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Living with ADHD: An Interpretative Phenomenological Analysis Study of Mothers’ Experiences

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The Research Dossier consists of a study exploring the experience of mothers who have a child with Attention Deficit Hyperactivity Disorder. This study utilises a qualitative methodology, specifically Interpretative Phenomenological Analysis.
LIVING WITH ADHD: AN INTERPRETATIVE PHENOMENOLOGICAL ANALYSIS STUDY OF MOTHERS’ EXPERIENCES.

Abstract:

Attention Deficit Hyperactivity Disorder (ADHD) is one of the most commonly diagnosed childhood disorders. This study aimed to explore the personal experiences of mothers who have a child with a diagnosis of ADHD. A qualitative methodology, Interpretative Phenomenological Analysis, was used to explore and illuminate issues that might improve our understanding and treatment of the difficulties associated with ADHD by an in-depth analysis of mothers’ accounts of their experiences. Eight mothers, whose children have a diagnosis of ADHD and who were also receiving ongoing support for their child’s behavioural problems, gave audio-taped interviews which were transcribed and analysed for common themes. Three main themes emerged from the analysis: Challenge to the meaning of being a capable parent; Reframing the problem; and Making sense of and coming to terms with ADHD, and these were discussed in the context of theoretical knowledge. It is suggested that although mothers’ experienced relief and a new understanding of their child’s problems, they continued to struggle with considerable ongoing difficulties that involved friends, family, school and wider social pressures. Some of these problems were complicated by the controversy surrounding the diagnosis of ADHD. The effects of the complex interplay of these many pressures upon the parent-child relationship were explored. Models of the maintenance of parent-child conflict were suggested with the focus on attachment and self-efficacy, and the impact of these as well as mothers’ attributions and cognitions, upon their experience of their child, were described. The possible implications of this study for clinical practice were considered.

Key words: ADHD, parenting, effectiveness, childhood disruptive behaviour disorders, qualitative research, parent-child relationship.
1. INTRODUCTION

Attention Deficit Hyperactivity Disorder (ADHD) is one of the most commonly diagnosed behavioural disorders of childhood (Barkley, 1990) and is described as a complex neurodevelopmental cluster of problems (Kendall, 1997; Zwi, Ramchandani & Joughin, 2000), the major symptoms of which are severe levels of inattention, hyperactivity and impulsivity which together result in challenging behaviour, poor family and social relationships and academic underachievement. The criteria for ADHD are listed in the *Diagnostic and Statistical Manual of Mental Disorders, fourth edition* (DSM-IV), (American Psychiatric Association, 1994). The DSM-IV describes ADHD as a discrete set of symptoms or behaviours that can be distinguished from normal childhood behaviour, and these criteria are used both clinically for diagnostic purposes and empirically for research purposes. The research suggests that ADHD has a prevalence of 1% of UK school-aged population and as high as 3-5% in the USA (Kendall, 1998; Searight, Nahlik & Campbell, 1995; Taylor & Hemsley, 1995) and there is an extensive body of literature on the diagnosis and treatment of ADHD (see review by Cantwell, 1996). The findings from these studies indicated advances in the understanding of aetiological factors, medication effects and psychosocial interventions, and identified the need for more studies on the long-term outcome of treatment.

The medicalization and labelling of this cluster of challenging childhood behaviours has given rise to a debate concerning the effects or consequences of a diagnosis of ADHD. It is argued that on the one hand that constructing a child’s behaviour as a neurological mental disorder potentially removes responsibility for a human problem from the parent and child. This in turn may affect the normal processes of parental expectations of their child’s development with the possibility of over-focusing on a child’s perceived disabilities (Nyland, 2000; Smelter, Rasch, Fleming, Nazos & Baranowski, 1996). Furthermore, the questionnaires and rating scales developed to establish prevalence and severity of the behaviours described as ADHD are based on norms derived mainly from white middle-class expectations of behaviour (Breggin, 1998; Diller, 1998; Nyland, 2000) further prescribing and describing specific values about normal child behaviour. On the other hand, a diagnosis may serve as an
explanation for long-standing and distressing behaviour problems, and offers the possibility of treatment and improvement of quality of family and social life (Klasen, 2000). This debate may also be understood as reflecting the social construction of diagnosis, i.e., that traditional diagnostic categories have a powerful influence to subject the individual to the dominant culture’s ideas about how a person should be, for example, how to be a “good parent” and raise well-behaved, co-operative children, with diagnosis being the culturally sanctioned means of labelling those who fail in these socially constructed ways of being (Gergen, 1999; Gorman, 2001).

Regardless of the position taken within the debate about ADHD, it is acknowledged that parenting a child with chronically challenging behaviours such as those described as ADHD, requires emotional adjustment and parenting skills that may be different to those for children without such difficulties (for example, Lewis-Abney 1993).

The recommended treatment of ADHD incorporates either medication alone or in combination with psychological interventions, which include parent skills training and behavioural interventions in the classroom (Nolan & Carr 2000; Pelham, 1994). Often, even with such input, improvements do not occur; children become more distressed and difficult to manage and parents exhausted. Parents are viewed as being of significant importance in the success of these therapies, requiring active participation in, for example, parent training and close liaison with school, and there is an expectation that parents need to be quite determined in their efforts to change their own behaviour and responses for these strategies to be helpful and effective (Barkley, 1997a; Hoza et al., 2000). The literature also acknowledges a high drop-out rate (15-23%) from parenting programmes, (Nolan & Carr 2000, pp.88-91) with the occurrence of significant parental difficulties such as depression, substance abuse, marital conflict, financial problems and personality disorder as being the major causes of non-engagement or not completing the treatment (Patterson & Chamberlain, 1994; Pfiffner et al., 1999). In their study of the parents of 105 children, Hoza et al., (2000) found that the mothers of children with a diagnosis of ADHD continued to experience low self-esteem and inefficacy following parent training. This study suggested that parental beliefs needed to be considered as possible targets for psychological intervention as parents are the implementers of the recommended treatments for most childhood conduct problems.
It therefore appears that the literature and clinical practice addressing challenging childhood behaviours in general, and ADHD specifically, has neglected the area of parental cognitions when considering effective psychological therapies. For example, if a parent believed that their child was being naughty and deserved frequent discipline, then they would be unlikely to carry out interventions that recommended ignoring bad behaviour and rewarding positive behaviour. Equally, if a parent believed their child misbehaved because of their own inadequacy as a parent, even simple boundary-setting around challenging behaviour would be difficult to carry out. Another example might be helping a child with managing their own anxiety; if the parent believed that 'facing their fear' might emotionally scar their child, a child would find it very difficult to carry out this difficult challenge if their parent anxiously responds to any sign of distress in their child. In all these situations the interventions are unlikely to be helpful and the family may withdraw from treatment. It would appear that the key to most of these interventions lie in parents feeling confident in their ability to understand and respond appropriately to their child. However, parents that request psychological assessment of their child have often lost confidence in making sense of their child's difficulties and their own parenting abilities. In the case of parenting a child with a diagnosis of ADHD there are possibly a number of factors that might make otherwise confident parents feel overwhelmed.

The basic position of this study was that the diagnosis of ADHD is widely accepted as a valid diagnosis, the assessment and treatment of which has been taking place for the past 20-30 years (Cantwell, 1996; Nyland, 2000) and is supported by an extensive literature. As a clinician involved in assessment and decision-making on the issue of diagnosing a child with ADHD, I regard it as important to hold in mind the possible risks and benefits of a diagnosis. This issue is further complicated by the added tensions and debates that still surround ADHD, especially around the use of a controversial medication as the recommended first line of treatment (Cantwell, 1996; Nyland, 2000; The MTA Cooperative group, 1999).

A diagnosis of ADHD provides a framework within which the unique characteristics of a child and family may be understood. I am aware that by applying a diagnostic label to a set of behaviours, I am participating in pathologising a child’s problems as
was suggested by Dallos, Neal and Strouthos (1997) whose study indicated that when child behaviours are coupled with a psychiatric diagnosis, families might interpret all challenging behaviour as illness, setting up "an escalating loop of increasingly pathological identification of the difficulties" (p.372). However, there have been many families that have benefited from the specific interventions for ADHD, as indicated in the ADHD Service Development article in this portfolio, where over 60% of children on the ADHD treatment list were reported to have no significant problems post diagnosis and treatment with medication; this percentage is similar to that found in other studies (Gillberg et al., 1997). Despite this positive response, there still remained a considerable number of families struggling with the implications and consequences of an ADHD diagnosis. Therefore the need to gain a deeper understanding of what it means to a parent living with a child who has been given a diagnosis of ADHD is important to me in both my continuing clinical practice and my own professional values as a clinical psychologist.

Therapeutically effective interventions are of particular significance when considering helping a child who has co-occurring conduct problems such as aggression, defiance and antisocial behaviour (Kuhne, Schachar & Tannock, 1997). These behaviours are not considered part of the core features of ADHD and the long-term outcome for these children has been found to be poor, with adjustment problems in adult life, such as continuing antisocial behaviour, poor employment records and difficulties with interpersonal relationships (Barkley, 1990; Kuhne et al., 1997). Studies have identified family problems as contributing to the development of conduct problems and are of a separate quality to the difficulties experienced by families with a child who has a diagnosis of 'uncomplicated' ADHD (Johnston & Mash, 2001). In children with co-morbid conduct problems, parent-child interaction has been shown to be rejecting, coercive and inconsistent, and the combination of a vulnerable child and family and parenting difficulties are thought to form a complex pathway which results in a child having a long-term conduct disorder. These families in particular need a comprehensive treatment 'package' which addresses all these difficulties appropriately.

Research in the field of ADHD tends to employ large-scale statistical studies using clinical and non-clinical subjects focusing on the clinical aspects of the disorder and
medical and/or behavioural interventions (for example see Barkley, 1997b and 1997c; Biederman et al., 1996; The MTA Cooperative Group, 1999). Although this trend in research offers interesting and important information, other issues have not attracted as much research attention; for instance, there appears to be little in the literature on ADHD about the parents’ experience of having a child with this condition, and how this may have affected their sense of confidence as parents and their relationship with their child. In a recent review by Johnston and Mash (2001) it was suggested that the social and interpersonal aspects of the impact of ADHD have been neglected in the research, with the emphasis mainly on the biological understanding and treatment taking the foreground in recent years. Hoza et al., (2000) found that parental cognitions (how they think and feel, e.g., negative beliefs, parenting self-efficacy, attributions for their child’s behaviour) about their child and themselves as parents had an impact on treatment outcome. It was suggested that components of treatment needed to be geared to addressing specific aspects of parental cognitions within training programmes and medical interventions. Little research has been conducted on linking treatment to parental experience and beliefs about their child and the condition being treated. Johnston and Mash further stated that areas such as the degree of difficulty experienced by these families with regard to relationships and parental adjustment remain relatively unexplored.

It is these areas of interest, i.e., parental cognitions and parental and family adjustment to the diagnosis of ADHD that the literature appears to have neglected, that this study wishes to address in order to expand our understanding of the lived experience of parents with a child with ADHD. By ‘lived experience’ I am particularly interested in how parents perceive their child, and how these perceptual mechanisms might influence their understanding of their child and the behaviour they are struggling to manage in the context of a diagnosis of ADHD.
2. DESIGN

2.1 Aims and Research Questions

The aim of this study was to explore the experiences of parents of children with ADHD. The accounts of their experiences may offer insights into their views and attitudes about their child and themselves as parents that could potentially enhance our clinical understanding and interventions with these families.

Open-ended questions (Willig, 2001) guided this study:

(1) How do mothers experience living with and parenting their child with ADHD?; and

(2) How do mothers’ accounts enrich our understanding of the clinical phenomena of ADHD?

In order to address these research questions, the following research method was chosen:

1. Qualitative study – interest in mothers’ experience and understanding

2. Exploratory study – attempting to map and describe this groups’ experience and not test hypotheses

3. Cross-sectional – An extensive interview on a single occasion was used to gather the data. However, this also contained a longitudinal element in that I gathered descriptions of how their
beliefs and experiences had developed retrospectively and in the present.

4. Set of individual case studies – to include broadly ethnographic summaries to contextualised case material to offer a holistic picture, which is especially relevant to the clinical applications of this study, as well as studying common themes shared by the individual participants.

As I was to enter the life-world of the participants through their accounts (Willig, 2001, p.54) my own interpretative engagement with their discourses would naturally be influenced by my training and experience as a clinician and therefore would inevitably shape the research process and the findings. In order to maintain an open-minded approach therefore, the use of personal reflexivity i.e. reflecting on the way my own experiences, interests beliefs and values influenced the study, was a crucial part of the research process. A reflective account of the research process can be found in Appendix A.

3 METHOD

As the research questions were exploratory rather than hypothesis driven, and sought to examine participants’ perspective of their experience, a qualitative methodology was chosen to gather and analyse the data (Chapman & Smith 2002; Jarmin, Smith & Walsh, 1997; Robson, 1993). Data collection methods needed to be flexible and open-ended to enable participant-generated meanings to emerge (Willig, 2001); consequently, a semi-structured interview method was chosen and is discussed in more detail below. The data analysis method chosen for the study was interpretative phenomenological analysis (IPA)(Smith, Jarman & Osborn, 1999). IPA is a method of exploring the participant’s view of the world, i.e., their thoughts, expectations, beliefs and judgements about the phenomenon being investigated, and enables the researcher to adopt an ‘insider’s perspective’ of the topic. It recognises that the process of the researcher’s interpretations of participants’ accounts will naturally be influenced by the nature of the interaction between participant and researcher and the researcher’s own world view, but this is not viewed as a bias, but rather a “necessary
precondition for making sense of another person's experience" (Willig, p. 66). The characteristics of IPA made it a very suitable method for investigating parents' experience of their child with ADHD.

3.1 Theoretical underpinnings of method

Phenomenological psychology (Giorgi, 1995; Willig, 2001) and symbolic interactionism (Denzin, 1995) form the methodological cornerstones of the study. Phenomenological psychology is mainly concerned with the individual's personal account of an event, "phenomenology focuses upon the content of consciousness and the individual's experience of the world" (Willig, 2001, p. 52), as opposed to a process of objective evaluation. In phenomenological psychological research, the account of the participant becomes the phenomenon that the researcher engages with. With symbolic interactionism, Denzin (1995) states that: "interactional experience is assumed to be organized in terms of the motives and accounts persons give themselves for acting", (p.57). It further considers that the meanings that individuals give to events are of primary concern and that those meanings occur 'in, and as a result of, social interactions' (Smith, 1995).

3.2. Data collection method

The author followed a semi-structured interview format that comprised key questions devised to draw on the areas of interest as outlined above. The questions were co-constructed in supervision to broadly cover parents' early memories of their child, the events leading up to and including diagnosis and the effect of the diagnosis on the parent, child and others. Questions eliciting information about parents' own childhood were included as well as questions relating to how things were for themselves and their child in the present. A copy of the interview schedule can be found in Appendix B. The interview schedule was used mainly as a guide to the topics of interests to the research, but it was used flexibly during interviews where sequencing, wording and focus were modified to facilitate participants in-depth account of their experiences, as suggested by Robson, 1993 (pp. 153-154, 237-240).
3.3 Sample

Participants were selected from the treatment list of a specialist ADHD community nurse who is part of the local Child and Adolescent Mental Health Service, and who was involved in helping parents with behavioural modification and parent skills training. This specific group represented those families where medication alone was not sufficient as their child presented with complex behavioural problems that were considered by the ADHD child psychiatrist as being severe enough to need intensive home-based interventions. These participants therefore represented cases within the more complex area of ADHD symptomatology. This particular group were studied as it was possible that they may be experiencing significant difficulties that may challenge the efficacy of recommended interventions and that there may be important information that has not yet emerged due to the specific focus of the main literature on ADHD e.g. biological aetiology, assessment and medication.

This form of purposive sampling, i.e., the principal of selections “is the researcher’s judgement as to typicality or interest” (Robson, 1993, p. 141) was carried out, as the purpose of the study was not to generalise the findings to the population of families with children with ADHD, but rather to enable the in-depth exploration of this group of parent’s experience of their child with ADHD.

3.4 Procedure

Potential participants’ names were selected from the specialist nurse’s list. I selected names on the basis that I would contact only those parents who I had not been involved with either in the assessment of their child or therapeutically as this may have hindered the interview process had the participants already been familiar with me. Invitations to participate in the study (Appendix C) were posted to potential participants. An information sheet that explained the proposed study, and included details of the reason for the study as well as the proposed format of their participation i.e. a taped interview accompanied the invitations. Confidentiality, the voluntary nature of their participation and the right to withdraw from the study were also emphasised; a time limit within which to respond was given. The contact details of the author were given and parents were invited to telephone if they wished to
participate. Twelve such invitations were sent out and nine responded. All those that replied had the mother as the main carer. One participant withdrew as they had changed jobs and moved to a different area. Therefore, eight mothers had agreed to take part in the study. This was considered an adequate number of participants by my supervisors, based on Turpin et al., (1997) guidelines. These participants were therefore self-selected as is the case in all ethics approved research where participants explicitly have the freedom to refuse to participate or can opt-out of studies. Those who did not respond were not followed up.

Before commencing the interview, all participants signed a research consent form that reiterated the information contained in the original details they had received relating to the voluntary nature of participation, the opportunity to ask for further information and confidentiality (Appendix C). Participants were interviewed individually in the Psychology Department as this was agreed as being the most convenient venue. Interviews lasted between one to one and a half hours, and were audio-taped.

When respondents telephoned to indicate their willingness to participate, interview dates were arranged. The time restraints of the study meant that it was not possible to transcribe and analyse each interview sequentially, but summaries were made following each interview in order to facilitate an active awareness of the predominant themes and emerging ideas.

On completion of the interview, participants were reminded that they could request a follow-up session should there be any issues arising from the interview that they found distressing. One participant requested a session, which took place a few days following her interview.

Permission for the study to take place was granted through the local NHS ethics committee after scrutiny of the research protocol.

3.5 Qualitative analysis

IPA is both dependent on and informed by the researcher’s own concepts which are required to make sense of and interpret the participant’s personal account. Although
this method does not examine predetermined constructs as in quantitative methodology, my own thinking is influenced by my training as a clinical psychologist and will therefore inevitably be part of the interpretive process. When thinking about human experience, I hold in mind many theoretical underpinnings that inform my understanding of clients' difficulties. In particular, I am interested in the influences of attachment theory on systemic and narrative therapies (Bowlby 1969, 1973, 1980; Byng-Hall, 1995a), attribution theory, specifically the impact of parental attribution for their children's behaviour (Miller, 1995; Reimers, Wacker, Derby & Cooper, 1995) as well as the influence of parenting self-efficacy (Coleman & Karraker, 1998). These and other influences had an impact on my interaction with the participants and in my interpretation of the data.

The analysis in this study was in two stages; Stage 1 presents summaries of the individual transcripts of the participants' experience. The aim of Stage 1 was to illustrate the process and context of mothers' descriptions, as this forms an important aspect of clinical formulation and therapeutic work. This process of "situating the sample" (Elliot, Fischer & Rennie, 1999) allows the reader to assess to some extent the applicability of the findings. These summaries therefore were used to form a broad background description of the mothers' experiences as a group (Robson, 1993, p.148) and provided the preliminary guiding structure for the interpretive analysis at Stage 2, which involved a detailed analysis of the individual transcripts. These summaries also provide the reader with a context within which to place the quotations in the analysis. Stage 2 analysis was carried out according to the guidelines by Smith, Jarman and Osborn (1999); each transcript was read a number of times in order to become as familiar as possible with the account. Margin notes were made to document emerging thoughts and ideas with comments and preliminary interpretations and codes (for examples of this early stage of the analysis, see Appendix E). As a means of checking validity, the first three transcripts were independently analysed by the author and supervisor (Rudi Dallos) and emerging themes, ideas and constructs were compared to ensure sufficient similarity of ideas was occurring. Overall, there was a satisfactory level of inter-rater agreement. Emerging themes were listed and studied in detail to identify connections between them and to identify master themes. The transcripts were checked at each stage to make sure these connections still related closely to what was said by the participant.
This close interaction between researcher and the text forms the foundation of the interpretative process that enables order to be created from the array of information from the participants’ responses (Smith, 1995). The codes for each transcript were then compared and contrasted with each other and connections between them recorded and sorted and further refined into larger categories and finally three main superordinate themes were identified. Parts of this process were carried out independently by the author and Rudi Dallos in supervision, and findings compared for similarity. Each of these superordinate themes was connected to the underlying themes that were connected across the cases.

In order to maintain an open-minded approach to theoretical models, an extensive literature search was carried out after the analysis of the semi-structured interviews (Robson, 1993; Willig, 2001) to expand upon the literature already referred to in the introduction. An electronic literature search was carried out using combinations of the analysed themes, codes and key words such as ADHD, parental beliefs, cognitions, parent-child interactions, attachment theory and family systems. This produced an extensive amount of literature that resulted in another complex sorting process of maintaining in mind the research questions and integrating the results of the analysis with theoretical ideas and the current literature. I then returned once again to the original transcripts to check for further sub-themes in the light of this expanded literature search.

4. RESULTS

All personal details have been altered to protect the anonymity of the participants and ensure confidentiality. A complete transcript of one interview can be found in Appendix D.
4.1 Stage 1

Case summaries

Participant A (P-A)

P-A is the mother of a teenager Peter, who was the younger of two children in an intact family. The older child was reported as not having any significant problems. Both parents are in full-time employment and also have a busy social life. P-A described many years of trying to make sense of her son's difficult behaviour. From the early years of school, this mother received reports and complaints from teachers about her son's behaviour. Towards the end of his primary school years a teacher suggested getting Peter assessed for ADHD. He was diagnosed and prescribed Ritalin. Initially P-A was relieved to find a reason for her son's behaviour and felt some respite from the self-blame and embarrassment she had experienced over the years. Despite getting a diagnosis, P-A found teachers continued to be unhelpful and critical and it seemed that Peter had been branded as a bad child and this label endured. P-A described continuing social stresses and family friction. P-A felt that she and her husband generally managed their son's behaviour reasonably well together, but from time to time there were arguments and tensions between them because of their different ways of responding to him. The main friction occurred between the two children with Peter frequently precipitating arguments. P-A described Peter as being like his father in that he also had a short attention span, didn't complete tasks and was very restless. When discussing her own family background, P-A described her mother as being critical and unaffectionate and P-A was closer to her father. Implicit in her narrative was the desire to be a warm and affectionate mother, unlike her own mother, and that this belief in her ability to be a good parent had been thwarted by the significant challenges Peter had presented her with.

Participant B (P-B)

P-B is a single mother of a six-year-old son, Simon. P-B has an older child who had recently left home to live independently. P-B reported having had no significant
problems with her eldest child. P-B described Simon as having been quite an easy infant but from two years onwards she interpreted his development as being at the extreme end of normal. P-B has been reading extensively for several years, trying to make sense of her son's behaviour. She read about ADHD and requested an assessment when Simon was five. He was diagnosed as having ADHD and put on Ritalin. P-B felt relieved by being given a diagnosis, but teachers disagreed with this diagnosis and refused to supervise his daytime dose of medication. With a great deal of input from P-B, school have become more helpful in recent months. There are still considerable concerns about Simon's continuing aggressive and disruptive behaviour. P-B has become confused as to which behaviours are part of Simon having a diagnosis of ADHD and which are part of oppositional and difficult to manage and how she should respond. P-B is trying alternative remedies together with Ritalin in the hope that she will find something other than stimulant medication as a treatment.

P-B thinks that Simon was like his father who she described as being arrogant and aggressive. P-B's childhood was difficult because her mother had a serious and enduring mental illness and her father had a "Jekyll and Hyde" personality and who used to discipline the children by hitting them with his belt. In the past, P-B needed antidepressants in order to cope with her own problems, which she attributes directly to the daily strain of parenting Simon. She also relies heavily on the help of the specialist ADHD nurse and the parent support group.

Participant C (P-C)

P-C is married and has two children, Greg, who is nine years of age and who has a diagnosis of ADHD, and a sister Sarah, who is six and has a chronic medical condition. Both parents work outside the home. P-C said that she had an instinct from birth that Greg was going to present with difficulties. She described not only Greg's early behavioural difficulties, but also his inability to understand and integrate with other children. At the age of five, after many years of concern, P-C finally had Greg assessed for ADHD. Greg was diagnosed with ADHD and given medication. The medication helped him to settle in the classroom, but his social behaviour remained worrying; Greg did not fit in at school and was not achieving his academic milestones despite having an above average I.Q.
P-C said that over the years she has become tired and depressed and there have been times when she felt she just couldn't cope with Greg's demanding and inflexible behaviour. She is grateful that Sarah is an easygoing child despite having a chronic condition that needs daily monitoring and treatment. P-C did not mention specific tensions between herself and her husband around managing Greg's difficult behaviour and she gave an unremarkable account of her own childhood.

P-C's was concerned about Greg's future. She felt very worried that he would never be able to fit into an independent working and social life. Despite an early diagnosis and treatment of ADHD no matter what they tried as parents and in collaboration with teachers (who she felt had been mostly unhelpful) nothing appeared to help Greg lead a more normal childhood life. P-C felt she has had to battle to get support both from the teaching and health professions.

Participant D (P-D)

P-D was a divorced parent with two children: Lisa who is fifteen and who has been diagnosed as having dyslexia, and Paul who is eleven and who has been diagnosed with ADHD. P-D runs her own business. The children have regular contact with their father and there remained an openly hostile relationship between the parents and this was a source of persistent stress for P-D.

P-D described Paul as always having been a "naughty boy" who had been in trouble since toddler group. She also described Paul as being bright and aggressive. He screamed a lot as an infant and she found it very difficult to settle him. Paul's behaviour attracted a great deal of criticism and rejection by the parents and children in the neighbourhood where they live, as well as negative labelling by teachers at the local school. She described feeling protective as well as resentful and angry with him on many occasions. P-D heard about ADHD in the media and requested a referral for assessment from her G.P. Paul was assessed for this condition and prescribed Ritalin. P-D reported that the medication initially had a very positive effect, but after a few months this effect seemed to wear off.
Having a diagnosis was a relief and she hoped that this would help both socially and at school, but this did not occur. She felt that the diagnosis was not taken seriously by their village acquaintances, or by Paul’s teachers. School was identified as disinterested in helping Paul or understanding his condition and she felt that Paul continued to be labelled as a naughty child despite his condition.

P-D’s own parents separated when she was ten. She was not close to her father and she described her mother as being “horrendously strict” and that she and her sister lived in fear of her most of the time. She tries to be very different to her own mother.

P-D finds being a single parent very difficult and copes by keeping up a positive front, but admits she often cries in private. She also values the help of the specialist ADHD nurse and sometimes attends a parent support group. She is hopeful that Paul will improve in the future.

