dose of tablets at the same time during break and they all seemed to be the little buggers that made my life misery for 2 years...this is bloody strange.

What was going through your mind that seemed so strange.

just that..I mean...(pause) I've always kind of enjoyed school in the way that it's a social environment and these people couldn't wait to get out of it. Kind of I don't know, I just don't understand I've always been very academic the kind of person that can say, eh...you may have 5 highers but I'm playing for the Sunday league football team and you'll never be able to join. The kind of person who sets store by completely different set of ideals but doesn't let other people but doesn't let other people other peoples opinions come in to it at all. If someone else is good at something that I'm completely crap at and doesnt really have any opinion of, then that's fair enough, I wouldn't sit and slag them for it. Like erm..I was junior chess champion of the whole school for 2 years, that was my big achievement. That was the kind of thing where people would say that's really bloody sad, I didn't think so. It probably was (laugh)

**Participant 7. Interview excerpt (start of interview)
Talking about making friends at primary school.**

I don't know... people have found it easier starting at different places ... so sometimes they've gone back to primary school and started there, and some people have found it easier to talk about life just now, where would you like to start?

I could start from primary school or what I remember of it! Seems like ages ago

Do you remember your first day at school?

No.

Not at all? Some people have really powerful memories. What do you remember about primary school?

Well one of my primary schools... it was quite a nice primary school but I didn't... find it so easy to make friends ... very easily and eh... sometimes I'd, you know, find things quite difficult and I'd get stuck and... I didn't always want to ask for help you know... I wasn't you know, someone up for asking for help. I wanted to do stuff on my own. But making friends was quite a bit of trouble for me... em...

Can you talk a bit more about that?

Em... I was ... I was always sort of out there sort of thing ... em I suppose, wild child!

What does 'out there' mean? Have you got a wee bit of an example?

Out there, em, I was.. quite a loud person, quite hyper quite a lot of the time and sometimes I was a bit too much for some people. I did try to make friends with, it was sort of slow down kind of thing... so that was quite difficult but in the end some of the primary schools em... I ended up making friends and I had a few who stuck with, but because I was sometimes just... out there as such, I got some trouble off people, you know, I ended up getting a bit of grief and stuff like that eh... which I thought was quite fair at school, but schooling ... em, sometimes you feel you get just a bit more pinpointed ... you know, because maybe you are a bit more hyperactive than other people, you know.

It seems to be something that's quite important about how other people react to you differently. Have you got any examples or memories that could give me a better picture?

Em... well one incident in one of my primary schools was I was playing with this boy and a couple of his other friends and he said bark like a dog and chase us for a joke, and I thought oh, fun, you know, they're trying to make friends with me, so I thought ok, so I did that and then they went back to the teacher and said I was chasing them barking like a dog. And they didn't say... they didn't say they asked me to do that, that was the big difference. And I was like, oh, I thought I was making friends here sort of thing and then I was just a bit... I wasn't too sure, you know.

That's really interesting so there's a couple of things there about being treated the same and also you ended up carrying the can for something which...

Yeah, well sometimes I did and sometimes... you know, I tried not to throw myself into making friends so quickly but I ended up throwing myself into making friends quickly because then I didn't really have many friends at all and I was really wanting to have friendly people to spend time and stuff like that. I mean, I had my mum, you know, but for friends as such. It wasn't the most important thing in the world but...to me, it really was.

So that was important. It sounds like at primary things gradually changed, you were aware of it being difficult and then later on?

Yeah.

Can we go back to where it was more difficult. So what did you notice was happening?

Well.... Most of the time I was just sort of singled out by the pupils themselves, so I was on my own most of the time. Eh... I mean, I ended up getting used to it, you know, your own company, you're bad company either way, but I was on my own quite a lot and I ended up just getting used to it and I thought you know, you're going to have friends, you know, ... later on sort of things, so sort of got used to it.

Is that what you were aware of thinking to yourself?

Yeah, I suppose.

You said other people were singling you out.