*Participant E (P-E)*

P-E is married and has three children, aged between 21 and 11. The eleven year old, John, has a diagnosis of ADHD. She talked in terms of John’s difficulties as being stressful on the family as a whole.

P-E stated that she always thought that John was not the same as the other two and she describes herself as coping variably, i.e., dismissing some things, not coping with others. She found it difficult to feel emotionally close to him in the early years. P-E delayed seeking help because she thought his problems were due to bad parenting. The family eventually reached the stage of exhaustion where they desperately needed help. The GP referred John to the local CAMHS team for assessment and was diagnosed with ADHD and prescribed medication.

P-E described feeling relieved about the diagnosis and there was a brief time of being able to make sense of all the difficulties. The feeling of relief was mixed with a sense of deep regret at not having had John assessed earlier and the damage this had done to
John’s personal development, especially in terms of family relationships, his self-esteem and his ability to make friends. P-E says John still experiences rejection by many of his peers, labelling by teachers as being naughty, and is still displaying antisocial behaviour e.g. stealing and being disruptive in the neighbourhood. He is now inclined to spend time with an antisocial group of youths and P-E is very worried about his future.

P-E described her own childhood as being generally uneventful and also did not specify any significant problems in her own marriage, but that they found it difficult to parent John and this caused tension between them at times.

Participant F (P-F)

Henry is the 15-year-old eldest son of P-F. P-F has been remarried for seven years and has two other children; She describes Henry as having been very active since early toddler hood. P-F became depressed with the strain of caring for Henry and was put on medication by the GP. When Henry was 4, P-F asked for help with behaviour problems, and they were referred to the CAMHS team. P-F felt blamed for Henry’s difficulties by the professionals involved. The problems continued and P-F requested another referral to CAMHS after a period of complaints about Henry’s behaviour at school when he was aged 10. This next assessment incorporated an ADHD assessment. Henry was diagnosed and prescribed medication. Despite her described difficulties with Henry, she did not seem to feel their family life had been badly affected by it and the other children were doing well.

P-F said that she cried with relief when Henry was diagnosed. She expressed regret that this condition had not been identified when Henry was a young child. P-F said that the 10 years of difficult behaviour and feeling responsible as a mother had damaged her relationship with Henry. P-F said the treatment worked and that the last five years have been very different for her son, and that he is planning for college education after completing his GCSEs next year, has hobbies and friends. She feels confident that he will cope with adult life.
P-F’s own history is one of a conflictual relationship with her mother, which continues to the present time. She experiences little support from her mother, who lives nearby, and still experiences her as critical and negative. She is much closer to her father.

P-F has found her local parent support group very helpful in coping with certain difficulties and has experienced secondary school teachers as being unsupportive in terms of trying to understand the specific problems of children with a diagnosis ADHD. P-F was disappointed that a more comprehensive package of aftercare was not offered to her upon diagnosis especially in terms of addressing her relationship problems with Henry.

*Participant G (P-G)*

P-G is the mother of four children, the eldest of whom if fourteen. Her nine year old, Clare, has a diagnosis ADHD. P-G described Clare as always having been a challenge for her. In infancy she cried a great deal and didn’t seem to respond to cuddles or soothing. There were significant behavioural difficulties, which continued through Toddler hood; P-G blamed herself for not being able to manage Clare and this was reinforced by her health visitor and GP who both felt that Clare was developing normally. Although the extended family lived locally, they were reluctant to help. P-G described Clare as being disliked by other children and the family were constantly telling her off. She was also the cause arguments amongst her siblings who openly expressed disliked for her. P-G felt sorry for Clare but also frustrated, overwhelmed and angered by her.

P-G was very relieved when Clare was diagnosed with ADHD and prescribed medication, which helped, particularly in the classroom environment. However, Clare still had significant problems with her behaviour and her relationships, and continued to be in constant conflict with her siblings who continued to dislike her. She is the cause of considerable conflict between P-G and her husband. P-G is worried about Clare’s future, both in secondary school and beyond into adult life. She feels that as a family they have not received sufficient input in terms of understanding the condition and emphasised the need for siblings to be offered a chance to be helped to cope with
ADHD. P-G also feels unsupported by her own mother who lives nearby but who has health problems. P-G looks after her mother as well as coping with her busy family life. She and her mother have always had a conflictual relationship. P-G’s father, who she was much closer to, died when she was a teenager.

Participant H (P-H)

Daniel, who is 12 years of age lives with his mother, P-H, father and older brother of 14. Maternal grandparents live next door to the family and are very involved with the children. P-H relies a lot on her own mother as someone she can go and talk to easily and feels very supported by her.

P-H started to worry about Daniel when he began playgroup as he was unhappy and didn’t integrate with the other children. Daniel found the transition to school difficult and after nine months there the teacher spoke to P-H about Daniel’s difficulties with poor concentration, not being interested in learning, and was disruptive and socially immature. She remembers being aware of feeling angry towards Daniel and embarrassed because of constantly being called in to school about his behaviour. Daniel’s behaviour was similar at home and caused increasing tension in the family over the years. P-H started reading up on childhood problems and she found out about ADHD.

When Daniel was 7 years old P-H requested a referral for assessment for ADHD. He was given the diagnosis and offered medication. She felt relieved to think that as a parent she had not been a failure. P-H explained ADHD to Daniel, who was initially quite compliant in taking the medication, but didn’t want other children to know about it. P-H has high expectations of the medication. P-H found that some people commented negatively on the fact that Daniel was on Ritalin, and remembers there were many stories about ADHD and Ritalin in the media. Because of this P-H didn’t tell many others about Daniel’s diagnosis because she felt embarrassed. She wished that a comprehensive package of help had been offered at the time of diagnosis.

P-H deliberately tries not to look too far ahead because it makes her anxious. She generally is not optimistic about his school career. He won’t want to take medication
at school, doesn't want to conform, likes to push the boundaries and wants to shock and be very different.

These case summaries indicate that six of the eight mothers were in stable relationships, five of who had been married for many years. All the mothers had other children who were reported to be doing well despite two siblings also having diagnosed conditions. None of the mothers reported significant financial hardship and their partners were in fulltime work. Mothers varied from fulltime, to part time work and two were not employed. All except two mothers were isolated from their extended families and felt unsupported by friends and the professionals involved in their child's life. One mother felt she needed to support her own mother, who lived nearby, but this was not reciprocated and the other had a close supportive relationship with her mother. Five mothers described conflictual unaffectionate relationships with their own mothers during childhood and in the present. It is possible that these polarised relationships with their own mothers may have left them vulnerable to seeing themselves as 'poor' mothers. Children's ages ranged from 5 – 15, seven of who were boys and one a girl. Within the limitations of a one-off interview, it would appear that these families did not suffer from significant financial hardship, unemployment and parental psychopathologies, e.g. substance abuse, antisocial personality disorder, that have been associated with children with the severe behaviour problems that can co-occur with ADHD. Several mothers reported problems with depression at some stage, which they attributed to the strain of coping with their child, but all had responded to antidepressant treatment.

Mothers described the impact of trying to parent their child who displayed the classic behaviours associated with ADHD, from an early age. Mothers described feeling guilty, frustrated and powerless to improve the situation for their child and family. Several accounts also indicated longstanding problems with showing and receiving affection from their child. Mothers reported feeling relieved at having received a diagnosis and they began to reconstruct the meaning of their child's behaviour. It would therefore appear that mothers in this study found the medicalization of their child's difficulties helpful. However, despite being relieved and understanding their child's problems in a different way, the ongoing disruptive effect of their child's behaviour continued to have an effect on their family and wider social life. Parents
and siblings seemed to have difficulties accommodating the child with a diagnosis of ADHD's needs, and mothers were faced with a continuing struggle to convince others of the legitimacy of the diagnosis. Mothers were simultaneously attempting to deal with their own ongoing sense of uncertainty, which may have been linked to their childhood experiences with their own mothers, as well as their experience of being unable to make a change for the better for their child.

4.3. Stage 2

IPA Analysis

These main themes will be presented individually as follows:

1) Challenge to the meaning of being a capable parent

2) Reframing the problem

3) Making sense of and coming to terms with ADHD

Table 1 below serves as an example of identifying superordinate themes. A table for each of the themes is not provided due to restrictions of space.

Verbatim reporting of mothers’ accounts throughout is in italics. These quotes are not exhaustive, but rather serve to illustrate by example the themes and concepts being described. Participant coding used in Stage 1 (e.g. P-A) is used to identify which mothers are quoted. Certain words, phrases or sentences have been omitted, such as repetition, expansion, hesitations, in order to make the account more succinct, and this is indicated in the quotations by ...
Table 1: Example of the development of the theme “Challenge to the meaning of being a capable parent from original text extracts.

<table>
<thead>
<tr>
<th>Text</th>
<th>Initial code</th>
<th>Code</th>
<th>Category</th>
<th>Theme</th>
</tr>
</thead>
<tbody>
<tr>
<td>“When he was one I fell and broke my leg, I was carrying (my son)</td>
<td>Difficulties resulting from an accident mother had.</td>
<td>Brain damage caused by mother’s accident</td>
<td>Mother directly responsible for the child’s difficulties.</td>
<td>Challenge to the meaning of being a capable parent</td>
</tr>
<tr>
<td>So I dropped him…. I thought I had given Him brain damage”</td>
<td>(guilt,fear)</td>
<td></td>
<td></td>
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<tr>
<td>(P-A)</td>
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<tr>
<td>“I had an instinct from birth… not a cuddly baby. He was not going</td>
<td>Difficulties due to mothers attitude to her child</td>
<td>Mother’s emotional responses damaging to child</td>
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<tr>
<td>to be an easy child. Some schools of thought would be that I</td>
<td>(guilt)</td>
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<td>encouraged…. my feeling could have affected the way his personality</td>
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<td>developed”</td>
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<tr>
<td>(P-C)</td>
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<td></td>
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<tr>
<td>“I thought it was down to me. Older mother, third child who was an</td>
<td>Difficulties due to a variety of unfavourable personal circumstances.</td>
<td>Unexpected child. Little time available for raising him.</td>
<td>Attributing child’s problems to personal failings as a parent</td>
<td></td>
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<tr>
<td>accident, busy household, and I did feel it was my own failing….</td>
<td>(guilt)</td>
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<tr>
<td>this is why my child was like he was”.</td>
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<tr>
<td>(P-D)</td>
<td></td>
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<tr>
<td>“I was being told it was me, there was nothing wrong… but I was</td>
<td>Difficulties attributed to mother’s inadequacies by others. (shame)</td>
<td>Mother perceived by others as being responsible.</td>
<td></td>
<td></td>
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<tr>
<td>perhaps not verbally told, but that is what they insinuated that it</td>
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<tr>
<td>was me as a mother – you are not disciplining him enough and things</td>
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<td>like that”.</td>
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<tr>
<td>(P-G)</td>
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</tbody>
</table>

4.2.1 Challenge to the meaning of being a capable parent

Mothers held beliefs and values about their role as parents that informed their expectations of their children in terms of how they responded to being parented by them, for example:

*I want to have the sort of children where you can say stand there and wait a minute, and they are not fiddling with things and they are not rude to people, they need to have good manners and that I try to instil in them.* (P-D)
For this parent, having a child who behaved almost in the opposite manner to her values, the experience of having a hyperactive, noisy and impulsive child was deeply distressing. Mothers spoke of the constant battles with their challenging child resulting in disciplining their children in ways that left them feeling ashamed.

*I hear myself saying things to him that horrify me, and it really pulls me up and I think no, this is my mother talking and I don’t want to be like that. (P-D)*

*I blamed myself. Was it the way I was bringing her up, wasn’t I doing things right? It didn’t matter what we tried it didn’t seem to work and I felt like giving up on her really. It didn’t make me feel at all good about myself. (P-G)*

*I always resorted to smacking him as the last resort...I think it was frustration and because I didn’t know any better. (P-E)*

Furthermore, because their children often behaved badly in public, and that complaints by teachers, other children and neighbours were a frequent occurrence, participants experienced embarrassment about their child’s behaviour as well as feeling exposed in their inability to have any appropriate control over their child’s behaviour. There was a sense that their child’s disruptive behaviour challenged the participants’ basic meanings about themselves as parents. As they struggled to gain control over what seemed to be senseless behaviour and sought explanations in reaction to the uncertainties about cause, they all identified being a failure as a parent as the cause of the difficulties with their child. This personally negative evaluation led to feelings of helplessness and lack of control and confidence, thus maintaining a cycle of self-blame and anger and frustration with their child.

*P. was a handful, so much so that if I went out with him I would worry what he was going to get up to. Everybody would come up to me and say, oh you are Tim’s mum aren’t you; everybody knew him, knew what he was like...just being completely over the top. (P-A)*

Some parents were outspoken about experiencing rejecting feelings for their child:
Perhaps we were not handling him as we should and maybe it was our fault, but we got to the stage where the family was exhausted, we needed some help...we had got to the stage where we didn't want him anymore, he was upsetting family so much. (P-E)

I wouldn't have had him. I've got him now and I'll do the job to the best of my ability. (P-B)

He stops me doing things, but I don't resent him now. I cope with it, but if I could go back and undo it, I wouldn't have had him in the first place. (P-C)

The analysis of these mothers' accounts signalled significant distress between parent and child as well as conflict within the family, and that these difficulties had been experienced from early toddlerhood i.e. in some cases, for many years. Common descriptions of the participants' child as “always in your face”; “over the top”; “has to have all the attention” were repeated throughout the interviews. Lack of support from other family members and friends added to the sense of isolation and being alone with their problems. Parents also reported not wanting to go out in public or to visit or to be visited by friends, and their child described as being actively ostracised by others.

He is so well known in the village, he has been totally exiled, he is persona non grata, he never gets invited, no birthday parties, no overnight stays. (P-D)

I have known some very cruel parents in the past who know he has ADHD but they don't want their children to associate with him, he never gets invited to stay. (P-E)

This complex web of self-blame and a sense of failure, together with frustration, anger and hostility towards their child that possibly established a negative pattern of interacting that was difficult to alter even after they found some relief in receiving a diagnosis.

Several participants expressed regret that they were unable to respond to or show affection towards this particular child and that they did not feel they were able to bond with their child during infancy and toddlerhood.
I found it particularly difficult to get close to him in the early years, the way that he was, so difficult to manage. (P-E)

I do find it hard to show her love, cuddle her, whatever. Most of the time I am mad at her...I find it very difficult to cuddle her, she never wanted it when she was small and she does find it difficult now... (P-G)

I don't think it ever has really, and its even today, there is no closeness...if H. does it (puts his arm around her) I cannot cope with it...I feel I have a barrier there... (P-F)

Participants who spontaneously spoke of difficulties with affection and closeness to their child, tended to also describe having had very negative experiences of their own mothers in their childhood when asked specifically about their own childhood experience of being parented.

She was horrendously strict...we obeyed her because we were in fear of her...we lived in fear of her...we lived in fear most of the time. (P-D)

I don't ever remember giving my mum a hug, and I suppose, when my dad died, I don't ever remember my mum giving us a hug then. (P-A)

Lack of closeness and affection with their own mothers possibly made their experience of similar difficulties with their child particularly painful and possibly was a significant factor in preventing these parents from experiencing the potentially positive aspects of this relationship.

Mothers were also able to identify positive qualities in their child that indicated both a liking for and affection for their child:

He's lively and incredibly bright...and his personality is a very sweet loving little boy, and also the other side which is much more difficult. (P-C)
We have some fun with P...the other day he had us in stitches...he was doing this really silly dancing with this impish look on his face that melts your heart...he can go over the top and he won't know when to stop. (P-A)

Even with these more positive descriptions of their child's character, the problems seemed to be just beneath the surface.

During the years before their child was diagnosed these mothers described experiencing ongoing problems such as feeling isolated, criticised, overwhelmed and emotionally distant from their child. However, once they had received a diagnosis, certain changes took place as to how they evaluated themselves and their child.

4.2.2 Reframing the problem

Most mothers expressed a sense of relief at receiving a diagnosis. There was a period following being given the diagnosis where mothers felt some respite from self-blame and guilt and with it, the hope that now they knew what was wrong with their child, solutions could be found to their difficulties.

I admit I was very relieved to feel that its not my fault, because you do feel that, and so having that label gave you something to hang on to, to say, this is what the problem is and its not all my fault, and you take that element out of it. (P-B)

This sounds awful, I was relieved. Its an awful thing to say, to find out your child's got something and to be given a label, but that actually helped me to cope with the fact that he wasn't just a really bad child or evil, it wasn't my bad parenting. (P-H)

Once I had the diagnosis, I could read up and think...I've learnt to find what is important and what's not. (P-G)

One mother, however, said she was shocked:
They (child psychiatrists) said 'your son is ADHD' which was very shocking... I mean there is no easy way of putting it, I mean my child has got a chemical in his brain that he does not produce and this is what makes him the way he is. (P-E)

This mother did not say that she was relieved, but rather dwelt on the fact that she had delayed getting help for many years because she thought she was a bad parent and felt ashamed.

Only one parent spontaneously described her husband’s reaction to the diagnosis:

*His father was devastated; he found it really quite hard. Not because of a stigma, but he didn't want P. to have something wrong with him.* (P-A)

Mothers generally felt that they now could begin to make more sense of emotions and behaviour that had previously been confusing and frustrating, and through learning about their child’s condition, a more positive and hopeful atmosphere could develop and relationships improve. Although participants reported being initially pleased with the improvement that appeared to take place once their child was on medication, especially in the classroom environment, their narratives about the ongoing difficulties their children faced changed from being critical and angry to being an advocate for their child. Once there was a sense of a legitimate reason for their child’s behaviour, i.e. a medical condition, parents tended to change their perception of both themselves and their child. One parent’s account changed from describing feeling overwhelmed and distressed after a parent-teacher meeting before her son was diagnosed: "I bawled and I bawled until my eyes ached", to speaking positively about her qualities as a parent:

*I guess S. is quite lucky having parents that are pretty articulate and professional...and can go up and talk to the teachers...on a level with them.* (P-A)

Upon having her child diagnosed, after many years of feeling worn out and depressed by her son’s demanding and challenging behaviour, another participant changed her expectations of herself of having to change her son, and somehow feeling responsible for his behaviour:
The best thing I could do for G. was to try to cope as a family and in order to do that I had to sort myself out. (P-C)

In this mother’s case, one of the ways she changed her life was to return to work, which she felt able to once free from a sense of guilt and failure. This change helped her to be less preoccupied with the negative aspects of her relationship with her son, and consequently became less tense herself and more easygoing with him.

Becoming less stressed about their child helped other parents to change their responses to their child’s behaviours:

Once I knew he had a problem and it wasn’t a case of just bad parenting, I could actually ease up and give him more...I’ve learnt when to back off and not get so uptight. (P-B)

Two mothers expressed feeling an enduring sense of sadness and regret, as well as resentment that their child’s difficulties had not been diagnosed earlier and therefore possibly preventing some of the disruptive and damaging events from happening. Some of the sadness may be part of the process of grieving for the loss of a ‘normal’ child in the light of a diagnosis of a chronic condition.

I do feel bitter that he didn’t have all this sorted out years ago, I feel very resentful. I feel that as a child he has missed out a lot. (P-F)

The first thing I’d do is get him diagnosed earlier...I think he would be a lot better if he had been diagnosed earlier...it would be nice to sort of think, well I wouldn’t have worked I would have given him more time. (P-A)

Despite expressing regrets about the past, by being able to move away from the position of self-blame and failure as a parent, participants appeared to re-appraise their child as suffering from a misunderstood medical disorder and their role became one of expert and advocate.
It made me realise that it's not her fault, where basically before we thought that she was a right little madam, so it's made it easier in that respect ...You think, well yes, she has got a problem and in a sense stop blaming yourself so much. (P-G)

The change in experience from being a failure to being a champion of their child’s cause may be construed as a positive shift in self perception, but this change in focus carried with it a new set of concerns, fears and frustrations from which the theme of uncertainty about many aspects of their child's life emerged, and the struggle to make sense of their child and their difficulties in the light of having a diagnosis.

4.2.3 Making sense of and coming to terms with ADHD

Prior to diagnosis mothers felt overwhelmed and found coping successfully with their child almost impossible. Upon being given a diagnosis, mothers described how they tried to find out as much information as possible about ADHD as a way of learning to cope with it. Participants discovered many confusing factors that made it difficult to apply this information to their child, both in understanding and responding to them.

There's no book I could give you or there is so many different elements to it. It's a learning stage constantly, no matter what mothering skills you've got or heard of before, it's a whole different ballgame. (P-B)

Despite now having an explanation for their child’s problems they were still confronted with considerable difficulties in knowing how to parent their child. As well as day-to-day practical parenting problems, there were several areas of common concern in the personal accounts.

a) Professionals

The participants’ accounts all identified their disappointment and at times anger at the professionals involved with their child. This was both retrospectively, in that their child’s condition went unrecognised and they had felt blamed, to the present, where professionals were perceived as being unhelpful, unsupportive and unwilling to alter their perceptions of a child in the light of their diagnosis. This particularly applied to teachers, but mental health professionals were criticised for not offering greater
support to families following diagnosis and inter-professional communication was inadequate or inappropriate.

_I think a more proactive approach to getting it sorted out early on from the healthcare professionals...I feel it was all led by me...I have just pushed this...its only because I have been upset about it and pushing it that anything has really happened._ (P-E)

_She (the teacher) didn’t like the fact that I was telling her what the problems were and it did caused a lot of friction. It got to the stage where I really didn’t want to go into the class because the teacher was very impolite to me at times._ (P-G)

_Even though they (teachers) accept it, they didn’t want to because they had already said, no, he hasn’t got ADHD, and no, he shouldn’t be on the Ritalin._ (P-B)

_Teachers don’t like the idea of the medical profession saying its this, no we can teach them, we can do it. Its that battle against, I think the problem is sometimes it’s the professional against the professional. Who is right. No one wants to admit they are wrong and the other profession could be right._ (P-H)

Participants were now focusing very much on the perceived failures and inadequacies of the professionals and this process may have served as a vehicle for change from self-blame and powerlessness to directing their frustration outwards, beyond their child and family, and gave them focus on what they needed in order for all their lives to improve

b) Confusing behaviours

All of the participants described what they experienced as confusing behaviours and emotions in their child that did not fit the diagnostic descriptions they read about e.g. stealing, aggression, defiance, mood swings. Now they had some information about ADHD, they found it difficult to understand whether these behaviours were due to ADHD, or to other conditions, or, indeed, to their child having significant behavioural or emotional problems that may be due to other causes. They also found it difficult to gauge how to respond to their child as their medication wore off at the end of the day.
You've got two different children in one day because you've got him when he's gone onto Ritalin and you can work and you can actually do a normal thing, and then when he's coming down, you then know you've to go into that other mode, do different things...is this something that just happened at school or is it normal or is it part of his ADHD, there is so much, so complex. (P-B)

I don't understand why, to take it (money stolen from disabled neighbour). Whether it shows immaturity in him, or whether its lack of understanding because of his condition, I really don't know. (P-E)

Even on medication she is not what I would call a happy child...it's still very hard to understand why she is doing the things she is doing. Things are still more difficult with her behaviour-wise, and just any general thing, it's never just straightforward. (P-G)

Is what I see a problem or is it a personality...am I trained to put a label on it, because at the end of the day, he does not make friends, he does not behave in a socially acceptable way, he can't function in a group, he can't concentrate in a group, how much of this is ADHD and how much of it is him. (P-H)

When asked what their child understood about the diagnosis parents felt that they had gone to considerable lengths to explain to their child about ADHD, but that the child had remained relatively disinterested or indifferent.

He was young when he started his Ritalin, he never asked why...never wanted to deal with 'why'. I wanted to talk to him before I answered anyone else's questions but he didn't really want to know...he knows it's there but he doesn't ever want to talk about it. (P-C)

I think he was probably relieved (to find out he had a condition)...I got the impression he was quite relieved to find out that the reason he was doing these things...there was a specific cause. (P-A)
I don’t think he really knows much about it; he knows there is something but I don’t think he really understands what it is...never really been willing to listen. (P-H)

c) Family
Siblings were reported as finding their sibling with a diagnosis of ADHD difficult to live with, and were also finding that the explanation of their sibling’s condition did not alter the irritation they felt towards that child.

He (the brother) finds him hard to deal with...there are times when he gets really frustrated, angry and shouts and swears...you can tell its sheer frustration at things. (P-A)

They tend to fight with each other, crack up with her very easily, even though they have been told about her problem...they tend to fall out with her a lot. (P-G)

...it’s affecting the whole family, so we’ve become a dysfunctional family because the other two children disliked him and the attention he has. (P-E)

Several mothers reported tensions developing with their partners around managing challenging behaviour:

If G. (dad) starts to shout at him, I shout at G. to ignore him, and of course he hears me shouting to G...I would say what is harder than having a child with ADHD almost, is the ability to deal with that ADHD within the family. (P-A)

Dad has found it difficult to understand and cope with his problems...his dad says how dare you talk to me (like that). Children don’t talk to adults like that...to him it’s natural to shout, but I tend not to. (P-E)

Two single parents had different experiences of coping on their own. The one stated:

I feel sorry for these mother that have husbands...I think I am quite lucky because I don’t have to put time and energy into anything else. Its made me a lonely person because I dare not, I won’t have a relationship, because I’m frightened that all the
good work we’ve done will go out the window...it works because there is nobody else. (P-B)

Whilst the other was still locked in a hostile relationship with her ex-partner where ADHD had become another area where he construed himself as being a better parent (together with his new partner):

*He says he knows all about it (ADHD) and he understands it all and he knows how to handle situations, and then he does things that are totally contrary to what I’ve been told to do. If I point it out to him, we have an argument. (P-D)*

Mothers felt they needed support in helping the other members of the family to understand ADHD, particularly how siblings should respond when they were feeling irritated or marginalised. This was yet another example of how being given a diagnosis may have helped mothers to feel they understood their child’s behaviour better, but others’ negative views about that child remained unchanged and their responses continued to be critical and conflictual.

d) Medication

Mothers described their concerns about medication. Most of the participants felt that although medication helped their child they were worried about the long-term effects and the fact that they were giving their child a controversial treatment.

*...there is not a medical reason as such for ADHD to give them the treatment, to warrant taking the tablet and obviously there is some side-effects and things of the tablet that make you worry...I would like to know if there was a real problem in her brain. (P-G)*

*If there wasn’t really anything wrong with him then you obviously worry that he shouldn’t be taking the medication (P-H)*

These statements reflect the underlying controversy about ADHD that continues to worry parents. Although none of the participants said they doubted the actual existence of the condition, there were wider social forces casting doubt at times as to
whether or not their own child had ADHD. Despite this, none of the parents had decided to reject this diagnosis in terms of their own child.

e) Prejudice
Some of the difficulty in being understood by teachers and family and friends was attributed to the negative views people had formed about their child prior to diagnosis. As well as greeting the news of a diagnosis with scepticism, misperceptions about ADHD meant that responses to their child’s condition included criticism, prejudice and disbelief.

*They (the school) made no allowances whatsoever for the fact that he’d just recently been diagnosed. He had a neon sign on his head that said I’m P. I’m a troublemaker.* (P-A)

*I think the media and people like that...because lets face it, if you ask anybody, any man in the street about ADHD, he’d probably say, oh, that’s naughty children...the focus of it has got to try and be changed to be seen as a medical condition rather than a behavioural problem.* (P-B)

*People have got this perception that if your child has got ADHD then he’s an absolute lunatic, he shouldn’t be allowed anywhere, the parents aren’t any good, its all the parents’ fault.* (P-H)

*They (parents-in-law) felt it was all our fault and that there was nothing wrong with him.* (P-C)

*...his teacher wasn’t keen on giving the Ritalin at first, and there was a big resistance there, and I think he thinks its just one of these new fangled things that they’ve found and I know that his headmaster wasn’t the slightest bit concerned, he just thought he was a naughty boy.* (P-E)

These kinds of negative responses to their child’s condition further reinforced the participants’ experience of fighting a lonely battle on behalf of their child. These mothers had not been able to sustain the peace of mind and relief that they
experienced upon receiving a diagnosis for their child. However there was a sense that although still exhausting to deal with, they felt it important to support and protect their child; they perhaps still hoped that by medicalizing their child’s difficult behaviour, others would become more tolerant and less critical.

P. has his condition. Some children have diabetes, some have cystic fibrosis. P. has ADHD. Let's face it if you ask any man in the street about ADHD, he'd probably say, 'that's naughty children'...I think the focus has got to try and be changed to be seen as a medical condition. (P-A)

f) Coping
Because mothers had experienced so many negative factors in trying to adjust to the complexity of ADHD, some participants discussed areas where they more successfully found support. Having someone to talk to when feeling stressed was one of the main coping strategies that participants identified. For some it was a trusted friend or colleague and for others, a specialist ADHD nurse, recently employed by the CAMHS ADHD team were both highly valued outlets for expressing emotions as well as problem solving.

S. (specialist nurse) is my rock. She might do nowt stuff, but just sits there and listens to me go on and that...sometimes in all this you do get bogged down and you can't see ways out of things, and somebody from outside, but somebody who is a professional, you can't ask an ordinary mum. (P-B)

I find I have a great deal of respect for R. (health visitor colleague) and you know, I can go and talk to her and just say, you know, and I can bawl my eyes out with her, I can scream and shout with her. (P-A)

Many of the mothers found a parent support group helpful and talked about comparing themselves with others in the group as a way of putting their own difficulties into perspective. Being able to support others and offer suggestions and ideas also had a positive effect on some mothers' self-esteem.
You get an awful lot from the support group...you realise that there are people a lot worse than yourself and you swap ideas, and now there is the national ADHD support group who sends lots of literature. (P-H)

I was very enthusiastic about it when we started up (a support group) and I really thought I could put something into it and help people and I felt I gave a lot, and people were able to take something away from my experience and I really thought I was doing some good. (P-H)

Others did not find comparing themselves with other parents or situations helpful and one parent became tearful when thinking about what she perceived other normal families having:

...why couldn’t I have a nice home to bring my children up in, I can’t have a stable marriage, why can’t I just be a normal person in a normal family with two cars, a holiday, work part-time, got a husband that’s got a job and just do normal things. I think of all the other people that’s far sadder than my situation, so in some respects I've got off lightly. (P-D)

The same parent also found exposing her problems to her support group resulted in her feeling vulnerable and exposed and has since withdrawn from it.

g) The future
Most of the mothers expressed considerable concern about their child’s future. Upon learning more about ADHD, they had read and heard that ADHD symptoms often continued into adulthood. Mothers expressed concern about their child continuing to have problems with relationships throughout their life, remain socially immature, or that they would continue on an antisocial trajectory that would bring them into contact with the police.

What happens when he leaves school? How ever is he going to cope and what support will he get after school...I fear sometimes the only support he’ll get is perhaps from the police. (P-E)
One parent expressed concerns about the genetic implications of her son having ADHD:

And in the future, I have heard its hereditary...in terms of H. in the future, the concerns are if it is hereditary,, what is the likelihood of him ever passing it on to his children. Is he and his wife ever going to have the life I had? (P-F)

Some mothers felt more optimistic: J. will learn to cope with it. One mother felt that once her child left the constraints of school life ...his personality will get him through adult life, and another mother, whose son was about to complete his schooling felt: he's growing up, he's learning to cope with it and another commented: I like to think when he's 18 or 19 he'll be mature enough to deal with it.

5. SUMMARY

The analysis gave depth and breadth to the emerging shared narratives of the mothers in Stage 1, by locating their account into three superordinate themes. This in-depth analysis sought to compare and contrast the individual mothers’ experiences of parenting their child before during and following diagnosis. Figure 1 gives an overview of the themes described above and illustrates the idea of a chronological sequence to the mothers’ descriptions.

Mothers described a sense of being ineffective and failing with their child whose difficult to manage behaviour became a challenge to their concept of themselves as adequate parents, with chronically stressful social and family lives. A sense of relief upon finding out a reason for their child’s difficulties enabled a change in understanding about their child’s difficulties to take place. Mothers reframed the difficulties as being medical rather than psychosocial, which released them from feelings of guilt; mothers were then able to approach their child’s difficulties from a different perspective with the hope that the professionals involved with their child would deliver appropriate treatment and support, and that life would settle down for their child and the family. However, they encountered further problems both with understanding their child’s continuing difficult behaviour as well as the negative attitudes of others inside and outside the family. Parents found they were now being
criticised for giving their child medication, and for some, the impression that they were looking for an excuse for their inadequate parenting. Trying to gain understanding and support from others became an ongoing struggle, and family tensions continued compromising the quality of family life. Mothers described ongoing worries about the future for their child who they now understood as having a chronic condition that could affect the rest of their lives.

Figure 1: Overview of mothers’ descriptions of the experience of parenting their child with ADHD

<table>
<thead>
<tr>
<th>Challenge to the meaning of being a capable parent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Early onset behavioural problems</td>
</tr>
<tr>
<td>Difficult parent-child relationship-discipline/affection</td>
</tr>
<tr>
<td>Parental guilt and embarrassment</td>
</tr>
<tr>
<td>Parent works hard to understand</td>
</tr>
<tr>
<td>Unsupportive and blaming community, teachers - labelling</td>
</tr>
<tr>
<td>Chronic family stress and tension</td>
</tr>
<tr>
<td>Overwhelmed</td>
</tr>
<tr>
<td>Isolated</td>
</tr>
</tbody>
</table>

↓

Reframing the problem

Relief

Problem understood as constitutional (within the child)
Change in perspective of self and child
(parent not to blame and child not naughty and bad)
Making new sense of difficulties
Child’s difficulties can be ‘treated’

↓

Making sense of and coming to terms with ADHD

Difficulty understanding ADHD in relation to own child
Difficulty in accessing support
Difficulty in helping others to understand
Ongoing behaviour problems
Ongoing personal and family tension
Concerns about medication
Concerns about their child’s future
Continuing sense of isolation
Prejudice
The future

6. DISCUSSION

Participant’s accounts gave a rich insight into how they experience their child with a diagnosis of ADHD. The research question was broadly stated to enable both the participants and the researcher the freedom to explore and examine both the process
of making sense of their child’s behaviour, and the impact of having a diagnosed condition on the parent-child relationship. The analysis resulted in three superordinate themes; Challenge to the meaning of being a capable parent; Reframing the problem; and Coping with and coming to terms with ADHD. The literature was explored as new questions emerged from the study and mothers’ experiences were then contextualised within current theoretical knowledge.

From the case summary material of stage 1 of the analysis, mothers described a sequence of experiences with their child with a diagnosis of ADHD. During the years before their child was diagnosed, mothers believed themselves to have failed in parenting their challenging child. These beliefs arose out of mothers’ own interpretation of their child’s behaviour, which in turn, were influenced by wider social constructions and interactions (Youniss, 1994). How parents make sense of their children’s behaviour is thought to be strongly influenced by their cognitions and beliefs (Grusec, Hasting & Mammone 1994). A review by Miller (1995) used the term “attribution” broadly by stating that it could be understood as “encompassing a variety of judgements that parents make as they attempt to explain, evaluate and predict their children’s behaviour”, (p.1558) and that these attributions influence parents’ own affect and behaviour. The importance of maternal attributions has been identified as influencing parental response to their child’s misbehaviour (Dix, Ruble, Grusec & Nixon, 1986; Slep & O’Leary, 1998). Accounts of the mothers in this present study suggested that pre-diagnosis, they were confused as to whether their child’s behaviour was because of their own bad parenting or a stable negative characteristics within their child, or because of some other externally located stress. This may have resulted in inconsistent responses to their child’s behaviour. Slep and O’Leary (1998) found that the direction of mothers’ attributed responsibility influenced their discipline styles and levels of anger, and this directly affected their child’s negative reactions. This process possibly resulted in a self-maintaining process of negative parent-child relating as suggested by Patterson, DeBaryshe and Ramsey, (1989) where parenting styles were identified in the aetiology and maintenance of behavioural problems in their children. Slep and O’Leary found that when mothers perceived their child’s behaviour as resulting from negative characteristics within themselves as parents, this led to lax discipline responses, possibly because of guilt-related processes (Smith & O’Leary, 1995).
theoretically explain why the children in the present study displayed challenging behaviour that is considered in the literature as co-occurring but not part of the core symptoms ADHD.

Figure 2: Model of inconsistent parental responses resulting from mixed maternal causal attributions

![Diagram of inconsistent parental responses]

Figure 2 illustrates the cycle of inconsistent discipline that possibly established and maintained chronic behaviour/discipline problems from early childhood. Unable to give meaning to their child's behaviour, mother's felt self-blame as well as blaming the child and oscillated between harsh and lax discipline. This cycle has been well documented in the literature (e.g. Greenberg, Speltz & DeKlyen, 1993). Furthermore, although parenting practices have been well researched, it remains unclear as to what extent these cycles caused the difficult child behaviour or resulted from it. Although the mothers in this study apparently thought that they had parented their other children adequately, by being prone to a sense of failure in relation to their child with a diagnosis of ADHD, they appeared unable to hold on confidently to an experience of successful parenting.
These proposed cycles of inconsistent responses to their child's challenging behaviour were possibly accompanied by feelings of being embarrassed, incompetent and overwhelmed. Although these emotional responses could not be regarded as unusual when parents are confronted by challenging behaviour on a daily basis, because these challenges dated back to toddlerhood (and for some, earlier), it might be reasonable to assume that certain cognitive, emotional and relational disturbances might have become so pervasive, that even the explanation of this behaviour in terms of a diagnosis ultimately did little to alter the fundamental beliefs that their child was difficult to parent successfully, and therefore parents continued to struggle with their lack of confidence in managing their child. These accounts were similar to those reported in Kendall’s study (1998) where parents were emotionally and physically overwhelmed by their child’s chronically disruptive behaviour and that these families often had little support and few answers as to how to cope.

This present study, however, introduced the idea that there was a change in parents’ perception of their child that might be understood as an attributional shift. In some ways this shift in how they understood their child helped to diminish their own sense of guilt as well as facilitating a more compassionate view of their child. However, they encountered significant difficulties in explaining this condition to other family members as well as to teachers and others outside the family system. Their sense of lack of support and social isolation continued, together with the added frustration of feeling that there were others with information and strategies i.e. teachers and health professionals, who were perceived as unhelpfully obstructing the course of possible improvement, by offering only limited information and support, or more seriously, being disbelieving and judgemental.

As the central agents of support and change for their child, parents also had to monitor their child’s medication and deal with the doubts and resistance expressed by others (including sometimes their child) about giving their child a controversial medication. Also, they carried the legacy of years of self-doubt in their ability to parent this particular child. The relief of receiving a diagnosis that the participants all spoke of may have carried with it the hope that they could at last make a difference in their child’s life by following recommended treatments and professional advice. The opportunity to redeem their confidence and self-esteem as parents (all of the
participants had other children who they acknowledged they had been successful with as parents) presented itself as they strove to learn about ADHD, medication and the various possible psychosocial interventions that would support improvement and change.

For the purposes of attempting clarity the themes will be discussed individually in the context of literature as indicated above.

6.1 Challenge to the meaning of being a capable parent

Mothers' guilt associated with their perceived responsibility and self-blame for their child's problems and failure of their relationship formed the core concept of this first theme. Mothers' accounts indicated that, from the very early stages of their child's life, they felt incompetent as parents. Unable to understand their child's behaviour, parents often resorted to ineffective and sometimes harsh attempts to discipline their child: "I would actually be over hard on him"; this in turn elicited negative affect and un-cooperative behaviour from their child. Unable to find ways of controlling misbehaviour, parents lost confidence in their ability to carry out such tasks, and not only did they experience negative child responses to their parenting, but also were unsupported in their efforts by other family members, friends, teachers and healthcare professionals. Even before diagnosis, the stage was set, with this particular parent-child relationship, for potentially enduring behavioural and relationship difficulties.

6.1.1 Self efficacy

Effective parenting, or parental self-efficacy refers to a parent's perceived ability to exercise a positive influence on the development and behaviour of their child. It has been suggested in the literature that self-efficacy is an important core cognitive process (Bandura 1977, 1989), together with parental attributions, in influencing the meanings parents construct of their children's behaviour (Coleman & Karraker, 1997; Grusec, Hastings & Mamone, 1994), and has been linked to important child health, development and relationship outcomes (Joiner & Wagner, 1996). Despite being able to identify having other children that they apparently had managed to successfully parent, the impact of failing with this particular child took precedence. Bandura
stated: “Competent functioning requires both skill and self-beliefs of efficacy to use them effectively...self efficacy is concerned not with the skills one has but with judgments of what one can do with whatever skills one possesses” (Bandura, 1986). Inefficacious parents may think that although there are ways of positively influencing their child’s behaviour, they are not personally capable of doing so. In all cases in this present study, mothers spoke of the lack of personal satisfaction experienced in parenting their child and perceived their ability to exercise positive influence over their child’s behaviour and development impaired.

At one level, it would be quite understandable that parents of children displaying such challenging behaviour might feel ineffective, particularly when considering the long duration and severity of the consequences of the problems. One might easily think that anyone under those circumstances would succumb to feelings of despair and incompetence. However, the question still remains about why are these children displaying such anti-social behaviour? Did these parents in some way respond differently to their child’s behaviour in its early stages to those parents whose child also had a diagnosis of ADHD, but without antisocial problems? Within this theme, parents’ spoke of their inability to experience or display affectionate feelings towards their child. It is possible that the issue of bonding and attachment has a specific influence to the quality of the parent-child relationship in the context of conflict and distress.

6.1.2 Attachment

Grusec, Hastings, and Mammone, (1994) proposed that parental self-efficacy beliefs arise in part from their own childhood experience and that ‘relationship schemas’, or internal representations of relationships are influential in guiding parental behaviour. The attachment literature addresses the formation of these schemas of relationships. It is postulated that they are gradually constructed over childhood and are crucial in the process of guiding behaviour and interpreting events. Although there is very little literature that examines the association between attachment orientation and maternal self-efficacy, Grusec et al., (1994) provided some support for continuity between the two constructs by linking adult attachment style to parental cognitions, e.g. a preoccupied parent (for details on adult attachment categories see George, Kaplan &
Main, 1985 and for child categories, Ainsworth, Blehar, Waters & Wall, 1978) would be inclined to have negative thoughts and attributions. For example, in Grusec et al’s., study (1994) they found that preoccupied mothers were more likely to attribute failure to the personalities of their children possibly because of the proposed difficulty that preoccupied individuals have in differentiating between themselves and others by virtue of their general enmeshment in relationships. Although this present study did not directly address the attachment status of the parent or the child, five of the participants described very difficult or hostile relationships with their own mothers. It is possible that these parents’ own attachment history may have resulted in their being particularly vulnerable to feeling ineffective and responding in a rejecting manner when faced with ongoing stressful behaviour from their child.

These accounts may give clues as to why, despite the causal attribution having changed, the conduct problems continued to be influence by attachment history and ineffectivity as is shown in Figure 3 below. This model of understanding proposes that underpinning the cycles of inconsistent responses to their child’s behaviour, some mothers’ ineffectiveness might have resulted from an insecure attachment history and that the responses as outlined in Figure 2 above continue, despite there now being a diagnosis.

Figure 3: Model of maternal attachment history and impact in cycle of ineffective parenting
6.2 Reframing the problem

A change in attributional direction when given a diagnosis may explain parents’ initial sense of relief, i.e., not mother-centred. Johnston and Patenaude (1994) found that when parents gave their child’s behaviour a different attributional direction i.e., although the cause resided within their child as a ‘disorder’, their child could not be held responsible for their behaviour and neither was the parent to blame. In this present study, the experience of understanding their child as having a medical condition may have enabled parents to develop a more sympathetic attitude to their child’s behaviour. Further, by finding something they could learn more about there was the opportunity to improve self-efficacy as suggested by Spoth and Conroy (1993). As found in the study by Klasen and Goodman (2000) realising their child was not just being naughty initially led to improved parent-child relationships in the context of having a diagnosis of ADHD. Although parents found it upsetting that their child had a chronic condition that may not resolve, they felt the advantages of having their child’s problems understood in terms of a medical condition outweighed the disadvantages. With the reported improved parent-child relationship and the opportunity to read about ADHD, join support groups and have access to expert help, parents believed they could now actively and appropriately help their child. Initially receiving a diagnosis enabled parents to feel more confident about being able to help their child: *There was something that was the root cause, and then I knew I could find out all the information and work within that.*

6.2.1. Overinvolvement and protectiveness

Mothers perceived their child as vulnerable and misunderstood, and had become very involved in the lives of their child with a diagnosis of ADHD. When speaking about this, mothers’ often framed themselves and their role positively, such as being articulate parents and becoming more knowledgeable and assertive. There was a sense that these mothers had already invested a significant amount of their emotional and physical resources on their child with ADHD prior to diagnosis, and that now this energy could be more purposefully applied. However, there were indications from
some accounts of ‘overinvolvement’, such as one mother who reported she had no social life or friends because of her young son’s unpredictable and aggressive behaviour. She saw this, however, as an appropriate sacrifice in order to give this child her full attention with the view that all that effort would pay off when he was older. Mothers appeared to have moved from a distant and angry relationship to a protective one, which at some level may have felt uncomfortable for both the mother and the child. The phenomenon of self-sacrifice and overinvolvement was reported in a study by Kendall (1998) who found highly enmeshed relationships had developed between mothers and sons with a diagnosis of ADHD. Kendall also suggested that this was more common in parents of younger children with a diagnosis of ADHD, and that once their children were older, and they had come to terms with the ongoing limitations that some children with a diagnosis of ADHD experience, mothers ‘individuate’ (p.850). In this present study one mother specifically identified ‘sorting herself out’ by going back to work and rekindling her interest in academic studies, as a way of helping the whole family to cope better. Kendall identified this process as ‘restoring self’ and that it tended to occur through the process of: “remembering, grieving, and individuating....they knew they had done the best they could” (p.850).

6.2.2 Avoidance of grief

One might argue that it is not altogether unusual for a worried parent to be somewhat ‘enmeshed’ with their child and the problem. A possible outcome of this might be explained by these mothers accounts of taking on the role of protector and advocate, with much of the frustration and anger that used to be directed towards their child, now being directed towards others, especially professionals. There is the possibility that through the process of overinvolvement, protection and advocacy, parents have perhaps managed to avoid the grieving process and letting go of the belief that their child could be just like everyone else if only they, as parent try harder and fight the system harder. Two of the participants did explicitly express an enduring sense of sadness and regret, but they framed it more as a missed opportunity that their child’s difficulties were not understood earlier, and that if they had been, things may be different.
6.3 Making sense of and coming to terms with ADHD

Within this main theme, there were several shared sub-themes which illustrated the similar difficulties that emerged post-diagnosis:

6.3.1 Comorbid problems

All of the participants appeared to be confused as to which behaviours were due to ADHD and which were as a result of their child’s temperament and critical external influences such as peer and teachers’ long-standing negative attitudes and mothers’ own responses. The implications of this confusion are potentially serious. As stated before, certain authors have identified the family environment and parenting behaviour as being of significant influence on the development co-occurring conduct disorders in children with ADHD, and it is this group that have the poorest outcome in adult life (Frick, 1994; Johnston & Mash 2001; Loeber, Green, Lahey, Frick & MrBurnett, 2000; Moffitt, 1990). By attributing the cause of certain antisocial behaviours to ADHD, these mothers run the risk of possibly unwittingly maintaining significant conduct problems. Nyland (2000) made the point that parents and teachers have lowered expectations of children once they are diagnosed with ADHD and Nyland expressed concern that there was an emphasis on the development of a deficit view of the child. For example, Jussim’s review on self-fulfilling prophecies (1986) suggested that if teachers have low or critical expectations of a child, they then treat the child according to those expectations. The child’s reactions to that treatment then reinforces the teachers’ expectations. For a child with long-standing behaviour and social relationship problems, a negative cycle could be occurring in several areas of a child’s life with impact on a child’s self esteem. Parents hoped that by having an explanation for their child’s difficulties, this would alleviate some of these negative self-fulfilling cycles, but this, to a great extent, apparently did not happen even though all the mothers reported that they experienced some improvement in their child’s behaviour. A contributing factor to this ‘deficit’ cycle may be that it is perhaps reinforced by a child’s own perception that they are somehow not responsible for their antisocial behaviour because they are suffering from a disorder, and this possibly inhibits the potential for a child to develop a sense of personal agency for their behaviour (Nyland, 2000). This links back to the issue of parental overinvolvement
and protectiveness, with the parent doing all the emotional work of ADHD (Kendall, 1998) thus preventing their child learning to take responsibility for their behaviour and learning from their mistakes.

6.3.2 Frustration with professionals and others

Parents’ accounts of their struggle to gain help and support for their child indicated a renewed sense of frustration and stress, although now this was directed towards professionals and others involved in their child’s life. Mothers felt unsupported in their attempts to facilitate the difficult process of teaching others about their child’s condition and how to respond to it, when even they continued to experience doubts and worries about these issues.

The possibility of improved parental self-esteem and self-efficacy as well as experiencing their child as benefiting from mothers’ understanding of their condition seemed elusive for these mothers. Their hard work to carry out the prescribed methods of helping their child, getting others to understand and support did not result in a more accepting re-evaluation by others.

It is proposed that the relief identified at the time of diagnosis helped mothers to feel less guilty and this facilitated a process of giving their child’s behaviour a different meaning. However, it also elicited a change in expectations of what the child was and was not responsible for in terms of their behaviour (is this ADHD or is it bad behaviour?), as well as being protective of their child now that they had an identified condition. This protectiveness together with uncertainty about expectations again linked back to the cycles described in Figures 2 and 3, i.e., inconsistent responses to difficult behaviour and attachment history. This would possibly account for the maintenance of early-onset severe behavioural problems that did not resolve or at least improve post diagnosis. As their child's behaviour did not improve spontaneously, mother’s expectations were directed towards the professionals for support and expert help.
6.3.2 **Impact on the family system**

The emphasis so far has been on the unidirectional influence of mothers’ attributions, attachment history and self-perceptions of efficacy and how these processes impact on how they experience their child with a diagnosis of ADHD. It would, however, be inappropriate to place all the responsibility maintaining the reported difficulties on the mother’s shoulders as well as the resolution of those problems. Mother’s did report on how difficult their child with a diagnosis of ADHD was to live with within the family and how their behaviour caused considerable tension between members of their family. All the participants had other children who were not reported as causing significant concern in the family despite there being other siblings with recognised difficulties (e.g. developmental and health problems.)

It is therefore important to also conceptualise child functioning in the context of the family system with both children and parents mutually influencing each other. Byng-Hall (1995b) expanded the concepts from attachment theory and the parent-child dyad to a secure *family* base (my italics): “a family that provides a reliable network of attachment relationship in which all family members of whatever age are able to feel sufficiently secure to explore”, (p.46) and ideally involves family members supporting and caring for each other. There are several situations that undermine this secure network, e.g. “attachment figure is captured”, where a member of the family captures an attachment figure and then this dyad excludes all others from gaining access. In several of the accounts mother’s narratives indicated a preoccupation with their child with a diagnosis of ADHD as well as the child with the diagnosis taking control of situations by being the centre of attention and conflict thus capturing the limelight from others in the family. This was often referred to in mothers’ accounts as being a source of tension and conflict between the children; *his brother will turn round and swear at him (because he was pushed), I shout at his brother, and he’s (child with ADHD) won again*, and causing disagreements between parents as to how to handle the behaviour: *I shout at G. to ignore him; of course my son hears me shouting...he knows he is getting the attention of both of us because we are having a lovely little argument over him*. Mother’s seemed to feel in the middle of these family tensions and unable resolve matters or improve family relationships; several accounts referred to their effort to get other family members to make allowances for the child with a
diagnosis of ADHD in the same way as they were advocating for better understanding from others in wider social contexts.

6.3.3. Prejudice

One of the factors that parents' spoke about in the context of their struggle to have their child's condition more sympathetically understood, was that they continued to encounter prejudice from others about ADHD which linked them directly into the psychosocial vs. medical causation debate discussed earlier. Therefore, by pathologising disruptive childhood behaviour, parents and health professionals were seen by some as colluding with the socially dominant medical model, and therefore not acknowledging possible environmental causes for their child's behaviour: *I told this woman who used to be a schoolteacher that (my son) had been diagnosed with ADHD. Oh has he, she said, I thought that was just bad parenting...he was like he was because of bad parenting.* Without the hoped-for backup by professionals, parents were faced with trying to defend their child's continuing difficult behaviour.

In her study of families with children with a diagnosis of ADHD, Kendall (1998) suggested that the biases and beliefs held by society at large reflected to some extent the uncertainties held by the parents themselves. Their long-standing belief that they had failed as parents possibly was easily triggered in the face of social prejudice about ADHD. Kendall found that parents who held the belief that the cause of their child's problems was a biological/medical one were more able to "deintegrate stigma" (p.851) as they were able to become less defensive of their competency as parents and therefore less emotionally affected by the prejudice of others. Kendall was writing from an American perspective where ADHD has been diagnosed and treated for over three decades. The relative recency of this diagnosis being accepted in the United Kingdom (Kewley, 1998), with the media fuelling the controversy, possibly reinforces the sense of uncertainty for parents attempting to make sense of this diagnosis. The different ways of describing the phenomenon of ADHD gave rise to different ways of perceiving and understanding it, and parents appeared to still be struggling with constructing their own understanding of their child within the dominant culture's idea of child behaviour and parenting.
Coming to terms with ADHD also involved the wider influences upon families such as cultural norms and expectations about child rearing, child behaviour, ways of parenting and family life. Society and its cultural norms and values clearly have some impact on how parents construe their role and the expectations they have of children’s behaviour. For example, broadly speaking, Western parents place emphasis on the fostering of independence and autonomy in their children, whereas other cultural groups place greater value on family affiliation and identification (Kelley & Tseng, 1992).