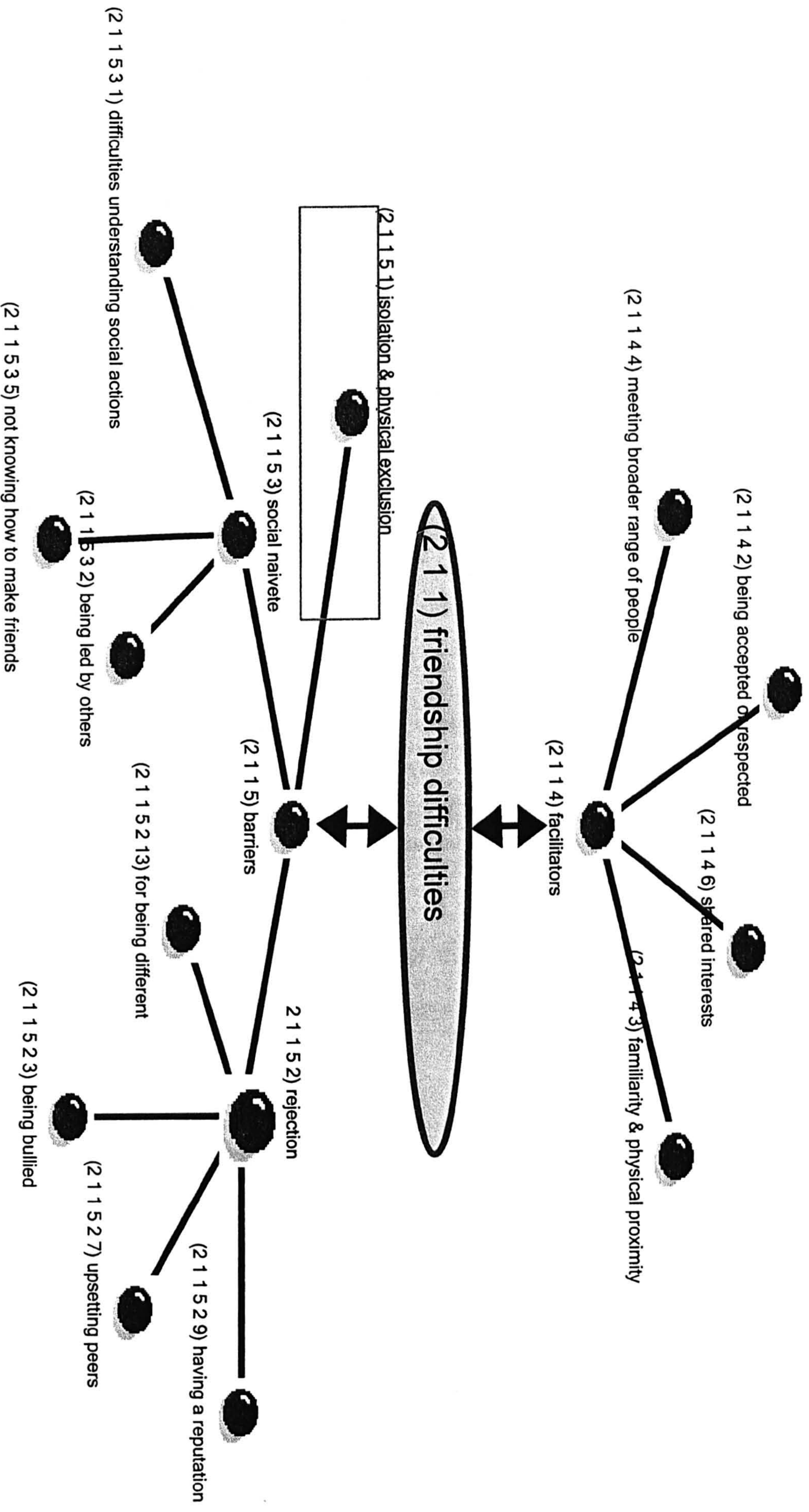
Yeah it was you know, we don't want to hang out with her you know, she's mad or whatever... em... so I was on my own for quite a lot but I ended up with some decent people who didn't judge me as for being a bit mad. It was oh well, you know, she's a mad person, fun to hang out with and that made me feel a lot better.

Tell me a bit more about that change then.