Norms for acceptable child behaviour also vary from culture to culture. For instance, one parent reported how her sister, who lived in Spain, had a boisterous noisy child, who would probably fulfil all the criteria for ADHD, but whose behaviour seemed acceptable by everyone there, and was not cause for concern, but when visiting in the UK, the same child “stood out like a sore thumb, like he was all over the place”.

With reference to their more direct social environment, mothers in this study tended to use social comparison (Hogg, 2000) to make sense of themselves as parents and their situation as a way of coping. Within the context of their support groups there was evidence of using downward comparison with others who seemed much worse off to help feel less incompetent and overwhelmed by their difficulties. In contrast, other accounts referred to their perception of normal families (upward comparison) and how, compared to them, they were living in a dysfunctional family and this, in turn added to their sense of alienation.

Despite social and cultural influences Grusac et al., (1994) believe that this is only one aspect that influences parenting behaviour and that “parents are not just passive recipients of their culture’s messages, but that they filter them” (p.7) and that individuals tend to selectively attend to societal messages that appear to match their own beliefs. This idea suggests that within the wider influences of culture and society, how the parent experiences these influences within the context of living with ADHD is subject to the individual’s own interpretation.
7. IMPLICATIONS FOR CLINICAL PRACTICE AND FUTURE RESEARCH

There are clearly many levels of difficulty which parents and their families experience when a child has a diagnosis of ADHD. Mothers’ accounts identified interpersonal problems between family members, as well as the relationships these families have with the larger systems involved with the child. Perhaps as a way of accommodating these multi-levels of difficulty, the concept of ‘goodness of fit’ first introduced by Thomas, Chess and Birch (1968); Thomas and Chess (1977) would be helpful in our clinical formulations. This model suggests that healthy development occurs when there is a good match between the capabilities of the individual and the demands and expectations of the environment. Conversely where there is a poor fit between these relationships at all levels of functioning, as appeared to be the case for the mothers in this study, development and functioning is severely compromised. The poor ‘fit’ these children and families appear to have experienced would suggest that better understanding of these complexities needs further scrutiny. It is apparent that the larger systems would need to modify their approach to these families in order for families to develop a sense of trust in being heard and understood. This in turn would facilitate better communication and relationships between parents and their child with a diagnosis of ADHD at all levels. The recommended multimodal model of intervention (Asen, 2001) requires extensive resources and not all families would need this level of intervention, even if there were significant behavioural problems. This study suggested that addressing parent’s needs initially in order to build their confidence might be an important target of intervention. However, sensitivity would be necessary in order to avoid parents feeling blamed once again as was identified by Klasen (2000), and this becoming a factor in the drop-out rate in parent interventions. Further studies are needed to explore and identify interventions that would meet parents’ needs in managing and relating more positively to their child with ADHD. However, some historic problems need to be acknowledged in the light of this study.

Mothers’ accounts indicate that they often felt misunderstood and unheard by the professionals involved in the treatment and education of their child. Parents’ models of explanation, including their views about professionals should be included as a routine part of assessment. This might go some way to establish a climate of open communication and trust that would be essential if meaningful interventions are to be
offered or developed. As part of this process, the enhancement of ‘consumers’ acceptability” (Reimers et al., 1995) needs to take place whereby parents’ attributions about the likely effectiveness of a proposed treatment is optimised. In other words, greater care needs to be taken by those involved with treatment and support to take the time to hear and facilitate making sense of parents’ ongoing fears and distressing beliefs. It is possible that because of the initial relief and hope that diagnosis appears to bring, professionals fail to consider what the implications of diagnosis are for parents and families and perhaps prematurely recommend behaviourally based interventions without addressing other parental issues first. For example, Hoza et al., (2000), and Reimers et al., (1995) both argued that as parents are the implementers of their child’s treatment for ADHD, the meaning they give to the causes of their child’s problems will relate to the types of treatments parents find acceptable, which would in turn relate to how well the treatments are implemented and influence overall adjustment as a parent to their child. Therefore, behaviourally-based interventions can be effective but not if the parent continues to have unresolved fears about their competence especially in the context of still experiencing residual hostile feeling towards their child, and feeling, unsupported, isolated and criticised by others; as Bandura (1986) states: “Competent functioning requires both skills and self-beliefs of efficacy to use them effectively. (p.391). A greater understanding of the content of these beliefs and how they may be addressed therapeutically needs to be developed.

Although the event of receiving a diagnosis set in motion a change in the way they defined themselves and their child, the family and wider social world to which they related with this ‘new’ perspective remained perplexed and generally unsympathetic. In terms of trying to make sense of ADHD, mothers appeared to be still formulating their beliefs about ADHD and feeling somewhat buffeted by the wider social messages and constructions of this disorder. As a way of helping with the process of formulating a shared understanding of ADHD the narrative family therapy approach recommended by Nyland (2000) may offer the opportunity to families of rescripting (Byng-Hall, 1995a) their experience. This may help to release family members from their problem-saturated stories and facilitate a more open, flexible and empowering understanding of living with ADHD. Without the opportunity to reformulate their experiences, mothers may continue to struggle to make sense of their child with ADHD, and continue to feel somehow responsible resolving the family tensions.
In order to further inform clinical understanding, a similar study needs to be undertaken which focuses upon parents of children and families that do well despite experiencing similar stressful issues surrounding living with a diagnosis of ADHD. This would broaden our understanding of this “invisible handicap” (Kendall, 1997). The wider social influences such as disagreement about and disapproval of the diagnosis of ADHD with the consequent prejudice and criticism possibly affects all those families who have a child with this diagnosis. As this study focused on mother’s views, it identified the possible impact of attachment and self-efficacy as having an influence on poor outcome. Other studies are needed that explore other possible influences on outcome. For example, the concept of resilience (Rutter, 1999), where this concept is considered important in providing a better understanding of risk and protective mechanisms; wellness (Kendall, 1997) which looked at the long-term goal of finding strategies that help families avoid difficult patterns of interpersonal relating and other associated problems linked to ADHD; and Dallos et al., (1997) which identified factors in families that result in non-pathologising outcomes for their children. Also, an understanding of children’s own perspective of their experience would help to inform service providers’ aims to meet their needs (for specific issues around interviewing children see Faux, Walsh & Deatrick, 1988). Follow-up of these mothers once their children had reached maturity would possibly add to understanding about outcome for children with ADHD and co-morbid behaviours.

Finally, other issues arising from the interviews that might inform future service development and are important to mention here are:

1) The lack of opportunity given to children with ADHD in helping them to understand their condition, possibly in a group format;
2) Siblings need help and support, especially around the time of diagnosis to understand ADHD and their own response to their challenging sibling;
3) Family sessions, focusing on how to cope as a family
4) A key contact person in mental health to liaise with other services;
5) The opportunity for parents to have support in their own right; mothers expressed dissatisfaction at not having the opportunity to talk through their concerns without their child being present.
6) Literature that is appropriate for a child’s understanding, and up-to-date information for parents about developments in the understanding and treatment of ADHD.

Certain of these identified services are all offered to some extent, but on a fairly ad hoc basis. They could be incorporated as a ‘package’ of aftercare, following a diagnosis of ADHD.

8. LIMITATIONS OF THE STUDY

This study does not claim to represent the experiences of all mothers of children with a diagnosis of ADHD. The aim of this study was not to find generalisable results, although some patterns or potential processes inform clinical practice. This group of participants represented a relatively homogenous group in that all their children were on medication for their condition as well as receiving extra input from a specialist nurse for the behavioural problems they continued to experience with their child. None of the families had significant socio-economic difficulties, so the accounts of parents struggling financially may identify further issues that need to be addressed within service provision. This was also a white English-speaking group, all of British background. Other ethnic groups may construct their children’s diagnosed condition from within a different cultural framework and a study looking at these dimensions may illuminate some of the eurocentric expectations of child behaviour and parenting as being of significant influence in the frequency of diagnosing childhood behavioural problems as ADHD. There are also many cases of children with a diagnosis of ADHD where the situation does seem to settle down and the families request very little further input from services for their child. This would be an interesting group to repeat this study on as their accounts may not be as ‘problem-saturated’ as in the present study and certain themes of resilience and positive reframing of ADHD may be apparent.

Another limitation of the study was that the participants were clearly self-selected and were aware of what the study was about as ethical guidelines required participants to be given information about the study, and to be able to ask questions in advance of agreeing to participate as well as having the freedom seek clarification at any stage of
the research process. Self-selection is an issue in any research as a sample usually only includes those that wish to participate. However, it may be possible that there was a degree of reporting bias, particularly as certain participants were uncertain if they had been helpful, given the open-ended nature of the interviews and may have therefore tailored what they said to what they thought they should say. As interview lasted usually an hour or more, however, it may have been difficult for participants to sustain an overly guarded approach. Due to the phenomenological nature of the study, priority was given to these accounts and every effort was made by myself to limit the amount of input I directly made during the interviews. My declared areas of interest informed my reading and analysis of the accounts, and by grounding the emergent themes in theoretical bases, enabled the iterative process to continue, informing and enriching the re-reading of the transcripts, and retaining the participants experiences at the centre of the study.

9. CONCLUSIONS

The aim of the study was to explore mother’s experience of parenting their child with ADHD, i.e., to represent and understand mothers’ situation (Elliot et al., 1999). Case summaries gave a broad clinical context to mothers’ accounts and the analysis of their interviews resulted in three main themes emerging i.e. challenge to the meaning of being a competent parent; reframing the problem, and making sense of and coming to terms with ADHD. By placing these themes into theoretical context within the current literature, the extent of complexity of their experiences was apparent. Certain problems that were identified pre-diagnosis period were still occurring at the time of interview, such as the uncertainties about how to handle difficult behaviour and problems with affection and emotional closeness with their child. Models of understanding the maintenance of early-onset severe behavioural problems were proposed within the parent-child relationship. Mothers and their child continued to encounter criticism and prejudice, now in the context of the debate around ADHD. Mothers continued to feel unsupported and isolated.

Mothers’ descriptions of their experiences shared many similarities, i.e. their feelings of guilt, embarrassment, confusion and emotional strain and ineffectiveness in dealing with their child’s disruptive behaviour as well as trying to understand and cope with
the chronicity, uncertainties and limitations their child’s condition imposed on themselves and their family. Mothers varied as to how much they emphasised the placed in their accounts on the impact of ADHD on their relationship with their partners, as well as differing on how worried they were about their child’s future.

Mothers were not asked specifically about their views on the medicalisation vs. psychosocial debate about ADHD. Although they all spoke about the difficulties they experienced in getting support for their child and the on-going stigma of having a disruptive child, even in the context of a diagnosis, the accounts did not indicate that mothers would welcome abandoning the diagnosis. This study highlighted the importance of taking into account historic causes for discontent and mistrust between parents and professional, as well as exploring parents understanding of and beliefs about diagnosis and possible interventions as a matter of standard clinical practice. Further studies are needed to expand our understanding of the impact of personal and interpersonal factors, such as parental attachment and self-efficacy, as well as larger systemic and cultural factors, on the experience of families living with a child with a diagnosis of ADHD.
References:


Appendix A

Self reflection

I have kept extensive reflective notes about the process of interviewing the participants, analysing the transcripts and writing up the study. I shall now attempt to summarise these notes in order to assist the reader in understanding my own reflective processes whilst doing this study.

To set the scene, some background as to why I undertook the challenge of a qualitative study:

I qualified as a clinical psychologist as a mature student in 1995. At that time I was living in Cape Town and our qualifying degree was at Masters level part of which I had carried out a piece of quantitative research. However, when comparing the content with my Doctorate colleagues in the UK, and in conversation with the BPS who accredited my qualifications without my having to do anything further to gain chartership, there appeared to be very little difference in content and complexity of the degrees. I was therefore reluctant to undertake what seemed like a similar academic task so soon after completing my qualifying degree. However, after being in my present post for three years, I was encouraged by my head of department to undertake the ‘top up’ doctorate as part of my CPD. There was no one at that time in the department doing any research, and it seemed like an interesting challenge as I was missing the stimulation of being in a university environment as I had been in when living in Cape Town. However, I felt I needed to try something different. The debate around quantitative vs. qualitative research had interested me and I was intrigued by the reported insubstantial nature and findings of qualitative studies compared with the ‘reliable’ and solid findings of quantitative studies. Also, in gaining some clinical experience, I had started to become interested in the complexity of clients’ descriptions of their difficulties and sometimes struggling to provide useful interventions, compared to the somewhat purist findings in the literature, which was, and largely remains, quantitative. In their article on Clinical Questions and “Real” Research, Strauss and Hafez (1981) encourage clinicians to have confidence in using
clinical abilities and experience as being an important contribution to learning more about everyday clinical phenomena. Such phenomena are often difficult to quantify and that qualitative approaches, i.e. careful description, inquiry, and development of hypotheses or models of understanding would be a more appropriate research approach.

When I broached the subject of doing qualitative study with colleagues, my idea was greeted with many warnings about overwhelming amounts of information, hours and hours or transcription, many more hours of analysis, learning to live with an almost constant state of confusion, not knowing, thinking you know a bit and then not knowing again, and the generally sceptical view the academic world had on qualitative research. Despite these warnings I decided to go ahead.

My involvement in the setting up of an ADHD service in my district seemed a good general focus for this degree, especially in the face of the debate surrounding this diagnosis and the interesting phenomena, in the early years, of parents wanting this diagnosis despite the somewhat public controversies surrounding it. I now supervise a specialist nurse in the ADHD service whose work is mainly behavioural. She is highly valued by the families she sees, but there are many cases where interventions have a very short positive effect and then things seem inevitably to revert back. Mothers in particular seem to need a great deal of time with the nurse just to unburden, which is useful, but it felt as if we were missing something in our understanding or somehow had not managed to understand the full implications and of having a child with ADHD had had on mothers.

Having decided on a focus for the research, found a supervisor and received permission from the local ethics committee, the study got underway.

I was interested in Interpretative Phenomenological Analysis (IPA) as it is an emerging method that focuses on people's experience of a phenomenon from their own perspective. Other qualitative methods, such as Grounded Theory and Discourse Analysis were more familiar, but as I was not wanting specifically to discover new theories (Grounded Theory) as the literature is extensive around conduct problems in childhood and ADHD, and my clinical interest is more grounded in cognitive and
interpersonal processes rather than people's use of language to achieve social and interpersonal objectives (Discourse analysis).

IPA aims to explore the research participant's experience for their own perspective, but recognises that "such an exploration must necessarily implicate the researcher's own view of the world as well as the nature of the interaction between researcher and participant" (Willig, 2001, p.53)). The method chosen in my case was by semi-structured interviews that needed to be open-ended and non-directive in order to provide the participants in my study with the opportunity to share their experience. Smith (1995) recommends that a researcher using a qualitative method needs to retain an awareness of their own conceptual framework and personal qualities, and "needs to look at the factors which may have influenced the project at each stage and at each level" (p.p.24-25). This means, right from the start, developing a self-awareness of one's own personal engagement processes with the research.

The semi-structured questionnaire was drafted in collaboration with my supervisor, Rudi Dallos, following a period of supervision that began to clarify my main theoretical and clinical understandings and practice as well as familiarising myself with the literature around qualitative research, and IPA specifically. Briefly, as I work with children and families I have several approaches that I find helpful depending on individual problems for example, attachment theory, systems theory, narrative therapies, cognitive therapies, behavioural strategies and parenting skills. Clearly I already had many ways of trying to make sense of client's difficulties and this made the task of designing a questionnaire quite difficult in that I needed to keep it flexible and open-ended within the tension of my well-practised style of clinical assessment and formulations. The difficulty of switching from clinician to researcher for the purposes to the interviews was difficult for me, especially for the first two interviews, as I wanted the mothers to express themselves openly about their experiences without the constraints of my own ideas.

I was expecting a research interview, of necessity, to be different to my clinical style, but I was aware of feeling quite uncomfortable initially with this change in style. In my clinical work, which is usually time-limited, I tend to have quite an interactive and collaborative style. I hold a strong belief that I need to try to be transparent with my
clients about what I am thinking and why I might be asking certain questions or suggesting particular strategies or interventions and try to retain an open dialogue in order to co-construct with clients a shared understanding of their difficulties, as well as jointly working towards possible changes. I was aware that this way of being with the participants in this study would have been inappropriate, bearing in mind the need for participants to give their accounts as freely as possible, with as little input from myself as was necessary. I felt some anxiety about how my clinical style might conflict with the requirements of a research interview style. I was aware of feeling at times too directive and at others having a sense that a great deal was being said but feeling unsure as to how I could convert all this information into a coherent and meaningful study. Trying to keep myself in a poised relationship between the various tensions so as to be able to listen and think sensitively seemed to become gradually less challenging, although for certain participants, particularly those who gave very inclusive and detailed accounts, I remained uncertain about how open-ended to keep the interviews. I was also aware of trying to be careful not to open up the narrative to too deep a level as these mothers needed to cope after the interview. All were offered a follow-up session, which one arranged as she had become more concerned about her increasing worries about how anti-social and aggressive other parents were saying her child was. I was able to refer her to the specialist nurse for further sessions.

Several mothers commented that they wondered if they had told me anything useful and felt they had been ‘rambling on’ rather unhelpfully; at that stage I reassured them about the unstructured nature of the research, but could empathise with their uncertainty.

Supervision sessions during this process helped me to verbally further reflect on my own experience of the interviews, for example, I often felt very tired towards the end of the interviews, finding it difficult to continue listening thoughtfully. Parents had so much to tell me about their experiences and their accounts were very full and at times exhaustive and exhausting. At times I was aware of finding concentration difficult or my prompts and comments feeling too directive. I think now that I have completed a qualitative study, I would have a great deal more confidence in the interview experience if I undertook a further such study.
Supervision discussions also highlighted some of the possible emerging theoretical concepts. For example, several of the interviews suggested a 'preoccupied' adult attachment status (Main & Hesse, 1990), i.e. passive and vague, confused, unobjective, conflicted and unconvincingly analytical (Grusec et al., 1994), and unobjective, mentally entangled in their descriptions of the past. Thinking about the literature on adult attachment and its influence on child attachment status and the development of behaviour problems (see elsewhere in this portfolio for a critical review on this topic), I explored how difficult it might be to know whether a parent was describing insecure attachment behaviour, or an actual diagnosable condition. Other ideas and theoretical concepts were also explored during supervision. To check my progress at understanding the analysis process, as well as a validity check, we individually and simultaneously read through and jotted down ideas and possible categories and theoretical concepts on the transcripts. We then compared this preliminary analysis process for similarity of ideas.

Initially, it was possible to interweave interviews with analysis during supervision. This proved essential in order to develop an understanding of working thoughtfully with qualitative data, which, particularly in the early stages of the research, felt somewhat confusing and unmanageable, (mirroring the participants' reported experience of their child). Analysis was a process of uncovering further levels of understanding, and as certain common themes emerged, so did repetitive theoretical ideas, giving a sense of locating the information meaningfully, e.g., I found the concept of attribution bias helpful in finding a cognitive pattern to the participants' accounts. I also found I became very sensitive to other influences upon my interpretation e.g., television programmes and written articles about parent's experience of their children's difficult behaviour and its consequences e.g., expulsion from school and fines and compulsory parenting skills classes. This all added to the richness and complexity of my understanding. Again these aspects were discussed in supervision.

Right from the beginning I was aware of the possible implications of my own view of the world (as a clinical psychologist) and how this might influence the interviews, the analysis and writing up the study. When listening to the mothers in this study, and reading and analysing the transcripts, I was aware that I was looking out for clues
about how much the parent seemed to still like their child despite their difficulties. Did they spontaneously describe any positive attributes in their child that they liked; I do this in clinical assessments in order to gauge if there are some strengths in the relationship to build on. Finding ways of empowering parents to feel confident in their role and consequently enjoy their child more is important, but I find it interesting to think about what the issues are that prevent this from happening in the first place. I was also aware of experiencing the difference between a clinical interview and the research interview, and was glad I had selected mothers who I did not know in my clinical capacity as I felt it would have had quite an impact on what they might say to me e.g., may not have been so forthright in their criticisms of professionals.

Each stage of the study seemed to present considerable challenges to me. When writing up the results, which meant selecting appropriate quotes from the transcripts, I found so many examples and then became over-critical as to which to omit and why. I became acutely aware of the potential for bias and preference, which reflected my experience during the interviews, of finding some of the relationships formed during the interview more challenging or tiring to process than others. As I became more and more familiar with the transcripts, it was difficult to retain an objective enough distance for analysis and to keep the work closely connected to the certain accounts. Most of the accounts were very long. These mothers had a great deal to say about the topic and I felt that there were many different ways of interpreting these interviews. Trying to find a focus and attain some coherence amongst the extensive amount of information remained an ongoing challenge with this study.

Distilling out the main or superordinate themes involved several attempts. At least three times I felt I had finally touched on the ‘essence’ of what all the codes and categories seemed to be pointing to, only to find, when writing it up, and selecting examples of dialogue to illustrate the theme, that in fact there was something more succinct or meaningful beneath what I was finding. This personal immersion into the research material is an essential part of the analysis, with self-reflection sometimes being one’s only way of keeping on track of the process.
Self-reflection became a habit with IPA and I found at times it led into overinclusive formulations as an attempt to avoid bias by not imposing my own formulations too prematurely. My own internal processes seemed to mirror the iterative nature of the study, i.e. by constantly checking back to my own understandings in order to retain a sense of self-authenticity as well as allowing for flexibility and opening up to new ideas by constantly returning to the transcripts and my evolving piece of research.

By focusing on mothers’ experience I realised from the start that the study would be limited as to how representative it would be for other family members. A family focus might have produced different themes, as would a partner, sibling or child based study, or indeed, the mother and father. However, I specifically chose mothers as they tend to be the main carers of children in this part of the country, and my clinical experience indicated that they appear to be extensively involved with the complexities of ADHD. Different participants would probably yielded some different themes and if time and energy allow, I would be interested in repeating the interview with different family members.

Equally, different themes may have emerged from a more specifically systemically oriented researcher with more emphasis on family functioning and ways of communicating, or, perhaps someone who has a psychodynamic approach where the focus would have been more on the participants’ underlying or unconscious motivations. IPA seems to offer the opportunity of very differently oriented researchers to explore people’s lived experiences.

Having reached the end of this study, I am left feeling uncertain as to the quality of the knowledge that I have generated. The idea that this study may be ‘overly generic’ (Chamberlain, 2000, p.289) in that the findings may be not be contributing to specific knowledge concerns me. Although I feel I have learned a great deal about mother’s experience of their child with ADHD, I am only tentatively aware of how this might influence my own clinical practice. I have recently paid more attention to the quality of clients’ self-statements, and have spent more time exploring the meaning of these before tackling the day-to-day problems that families with a child with ADHD bring to our service. I have also shared these ideas with the specialist nurse during supervision, and she feels this has been helpful in deepening her understanding of
some of her clients. Again in the culture of transparency, I am also sharing with clients (and encouraging my nurse colleague to do the same) why I might be exploring such things as self-efficacy and meaning making via cognitions and attributions, and hope that by having a more cognitively informed approach, a more solid foundation may be in place before introducing more behaviourally based approaches. I can also see how bringing together other family members and exploring the meanings they give of their experiences of their problems, not just in the ADHD service, and incorporating some of the ideas from the themes from this study could continue to enhance my clinical understanding and practice.

The nature of a doctorate degree requires commitment and is a challenging process to undertake in the context of full-time clinical work. I have found the nature of qualitative research quite demanding, particularly the need to make use if myself as the main instrument of interpretation and remain reflective of this process throughout. I do, however, feel it was a valuable personal experience and that the intrinsic uncertainties and depth of thought, self-discipline and perseverance required complete this task have matured me both as a clinician and a researcher.

References:
Appendix B

Semi-structured interview schedule

1. Scene setting – who is in your family?
   - Brief descriptions of everyone
   - Description of child with diagnosis
   - Description of family relationships

2. When did you first start to worry about your child?
   - Events leading up to assessment
   - Reaction to diagnosis – how did it affect you, child, family etc?

3. Mothers childhood
   - What was your relationship like with your parents?
   - Description of family life and relationships
   - Similarities with own family life now
   - Parenting similarities and differences with own children

4. What do you think you have learned from your experience with parenting your child with ADHD?
   - What helps?
   - What are the difficulties?
   - What difference has having a diagnosis made?

5. If you could turn the clock back, what, if anything, do you think might have made things different to how they are now?

6. What advice you would give other parents in a similar situation?

7. Is there anything else you would like to add?
Dear

Re: Invitation to participate in a research study

I would be grateful if you could read the enclosed information and let me know if you are interested in taking part in this study.

If you would like to arrange an interview with me, then please let me know by telephoning the psychology department at the above number by .......(date).

Thank you very much for your time.

With best wishes

Yours sincerely

Ann Colborn
Clinical Psychologist
INFORMATION FOR RESEARCH PARTICIPANTS

I would like to invite you to take part in a research project, which aims to explore the nature of parents’ own perceptions and experience of their child who has a diagnosis of Attention Deficit Hyperactivity Disorder (ADHD).

The study will consist of a one-hour interview with myself. This interview will be audiotaped. The interview questions are designed so that you can answer them as openly as possible and I will then listen to the tape and write down exactly what you said. Counselling will be available if you are worried by any of the issues that are raised. The interview will take place at a venue that is convenient for you.

All information will be strictly confidential. The recording will be deleted following the study. Your name and details in all reports will be altered to ensure confidentiality.

It is hoped that information provided by this study can be used in the future management and provision of services for children with ADHD and their families.

Your participation in the study is entirely voluntary and you have the right to withdraw at any time without giving a reason and without affecting you or your family’s future medical or mental health care or relationship with staff.

Ann Colborn
Chartered Clinical Psychologist

Please reply to:
Psychology Department, telephone ..........................................................
CONSENT FORM

Study Title: Parents’ experience of their child with Attention Deficit Hyperactivity Disorder

I have read and understand the purpose of the study as described in the information sheet. I have also had the opportunity to request further information and ask questions about what is involved. I am fully aware that participation in the study is voluntary and that I am free to withdraw from it at any time. It has been explained to me that all the information I will provide will be treated confidentially and that should I decide to do so, I may request to withdraw information I have provided during the course of the study.

I agree to take part in the study.

Name:                                      Date:

Signature:
Appendix D

A. Well, thank you very much for coming into talk to me about Clare, is that right.. Is there anything you’d like to ask me before we start?

S. No I don’t think so..

Would you please read this consent form And sign it if is sounds OK...

S. Yeh

A. Thank you... I like to start off, just so as to get an idea, could you tell me a little bit about the family at home..