Well... one of my friends, em... we ended up becoming really good friends, she was just always so nice to me and she realised that... she just had to get to know me better and we ended up just chatting and... then... em... becoming best friends pretty much, just hanging out all the time, you know. I was really happy to have a good friend who didn't judge me at all. And it was good to have someone there.

What was different about the way she was with you?

Well, she treated me the same as everyone else, as if... I wasn't different. You know, she would just... I was just another person to her, pretty much. You know, other people would like, you know, oh she's a bit over hyper and stuff like that, and she'd be like you know, so? 'It doesn't mean anything to me, we're good friends'.



Node: /ADHD as a problem of felt exclusion/Causal conditions/friendship difficulties/barriers/isolation & physical exclusion

Treenode address: (2 1 1 5 1)

Created: 12/06/2005 - 17:23:20

Modified: 30/06/2005 - 21:52:04

Documents in Set: interviews

Document 1 of 9

Passage 1 of 5 Section 0, Para 9, 349 chars.

9: No not really, we were uh staying my dad was is a priest he was working on the you know the xxxx in xxxxx go down towards BF there is the white church and white house right at end at mid xxxx and of course this is the late 80 and er mid xxxx is about the minkiest place in the whole of xxxx so of course you just didn't go outside so..

Passage 2 of 5 Section 0, Para 17, 44 chars.

17: didn't really know anyone outside out church

Passage 3 of 5 Section 0, Para 21, 132 chars.

21: I used to have to spend a fairly high % of my lunchtimes inside and breaks doing work that I'd forgotten and daft things like that.

Passage 4 of 5 Section 0, Para 39, 74 chars.

39: I got sent home for half the day once for telling the deputy head teacher,

Passage 5 of 5 Section 0, Para 97, 187 chars.

97: I think 5 years ago I would have felt left out but now I more or less don't care because the time I spent not watching TV I spend reading books which I think was probably better for me.

98:

Document 2 of 9 Interview 2

Passage 1 of 5 Section 7, Para 126, 87 chars.

126: I'm not doing it any more because she's not even letting me go into the class any more

Passage 2 of 5 Section 7, Para 334, 39 chars.

334: It's just like people can't get to you

Passage 3 of 5 Section 7, Para 350, 145 chars.

350: It's stopping, it's like stopping things happening. I can't get to do the same things as other people because I can't get out to do these things

Passage 4 of 5 Section 7, Para 350, 109 chars.

350: I have to do different stuff from other people because they think I can't do the same stuff as other people.[8]

[8] Internal DB: others pre-judging because of label?

Passage 5 of 5 Section 7, Paras 381 to 382, 65 chars.

381:

382: It does make me feel different, it just makes me feel different.

Document 3 of 9 Interview 3

Passage 1 of 2 Section 1, Para 29, 259 chars.

29: because I've been in trouble a lot my Play Station and my television has been taken off me and before we had some stuff put on the doors I was going into my brother's room to play his Play Station and my mum caught me one time and then she put me into my room

Passage 2 of 2 Section 1.3, Para 161, 121 chars.

161: And there's been quite a few days when I've had bad days, I've been sent out and had punishments home, been letters home.

Document 4 of 9 Interview 4

Passage 1 of 2 Section 0, Para 69, 80 chars.

69: there used to be this screen thing and I used to be put behind it all the time.

Passage 2 of 2 Section 0, Para 73, 159 chars.

73: It was like a screen thing and it was put to separate me and... from all my mates and that because we used to muck about in the class and they just separated us.

Document 5 of 9 Interview 5

Passage 1 of 3 Section 61, Para 453, 71 chars.

453: Don't know. Probably sent to a children's home or something like that.

Passage 2 of 3 Section 64, Para 461, 71 chars.

461: I'll be expelled from school so I'm not... I'm not doing well for myself.

Passage 3 of 3 Section 75, Paras 548 to 549, 115 chars.

548:

549: Just asked them. But they've got other friends and they could be going out with their friends so I just stay in.

550:

Document 6 of 9 Interview 6

Passage 1 of 5 Section 0, Para 225, 159 chars.

225: if I reacted in some way, if someone was annoying me, I'd get upset or something and then they'd just like not want to talk to me so you're like... I've no-one.

Passage 2 of 5 Section 0, Para 241, 74 chars.

241: I never got along with anyone eh. I didn't really like anyone in my class

Passage 3 of 5 Section 0, Para 241, 580 chars.

241: It was about three months or something before the end of term, it must have been two and I was meant to be moving to xxxxx but I was in the middle of an exclusion and the xxxx primary teacher

never wanted me in. Because they thought that I might have still needed some more help ... which I thought if I was at a different school making a fresh start, different people, they don't know anything about me which... I thought that, but they wouldn't let me in because I was in the middle of an exclusion and I already had three before that, and they just thought I needed help.

Passage 4 of 5 Section 0, Para 329, 149 chars.

329: and they knew that if they did... like really wind me up, I would do that, and then just... lose them as a friend and things like that. Which was tough.

Passage 5 of 5 Section 0, Para 393, 264 chars.

393: Em... it was... it was just weird cos I never... before I like went up to the ... psychologist I couldn't... I never... I just kept everything bottled up so it was... when I was going through it I just had a lot of things on my mind that I couldn't... em, deal with it, so I just...

Document 7 of 9 Interview 7

Passage 1 of 7 Section 0, Para 39, 118 chars.

39: Well... Most of the time I was just sort of singled out by the pupils themselves, so I was on my own most of the time.

Passage 2 of 7 Section 0, Para 127, 163 chars.

127: my maths teacher Mr M, maybe he'd just say go outside, take five minutes. And you didn't... you ... I didn't really personally like being chucked out of the class,

Passage 3 of 7 Section 0, Para 127, 44 chars.

127: some other teacher would just chuck you out,

Passage 4 of 7 Section 0, Para 147, 49 chars.

147: Em... I think she maybe felt quite on her own a lot

Passage 5 of 7 Section 0, Para 147, 76 chars.

147: but I think she felt on her own quite a lot, but other than that she was ok.

Passage 6 of 7 Section 0, Para 335, 37 chars.

335: would go out of their way

Passage 7 of 7 Section 0, Para 411, 428 chars.

411: Yes, sometimes I feel really on my own even if I had friends, I just feel singled out, em... but then ... when I got to high school I met other kids like me and I thought oh, I'm not the only one, you know. Even though mum and the psychologist and that had told me, you know, that there was loads of other kids like me, ... sometimes I just thought I was totally singled out and all on my own, but then I realised I wasn't, I was ok.

Document 8 of 9 Interview 9

Passage 1 of 4 Section 0, Para 53, 97 chars.

53: they'd send me out and I'd get into trouble, get... phone my mum and dad to get me and take me home.

Passage 2 of 4 Section 0, Para 61, 129 chars.

61: I was sent outside and the head teacher got phoned, I didnae get on with him at all and we got a big argument and he excluded me.

Passage 3 of 4 Section 0, Para 85, 93 chars.

85: into trouble because I'll talk, they'll shout and I'll raise my voice back and that's me out.

Passage 4 of 4 Section 0, Para 483, 16 chars.

483: kicking me out.

Appendix V: Ethics Approval

Tayside Committee on Medical Research Ethics
Level 9
Ninewells Hospital & Medical School
DUNDEE
DD1 9SY
Telephone Number: 01382 632701
Fax Number: 01382 496207
www.nhstayside.scot.nhs.uk



Ms Elizabeth Ross-Gillies
Trainee Clinical Psychologist
Child & Adolescent Clinical Psychology
Centre for Child Health
19 Dudhope Terrace
DUNDEE DD3 6HH

Date 12 April 2004
Your Ref
Our Ref NFB/FB/050/04
Enquiries to Mr Nigel F Brown
Extension 32701
Direct Line 01382 632701
Email nigel.brown@tuht.scot.nhs.uk
or
fiona.bain@tuht.scot.nhs.uk

Dear Ms Ross-Gillies

Ref: 050/04 A qualitative study of how many young adults perceive having been diagnosed and treated for Attention Deficit and Hyperactivity Disorder (ADHD) as children

Thank you for your email of 31 March 2004 with version 4 dated 31/03/04 of the Participant Information Leaflet. This is entirely satisfactory and I am pleased to confirm approval on behalf of the Tayside Committee on Medical Research Ethics to this study proceeding subject to the following conditions:

Conditions of Approval:

- The research may proceed only when you are also in possession of a final approval letter from the NHS Tayside R & D to whom I am copying this letter.
- You should follow the protocol agreed and advise the Committee of any proposed amendments – no significant changes to the protocol should be made without Ethics Committee approval.
- You must promptly inform the Ethics Committee of deviations from or changes to the protocol which are made to eliminate immediate hazards to the research subject; of any changes that increase the risk to subjects and/or affect significantly the conduct of the research; all adverse events that are both serious and unexpected; new information that may adversely affect the safety of the subjects or the conduct of the research; if the research is abandoned for any reason.
- Each research proposal will be subject to a follow-up review and may be selected for a monitoring visit on behalf of the Tayside Trusts.
- You must start the project within two years of the date approval is given or the approval expires; extensions can be applied for.
- You are required to provide an annual update on the progress of the study and notify the Committee of its termination.

Yours sincerely

LREC ADMINISTRATOR

cc: Mrs K Coll, NHS Tayside R&D



Members: Dr J Davidson (Chairman); Mrs D Campbell; Dr C Jackson; Dr F Daly; Mr A S Jain; Dr S MacAndrew; Mr A MacConnachie (Medical Advisor); Mr G MacLaren; Dr W Stevenson; Dr M A R Thomson; Mrs F Valentine; Mrs L Van Aalten.
Deputies: Dr D Cuthbertson; Dr E Mitchell; Dr D Carson
Administrator: Mr N F Brown

Appendix VI: Caldicott Approval

CONFIDENTIALITY STATEMENT - for users of person identifiable data



| | |
|---------------------|--|
| User Details | |
| Name: | Elizabeth Ross-Gillies |
| Position: | Trainee Clinical Psychologist |
| Organisation: | NHS Tayside & NHS Lothian |
| Address: | Child and Adolescent Clinical Psychology, Dept of Child Health, Dudhope Terrace, Dundee |
| Tel: | 01382 632424 |

| | |
|------------------------|--|
| Sponsor Details | |
| Name: | Dr David Coghill |
| Position: | Consultant Child Psychiatrist |
| Organisation: | NHS Tayside |
| Address: | Dept of Child Psychiatry, Dept of Child Health, Dudhope Terrace, Dundee |
| Tel: | |

| | |
|---|---|
| Data Protection Reg. No. : | |
| Data Requested : | Access to Dept of Child Psychiatry Medical Records to identify young adults previously diagnosed and treated for ADHD. Contact details (name and address) only required. |
| Co-Users of the Data : | Researcher is sole user of data. |
| Intended use of data (inc. publications) : | Doctoral thesis. D.Clin.Psychology, Univ of Edinburgh. |
| Period for which Data to be Retained : | Medical Records will not be removed from the psychiatry department. A record of participants consenting to take part will be retained by the researcher in a locked cabinet in Dept for Child Health, between March 2004 to Dec 2005, then destroyed. |

| |
|--|
| User's Declaration |
| I declare that I understand and undertake to abide by the rules for confidentiality, security and release of data received from NHS Tayside. |
| Signature |
| Date |

| |
|--|
| Sponsor's Declaration (to be signed by a consultant if patient data is requested and the applicant is not of that status or is not medically qualified) |
| I declare that the above named user of the data is a bona fide worker engaged in a reputable project and that the data requested can be entrusted to this person in the knowledge that they will conscientiously discharge their obligations in regard to confidentiality of the data. |
| Signature |
| Date |

| |
|--|
| On completion, please return this form to: The Information Security Officer NHS Tayside Ashludie Hospital Monifieth Dundee DD5 4HQ |
|--|

| | |
|--------------------------|--------|
| For NHS Tayside use only | |
| Release authorised by | |
| Date | 2/6/04 |
| Ref.No. | |

All requested documentation received.
This is a replacement statement, signed original lost.
I have confirmed both user and sponsor declarations.

Appendix VII: Letter of Invitation

Primary Care

**Area Clinical Psychology Department
Child & Adolescent Psychology**



Invitation to participate (for participants over 16yrs of age)

Dear

I am writing to advise you about a research project that I am running in the child clinical psychology department, which I wondered if you would consider taking part in.