S. My husband P. and 4 children, K, D, Clare and K 13, 12, 9 and 7...

A. Right, and could you tell me a little bit about them... how would you describe them

S. K is very shy, very quiet, very within herself really, D is more grumpy, stressy and very sensitive too, and Clare... very outgoing, in your face sort of girl, K, she is very loving and affectionate, like to be with you quite a bit, also got a very good sense of humour...

A. And how would you describe yourself and P (husband)...

S. P. very quiet really I suppose, very much doesn’t do much really. Me... I can be very loud, shout quite a bit. Kind nature, I’d say that about myself........

A. And if we were to think a little about Clare what would you say her strengths and weaknesses were... could you describe her a bit more...

S. She’s very loud child, she is very much, always wants to be there involved in everything... its like she doesn’t care but then on the other side she is quite sensitive in that she doesn’t always realise until after. She does seem to thrive on being told off I feel, she gets something out of that because she’s getting the attention she wants... very hard work...

A. Can you tell me something about when you first noticed something, when you first thought about something worrying about Clare...

S. Not so much when she was first born, because all my children cried anyway, quite a lot, and Clare was worse, but it wasn’t until she got to about 1 year old maybe that I started to really notice it then something just wasn’t right. She’d push you away, she didn’t want to have a cuddle or nothing, didn’t want to know, so that is when we first started to notice it, that she was somehow different.

A. And then what happened next.

S. Well things just continued... she got to the (?) when things got worse...

A. What sort of things was she doing that worried you

S. She couldn’t, we felt that she couldn’t click in what was right and what was wrong and it didn’t matter how many times you told her she still continue whatever she was doing, or just ignoring you, basically thinking that everything was funny...

A. So what was that like for you as her mum
S. Very difficult because I blamed myself thinking that I'd done something wrong, what could I have done or done differently, blaming myself for all the....

A. Did you share those thought and feelings with anybody.

S. I did with friends, health visitor, and basically I just got told that its just the age she's at...

A. So in the early years you were told that it was part and parcel of....

S. The child just had her own mind and she was like that but she would grow out of it

A. So what happened then

S. Before she went to school, at the playschool age she was at the stage where she, any chance of running off and going. She always managed to get out of her car seat, she just screamed wherever we were. Basically nobody else would look after her because of her behaviour and actually one day the health visitor came round to me and had never really seen Clare in her true light....she kicked hell out of her really, Clare kicked the health visitor and I think that was the first sort of sign of them actually seeing that there was something not right and she actually went to Highfield (for children with special needs) before she was 3 because of the behaviour problems with her, and they also recognised that something was wrong when she was there, but really it still got left, its just that she was a child that wasn't going to behave herself, a naughty child...

A. Well, again I am wondering how that left you feeling

S. By then I think I felt very, I still blamed myself, well, was it the way I was bringing her up, wasn't I doing things right, and I felt like giving up on her really. It didn't matter what we tried it didn't seem to work, and it didn't make me feel at all good about myself, also I felt sorry for her because nobody wanted to know her, nobody would look after her, and I felt hurt that people wouldn't, for her sake, nobody wanted to play with her, the rest of the family was forever telling her off, well it put the whole family under strain for quite a while, definitely....

A. So that went on for a while, how did you get to the point where you started thinking About ADHD....

S. When I started to come an see a psychologist here and we talked about Clare, and I talked about it quite a bit and suggested that maybe that might be what was wrong and it went from there, and we brought her up to be tested

A. What was that like?

S. It felt like a breakthrough really, I felt at last somebody is listening to me and that maybe there is a problem there and its not all the things I have done wrong...in a sense when I brought her up to be tested I was wishing that it was, in some ways to get me off the hook, so it seems, also to get her the help she needed, you know, nobody seemed to have listened in the past. It was very tense waiting to hear, I expected them to come back and say no, and then I think, I would just have been shattered, I would have felt it is my fault, what have I done to make this child like she is....

A. We might come back to that in a minute, but you have brought up a bit about how difficult it has been to parent CLARE and I guess that makes me wonder...perhaps you could tell me a little about your own childhood...perhaps describe your mum and your dad, how you remember them...
S. My mum she was in all the time, didn’t go out, sort of thing, but she was very, wouldn’t listen much which I used to find quite difficult... I had one sister and two brothers, I was the youngest, so basically my mum really never really listened or just let things ride over her head, never seemed interested, you’d end up having to shout to get her to listen which was very difficult. My dad wasn’t around a lot because he worked a lot but he was the strict one but always had time for me, I felt he had time for me, he showed me how to love somebody really.....very kind hearted...

A. It sounds as if you were very close to your dad,

S. Yes, I spent a lot of time with my dad when he was at home, I was much closer to my dad when I was younger...

A. An if you think about the influence of each of them in your development and how that might influence how you parent....do you think there are things you brought into your parenting that you experienced as a child, both positive and negative..

S. Yea, the positive side is obviously to love a child or how to love somebody else I’d got from the love of my dad and also there are certain things I got from my mum like not taking notice, I always thought I would take notice, and I would appreciate friends and not run them down like my mum did, we used to hear quite a lot and not always go on about myself to think of others first. And I must say me mum was a bit like that she would do things for other people, I think I bought that with me. I always thought that it was wonderful that she could do that...some things are a lot different. My mum would try and keep me home from school and things and I always said I would never be like that with my children. I didn’t want them to go through what I went through in school because I didn’t go there half the time.....because mum used to feel lonely because she didn’t go out she wanted company so she used to keep me home and make me lie to my dad which I didn’t like, I don’t want that, my children having to lie and missing school and not being able to...you miss out a lot, you miss out on friendships and the schoolwork. You lag behind and you never catch up again, and you get to the stage when you never want to go to school anymore and I feel guilty if I did go to school knowing my mum was at home upset because I wouldn’t stay at home and I didn’t want to put my children through that, let hope I haven’t....

A. So thinking about all that, and thinking about parenting Clare, how has that been, you sound like you have got quite good ideas about how you want to be a mum, so how that all worked out with Clare

S. I wouldn’t say its all worked out, I mean, as far as persevering with her school, yea, I have done that, that’s worked. As for the loving side of it, that’s been very difficult. I do find it very hard to show Clare love, cuddle her whatever. Most of the time I am mad at her or, so in that part I feel I have failed with Clare in that sense. I find it very difficult to cuddle her, she never wanted it when she was small and she does find it difficult now, in that respect I feel I have failed with Clare I also feel, when it comes to thinking of other first I mean that is not Clare where maybe the other children do more so Clare doesn’t. That hasn’t passed on to Clare that side of things....

A. How do you feel about that

S. I find it very to think that she could be like she is to other people sometimes because I never brought her up to be like that, but she is, she thinks of her self, self, self, basically, she doesn’t care what, well she doesn’t seem to care what other people think, even though sometimes she does let on that she does...

A. Does that link in with what you were saying that underneath she is quite sensitive.

S. Yea
A. And I suppose that brings us back to getting the diagnosis, has having a diagnosis made any changes in how you experience her

S. It made me realise that it’s not her fault, where basically before we thought that she was a right little madam, so it’s made it easier in that respect even though sometimes you don’t see it, but you think, well yes, she has got a problem and that’s why she is doing it, and in a sense stop blaming yourself so much. Obviously the medication has helped, its made her better at times, more easy to talk to and get to know, really, a lot about CLARE that in a sense we don’t know because we have never been able to get close enough to know, so, since she has been diagnosed, yes that has changed and made things easier. We get support now, which we never used to have, so that’s nice, we’ve got people to talk to about it which does make it easier to offload it and not have to, and also not have to think you are the only one when you know there is other children like that and parents going through the same thing...

A. So would you say that things have changed

S. It improved, but its still difficult..

A. Could you say a little about what is still difficult

S. Um... even on medication she is still not what I would call a happy normal child, not as easy as the others then, I mean all children have problems, I know, but she is still very hard to understand why she doing the things she is doing... things are still more difficult with her behaviour wise and just any general thing, its never just a straightforward in the bath CLARE like the others it would be, its getting her there, its getting her changed, its get in the bath, to be sensible in the bath, then its getting her to dry you know, its just not, its just not like the others, we still seem to find things hard..

A. Does it effect the other children

S. Yes

A. How do they react

S. Now they are a bit it tends, with the older two, they tend to fight with each other, crack up with her very easily, even though they have been told about her problem but like as a parent myself it doesn’t always seem to be in your mind at the time so they tend to fall out with her a lot. K. doesn’t like her at all and D. puts up with so much and then flies. K. not so much, she will fall out with Clare but its like Clare just rides over K. she doesn’t take so much notice of her only at times when Clare keeps her awake or wakes her up at night, that’s when K. does take more notice of whats going on....ongoing problems every day in one way or another

A. Are there other things that Clare does that cause you to worry. We have talked about generally being difficult to manage, but...

S. The way she is, I worry that she hasn’t got any friends really, that worries me that she is very much on her own... I was very much on my own as a child and it wasn’t very nice going through school being like that and I worry about that. I also worry about when she is older, how she will cope with things. I just find it hard to think that she will ever get on well in school and go on to have a job or whatever, maybe by then things will be different, I worry about her being a mother and relationships, relationships more than anything, I do worry about that.....

A. That sounds like something that’s hard to know how its going to work out but its still difficult not to worry about it

S. I worry how she actually feels inside herself as well. She can feel quite low in herself at times, upset. Says she doesn’t want to live things like that, it does worry me....
A. Who is she like in the family

S. People say she is like me (laughs) some things she is like me, but in other ways she is not, more so that my mum has said that she’s like me, the things she does are things I used to do as a child. I feel she thinks different to what I think...I couldn’t say...if she never had ADHD then she would be more like me in the sense that she does really think about things, she does get emotional, very emotional, which I used to, and I think deep down inside she does really care about friends and things and I was very much like that, I think she is like me in that way, obviously her problem is that its difficult for her to show that most of the time..

A. So are you able to see what is the ADHD and what is Clare

S. Yea, not very often you see the difference, but you can sometimes...

A. About what age was she when she was diagnosed

S. I think she was 6 or 7

A. And has she got an understanding about it

S. She, I don’t think she really knows much about it, she knows there is something, but I don’t think she really understands what it is, no I don’t think she does. She knows there is some reason why she is having the tablets, she is not exactly 100% why and never been willing to sort of listen anyway...we tried to explain to her in the beginning when she first started taking then but she didn’t want to listen and basically she knows now that when she has her tablet it makes her a nice person, she feels that, well that what she thinks, she’s a nicer person if she has it.

A. And what do you think about Ritalin and the whole business of ADHD

S. More concerned about it recently. You hear a lot more about it and it sort of makes you think, are you doing the right thing by giving them the medication. Basically people on television saying if somebody got an illness you’d get it diagnosed medically either by scan or whatever with ADHD basically its pen to paper there is no medical evidence of that going on whereas if there is a medical reason they give you treatment to treat it but there is not medical reason as such for ADHD to give them the treatment, to warrant taking the tablet and obviously there is some side-effects and things of the tablets that makes you worry. I wouldn’t say I know a lot about the medication, its just some of the side effects where they can effect their eyesight, I’ve heard that about it and long term, and twitching and ticks, quite a few, I cant remember them all now but there is worrying things to it. If there wasn’t really anything wrong with her, in her brain, then obviously worry that she shouldn’t be taking the medication and what will happen. If it wasn’t that and you were giving it to them and they didn’t need it, cos there wasn’t that problem there, really it makes you feel that you are forcing amphetamines on children for no reason. That is worrying.

A. What do you feel you want to do about that, if anything...

S. I’d like to know if there is a real problem in her brain, I would like to know that. I mean there is the other side to the drug as well, don’t get me wrong, I feel that it has helped Clare herself by being on it and family. It has changed her in lots of ways, it does make a big difference and I dread to think what things would be like now if she hadn’t been on it so I meant you’ve got the good side and the bad side to it but here is still that bit at the back of my own mind thinking is there something really wrong there to be taking those drugs

A. Do other family members have anything to say about the ADHD and medication
S. Well, P's view on the actual medication, we wouldn't have got as far as we've got if she hadn't been on it, he thinks there is not too many worries about it....maybe the side effects but at the end of the day, its made her different, its made her cope with things better, us cope with things better, and there are things we can control now than if she didn't have it....

A. So he sees is as being quite useful

S. Yes, definitely, but then he hasn't gone into the reading about the medication so....but he reckons she needs it, that's it.... And my family, really, my mum and things and relations, one particular one thinks that I'm really stupid and they wouldn't give it to their child if it was the last thing on earth...they've got problems with their child but they will not go to having that even though we think that child has got ADHD as well and so they have always been dead against the fact that I've let her go on to Ritalin, they do agree that some children have got ADHD, they do that, um...my mum also believes in that as well, she thinks that Clare does need the tablets. Friends, you know, have mixed feelings. Some you ask think it's a good idea, some say no, it makes you feel in the end you don't know what you're doing, if its right or wrong, but then my answer to them is, when she wasn't on the medication, why weren't they willing to help, cos they must see a difference where they do now, they will say Clare come over for an hour or say yes I'll look after her while you go out, so obviously they must see a difference to do that, definitely..

A. But is sounds a little bit as if, although there have been a lot of positive things happening, getting the diagnosis and treatment, you are having to live with a great deal of uncertainty still about whether it is the right thing to be treating her for and thinking about....do you think you have learnt from your experience, what do you think you have learnt from having this experience of having a child with this condition

S. I think you learn that when you see a child like Clare its not just always because they want to misbehave there could be a problem at the end of it, you know, you go into town and shop whatever, and you see kids screaming or being naughty, and you would have thought, look at those little sods, you know, that how I used to think, why are their parents putting up with that, where you sort of learn, now I think, well you don't know why they are like that, there could be a problem in their family there could be something wrong with them. You see the whole look of children who are misbehaving for one reason or another, could be lots of reasons why they are, you do see that a lot different..

A. So it changes you view of how you would look at children with behaviour difficulties, and how is that for you, having that view

S. I suppose its different for me because you don't feel you are criticising everybody, because sometimes you do, you do criticise people, oh they should be doing this, they should be doing that or whatever, if you don't know the background then you don't know why that's happening I the first place...

A. Has it changed how you feel about yourself as a parent...

S. Yeh, in some ways I suppose it does, because I mean you go out and you used to feel, well Clare misbehaves that everybody is looking at me and saying it was, thinking, I bet they would think, it was my fault, you know, I shouldn't control my child or whatever, but now she is out there and she is doing it, I still get embarrassed but I don't tend to think what other people are thinking anymore, I think well its none of their business, they don't know what's going on in my home, or what problems are, so it has changed me in thinking differently, things like that, so, in a sense I suppose its made me stronger in that way, not to think what other people are thinking what I am as a mum to deal with my child, whereas before, with any of my children the thought of having to go out into town and to have them go off in the street would really, no way, I didn't want people seeing me shouting at my children or anything, but its changed in that respect, I think,
well you know, everybody does things different, and I'll deal with it the way I can, its none of their business really, not any more, so its changed that, where I would be really worried, well I was at first when I used to take CLARE out I used to think people saw me shouting at her, dragging her along, people would think what a mother I was...

A. How has school been...

S. Not too bad in school, school is not too bad...she is lagging behind....

A. How have the teachers been...helpful..

S. Not the one she is with now, no, the ones she has had before have been quite good, they have actually understood her, one in particular, and instead of letting her go out to play, which she doesn’t get on with the other children, he would actually let her stay in, tidy the book, clear up the paint, things that she really enjoyed doing and she preferred to have done that than go out and try and join in with the other children and end of falling out or whatever, so, he also, he realised her sort of lagging behind and things like that, finding it difficult in the classroom and finding it very difficult with other children not so bad on a one to one with an adult, or a one to one with a child, but any more involved, its difficult, she finds it difficult to get involved in group discussions, group games and the actual teacher she is with now doesn’t seem to know much about ADHD, I don’t think even though she says she does, and moans and complains about Clare not listening daydreaming, not taking it in. Clare actually finds school more difficult now, a lot more upset about school. She cries about the work, homework, doesn’t understand so she finds its more difficult now....

A. Is that because of the particular teacher, or do you think its because the work is getting more challenging

S. Obviously the work is getting harder, in another year or so she is going into secondary school, so obviously there is a pressure there, I think also with Clare things do not go straight in. The teacher says blah, blah, blah, do the homework or whatever, Clare comes home crying because she doesn’t know what the teacher said, and she finds it difficult to get hear head around what actually she has got to do even if we explain it to her, she finds that difficult. The teacher, I don’t think, she gets on so well with this teacher anyway. She doesn’t get the help anymore apparently, I went up to the school, and they don’t give help in year 5 and year 6, and she is in year 5, they don’t get the help anymore. They can’t fund that, and I feel Clare does need it, um, she does find school difficult and its been more difficult for me to try and help her with school at the moment, with her not understanding, and some of it, I must say, I don’t understand, but I have got fed up going into the classroom about it and not getting anywhere....

A. so you are having to chase a lot, but you are still not getting support

S. No, the actual school psychologist is supposed to be going to look into it for me now, so hopefully we will get somewhere.....its caused Clare nightmares and everything in school recently, nightmares about school, and waking up at night again, we think its all tied in because of the worry at school so obviously she is finding it difficult. The teacher says she isn’t, she is in the lowest group. She is in a group that she can manage... but obviously to CLARE she is not managing....its hard to know about the people to see, to get these things done, you don’t know who to go to first, you have got to find out, its never there for you to just pick up things, its like you are fighting all along the way....

A. What do you think might make that process easier for parents.....what would have made it easier for you for instance...

S. Well, to know what she is entitled to, what help. People that you need to see. Well you know, I saw the teacher but that didn’t work, you need to step on a bit more, and you know, well what do you do, who do you go and see...
How did you find out...

S. S. (CPN) we talked to her about it and she got hold of the school psychologist for me, but if she wasn’t there to tell me that, I wouldn’t have known where to go or who to see, she is a key person, definitely, she helps a lot. Helps you with things you need to know, helps you understand, she was basically the one to say, well you’ve seen the teacher, don’t go to the headmistress, you need to go up to somebody a bit higher if anything is going to be done so that was done. But then for some parents out there that is not always available, they haven’t got somebody like Sally to speak to, not everybody, and it’s very difficult...it should be...if you don’t ask you don’t always know, and some people don’t think of asking so I think it should be made more freely of these things to know what to do or to see or whatever.....

It sounds as if you are saying that it is quite difficult to work out how to get help how to sort it out and what sort of things are available. It sounds as if you find out by chance

yes, you don’t know for yourself, it’s not freely known and I think that what parents need for children with ADHD, they do need help, they do need somebody to talk to and do need help with difficulties in school and things...

So getting the diagnosis and medical treatment sounds as if that has been helpful, but there are a lot of other things that happen...

You need more support with that, you need, as I said, medication does improve things, but there are still a lot of problems that you face, even the simplest little things, with a child with that (ADHD) raises, you know, you need somebody to help you along, give you ideas, give you information what to do or where to go, definitely.....

So if you could turn the clock back do you think there is anything that could have made things different to how they are now...

No...I don’t think so. Well understanding would have made things different, if I understood what was going on when she was small understanding that may have made things a bit different, but otherwise no, not really, she still would have been like that....

And based on your experiences, what advice would you give a family facing similar difficulties...

Get the support that is needed to help them...persevere and keep going, things can improve. I don’t know what I would actually say, other than get support, because things are always so difficult anyway, and to actually say look you are going to have trouble for the next so many years, it wouldn’t be the right thing to pass on.....you wouldn’t want to say that to somebody else. I would encourage them to have their child tested, not only for their own sake but for the child, definitely, I have done that with somebody and things are a bit better so I would advise that....I can just see it in their eyes, I’ve been right a few times now (laughs)

Have you....

Its just a look in their eyes....definitely to get them diagnosed, get it checked out

So despite all the uncertainties about this diagnosis that we talked about earlier, it sounds like you are saying its still worth going along that route...

its still worth it. As a parent you still worry....there are both sides...

So thinking about all this, that we have been talking about today, is there anything else you would like to say about your experiences in parenting a child with ADHD...

Yes, more help in the way, what I felt I needed was the time away from each other, I don’t mean going away for a week or anything like that, I mean maybe a day a week, even from quite
small, even to now, I mean, fair enough she is at school now just that time for the rest of your family to do something without the child interfering, breaking it up, causing chaos, I feel that is one thing you never got offered, or even suggested, and I feel that would be a thing that would make a big difference, I don’t know in what way or anything, but just to have the space between you, give the child without being at home being told off, away from that, and also the family left behind to have the space without the chaos...not for a long period of time, I don’t mean nothing like that, just a break, because it gets very wearing on the whole family, not just me as a parent, it effects the whole family. I mean we went through stages when CLARE was younger of not actually going anywhere because we knew what she would be like and what would happen. The whole day would be outrageous, it just too stressful for everybody and we just never used to bother. Even now, even on medication, we have got to think where we are going before we go because we know things can always erupt and go wrong, even simple shopping trips we try not to take her with us...so I think that would have been a big...especially, I mean, I don’t know if other people felt the same but, when CLARE, before she was on medication, nobody would look after her for me. They were just not willing to put up with her behaviour so we never ever got a break from her, it effects the whole family. Your are tired and stressed with that child and you haven’t always got time for the other children...its very hard to fit that in when the child with ADHD want all your time.....

A. do you think you were given enough information about ADHD initially, when you first got the diagnosis.....

S. I found out a lot about it anyway, that was quite good...I read a book about it, so I knew quite a bit about it then...I think actually to make it easier at the time would have been for more people to know about it, mainly schools and things, I meant they didn’t and it was like me against them, that was difficult. Teacher didn’t want to know didn’t believe CLARE had that. It doesn’t always meant to say that when they’ve got ADHD they are going to run around the classroom and not sit down, there is other parts of it, so that was difficult...I wish that had been easier, it was like I was fighting against the school at one stage...not so much now. I felt I knew a lot more than they did, where in my mind really they should have known about these things. Actually, I had not fell out with the teacher, but things were very difficult from then on with the teacher CLARE was with at the time. She didn’t like the fact that I was telling her what the problems were and she didn’t like that and it did cause a lot of friction. It got the stage where I really didn’t want to go into the class because the teacher was very impolite at times, but that was difficult, definitely. I suppose when CLARE was diagnosed, people, not many people did know about it then, I don’t think, where now its more talked about, more children have got it, but with CLARE I think was the only one in her school at the time, as far as I know, I suppose you really couldn’t talk to anybody about it much...

A. Do you know any other families now..

S. Yes, I do, one more so than the others, she very often stops and talks over at the school. I mean I know her just from over school, she gave me information at times....I think I have told her a few things, she is still finding it difficult. Yes, it does help, whereas at first it was just me, and it did feel a bit as if my child was the only one so that was difficult but things have come on a long way since then. I think most parents, without children it know more about it...its more talked about now and its easier in that respect, you know Clare can be really being rude and naughty, swearing at somebody or something and I will say, oh she’s got ADHD and Oh right, its accepted more, whereas before it was how dare that child swear at me, you know, they wouldn’t understand so that’s changed. Back when I was told, things were a lot different to what they are now, there’s groups and things now where there was nothing like that in place then as far as I know, there may have been, but not so well known.

A. So things have moved on, teachers are a bit more aware, although some are more helpful than others, other parents perhaps understand better some of the difficult behaviour, so there is the sense that things are better, but it does sound also like you are flagging up some things
that we could be tackling right at the beginning that might be more helpful so set people up with support, information, some contact with schools, things like that that might improve things....

S. Its hard work, its an ongoing thing...never seems easy...I know children are not easy anyway, but its very difficult and it does effect everybody in the family...

A. Could that be helped in some way...

S. I suppose it could be in the fact that basically what I was saying is the space, I know CLARE is part of the family, and you should to family things as well, its difficult on the rest of the children, its continuous CLARE on at them, even though we have gone at her, its on at them too, especially K. she is the one that finds it most difficult, CLARE just will not leave her alone and yes you can make the child stay downstairs and hear screaming for an hour, but she will get back up there somehow. Maybe they should have somebody to talk to as well, the children, because, I mean, they don’t talk to anybody about it, thinking about it now, they don’t do they. Its not really a thing we all sit down and talk about, even though I am trying to explain it to K. and D. they sort of understand. I know they are older but they are not 100% on the idea, well she still shouldn’t do whatever, but maybe they should have somebody to talk to as well to help them because it does effect them, they could be helped by somebody talking to them and to handle the way CLARE is or what they could do to try and make things easier, or understand, cos I think its as you say, its just the one child, but it’s the whole family involved, its not just one child and that’s the problem, it’s the whole family, so support should be there for all of us really....

A. Yes, and in a way the diagnosis is just the beginning. As the child gets older it, other things become difficult. Obviously as any child gets older they go through different phases of things, but obviously CLARE with that finds these phases very difficult, more hard to cope with and then I find as well, its sometimes part of her getting older, the things she does, and you tend to think her ADHD, its to distinguish between the two. You’ve got to sit back and think what the others did at that age....and what they didn’t, sort of thing. I know they are all different anyway, but you expect certain things, they will get in a temper, or will shout back. Its hard to distinguish between the two...

A. What is ADHD and what is not....

S. We have had so many years of so many things you just tend to go along and think, well no, they shouldn’t be doing that no matter what age they are, and you take no notice of what a child of that age would be doing anyway or going through, it also will also bring up that, you know, CLARE is very immature for her age, she doesn’t realise certain things we wont let her do that maybe children a bit younger are now allowed to do...that causes problems, but she is very immature. Other people noticed it more recently, that she is very immature. Sally noticed it, said it the last time I saw her. This is why she is most probably not getting on with friends quite so much..people still don’t want to play with her....she gets on sometimes with the younger ones. She still wander off at times, and the way she acts sometimes, its more like a 3 year old than it is a 9 year old. Like the temper tantrums, eating food, she thinks everything is hilarious, you know, silly things it shows how immature she really is and that’s only really sunk into me recently...the first time I really thought about it like that. Its not so much.....somebody actually said it to me on the phone a few months ago, heard CLARE screaming, and she said, she sounds like a 3 yr old in the background and I sat and thought about it and S.had said to me a few days before that, how immature Clare was when she was speaking to her and then I actually sat and thought about it. For about a week I kept thinking about it, that’s it, that is the biggest problem, she is just very immature, and she is still going through tantrums and things like a 3 year old would do. And S. did explain to me a bit about that, that is most probably because ADHD children do find it hard to learn things, they take a lot longer to learn that they shouldn’t have tantrums, so that was something new that came to light to me recently...
A. Has it made a difference...

S. A little bit, I think it has, I tend to think, how would I treat a 3 year old child that was having a tantrum. Thinking back on the things you would do then and basically that's some of the way you've got to treat it now even though she is older. I thought well that's why I don't let her go to the shop on her own or whatever because a 3 yr old would wander off, a 3 yr old would touch everything, a 3 yr. Old might pick up something in the shop....I am not saying she is a 3 yr old (laughs) so it makes it all the more understanding for me at the moment, even though it still is hard work, you don’t always see it so clearly as that...

A. So perhaps you are saying that by understanding some of the more confusing behaviour helps, it doesn’t make the behaviour go away but it maybe, does it help to cope with it better...

S. I doesn’t make it quite so stressful. I mean you tend to forget about all that by the end of the day sometimes, but it, because I understand it a bit better now, I thinks, of what the real problem is there, you tend to think when shes being really silly or whatever, then you think, a child younger than her would be like that....

A. Does it help with things like getting frustrated and angry because its easier to make sense of

S. You still get angry and frustrated because if a child, a 3 year old, has a tantrum, kicking whatever, you take them into another room, shut the door and walk out, well obviously with Clare you cant do that so its not always over and done with in 5 minutes, like it would be then. I mean, you put her in her room and shell come out and you can keep putting her back and she would still come out and she is still screaming and still crying so you still got the stress of all that even though you understand more its not so easy.....with a younger child, you can put them up to bed, sit them on a chair...none of that work anymore, so its still difficult. Obviously Clare knows certain things, like if you send her up to her bedroom, I'll jump out the window then, whereas a 3 yr old wouldn't say that so you've got to be careful with things like that....well that's still difficult and still stressful...the tantrum will go on for an hour or even more, its not 5 minutes in another room, they calm down and they come out fine..

A. so its very hard having a 9 yr old behaving emotionally like a 3 yr old, even if you can make sense of it

S. Yes, because they have still got the physical strength not to sit there, even if you want them to sit there you cant hold them back so much or anything like that...

A. So all the way along you kind of learn a bit more but the problems are still daily, exhausting and hard work

S. Yes, you know nothing is going to be easy where she is involved, anything, mealtimes, bedtimes, bath, teeth, get dressed, everything is always, its never just easy, never....

A. Yes...is there anything you would like to add...

S. Not really, I do know I have said about the other children having some support that has really sunk into me. I think, well yeh, that is the thing they should have, they have got to sit opposite her eating like a baby, me telling them not to. It must be very confusing for them, as well as it is for Clare herself, you know, going through things...i have never really sat and thought so much about them, because Clare has always been the highlight of our lives, just Clare....maybe it would help them..no question about that now..I think that's it...(pause)...I can't think of anything else....

A. Good, thank you very much....
APPENDIX E

Excerpts from transcripts showing initial IPA coding
M. Sensitivity...yea...that's the word I think I would use...but, until I had the diagnosis of ADHD I wasn't as sensitive as I am now I understand he's got ++++++++ something...you see what I mean....it's silly, because before I kept thinking...until I knew what it was...I would actually be over-hard with him, I felt...you shouldn't be doing this, and no...you don't do that and and stop that and stop that....once I knew he had a problem then I could see how it was with my mum and I suppose in that sense...do you see what I mean...which is awful cos I've waited for a diagnosis, which ....I hated to be seen as someone who was going to be too soft on him, so I used to be harder on him....once I knew he had a problem and it wasn't a case of just bad parenting and bad giving in or things like that....I could actually ease up and give him more...I was actually quite hard to stop him just being a naughty child whose parents gave into everything so I was quite firm with him, whereas once I had the diagnosis, I could read up and think look that's not going to work in any case because of this...I could then soften up with him and be firm on the important things...I've learnt to find what is important and what's not...when I see the mothers having a go at the kids for all sorts of things I think well is it doing anybody any harm is it doing this...and I look at those things now which I didn't before, now I can think, I've got to learn to readjust my life...is it important that he does that...no...well let him get on and find something...rather than have a battle and keep saying do this, do that....these kids don't listen and understand in any case, or he'll listen and say yea...and turn round and completely forget what I've just told him to do...and I was getting so worked up...I really was getting stressed...went on to the antidepressants, pulled through, and then I certainly started looking at it properly and...
thought...no...and I now know what is more important in life ....that's another thing I've learnt through all this ....when to back off and not get so uptight...

M. So it sounds like you are more, sort of more calm with the whole thing....

A. A lot more than I was....but that is because I've had, I mean, that's me changing....changing, school coming on board, Sally...it's the whole lot again...and another thing that scares me, if some of that breaks away could I still keep going...I think I can now, but there are days when I think if Sally was to go .....where is my support then to keep me going...he changes school...do I have to start all over...it's that makes me tired...fears about the future or fears about change...because with...everything is about change he struggles with change....so I'm having to look ahead, prepare for that change and think right, we've now got a good even balance here ....in two weeks time we are going to move, right, so the first thing...I've got to prepare him, so I've sort of worked my way round that...and I've needed him to stay where he is at school, to change would be too drastic...if I do look next year, and then will I have to go back quite a bit and will I have to start challenging schools again, will start misbehaving, not because he's...cos he does still get the occasion where if things stay consistent he's a lot easier to work with when there is change he still has problems, I'm usually prepared, I'm a lot better now, now I know what it is and what we have got to do, a lot of it is about preparation...
I think I got to the stage in the family when we knew we were not handling this child for the best for us and for the best for him and I just got to the stage where, my gosh, I've got to shout at somebody...to get some help after all these years....

A. Was that because you had not been offered any help, or.....

No I think its simply because I hadn't particularly asked...so all the time I thought we'd got this child who was totally different to the other two, older parents, lack of patience...perhaps we were not handling him as we should and maybe it was our fault, but we got to the stage where the family was exhausted, we needed some help, whether it was for ourselves or if it was for the child, so I went along to my GP and said this is what this child is like, please can I have somebody see him because we have got to the stage where we didn't want him anymore....we literally thinking about, he was upsetting the family so much, and the people around us that we are going to have to get rid of him...its a terrible thing to say (cries)....to be like that about your own child...but our GP said straight away, Ok I will get you referred...he picked up straight away that this child is needs some help...we actually got an appointment with Family Consultancy straight away to get him assessed, because I thought there was something psychologically wrong with him and to have him diagnosed as being I thought well that is, that sums it up, obviously I had doubts in the past but its just it was quite devastating to realise that your child's got something that he's always going to live with, and he's got to learn to cope with it, and you've got to learn to cope with it, and I felt that all the years have been wasted, if only we'd perhaps done something earlier, that he'd be perhaps a little easier now, cos he's still going through a lot of, he still can't cope very well, so his social skills are quite poor, whether he's with his peers or with adults and has very little understanding of cause and effect, and some things he takes in a literal sense...the problem we have got with him at the moment is thieving, taking money, he doesn't realise that thieving is naughty, shouldn't be done and he's going to get into trouble for it so he'll help himself to money, whether its mine in my purse....if he wants something he has to have the money and he will take it...he doesn't realise that it is not
allowed socially, it's the wrong thing to do......recently he's actually taken it from a neighbour, he got a little part time job with a disabled neighbour, who can't water her own garden, so he's been going there and watering her flowers for her for which he gets paid, and what he doesn't understand one day he actually took the money she paid him his two pound pocket money and as he left her house he saw some money she had left in the porch to pay a bill and he took that as well....and having earned his money on one hand he still thought there is money there, I want to buy sweets, I'll take that money to buy my sweets...and even when I explained to him why it was wrong he shouldn't have done it, he had his own money that he could buy his sweets with, he still felt the need, for whatever reason, I don't understand why, to take it......whether it shows immaturity in him or whether its that lack of understanding because of his condition I really don't know....

A. So even though you've been given an explanation, and a diagnosis, something to call what's going on, it sounds like you are still puzzling over a lot of what is happening...

It's things that seem obvious to us is not obvious to him...

A. What does he feel about having this diagnosis...

He knows he's got ADHD and he knows that its, as far as children understand these things, he knows that its something like a chemical that doesn't produce. He doesn't fully understand the why...all he knows is that he's got a label...he doesn't really understand any more than that, he knows he gets extra help at school because he can't understand things sometimes and to help him not get frustrated, he's just been through his SATS recently and he was in a terrible panic over that, when they were going through the trial papers, they go through the papers first of all to get them used to the whole regime of sitting there and concentrating and what is expected of them, and he got into a dreadful state over that, but when it came to the actual papers themselves, he was given a support worker, one to one, to sit with him, just to explain some of the things he may not have understood and he coped admirably and did very well, but without the backup in
S. I guess I don't see it as a label...I like to not think of it as a label, I like to think of it as, well, got this condition, he's got ADHD, you know, some children have diabetes, some children have cystic fibrosis, you know, got ADHD, and I think, I'm not criticising that what you said, because that's what people think of it, as a label, but I think that's where, that kind of needs to stop, like you said, really, it would just stop the media and people like that thinking of these children, because lets face it, if you ask anybody any man in the street about ADHD, he'd probably say, oh that's naughty children....you know, so I think its got, the focus of it has got to try and be changed to be seen as a medical condition...rather than a behavioural problem, because although it is a behavioural problem, its caused by that condition...

A. Yes...that's right...so if you could turn the clock back now what would you change...

S. (sighs)...I guess I would try to deal with it differently...actually the first thing I'd do is get him diagnosed earlier, if I could turn the clock back and know what.....I could have known then what I know now, I think would have been a lot better if he had been diagnosed earlier...(starts to cry)........I don't quite know what I would have done differently though really, it would be nice to sort of think, well I wouldn't have worked I would have given him more time, but then, life's not like that is it, you know, I couldn't not work........I think I definitely would have wanted to know sooner

A. Yes...so based on your experiences what sort of advice would you give a family facing similar difficulties

S. I think the important thing is to get everybody who can help you to help you, because, like you said, its so easy, I mean I
can remember somebody said, after had been diagnosed I actually, I was in the pub with this woman who used to be a schoolteacher, and she said something and I said, actually been diagnosed with ADHD, oh has he, she said, I thought that was just bad parenting....and I nearly hit her, I mean this woman, goes in the pub until lunch time and her children go wandering round the streets trying to find her...you know...and she turns round to me and says she thought was like he was because of bad parenting, you know, that is the last thing you need..you know, you need people to be supportive really, which I mean I do find that everybody I’ve spoken to...I mean Sally is brilliant , and I think you just need to get people behind you, to get people to realise that a...its not bad parenting because there is a stigma with it, and I think that just sums it all up really, people have got this perception that if your child’s got ADHD then he’s an absolute lunatic, he shouldn’t be allowed anywhere, the parents aren’t any good, its all the parent’s fault, and its not like that...you don’t wish this on your child...you don’t want your child to have this, and although I’m relieved, in a way, because I have got a reason for it, I don’t want him to have it....and I guess if you want the honest answer if I could turn the clock back I’d have a child that didn’t have it (cries)..........cos it is hard work...........cos he’s so lovely one minute but then the next thing he’s sort of swearing at you and its, you think, well, why.....

A. So its hard, even knowing that there is this condition behind some of the behaviour, at times its still very difficult to understand

S. Yeh...because he just changes, its like somebody flicks a switch, and they’re off, you know..and I guess the other worrying thing in a way is that, I mean I’ve not sort of looked into it in any great detail but as far as I am aware, um..a lot of the other behavioural problems are linked with
ADHD...aren't they...like I was talking to a girl...the other day, I was on a course with her and she said, oh that's right, they had an aromatherapist came to talk to this, it was teaching in parent education, it's a module I've just done at Taunton, and she said, can you suggest something for my little boy, he's got Tourettes Syndrome...so I was talking to her over the lunchtime and I said that must be really hard to deal with, but when she was talking to me, some of things her child does, that's you know, now I'm sure he hasn't got Tourettes Syndrome, but the swearing, you know...told me to f...off before now and I think that's what children with Tourettes do...and you're thinking, because there's this, what do you call it...associated problems, you know I can't remember the names of them now, but there's, to me I think, like you know there all these different bits to the condition aren't they. And I think, how would I know if he's got any of those, or how would I know if he's not got any of those...

A. So the worry can sometimes become overwhelming...what else might be wrong....

S. Yeh...you know especially when he is like he is and swearing and slamming doors and...

A. And it also comes back again to how of that is being adolescent or preadolescent and how much of it is.....

S. You know, is he just picking it up at school, all the kids are saying it, its part of the language these days, it doesn't excuse it, but it is part of the language these days...every other word, you know, if you walk around Barnstaple, hear other kids talking you know its every other word....so..
Professional Dossier

1. Development of a service for assessment and treatment of ADHD

2. Curriculum vitae
DEVELOPMENT OF A SERVICE FOR ASSESSMENT AND TREATMENT OF ADHD.

1. Introduction

North Devon is a rural area with a population of 140,000 with a provincial NHS hospital located on the outskirts of the main town. The children's health and mental health service comprises a paediatric in-patient acute ward headed by three consultant paediatricians, and two child clinical psychologists located in the hospital-based Department of Clinical Psychology. There is also a community-based multidisciplinary Child and Adolescent Mental Health Service (CAMHS) within which the clinical psychologists have sessional commitments.

This paper covers the period in the North Devon children's health and mental health service from late 1997, when a specialist service was initially conceptualised for the assessment and treatment of children for Attention-Deficit/Hyperactivity Disorder (ADHD) until mid-2000 at a point when the future of this service's development was reviewed in the light of a new consultant child and adolescent psychiatrist taking up post. The paper aims to discuss the process of service development up to this point in time in the context of demand for such a service by parents, but with limited resources on the part of the Child and Adolescent Mental Health service (CAMHS). Future development of the service is also discussed incorporating information from a survey carried out with parents of children with a diagnosis of ADHD.

2. Background to Service

ADHD, (American Psychiatric Association DSM-IV Diagnostic Manual, 1994) or Hyperkinetic disorder (HKD, International Classification of Diseases diagnostic manual (ICD-10) 1992 and 1993) are the two currently used terms for a common and relatively chronic childhood condition the core symptoms of which are described as inattention, hyperactivity and impulsivity. These symptoms together with the associated features of peer and family relationship difficulties and disruptive behaviour can occur with such severity as to hinder a child's cognitive, social and emotional development.
The core aim of the service plan was to establish a procedure for in-depth assessment of referred cases and regular monitoring of those diagnosed with ADHD and prescribed the recommended medication, Ritalin. In effect, although we could offer assessment, diagnosis and medication, due to lack of resources, we were unable to offer a full ‘treatment package’ for all those who were diagnosed i.e., parent counselling, family therapy/support, child-focused and school focused interventions (Barkley, 1991; Nolan & Carr, 2000). Similar problems were also identified by Jefferis (1999) in setting up an ADHD service. In order to address the complexity of the referred families’ difficulties in the context of an assessment and diagnosis we needed a multidisciplinary and multi-agency approach. Despite the logistics and timing difficulties in setting up a regular sessional slot, we successfully formed a multidisciplinary assessment team comprising a child psychiatrist, clinical psychologist and educational psychologist.

3(i) Referrals and assessment

At the time of our setting up of a service, clinical guidelines were not available although there was a local Devon county multidisciplinary working group compiling a consensual code of practice that was still in draft form. We were therefore largely dependent upon our reading of the literature as to how to assess and treat ADHD. As with most psychiatric diagnoses, there is no optimal diagnostic test and the literature suggested that an extensive history of the behavioural problems needed to be gathered from both teachers and parents together with the use of behavioural and diagnostic checklists (Barkley, 1991; Kelly & Aylward, 1992).

Referrals were initially on a case-by-case basis and were received either into the Psychology Department or to my psychiatrist colleague in the CAMHS team with a specific request for assessment for ADHD. The keenness of parents to have their child assessed was often met with a certain amount of hesitancy by referring agencies for the reasons discussed above, but the pressing nature of the requests from worried families tended to effectively precipitate a referral. Families were then invited for an assessment session that included an extensive family history-taking and an individual interview with the child. Permission was obtained to contact the child’s teacher for further information.
By January 1999 our protocol for ADHD assessment had developed into a more structured format as illustrated in Figure 1. Checklists and a questionnaire were sent to the parents and once these were returned, they were discussed at a fortnightly referral meeting attended by the clinical psychologist and child psychiatrist. Parents and teachers completed a behaviour checklist, based on the Conners Behaviour Checklist, (Sattler, 1995), the Attention-Deficit/Hyperactivity Disorder Test (Gilliam, 1995), and a questionnaire which we developed to document certain key family and developmental events (Appendix B). The available information was then considered. An apparent uncomplicated history and clear evidence on the questionnaires would result in an assessment by the child psychiatrist. All children being assessed for ADHD completed a computerised test of attention. On the basis of this interview and test results together with the completed questionnaires, the psychiatrist decided if there was enough evidence to warrant a diagnosis of ADHD and to discuss with the family the implications of treatment with stimulant medication (Ritalin). If all were agreed that this was the best way forward an initial trial small dose (5mgs morning and lunchtime) was set up with a review arranged within ten days to adjust the treatment if necessary.

If, on the other hand, there were indications in the referral of complicating factors, and the returned questionnaires suggested a complex pattern of behaviours with an unclear family and personal history, the family would be invited to the ‘Complex Clinic’. Two or more team members would participate in further assessment of the family, parents and child. This session was used to gather a more detailed history and time was spent with the child talking about factors such as coping with schoolwork, peers, day-to-day routines, relationships and activities in the home and classroom. The child would also be observed in interaction with the family as well as with the toys and equipment in the room where the family meeting took place. If, after this more extensive assessment, it was decided that a diagnosis could be made, then treatment was discussed, and if all were in agreement, medication prescribed. If, on the other hand, there was insufficient evidence of ADHD as being the underlying cause of a child’s difficulties, in-depth discussion was offered to the parents and the reasons for this decision carefully considered with them. If appropriate the family would then be referred on to the CAMHS team.
### Figure 1 – referral-assessment-intervention process

Referral received – Psychology Dept. or Family Consultancy

Send to parents:

- Family and personal history questionnaire
- *Child behaviour checklists for parents and teacher
- DSM-IV diagnostic criteria checklist

#Questionnaire and checklists returned completed

<table>
<thead>
<tr>
<th>Questionnaire indicates</th>
<th>Questionnaire indicates</th>
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<tbody>
<tr>
<td>probability of ADHD</td>
<td>more complex problem,</td>
</tr>
<tr>
<td>without complex family</td>
<td>still possible</td>
</tr>
<tr>
<td>issues</td>
<td></td>
</tr>
<tr>
<td>↓</td>
<td>↓</td>
</tr>
<tr>
<td>Child and parents seen</td>
<td>Joint assessment by</td>
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<tr>
<td>by single clinician and</td>
<td>psychiatrist and</td>
</tr>
<tr>
<td>**computer test</td>
<td>psychologist</td>
</tr>
<tr>
<td>undertaken</td>
<td>(including computer test)</td>
</tr>
<tr>
<td>↓</td>
<td>↓</td>
</tr>
<tr>
<td>Clinician considers</td>
<td></td>
</tr>
<tr>
<td>medication with the</td>
<td></td>
</tr>
<tr>
<td>family and refers if</td>
<td></td>
</tr>
<tr>
<td>necessary</td>
<td></td>
</tr>
</tbody>
</table>

**Psychiatrist confirms diagnosis**

<table>
<thead>
<tr>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>Medical examination</td>
<td>Reformulation</td>
</tr>
<tr>
<td>medication initiated if</td>
<td>of problem and</td>
</tr>
<tr>
<td>agreed with family</td>
<td>further assessment</td>
</tr>
<tr>
<td></td>
<td>if appropriate</td>
</tr>
</tbody>
</table>

For those questionnaires that do not indicate an ADHD-type problem, the referral is then placed on the list for assessment by a member of the Family Consultancy or Child Psychology team.

*Conner’s Abbreviated Behaviour Checklist (completion by parent and teacher)*

**Conner’s Continuous Performance Test**

#Note: Questionnaire and checklists not returned were followed-up with reminder letter and if still not completed and returned, then the case would be closed to the ADHD Service.

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### 3(ii) Intervention

When the decision was made that a child’s presenting problems indicated a diagnosis of ADHD, most families opted for a trial of medication as an initial intervention. We did not keep a record of these numbers i.e. those who did and did not decide on this option, but it was clearly the preferred treatment.
If progress was satisfactory for those children prescribed Ritalin, (i.e. teachers and parents reported a noticeable improvement in the child’s condition within the first two weeks of commencing treatment), then medication reviews would take place termly and the GPs requested to take over the ongoing prescribing. During 1998, a school doctor joined the assessment team and a more comprehensive medical check-up was carried out prior to pharmacological treatment. Further, because of this added resource, a child’s response to treatment and progress could be regularly monitored at the school with parents having the opportunity to discuss with the school doctor any concerns they might have because of their child’s condition. Ongoing and significant behavioural problems could result in a referral to the CAMHS team, but they would then have to be placed on the waiting list. However, although we were unable to offer a quick response to ongoing difficulties, this was a considerable improvement on our earlier service. Families were also encouraged to contact support groups and were given recommended reading (for example, Green, 1995) as a way of encouraging a model of self-help and empowerment. For some children, progress on medication was not straightforward and the psychiatrist would continue to supervise the child’s treatment directly. Similarly if a trial of medication did not result in improvement, a reappraisal of the child’s needs was carried out.

In February 2000, a new Consultant Child Psychiatrist joined the team upon the retirement of her colleague and on taking up post a review took place of all the children on medication for diagnosed ADHD. Those children who were diagnosed, but were not receiving medication were not included in this review. This information was not readily accessible as these children would then be seen in the context of the generic caseload of the CAMHS team and be receiving interventions for challenging behaviour. Patient files were checked against an up-to-date patient list of children on medication for ADHD.

The information in Figure 2 below shows the results of this medication review, and is reproduced with kind permission of the Consultant Child and Adolescent Psychiatrist at the Family Consultancy, North Devon.
These results suggest that over half (57.14%) of the children on Ritalin alone have settled on medication and there are no further reported problems when reviewed by the Consultant. A further 5.88% on Ritalin plus other medication are also recorded as having no problems. This was assessed by follow-up medication reviews where the school doctor or the consultant psychiatrist interviewed the parents and child (and sometimes the teacher) to evaluate medication side-effects and behavioural problems.

**Figure 2 – Details of medication review.**

**Age range and number of children on medication for ADHD (April 2000)**

<table>
<thead>
<tr>
<th>Age Range</th>
<th>Numbers of Children</th>
</tr>
</thead>
<tbody>
<tr>
<td>5 - 8 yrs</td>
<td>26</td>
</tr>
<tr>
<td>9 - 12 yrs</td>
<td>71</td>
</tr>
<tr>
<td>13 - 16 yrs</td>
<td>22</td>
</tr>
<tr>
<td>Total</td>
<td>119</td>
</tr>
</tbody>
</table>

Outcome of treatment, co-morbidity and continuing problems

84% of the patients have been prescribed Ritalin alone. The remainder are on either Ritalin plus another drug or on an alternative drug treatment for ADHD.

<table>
<thead>
<tr>
<th>Treatment Description</th>
<th>Number of Children</th>
</tr>
</thead>
<tbody>
<tr>
<td>On Ritalin alone – no reported problems</td>
<td>68 (57.14%)</td>
</tr>
<tr>
<td>Ritalin, *continuing behaviour problems</td>
<td>16 (13.45%)</td>
</tr>
<tr>
<td>On other drugs +/- Ritalin – no reported problems</td>
<td>7 (5.88%)</td>
</tr>
<tr>
<td>On other drugs +/- Ritalin – **recorded co-morbidity or *continuing behaviour problems</td>
<td>11 (9.24%)</td>
</tr>
</tbody>
</table>

Remaining 17 children (14.29%) are found in both the “Ritalin alone” and “other drugs +/- Ritalin” categories and experienced other difficulties such as refusal to take medication, difficulty adjusting dosages and parental problems.

* refers to behaviour problems specific to the co-morbid diagnoses of Oppositional Defiant Disorder, or Conduct Disorder (DSM IV)

** a co-existing diagnosis e.g. developmental delay or disorder such as Asperger’s Syndrome

The overall response to medication indicated that over half of these children were reported to have improved behaviour and concentration. However this result is less than was found in a review by Swanson et al., (1998) which stated that many controlled trials have established “about 80% of patients have clinically meaningful benefits” from the use of stimulant medication. However, our figures, by their nature, i.e., problem focused (based on parent and teachers verbal reports), are less specific,
so more detailed information about progress and improvements in family, academic and social life may not have been reported.

Over 22% of the children, however, continued to experience behaviour difficulties ranging from disruptive behaviour problems to developmental delays and disorders (e.g. Asperger's Syndrome). It was this group in particular that the issues of the appropriateness of the diagnosis of ADHD were the most challenging and where, in the early stages of the development of the service, our greatest worries lay in terms being able to offer a sufficiently intensive level of monitoring and support.

4. Parent ADHD service evaluation

In order to assist our future planning, a postal survey was distributed to all those families in the medication review (Figure 2).

**Method of survey**

Our aim was to gather information about how our ADHD service was perceived by those families currently on our medication treatment list. In particular we wanted to find out more about what they felt about the assessment process and what changes and unforeseen difficulties they might have noticed in their child since diagnosis, and their suggestions for improvement in the service.

The author together with the other ADHD team members compiled the format and questions on the survey (see Appendix C). A survey method was decided upon because it was a cost effective and time saving method of accessing the information. As the questionnaires were anonymous and the questions largely open ended, we hoped that respondents would feel free to answer frankly. The major disadvantage of this method is that response rates are notoriously low and there would possibly be a response bias in relation to who would take the time and effort to complete and return their questionnaire.
Summary of results

119 questionnaires were posted (all the parents whose child was on the treatment list for ADHD). Forty questionnaires were returned and thirty-seven of these responses were analysed. Three of the responses were excluded as the children in question had not been assessed by our service. Responses were analysed according to the nature of the question and are reported in detail i.e. percentages were calculated for the closed quest below.

The average age of the children in this survey was 10.4yrs. The majority of the questionnaires were completed by mothers (n=35). The children had been on treatment from 1 – 3yrs; thirty-five children had been prescribed Ritalin as their only treatment, and two others were on Ritalin as well as other medication. Two children who had been taking Ritalin only (2 of the 35 above) had recently stopped their medication (this information had not been updated on our treatment list), one because of side effects and the other because of a query about petit mal-type episodes. Twenty-eight of the respondents had been referred to the ADHD service by their GPs and the others through health visitors, teachers and social workers.

The following questions elicited a broad range of responses and are reported in more detail in order to document them more fully.

How did you feel about the assessment of your child for ADHD?

Responses fell broadly into ‘satisfactory’ and ‘unsatisfactory’ categories:

Twenty-seven respondents felt the assessment process was acceptable with comments ranging from “satisfactory” (n=5) to relieved and happy with the outcome (n=22) e.g. “relieved that the problem had been diagnosed”, “very relieved that a long-term problem had been identified”. These responses were further elaborated by comments such as “very quick and easy”, “I was pleased that this had been found”, “very helpful”, “it all went very smoothly”.