I am interested in finding out about how people who were diagnosed and treated for ADHD as children, think and feel now about that experience. To find out more about this I would like to interview people who are now young adults about their ADHD experiences.

If you consented to take part in the study you would be asked to meet with me to discuss the study in more detail and sign a consent form. We would then meet again and I would ask you to talk about your experience of ADHD. An information leaflet has been enclosed with this letter, which will give you a lot more information about the study.

Participating in the study is entirely voluntary and you can withdraw at any time without having to give a reason. If you did agree to participate any information you give me will remain private and confidential.

If you would be interested in taking part in this study please could you contact me either by telephone on 01383 346565, or email beth.ross-gillies@tpct.scot.nhs.uk giving me your name and a contact telephone number so that I can call you back. Alternatively you can complete the reply slip below and send it back to me in the enclosed reply paid envelope.

Thank you very much for your time.

Yours sincerely,

**Beth Ross-Gillies
Trainee Clinical Psychologist with
Senior Clinical Child Psychologist**

Please complete this slip and return to: Mrs B. Ross-Gillies, Trainee Clinical Psychologist, Clinical Child and Adolescent Psychology, 

I am interested in taking part in the research, please contact me on the telephone number below:

Name:..... Tel number:.....(best times to call)



Invitation to participate in a study

Dear ,

I am writing to advise you about a research project that I am running in the child clinical psychology department, which I wondered if you would consider taking part in.

I am interested in finding out about how people who were diagnosed and treated for ADHD as children, think and feel now about that experience. To find out more about this I would like to interview people who are now young adults about their ADHD experiences.

If you consented to take part in the study you would be asked to meet me along with your parent(s) or guardian to discuss the study in more detail and sign a consent form. We would then meet again and I would ask you to talk about your experience of ADHD. An information leaflet has been enclosed with this letter, which will give you a lot more information about the study. As you are 16 years old or younger your parent or guardian also needs to consent for you to take part in the study and so I have also sent the same information to your parent(s) or guardian.

Participating in the study is *entirely voluntary* and you can withdraw at any time without having to give a reason. If you did agree to participate any information you give me will remain private and confidential.

If you would be interested in taking part in this study please discuss this with your parent(s) guardian so that they can contact me.

Thank you very much for your time.

Yours sincerely,

**Beth Ross-Gillies
Trainee Clinical Psychologist with**



Appendix VIII: Information Sheet for Research Participants

A study of how young adults perceive having been diagnosed and treated for Attention Deficit Hyperactivity Disorder (ADHD) as children.

PARTICIPANT INFORMATION LEAFLET.

I would like to invite you to take part in a research project. However, before you decide whether or not to take part, I need to make sure that you understand why I am doing the project, and what would be involved. I am therefore providing you with the following information about the project.

Read the following information carefully. If you want, discuss it with friends or family. You do not have to make a decision right away. You do not have to take part if you don't want to.

WHAT IS THE STUDY ABOUT?

- I am doing research to try to understand more about the impact receiving an ADHD diagnosis and treatment has on young people. I am interested in finding out what young adults think and feel about their ADHD experiences. Both at the time they were first diagnosed and now, looking back.
- I aim to do this by talking to young adults who were diagnosed and treated for ADHD as children.
- Ten young adults between 14 and 18 years of age have been asked to take part in the study.

WHY HAVE I BEEN ASKED TO TAKE PART?

- You have been asked to take part in this study because you have received, or are still receiving, ADHD treatment.

WHAT WILL I BE ASKED TO DO?

- If you are interested in taking part you will be asked to contact me. You can do this by telephone on 01382 346565, or email on beth.ross-gillies@tpct.scot.nhs.uk or by returning the reply slip. A stamped addressed envelope has been enclosed for you to use.
- Once I know you are interested, I will contact you by telephone. I will arrange a time to meet you to discuss the study, and answer any questions you may have. You will be offered the choice of meeting me at the Centre for Child Health or at your home.
- At the end of the meeting if you want to take part, I will ask you to sign the enclosed consent form. I will then arrange to meet you again to interview you about your ADHD experiences. If you are under 16 years old I will also discuss the study with your parent or legal guardian and ask them to sign a consent form too.
- At the interview, I will check you are still happy to take part. Then I will ask you to talk about your ADHD experiences. The kinds of questions I will ask are "*how did you come to be diagnosed and treated for ADHD?*" "*What do you think and feel now about the experience, looking back?*" "*How has the experience affected your views about yourself, or how others view you, or your future?*" With your permission, the interview will be audio-taped so that I can go over what you have said. The length of the interview will depend on how much information you wish to share, but last no more than 2 hours. You can stop the interview at any time for a break. Or if you wish, the interview can be divided into shorter sessions on different days. If the interview lasts over an hour then a short break in the middle will be arranged.

WHAT WILL HAPPEN TO THE INFORMATION COLLECTED IN THE STUDY?

- All information you give me will be treated as confidential. I will give a code number to your interview so that you will not be identified. The only people who will see the information will be myself, and my research supervisors.
- All the information you give me will be stored in a secure place (e.g. in a locked filing cabinet). Transcripts of the interviews will have personal identifiers such as names removed and be stored in a secure password protected computer file. At the end of the study the audio-tapes will be destroyed.
- So that other professionals can learn from the findings of this study, some articles and papers may be published. However your name will not be used, and you will not be able to be identified in any publication from the study.

WHAT ARE THE RISKS AND ARE THERE ANY BENEFITS TO TAKING PART?

- This study may not benefit you personally, but by sharing your experience and having your views heard, you are able increase the knowledge of others. This may help us to develop the services young people with ADHD receive in the future.
- As you do not have to share any information in the interviews that you do not wish to, there should be no risks in taking part. If however you feel upset or distressed during the interview it will be stopped immediately. You also have the right to withdraw from the study at any time.

WHAT ARE MY RIGHTS?

- The decision to take part in this study is entirely voluntary. You can refuse to take part or to withdraw from the study at any time. You do not have to give a reason.
- This will not affect your future medical care or your relationship with medical staff looking after you.
- You can get more information about this study by writing/e-mailing/ telephoning me at the address/number below.
- Please feel free to discuss this study with friends and family before deciding to take part.
- You can refuse to take part or withdraw from the study at any time, even if you agree to take part now

THE TAYSIDE COMMITTEE ON MEDICAL RESEARCH ETHICS

- The Tayside Committee on Medical Research Ethics, which has responsibility for scrutinising all proposals for medical research on humans in Tayside, has examined the proposal and has raised no objections from the point of view of medical ethics.
- It is a requirement that your records in this research, together with any relevant medical records, be made available for scrutiny by monitors from NHS Tayside.

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

If you wish more information regarding this project please contact me:

Beth Ross-Gillies
Trainee Clinical psychologist
Department of Clinical Child Psychology
15 Dudhope Terrace, Dundee
01382 346565
beth.ross-gillies@tpct.scot.nhs.uk

Appendix IX: Consent Form for Research Participants

A study of how young adults perceive having been diagnosed and treated for Attention Deficit Hyperactivity Disorder (ADHD) as children.

Consent Form for participants (and parent(s) of participants aged under 16yrs)

Please tick (✓)
appropriate box

Have you read and understood the Project Information Sheet? Yes No

Have you been given an opportunity to ask questions and further discuss this study? Yes No

Have you received satisfactory answers to all your questions? Yes No

Have you now received enough information about this study? Yes No

Who have you spoken to Dr/Mr/Mrs/Miss?

Do you understand that your participation is entirely voluntary? Yes No

Do you understand that you are free to withdraw from this study at any time? Yes No

Without having to give a reason for withdrawing? Yes No

Without this affecting the present or future medical care of you or your family? Yes No

Do you agree that your records in this research be made available for inspection by monitors from NHS Tayside Monitors? Yes No

Do you agree to take part in this study? Yes No

Signature Date

Name in Block Capital Letters

Telephone Contact

For participants aged under 16yrs only parent or guardian must also sign below:

Signature of parent or legal guardian

Signature..... Date.....

Consent form continued

Relationship to participant

Telephone Contact (Home) (Work)

Signature(s) Witnessed ByDate

Witness Name in Block Capital Letters

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