99
Ten respondents had an unsatisfactory experience. Frustration was expressed about the referral process itself, and poor communication by the team about assessment and diagnosis that resulted in parents feeling confused and uncertain. For example “the social worker did the paperwork (referral) reluctantly”, “referral took a long time”; “I felt that one test (computer test) to diagnose was not enough”; “(they) didn’t require as much information as I had imagined”; “within 5 minutes I was asked if I thought my child had ADHD. I am not sure this diagnosis was correct”; “it seemed very quick, we left feeling shell-shocked, not sure if the diagnosis was right”; “there has been a lack of communication between the specialists and us the parents”; “we felt we were not told much, they just took over. We felt like we were pushed aside”. These comments alerted us to the fact that we needed to be explicit and transparent about what we were doing and why, and to remain mindful of how we needed to maintain a sensitive awareness of the stressfulness of this process for families.

Do you think the difficulties your child was referred for were appropriately responded to?
Twenty-eight respondents stated they were satisfied and a further five were satisfied but with reservations: e.g. “it was a pity he was not diagnosed at an earlier age”; “I wish that something more was being offered in respect of support” “much more support is needed for the whole family”. Three respondents stated that they did not feel their child’s difficulties had been appropriately addressed “I felt too much attention was paid to family history”; “diagnosis had taken too long”,

Have there been changes in your child’s behaviour at school and home?
The more noticeable changes commented on tended to cluster around some of the core features and associated features of ADHD. Twenty-seven respondents noted positive changes such as ”can now sit and listen to stories and reading dramatically improved”; “like a different child”; “he can now concentrate on tasks”; “more focused”, reflecting improved ability to pay attention, and “I am able to reason with her”; “gets on better with peers”; “he seems to cope better with life now”. These comments indicate improved relationships and social adjustment as noted by parents and teachers. About a third reported ongoing difficulties: “initial improvement but now he’s going back to his old habits”, as well as there being mixed responses: e.g. “better at school than at home”; “better on Ritalin, but has real problems in the
playground when it wears off'. Some of these responses reflect the variable response to medication as is reported in the literature i.e., medication has been found to be helpful in over 70% of children with ADHD, but that more complex treatments are necessary for up to a third of diagnosed children.

Have there been any unforeseen difficulties since your child has been assessed and treated for ADHD? If yes, please give details

Eighteen responded “yes”. Of these, nine reported medication-related difficulties such as irritability or being ‘high’ when medication wears off (n=3); “the come-down when Ritalin wears off is so apparent”; difficulties with sleep patterns (n=3); and other side effects such as some anxiety, loss of appetite and bedwetting (n=3). These are specific side effects of Ritalin and usually they either wear off after two to three weeks, or the medication dosage needs to be altered. One respondent’s child was an athlete, and they had encountered difficulties with her taking a controlled drug when competing at athletic events. The respondents did not indicate whether or not they had sought advice from the psychiatrist about these side effects. The other nine responses were linked to continuing behavioural problems despite medication: “as she gets older she becomes more difficult to handle”; “still behind academically and attention seeking”; “he still seems to mess around at school and not concentrate”, as well as difficulties with other family members and teachers accepting their child had a condition that needed specific parent and teacher management.

With just over half of the respondents reporting no unforeseen problems, these results are less than the review figures of the whole group of 119 at 63% (see Figure 2) as having no problems. It is possible that the group who responded to this survey were motivated to do so because of wanting to record their on-going concerns, and therefore the group with problems are over-represented here. Alternatively, parents may possibly be under-reporting their difficulties at the medication reviews and perhaps this might reflect some ambivalence with the ADHD service. Closer scrutiny of the responses revealed that five of these respondents had also reported being dissatisfied with the assessment process as well and so may feel reluctant or disempowered to report their problems directly to the professionals.
What suggestions do you have that would help up provide a better ADHD service?

Thirty-six of the respondents were clear in their request for more information about ADHD and support from professionals as well as the necessity of support groups: “I feel very strongly that there should be support groups so parents can get together and not feel that they are on their own”. Others included family sessions focusing on parenting strategies, as one respondent called it, “Parental Survival”. Another common request was for more support and understanding from teachers and group or individual input for the children and one respondent identified the need for including siblings in therapy as the often “suffer in silence”. Only one respondent did not feel the need for any extra support “we have never felt the need for counselling as we feel our daughter is not as bad as some ADHD children”.

I would also welcome any comments your child might like to make about the experience of being assessed and treated for ADHD, and any suggestions as to how to improve the service.

Ten children responded to this question. Some replies were more positive than others, such as “Ritalin makes a difference without making me feel different” in contrast to one child stating they felt frustrated and angry about having a diagnosis of ADHD – “why me”, and another stating that the first meeting was “very daunting”. Other comments were more ambivalent, such as one child stating that he hated going to clinics but “love my concentration tablets”, and “parents should be seen regularly but the kids should be left to get on with it”.

5. Future service development

It is important to note that as there was a relatively low response rate to our survey, the issue of response bias cannot be ignored i.e., that those who did respond felt strongly enough to want to document their comments. For those that did reply, it would appear that the anonymous nature of the questionnaire enabled respondents to express their concerns openly. On the other hand anonymity made it impossible to compare the characteristics of the respondents, or to follow-up the families concerned. However, despite these limitations and the fact that the survey was not designed with a view to extensive analysis, much useful information was gleaned which has assisted
us in terms of identifying and clarifying specific areas of concern in our future planning.

The results suggest that many of those who responded were generally satisfied with their child's assessment, and that medication was found to be helpful in reducing the core symptoms ADHD. There was also some indication that associated difficulties of ADHD, such as peer friendships and family life improved for the majority of the respondents. The actual assessment procedure i.e., questionnaires, checklists, teacher's report, computer test, family and individual child assessment by a multi-professional team does appear to give a thorough profile of a child's difficulties, and this procedure will continue in the service. However, there are also certain aspects of the assessment process that need to be improved upon and are seen as an important outcome of the survey. Of concern are the ten of the thirty-seven respondents who reported unsatisfactory experiences and dissatisfaction with the process. We need to take to heart the anxiety and sensitivity often experienced by families referred for ADHD assessment. Improvement in both the giving of information about the assessment and diagnosis of their child, as well as offering a follow-up session to talk through the implications of this diagnosis is recommended.

In response to our concerns about lack of follow-up support and therapy, an issue that was amply confirmed by the survey, and in keeping with clinical guidelines compiled by clinicians from the United Kingdom, Germany and Holland (Taylor et al., (1998) a specialised ADHD therapy service is now being set up which will directly support those families in need of extra therapeutic input as well as improving liaison with schools. A Specialist Community Psychiatric Nurse has been appointed to develop this side of the service together with the psychologist who will be responsible for supervising the clinical work.

The issue of "unforeseen difficulties" about medication side-effects, and a child's health and social development is to be addressed by improving our ongoing monitoring of diagnosed children's progress. We are proposing to set up termly behaviour and medication side-effects checklists in order to supplement reports from teachers, parents and children. Follow-up for these children continues to be carried out through the school health system with regular physical checks and medication
reviews. The ADHD team will continue to provide an informal consultation service for school-based practitioners, for example, should they have queries or on-going concerns about a child they are monitoring, liaison meetings are arranged to decide if further treatment or psychological intervention would be necessary. Plans to have an allocated ADHD mental health worker to consolidate the mental health/health/education liaison are being developed.

Although continuing lack of resources made it difficult to adequately respond to parents' request for family, individual and group therapy, as a way of encouraging parents, one of our first plans for the September 2000 school term was to invite interested parents and children to a meeting where we hoped to generate enthusiasm and gather ideas as to how to set up self-help groups in the different areas in North Devon. One enterprising parent had already advertised in their local GP surgery for other interested parents to make contact.

At a practical level, the process of undertaking and analysing this survey has highlighted the need for the service to set up a suitable database that documents specific details of all the children with the diagnosis of ADHD. This would have enabled a more detailed analysis of the questionnaires that were returned against this group as a whole. Our present system of having a list of names and having to hand-search addresses and other details is time consuming and inadequate for future auditing of a more complex and evolving service.

6. Conclusion

This paper has described the setting up and development of a specialist service for the assessment and treatment of ADHD. In retrospect our main difficulty was in justifying some of the decisions to label a child's condition as ADHD and to treat with pharmacotherapy and we are still sometimes confronted with the dilemma of ADHD being seen by some families as a label of forgiveness (i.e., not due to bad parenting), or when not given, being perceived as having been given a 'diagnosis' of blame.
The sensitive process continues of developing a shared understanding of the implications of a child with a diagnosis of ADHD in the light of the tensions, and at times, disagreement of some close colleagues in our different disciplines. This important issue continues to be of critical value in our assessments and we are ever mindful of the complexity of trying to diagnose a disorder that is still held to be controversial. Our current service follows the recommendation to offer medication to those children who are diagnosed with ADHD, and therefore, to some extent, ADHD has been medicalized in our current service. In a recent study by Klasen (2000), which explores the attitudes of parents and GPs on the 'medicalization of hyperactivity', half the parents reported that receiving a diagnosis was the most helpful event in understanding their child's difficulties. This view was supported by many of our respondents who expressed relief at being given a diagnosis. Our aim, however, is to expand our service to increase psychological intervention to enhance pharmacotherapy. As the clinical psychologist on the ADHD team, part of my role is to keep alive the complexity of the debate around diagnosing this condition. To do this I will need to ensure that the psychosocial issues that may be impacting upon a child and may possibly better explain hyperactive, inattentive and impulsive behaviour, remains at the forefront of assessment for ADHD.

The results of the review (Figure 2) indicated that over half the children prescribed medication for ADHD were reported to have improved. However, a considerable number of children continued to have behaviour problems that did not respond to treatment. According to the literature, the more severe the symptomatology, together with co-morbid conditions such as oppositional defiant disorder or conduct disorder (found in up to 30-50% of children diagnosed with ADHD, (Kuhne et al., 1997; Leung et al., 1994), the poorer the prognosis despite multi-treatment intervention (Kuhne et al., 1997). These children and their families clearly highlight the concerns about the usefulness of a diagnosis such as ADHD, especially if this results in inappropriate and unhelpful interventions, with diagnosis being used as a smokescreen for more severe psychosocial causes of childhood distress. However, this service was established in response to parents' insistence that they have access to ADHD assessment for their children. With the emphasis now in the NHS on user and carer-led services, and in the light of the continuing requests for assessment and treatment of ADHD, we will continue to offer this service. As our service develops
further, it is our aim to inform, treat, support and enable children and parents who
struggle daily with the distressing and stressful effects of inattention, hyperactivity
and impulsivity.

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Appendix A

Diagnostic criteria:

DSM-IV

Attention Deficit Hyperactivity Disorder

A.1. Inattention: At least six of the following symptoms of inattention have persisted for at least 6 months to a degree that is maladaptive and inconsistent with developmental level.

a. Often fails to give close attention to details or makes careless mistakes in schoolwork, work, or other activities.
b. Often has difficulty sustaining attention in tasks or play activities.
c. Often does not seem to listen to what is being said to him or her.
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 or expresses reluctance about, or has difficulties in engaging in tasks that require sustained effort (such as schoolwork or homework).
g. Often loses things necessary for tasks or activities (e.g. school assignments, pencils, books, tools or toys).
h. Is often easily distracted by extraneous stimuli.

A.2. Hyperactivity-Impulsivity: At least five of the following symptoms of hyperactivity-impulsivity have persisted for at least 5 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. Leaves seat in classroom or in other situations in which remaining seated is expected.
c. Often runs about or climbs excessively in situations where 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 always ‘on the go’ and acts as if driven by a motor.
f. Often talks excessively.

Impulsivity

g. Often blurts out answers to questions before they have been completed.
h. Often has difficulty waiting in lines or waiting in games or group situations.
B. Some symptoms that cause impairment were present before age 7

C. Some symptoms that cause impairment must be present in two or more settings (e.g. at school, work, and at home).

D. There must be clear evidence of clinically significant impairment in social, academic or occupational functioning.

E. Does not occur exclusively during the course of a Pervasive Developmental Disorder, Schizophrenia or the Psychotic Disorder, or Personality Disorder.

ICD-10

*Hyperkinetic Syndrome*

A. Demonstrate abnormality of attention and activity at home for the age and developmental level of the child, as evidenced by at least three of the following attention problems:

1. Short duration to spontaneous activities.
2. Often leaving play activities unfinished.
3. Overfrequent changes between activities.
4. Undue lack of persistence at tasks set by adults.
5. Unduly high distractibility during study (e.g. homework or reading assignment); and by at least two of the following:
6. Continuous motor restlessness (running jumping, etc.).
7. Markedly excessive fidgeting or wriggling during spontaneous activities.
8. Markedly excessive activity in situations expecting relative stillness (e.g. mealtimes, travel, visiting, church).
9. Difficulty in remaining seated when required.

B. Demonstrate abnormality of attention and activity in school or nursery (if applicable), for the age and development level of the child, as evidenced by at least two of the following attention problems.

1. Undue lack of persistence at tasks.
2. Unduly high distractibility i.e. often orienting towards extrinsic stimuli.
3. Overfrequent changes between activities when between activities when choice is allowed.
4. Excessively short duration of play activities, and by at least two of the following activity problems:
5. Continuous and excessive motor restlessness (running, jumping, etc.) in school.
6. Markedly excessive fidgeting and wriggling in structured situation.
7. Excessive levels of off-task activity during tasks.
8. Unduly often out of seat when required to be sitting.

C. Directly observed abnormality of attention or activity. This must be excessive for the child’s age and development level. The evidence may be any of the following:
1. Direct observation of the criteria in A or B above i.e. not solely the report of parent and/or teacher.
2. Observation of abnormal levels of motor activity, or off-task behaviour, or lack of persistence in activities, in a setting outside home or school (e.g. clinic or laboratory).

D. Does not meet criteria for pervasive developmental disorder, mania, depressive or anxiety disorder

E. Onset before the age of six years.

F. Durations of at least 6 months

G. I.Q. above 50
Appendix B

Contents:

Home and School Behaviour Checklist

Background Information Questionnaire

Attention-Deficit Hyperactivity Disorder Test
Weekly Assessment Sheet

Week Commencing:

Childs Name:

Home or School (delete as appropriate)

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Comments:
ATTENTION DIFFICULTIES CLINIC
BACKGROUND INFORMATION

Child's name: 

Birthdate: Today's date: 

Age: 

School: Year: 

Main Carer Relationship to child 

Occupation 

If parents are separated or divorced, how old was the child when this occurred?

List everyone living at home:

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<th>Relationship to child</th>
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What activities do your family enjoy doing together?

Briefly describe your child's current difficulties:

How long has this problem concerned you?

What seems to help the problem?

What seems to make the problem worse?

Has your child previously been assessed and treated for this problem? yes/no

If yes, when and with whom?

What do you most like about your child?

What have you found to be the most satisfactory way of helping your child?
Developmental details

Was the pregnancy normal? yes/no

If no, please give details

Was the birth normal? yes/no

If no, please give details

Were there any feeding problems? yes/no

If yes, please give details

Were there any sleeping problems? yes/no

If yes, please give details

How would you describe your child's temperament as an infant?

How would you describe your child's temperament as a toddler?

As an infant, did your child like to be held? yes/no

As an infant, was your child alert?

Were there any special problems in the growth and development of your child during the first few years? yes/no

If yes, please describe:

Were there any significant separations or losses in your child's early life? yes/no

If yes, please describe

How did your child settle into playgroup/school?

Has your child has any significant health problems? yes/no

If yes, please describe

Has your child had a head injury? yes/no

If yes, please give details
Does your child have any allergies? yes/no
(include reacting to food colourants)
If yes, please give details

What are your child's favourite activities?

What activities does your child like least?

Does your child have friends?

Does your child have special fears, habits, mannerisms? yes/no
If yes, please describe

Does your child engage in behaviour that could be dangerous to self or others? yes/no
If yes, please give details

Would you say your child was aggressive? yes/no

Shy, anxious yes/no

Does anyone else in your family have or did have similar problems to your child? yes/no
If yes, please give details

Has anyone in your family been treated by a psychologist/psychiatrist? yes/no
If yes, please give details
# Attention-Deficit/Hyperactivity Disorder Test

**A Method for Identifying Individuals with ADHD**

## SUMMARY/RESPONSE FORM

### Section I. Identifying Information

<table>
<thead>
<tr>
<th>Subject’s Name</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Address</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Rater’s Name</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Relationship to Subject</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Examiner’s Name and Title</th>
<th></th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th>Date of ADHDT Rating</th>
<th>Year</th>
<th>Month</th>
</tr>
</thead>
<tbody>
<tr>
<td>Subject’s Date of Birth</td>
<td>Year</td>
<td>Month</td>
</tr>
<tr>
<td>Subject’s Age</td>
<td>Year</td>
<td>Month</td>
</tr>
</tbody>
</table>

### Section II. Score Summary

<table>
<thead>
<tr>
<th>Subtests</th>
<th>Raw Score</th>
<th>SS</th>
<th>%</th>
<th>SEM</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hyperactivity</td>
<td>1</td>
<td></td>
<td></td>
<td>1</td>
</tr>
<tr>
<td>Impulsivity</td>
<td>1</td>
<td></td>
<td></td>
<td>1</td>
</tr>
<tr>
<td>Inattention</td>
<td>1</td>
<td></td>
<td></td>
<td>1</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Sum of Standard Scores</th>
<th></th>
</tr>
</thead>
</table>

| ADHD Quotient | 3 |

### Section IV. Profile of Scores

<table>
<thead>
<tr>
<th>Subtest Standard Scores</th>
<th>ADHD Quotient</th>
<th>Degree of Severity</th>
<th>Probability of ADHD</th>
</tr>
</thead>
<tbody>
<tr>
<td>17–19</td>
<td>131+</td>
<td>High</td>
<td>Very High</td>
</tr>
<tr>
<td>15–16</td>
<td>121–130</td>
<td>High</td>
<td>High</td>
</tr>
<tr>
<td>13–14</td>
<td>111–120</td>
<td>Above Average</td>
<td>Above Average</td>
</tr>
<tr>
<td>8–12</td>
<td>90–110</td>
<td>Average</td>
<td>Average</td>
</tr>
<tr>
<td>6–7</td>
<td>80–89</td>
<td>Below Average</td>
<td>Below Average</td>
</tr>
<tr>
<td>4–5</td>
<td>70–79</td>
<td>Low</td>
<td>Low</td>
</tr>
<tr>
<td>1–3</td>
<td>≤69</td>
<td>Very Low</td>
<td>Very Low</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>ADHDT Subtests</th>
<th>ADHDT Composite</th>
<th>Other Measures of Intelligence, Achievement, or Behavior</th>
</tr>
</thead>
<tbody>
<tr>
<td>ADHD Quotient</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Test Used</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Test Used</td>
<td></td>
<td></td>
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<tr>
<td>Test Used</td>
<td></td>
<td></td>
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<tr>
<td>Test Used</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

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Additional copies of this form (#6882) are available from PRO-ED, 8700 Shoal Creek Blvd., Austin, TX 78757, 512/451-3246.
DIRECTIONS: Please indicate which of the following behaviors/characteristics are a problem for this individual. Mark or circle 0 if the behavior is not a problem (the subject rarely demonstrates this problem, and it does not impair his or her functioning) or if you have not had the opportunity to observe the behavior. Mark or circle 1 if the item refers to a behavior that is a mild problem (the subject sometimes demonstrates this behavior, and it occasionally causes problems and impairs his or her functioning.) Mark or circle 2 if the item refers to a behavior that is a severe problem for this individual (the subject frequently demonstrates this behavior, and it usually causes problems and impairs his or her functioning.) Do not skip any items.

### Hyperactivity Subtest

<table>
<thead>
<tr>
<th>Behavior</th>
<th>Not a Problem</th>
<th>Mild Problem</th>
<th>Severe Problem</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Loud</td>
<td>0</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>2. Constantly “on-the-go”</td>
<td>0</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>3. Excessive running, jumping, climbing</td>
<td>0</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>4. Twisting and wiggling in seat</td>
<td>0</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>5. Easily excited</td>
<td>0</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>6. Grabs objects</td>
<td>0</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>7. Excessive talking</td>
<td>0</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>8. Difficulty remaining seated</td>
<td>0</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>9. Constantly manipulating objects</td>
<td>0</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>10. Inability to play quietly</td>
<td>0</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>11. Fidgets</td>
<td>0</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>12. Restless</td>
<td>0</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>13. Squirms</td>
<td>0</td>
<td>1</td>
<td>2</td>
</tr>
</tbody>
</table>

Hyperactivity Sum
### Impulsivity Subtest

<table>
<thead>
<tr>
<th>Not a Problem</th>
<th>Mild Problem</th>
<th>Severe Problem</th>
</tr>
</thead>
<tbody>
<tr>
<td>0</td>
<td>1</td>
<td>2</td>
</tr>
</tbody>
</table>

14. Acts before thinking
15. Shifts from one activity to the next
16. Fails to wait for one’s turn
17. Difficulty waiting turn
18. Blurts out answers
19. Impulsive
20. Interrupts conversations
21. Intrudes on others
22. Does not wait for directions
23. Fails to follow rules of games

**Impulsivity Sum**

### Inattention Subtest

<table>
<thead>
<tr>
<th>Not a Problem</th>
<th>Mild Problem</th>
<th>Severe Problem</th>
</tr>
</thead>
<tbody>
<tr>
<td>0</td>
<td>1</td>
<td>2</td>
</tr>
</tbody>
</table>

24. Poor concentration
25. Fails to finish projects
26. Disorganized
27. Poor planning ability
28. Absentminded
29. Inattentive
30. Difficulty following directions
31. Short attention span
32. Easily distracted
33. Difficulty sustaining attention
34. Difficulty staying on task
35. Difficulty completing tasks
36. Frequently loses things

**Inattention Sum**
Section VI. Key Questions

1. Does the person demonstrate six or more symptoms of inattention, or six or more symptoms of hyperactivity, or impulsivity listed in each subtest?

2. Does the person exhibit the behavioral problems in a variety of environments?

3. Does the person demonstrate the behaviors considerably more frequently than do most people of the same mental age?

4. Has the person demonstrated the behaviors for at least 6 months?

5. Did the person first demonstrate the behaviors before age 7?

6. Is the person’s functioning (at school, home, and work) significantly impaired?

7. Are there other conditions that could possibly be causing the behavioral problems? If yes, what are the conditions?

8. Who has previously evaluated this person and what were the results?

9. What specific interventions have been attempted to treat the person’s problems?

10. What additional information needs to be collected?

Section VII. Recommendations and Comments

________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________

4
APPENDIX C

ADHD SERVICE EVALUATION

We have been running a special service for children with attention difficulties for some time now at the North Devon Healthcare Trust and I would like your comments, as parents who have had a child diagnosed with ADHD, as to how we might improve our service. The information you give will be an important part of an evaluation of the ADHD service and its future development.

The information given is confidential in that we do not ask that you give your own or your child’s name.

1. How old is your child?

2. Relationship of respondent to referred child: e.g. Father, mother etc.

3. When was your child diagnosed as having ADHD?

4. What treatment was your child given?

5. Is your child still receiving treatment?

6. If no, when did treatment stop?

7. What was the reason for stopping?

8. How was your child referred to the Psychology Department/Family Consultancy?
   a) GP
   b) Health Visitor
   c) Paediatrician
   d) Teacher
   e) Other (give details)

9. How did you feel about the assessment of your child for ADHD?
10. Do you think the difficulties your child was referred for were appropriately responded to?

11. Have there been changes in your child’s behaviour at school and home?

12. What changes (if any) have you noticed most?

13. What changes (if any) have teachers commented on?

14. Have there been any unforeseen difficulties since your child has been assessed and treated for ADHD? YES/NO

If yes, please give details.

15. What suggestions do you have that would help us to provide a better ADHD service? E.g. support groups, individual counselling, family therapy, or any other ideas you might have thought of or heard about.

16. I would also welcome any comments your child might like to make about the experience of being assessed and treated for ADHD, and any suggestions as to how to improve the service.

THANK YOU VERY MUCH FOR TAKING THE TIME TO FILL IN THIS QUESTIONNAIRE.
CURRICULUM VITAE

ANN COLBORN
DEPARTMENT OF PSYCHOLOGY
NORTH DEVON DISTRICT HOSPITAL
RALEIGH PARK
BARNSTAPLE
NORTH DEVON
EX31 4JB

PRESENT POSITION:
April 1995 – present  Senior A Grade: Psychology Department, North Devon.

Clinical responsibilities:
I am a member of a small children’s psychological service team of three based within the Psychology Department at a provincial hospital that serves a largely rural community. We also undertake sessional work as part of a CAMHS team based at a local Health Centre where we often co-work with colleagues from Social Services and Child Psychiatry.

I am clinically responsible for the assessment of children, adolescents below the age of 18 years and their families who present to the Psychology outpatient clinics at the North Devon District Hospital. Patients are referred by paediatricians, GPs, Health Visitors and colleagues in Social Services and Education.

Interventions vary according to formulations but individual psychotherapy, family therapy and parent counselling are the predominant therapies I offer. I am also interested in developing cognitively-based interventions with parents and families as well as individual cognitive work with adolescents.

Service Development:
Over the past four years a child psychiatrist colleague in the CAMHS team and myself have been involved in developing a service for the assessment and treatment of Attention Deficit/Hyperactivity Disorder. This service now includes a specialist community psychiatric nurse and we are able to offer a more comprehensive follow-up service including regular medical monitoring through the school doctors and nurses.

Supervision and training:
1) Fortnightly peer supervision takes place within the children’s speciality where clinical cases as well as practical and professional issues are discussed.

2) I am a training supervisor of clinical psychology doctoral trainees from the Universities of Exeter and Plymouth.
4) I supervise a CPN colleague’s clinical work that mostly involves home interventions with families with a child with ADHD and ongoing behaviour problems. We also do some joint family sessions.

3) I have contributed to specialised workshops and talks to GPs, school nurses, paediatric nurses, social workers, mental health colleagues and parents on a wide range of topics including eating disorders, conduct problems, ADHD, anger management and behavioural interventions.

4) I offer teaching and supervision to the CAMHS team e.g. introduction to CBT.

Continuing professional development:
1) Continuing professional development has mainly been in the form of attendance at study days, conferences and workshops which included such topics as Asperger’s Disorder, Attention Deficit Hyperactivity Disorder, Dillingtons Family Therapy Annual Conference, Dissociative Disorders, Borderline Personality Disorder, Child Protection, Assessment and Intervention with children with special needs, Cognitive Therapy for Children, Adolescents and their Families.

2) Completed a six-month clinical Family Therapy course at Exeter University Department of Clinical and Community Psychology. The course comprised the clinical application of systemic theory to families and couples referred to their outpatient clinics. Therapeutic processes were facilitated by live team supervision.

3) Therapy workshops:

- Parent-child attachment therapy
- Level One Eye Movement Desensitization and Reprogramming
- 2 day workshop on Interpersonal Therapy
- 2 day workshop on Solution Focused Therapy

Other areas of clinical interest:

I am developing specialist skills in interventions for PTSD and OCD in childhood, working with both the child individually and the family.

I do a regular clinic with a family therapist which offers sessions to families who have a child with a chronic medical condition e.g. diabetes, cystic fibrosis, childhood leukaemia.

I would like to develop group work for parents and children, but unfortunately lack of resources have meant that there have been no opportunities for this sort of work in North Devon for several years.

Setting up and running a couple’s clinic with a colleague in the Adult Mental Health speciality. A colleague and myself saw couples and the clinic was also
a venue for training two therapists interested in couples work. The use of a one-way mirror and live supervision was the predominant teaching method. This clinic has now closed but I continue to see couples with the same colleague from time to time.

**Academic development:**

PsychD Clinical Psychology Conversion Course – due to complete October-November, 2002.

Topics in doctoral portfolio:

*Academic Dossier:*
- Reviews: 1. Adult Attention Deficit Hyperactivity Disorder
  2. Attachment Theory and Childhood Disruptive Behaviour Disorders

*Professional Dossier:*
- Development of a Specialist ADHD Service

*Research Dossier:*
- Qualitative study – Mothers’ experience of parenting their child with ADHD. An Interpretive Phenomenological Analysis study.

**Previous position:**

July 1994 – March 1995 - Junior Lecturer, University of Cape Town Medical School. Responsible for Human Behaviour course for 1st year medical students on a special bridging course because of their disadvantaged schooling due to South African apartheid regime.

- Sessional Clinical Psychologist at the Child Guidance Clinical, University of Cape Town

July 1994 - Graduated MA Clin Psych, University of Cape Town

**Publications:**


Academic Dossier

1) Adults with attention deficit hyperactivity disorder? – the dilemmas of diagnosis

2) From early-onset childhood disruptive behaviour disorders to adult antisocial and criminal behaviour: How can attachment theory inform understanding of early risk and intervention?
ADULTS WITH ATTENTION DEFICIT HYPERACTIVITY DISORDER? – THE DILEMMAS OF DIAGNOSIS

...it is useful to remind ourselves that diagnoses are concepts that evolve over time and their usefulness is judged by their ability to inform us about pathophysiology, treatment, possible prevention and prognosis. In psychiatry, most diagnoses continue to be based on symptomatology and course of illness, and their validity must be determined in the absence of gold standards.

Sachdev, 1999

1. Introduction

Attention Deficit Hyperactivity Disorder (ADHD) is now a well recognised disorder of childhood and adolescence; it is thought to be one of the most commonly diagnosed psychiatric disorders of childhood (Cantwell, 1996; Taylor, Sandberg, Thorley & Giles, 1991; Leung, Robson, Fagan & Lim, 1994) and accounts for up to 50% of referred child mental health problems in the USA where it is estimated that up to 10% of boys and 5% of girls in primary school suffer from this condition (Cantwell, 1996; The Work Group on Quality Issues of the AACAP, 1997).

Follow-up studies carried out in the United States of children with a diagnosis of ADHD into adolescence and adulthood suggest that this disorder frequently persists and can be associated with significant psychopathology and dysfunction in adult life (Biederman, 1998; Gittelman, Mannuzza, Shenker & Bongura, 1985; Shekim, Asarnow, Hess, Zaucha & Wheeler, 1990; Toone & van der Linden 1997; Wender, 1998) albeit an often unrecognised cause of adult mental health problems. Up to 30% of those diagnosed with the childhood condition had significant co-morbid psychiatric symptomatology (Cantwell, 1996; Hansen, Weiss & Last, 1999; Toone & van der Linden, 1997). Toone and van der Linden further extrapolated from the studies they reviewed to suggest that approximately 0.5% - 1% of the young adult population in general had symptoms associated with ADHD.

The Diagnostic and Statistical Manual of Mental Disorders (DSM-IV) (APA, 1994) identifies the adult condition as a residual form (ADHD-R). ADHD-R has been diagnosed and treated for some time in the USA but has only recently appeared in the literature in the UK as a possible diagnosis, and, until very recently, appeared to have been largely dismissed by adult mental health professionals (Riddall, 1996; Toone & van der Linden, 1997). The controversy surrounding the diagnosing of adult with a diagnosis of ADHD mirrors to some extent the debate that occurred when ADHD in
children was well recognised and diagnosed in the United States, but less frequently diagnosed in Europe and the United Kingdom where the diagnostic criteria used were far more stringent (Kewley, 1998).

There are two main groups of adults that may present with ADHD; those with a diagnosed childhood condition, and those who retrospectively recognise this condition in an undiagnosed form from their own childhood, due to greater public awareness in recent years. Self-diagnosis is viewed with scepticism by professionals as there is the danger that blame for personal failures and disappointments could then inappropriately be laid at the door of a medical diagnosis whether diagnosed in childhood or recognised later (Spencer, Biederman, Wilens & Faraone, 1998). Furthermore, Barkley, Murphy and Kwasnik (1996) point out that there is still uncertainty about the presentation of ADHD in clinic-referred adults who have never been diagnosed.

This article aims to explore some of the evidence from the existing literature in order to examine the validity of a diagnosis of ADHD in adulthood. The main focus will be on papers published from the mid-1980’s onwards, although some key earlier papers will be included. Studies carried out in the 1970’s, took place prior to the introduction of standardised diagnostic criteria in the DSM-III (1980) for the childhood disorder (for example Mann & Greenspan, 1976). These articles were of historic interest as the belief that ADHD was a disorder that resolved with maturation began to be challenged. However, studies of this era have been criticised as selecting from a heterogeneous subject pool weighted towards a more severe psychiatric population, not using traditional measures of psychological impairments, and being largely anecdotal in nature (Barkley et al., 1996). Furthermore, without the framework of diagnostic criteria, there was an overemphasis on hyperactivity as selection criteria that can, in the more severe clinical population, be due to many other significant disorders, e.g. bipolar affective disorder (Toone, Clarke & Young, 1999). Most of the studies discussed here have been at the forefront of research into a diagnosis of ADHD in adulthood since these earlier times and represent the most widely cited authors to this field. A literature search was carried out to obtain the most recent work by these authors as well as more contemporary authors cited by them.
Spitzer and Williams (in Kaplan and Sadock, 1985) specify the criteria of a valid clinical diagnosis, i.e., documentation of its characteristic signs and symptoms (descriptive validity); evidence for a specific course, outcome and treatment response (predictive validity); and evidence regarding aetiology and physiological pathology (concurrent validity). Kendell (1989) concludes that of these three, predictive validity is pre-eminent in the determination of most diagnoses. Therefore the emphases in this review will be on predictive validity, although all three will be considered, based on the format of presentation used by Spencer, Biederman, Wilens and Faraone, (1994, 1998). Although these criteria are individually presented, they are not necessarily discrete, and some overlap is inevitable.

(2) Descriptive validity (documentation of characteristic signs and symptoms)

Several studies describe a pattern of symptoms that may be considered to be clinically similar to the childhood presentation of ADHD. One of the earliest studies that attempted to identify ADHD symptomatology in adults was carried out by Borland & Heckman (1976), using a cross-sectional methodology. They interviewed a group of 20 men and their sibling's 25 years on from when they had presented with 'hyperactive child syndrome' (p.669) at a Child Guidance Clinic during the 1950's. The results of this study were limited by the fact that on childhood presentation the definition of hyperactivity as we understand it today did not exist. They were therefore retrospectively diagnosed based on opinions recorded in the clinic records, and the ability of these men to recall details from childhood. This study suggested, however, that over half the subjects continued to have problems with restlessness, nervousness and difficulty controlling temper and other difficulties, as compared to their brothers.

There followed a comprehensive number of prospective longitudinal follow-up studies that tracked the progress of ADHD from childhood into adolescence and adulthood (Weiss, Hechtman, Milroy & Perlman, 1985; Gittelman et al. 1985; Mannuzza et al. 1991). A consistent pattern of enduring symptomatology was found in 30-60% of adolescents and 31-44% of young adults with childhood-onset ADHD, although adults appeared to have more inattentive symptoms than hyperactive-
impulsive symptoms (Hart, Lahey, Leober, Applegate & Frick, 1995; Millstein, Wilens, Biederman, Spencer & Thomas, 1997).

A significant factor when considering the signs and symptoms of a disorder is co-morbidity. Psychiatric co-morbidity complicates the effective assessment, diagnosis and treatment of adults with ADHD symptoms (Hornig, 1998; Bramble 2000; Rosa-Rebaudengo, Durst & Dickman, 2000). It is currently thought that 20 to 30% of ADHD adults have experienced depression, 40% clinical anxiety, and 5 to 10% bipolar disorder (Biederman, Faraone, Spencer, Wilens, Mick & Lapey, 1993; Shekim et al., 1990). Biederman, Faraone, Spencer, Wilens, Norman & Lapey, (1993) found that 25-30% of the adults with ADHD in their study had alcohol dependency, and 15-20% had drug dependencies and several studies suggested that ADHD preceded the onset of most of these co-morbid conditions (Prince & Wilens 2000; Mannuzza, Klein, Bessler, Malloy & LaPadula, 1993). Diagnosis in adulthood can therefore be complex; for example, symptoms of hyperactivity or impulsivity can be part of the presentation of mania, and inattentiveness or poor concentration may be a symptom of anxiety (Mancini, Ameringen, Oakman & Figueiredo, 1999) or depression (Hornig 1998) although a higher than expected number of patients with long term depression were found to have ADHD symptoms in childhood. It has also been documented that up to 25% of children with co-morbid conduct or oppositional defiant disorder go on to develop antisocial personality characteristics in adulthood (Weiss & Hechtman, 1993). The sceptical approach may see the high rate of co-morbidity as evidence that ADHD is possibly a secondary feature to these psychiatric conditions, or is a prodromal or neurodevelopmental precursor to other disorders (Spencer et al., 1998) rather than a residual form of the childhood condition.

Bearing in mind the complications in diagnosis presented by the issue of co-morbidity, the importance of childhood onset appears to be crucial. In their review, Spencer et al. (1994) emphasise this point by stating that there is evidence of descriptive validity in studies of patients who had ADHD symptomatology in childhood and where the clinical features of the childhood condition were still causing significant difficulties in adulthood. They found that in nine major studies that compared adults with a diagnosis of ADHD with either siblings or outpatient psychiatric controls there was strong evidence (up to 50% with a diagnosis of
childhood ADHD vs. 5% in controls) that had full or partial symptoms of ADHD in adulthood. These symptoms invariably resulted in less satisfactory close personal relationships and erratic or unsuccessful occupational lives despite having similar abilities to control subjects. A higher incidence of conduct, anxiety and mood disorders was also found in the adults with a diagnosis of ADHD.

In a recent study by Berkley et al., (1996) a group of 25 young adults referred for assessment, and who met the DSM-IV criteria for a diagnosis of ADHD, were compared to a control group recruited from the community. The study focused on possible social, educational, occupational and psychological impairments. Their results showed that where significant group differences were found, they were consistent with studies that followed up children with a diagnosis of ADHD into adulthood, as well as studies of psychological impairment in children with this disorder. These authors were therefore supportive of the argument that ADHD should be considered a valid and useful diagnosis for adults despite the limitation of their study i.e. small numbers, restricted age range, referral bias and possible bias in interview recording because of non-blindness to diagnostic membership. However, studying clinic-referred adults does not give an indication of prevalence of ADHD symptoms in the normal adult population (Murphy & Barkley, 1996). Such information would be required to evaluate the recommended DSM-IV guidelines for diagnostic thresholds for use in determining the diagnosis of adults, as well as establishing a more developmentally appropriate understanding and wording of the DSM-IV symptom list.

In order to address the need for more appropriate criteria in the identification and diagnosis of ADHD in adults, Murphy and Barkley (1996) assessed 720 volunteers recruited from adults entering a Department of Motor Vehicles for application or renewal of their driver's licence, age range 17-84 who completed two rating scales, one pertaining to current behaviour and one retrospective recall of their own behaviour between ages 5-12yrs. Rating scales were scored using the diagnostic thresholds DSM-IV i.e., 6 of 9 Inattention symptoms and 6 of 9 Hyperactive-Impulsive symptoms. The relationship between both current and retrospectively recalled symptoms was examined as well as symptom relationship with other variables such as age, gender, education, ethnicity and socio-economic status.
They concluded from their results that symptoms of ADHD are relatively common in an adult group (0.9 to 2.5 percent), but this declines in the older age groups and that ADHD symptoms might be understood as falling along a continuum of severity. This result was well below that found in childhood samples, but it was suggested that these results indicated that diagnostic thresholds were too high for an adult population. Developmentally inappropriate diagnostic criteria and thresholds were seen to suggest that many children with a diagnosis of ADHD may not outgrow this condition by adulthood, but rather outgrow the criteria used for diagnosis. A small but significant correlation was found between levels of education and socio-economic status and ADHD symptoms i.e. the higher the number of symptoms, the lower the education attainment and socio-economic status. Identified limitations of this study were sample bias e.g. adults licensed to drive and who volunteered, and the self-reporting of symptoms without corroboration from long term partner, relative or friend may have lead to under-reporting of symptoms. Despite its limitations, this study appears to have established a prevalence of ADHD symptoms in a non-clinical adult population as well as anomalies in diagnostic thresholds when applied to adults.

However, the inaccuracy of retrospective reporting of childhood symptomatology, even if given by a parent or close relative, is well known (Manuzza et al., 1993). Long-term prospective studies, by their very nature, have attempted to address this by tracking children with a diagnosis through into adulthood (Biederman 1998; Gittelman et al., 1985; Manuzza et al., 1991, 1993; Weiss et al., 1985; Hansen, Weiss & Last, 1999). They do not, however, address the difficulty of assessing adults who present for first-time diagnosis.

Despite the suggested diagnostic threshold discrepancy, and the issues of retrospective reporting, it appears that there are still sufficient similarities in the signs and symptoms of ADHD in adults for it to be understood within the descriptive framework of the childhood condition. However future research will need to aim for clarification of these issues.
3. Concurrent Validity (aetiology and pathophysiology)

The aetiology of ADHD appears to be unclear and it is possible that a combination of factors would influence the predisposition and manifestation of this condition. Environmental influences such as pre- and perinatal complications, dietary factors and toxins have been cited, although have not been shown to have a significant influence in aetiology (Toone et al., 1999). The focus of this part of the review will therefore be on biological factors.

There have been numerous studies that document familial transmission of ADHD. Faraone (2000) reviewed seven family studies that demonstrated that parents of children with a diagnosis of ADHD had a significantly increased risk of a diagnosis of ADHD themselves (fathers – mean prevalence of 24% for families with ADHD, controls 7%). Two further studies, identified by Faraone, found higher rates of ADHD among proband relatives (mean = 49%) compared to controls (mean = 2.5%). Such studies therefore suggest that the biological relatives are at an increased risk for this disorder. In studies that use clinically referred subjects, however, these findings may be less reliable as many other factors in the family system might account for the symptomatic presentation of an attentional disorder in parents and siblings.

Biederman (1998) discussed evidence of a substantial genetic component to this apparent familial predisposition stating that twin studies find greater similarity between a diagnosis of ADHD in monozygotic twins compared with dizygotic twins. Biederman also cites adoption studies as suggesting that the adoptive relatives of ADHD relatives are less likely to have ADHD and associated features than are the biological family members. This suggests that ADHD has been found to be a familial disorder and that transmission is mediated in part by genetic factors. In their recent review, Faraone and Biederman (1998) conclude by stating that ADHD is a disorder of the brain that has multiple causes: genes, biological and psychosocial adversity, but it is unknown how these components might combine to cause ADHD. Faraone and Biederman also state that at present there is no pathophysiological profile of ADHD but that a dysfunction of the frontosubcortical pathways that control attention and motor behaviour may be implicated.
A further debate in the literature revolves around the issue of the diagnosis of ADHD being conceptualised either as a categorical disorder, or the tail end of a continuously distributed trait in the population. Conceptualised as a continuum approach, heritability would then involve the inheritance of a trait rather than a disorder, whereas the DSM-IV by describing specific diagnostic criteria may be artificially imposing a categorical approach to diagnosis. A recent large-scale twin study by Levy, Hay, McStephen, Wood and Waldman (1997), however, reported high heritability of a diagnosis of ADHD irrespective of a categorical or continuum approach. Sachev (1999) argues that a longitudinal research approach that looks at both genetic and environmental factors is necessary to further this debate. Furthermore, recent interest in neuroimaging has lent credibility to the pathophysiology of a diagnosis of ADHD in adults in establishing neurobiological abnormalities that may underpin a diagnosis of ADHD (Sachdev, 1999). Brain structures have been examined by magnetic resonance imaging (MRI) scanning and brain mapping and the study of evoked responses have been carried out using electroencephalographic (EEG) although there are no EEG studies of adults with ADHD symptoms. Certain studies have suggested that a neurobiological link between a diagnosis of ADHD in childhood and adulthood may eventually be found. (for example Sachdev, 1999, Spencer 1998).

4. Predictive Validity (course, outcome and treatment)

(i) Course and outcome

What is the evidence in the literature of predictive validity? It is suggested that the most effective way to assess the course of an illness is to study it longitudinally (Spencer et al., 1998). However, to date there are no long-term studies of adults with a diagnosis of ADHD available. Over the past fifteen years there have been many studies that have demonstrated the persistence of ADHD symptoms into adulthood (Weiss et al., 1985; Mannuzza et al., 1991, 1993). By its nature, predictive validity requires a more specific account of the course and outcome of the disorder. Prospective follow-up studies seek to track ADHD from childhood into adulthood and vary in their methodology. For example certain prospective studies examine groups
of adults who were diagnosed and treated as children and then interviewed at a single point (i.e. 5 or 10 years) in the future. Other studies track a cohort from childhood into adulthood at regular intervals. There are limitations to these longitudinal follow-up methodologies. For example, single point cross-sectional follow-up studies fail to control or detail intervening history that may have been an important outcome determinant (Whitman, 2000). Also, the maintenance of a full subject cohort appears difficult and can lead to a bias in results. Furthermore, there is an emphasis on negative outcomes with Hansen et al., (1999) study as discussed below, being an exception.

Weiss et al., (1985), carried out a 15 year prospective follow-up study. Sixty-three of an original group of 104 subjects who had first been identified as being hyperactive in childhood now aged 21-33 years, were compared to forty-one matched normal controls on several variables. This group had been followed up at five-year intervals over the 15 years. Results of this study indicated that over half of the hyperactive group still had at least one symptom of ADHD to a disabling level and that 23% of the proband group fulfilled the criteria for a diagnosis of antisocial personality disorder. Overall the hyperactive group functioned less well and displayed more psychopathology than the control group. The impression by the authors was that subjects lost to the study from the original childhood group may represent those whose outcome was worse and that their results from this study probably represented a minimal estimate of adult psychopathology.

A study by Gittleman et al., (1985) also prospectively followed-up boys who had been diagnosed as being hyperactive as children. This study retained 98% of the original cohort and compared them to normal controls. This group were aged 16-23 years and therefore represented a late adolescent/early adulthood group. This study found that 31% of the probands as compared to 3% of controls had all the symptoms of ADHD. The group with a diagnosis of ADHD also had a higher prevalence than controls of substance abuse and conduct disorders including use of weapons and stealing. Similar results were reported in Manuzza et al’s study (1993) (ADHD symptoms, 11% vs. 1%; antisocial disorder, 18% vs. 2% and substance abuse, 16% vs. 4%).
Two more recent prospective studies by Manuzza, Gittelman, Boïngura, Malloy and Giampino, (1998) and Hansen et al., (1999) identified ongoing difficulties in their subjects who had a childhood diagnosis of ADHD. The study by Manuzza et al. also found a significantly higher risk for substance abuse and antisocial disorders in the index group (n=85) with 11% of the cohort still experiencing impairing symptoms of ADHD at the age of 24 years. Hansen et al. identified continuing problems with psychological functioning in the group of 32 individuals with a diagnosis of ADHD with childhood histories of a diagnosis of ADHD. However, this study also found that the group with a diagnosis of ADHD would seek help for their difficulties and as young adults, had overcome many of the problems they had experienced in childhood, and a cautiously optimistic prognosis was offered. All the young men in Hansen’s study had received treatment for a diagnosis of ADHD in childhood and for both studies the subjects were all in their late teens or early twenties. Manuzza’s cohort represented 82% of an original childhood group and Hansen’s 56% of an original group with ADHD. It is therefore possible that Hansen’s more favourable outcome was due to the same limitation in Weiss’s 1985 study i.e., that the subjects who may have had the more negative outcomes were not traced for the current study. Both studies were limited by their subjects being from predominantly middle-class white families and who had received extensive therapeutic support over the years, and consequently do not account for those who might come from lower socio-economic backgrounds who may not have received such optimal treatment.

Despite the variation and limitations in longitudinal methodologies, there are consistent findings of a significant number of subjects in these studies being identified as experiencing features of a diagnosis of ADHD during childhood. At their most benign, these difficulties can cause day-to-day tensions and disorganisation, and at worst, can result in severe adult psychiatric symptomatology.

(ii) Treatment

There is extensive literature on the subject of treatment and outcome, although in treating adults, pharmacotherapy tends to be more complex than that in childhood utilising both stimulant and non-stimulant medication (Spencer et al. 1998; Prince & Wilens, 2000). Several studies have investigated the efficacy of stimulant medication
Shekim et al., 1990; Wilens, Biederman, Spencer & Spencer, 1995; Mattes, Boswell & Oliver, 1984; Spencer, Wilens & Biederman, 1995., Wender, Wood & Reimherr, 1985). Although these studies appear to demonstrate pharmacotherapeutic effectiveness there is no evidence that similar doses of stimulant would not have a similar effect on a sample of normal subjects. Consequently, the premise that this disorder exists because ADHD symptoms in adulthood appear to respond to stimulant treatment might be misleading, and further investigations are necessary to rule out a general effect. Combined medications including antidepressants have also been found to be effective in stabilising mood and helping with impulsive inattentive symptoms in adults (Wender, 1985, Prince & Wilens 2000). Treatment of comorbidity in adulthood is essential (Homig 1998) and psychological therapy an important part of a multidimensional treatment package (Young 1999).

In a study by Wood, Reimherr, Wender and Johnston, (1976), when ADHD was termed ‘minimal brain dysfunction’, a group of 25 adult patients with a long-standing history of impulsivity, inattentiveness, restlessness and emotional lability were screened. The authors attempted to identify a group with a childhood description of hyperactivity by their parents and 15 met the preliminary criteria; 11 of the 15 agreed to participate in a drug trial. These patients were entered in a cross-over double-blind study of methylphenidate. Self-report rating scales showed there was a significant improvement, with 60% of patients reporting a decrease in emotional lability and an increased in concentration, energy and calmness. However, at that time there were no operational criteria for a diagnosis of ADHD in adulthood and no standardised rating scales to assess the presence of a diagnosis of ADHD in childhood, one of the criteria for a diagnosis in adulthood. They were also unsure if the results were based on the patients simply feeling better having been administered a treatment that would be experienced as a euphoriant in normal adults (i.e. without a diagnosis of ADHD).

In a subsequent study, Wender, Reimherr and Wood (1981), attempted to correct the weaknesses of this previous study by using operational criteria for the diagnosis of ADHD in adults; these authors achieved this by constructing a questionnaire of diagnostic criteria for adults and utilised a psychostimulant drug that was thought not to be a euphoriant in normal adults. Qualitative responses from a group of 51 patients ranged from easier concentration, less motor agitation, less over-talkativeness and a
decrease in temper outbursts. These results differed from reported amphetamine abusers in whom the drug induces exhilaration, excitement and mind racing. Consequently the results suggested that the results of successful treatment with stimulant medication differed from effects seen in stimulant abusers. This finding may, however, be as a result of low dosage; what the response to larger doses, commonly taken by abusers, by the same subjects was not known. Regardless of these uncertainties, close family members reported the most significant improvements with frequent reference to improved relationships better educational achievements and job promotions.

In a further study by the same authors (Wender et al., 1985), investigated whether or not adults respond differently to children to stimulant medication, in this case in the treatment of what they term Attention deficit disorder, residual type (ADD, RT), Wender et al., (1985) had to establish a way of tracking specific signs and symptoms retrospectively as virtually none of their 22 subjects had been diagnosed in childhood. They developed questionnaires which identified both childhood symptomatology (completed by a close relative) and the presence of both attentional deficit and hyperactivity and two of the symptoms – affective lability, impulsivity, hot temper, disorganisation and sensitivity to stress. 60% of the subjects with a diagnosis of ADD,RT in this study responded with a moderate-to-marked therapeutic response to the medications tested. The possibility of stimulant abuse was addressed in that they state that “it appears (authors’ italics) that larger than prescribed doses do not produce euphoria” (p.227) in the patients with ADD,RT but, the possibility does arise that certain individuals may falsify symptoms of ADD in order to obtain medication. They also point out that adults who respond to medication, as often occurs with the childhood condition, do not have an awareness of how their behaviour effects others, and therefore underestimate the improvements with medication, with consequent discontinuity of treatment. They therefore identify the importance of the psychological issues that need to be addressed in order for the pharmacological interventions to be effective. This finding was concurred with by Toone et al., (1999) in a recent review where they state that the evidence of the efficacy of pharmacotherapy and psychological therapies is “encouraging” but that clinicians need to continue to be alert to the risks of self-diagnosis.
The emphasis in the literature was on pharmacotherapy being the mainstay of treatment for adults with ADHD, but Prince and Wilens (2000), Young (1999) and Rosca-Rebaudengo, Durst and Dickman, (2000) all recommend a comprehensive treatment plan that not only addresses the core ADHD symptoms, but also the negative psychological consequences and co-morbid conditions associated with this disorder. In the light of the uncertainties around the effectiveness of psychopharmacology, however, it would be interesting to investigate whether psychological therapy alone would be an adequate and appropriate intervention, particularly if there is no co-morbid diagnosis. To date, there do not appear to be any studies that examine this issue.

Conclusions

This study has sought to critically examine the current literature in order to address the issue of the validity of a diagnosis of ADHD in adulthood. Most of these studies have not explicitly challenged the ADHD diagnosis of their probands, and some have attempted to diagnose it retrospectively so there is an inherent assumption of validity of such a diagnosis. Studies that overtly challenged this assumption were not found, although several authors cautioned as to the complexity of assessing this condition in adulthood. Within the chosen framework of this discussion i.e. descriptive, predictive and concurrent validity, there were numerous studies that seemed to largely satisfy these criterions of validity. Even with the limitations and differing methodologies, there appear to be a significant number of subjects who continue to struggle with symptoms of a childhood condition or who, retrospectively can identify these symptoms as having had, and still continue have a negative impact on their functioning. Longitudinal studies that track the progress of a diagnosis of ADHD from childhood well into adulthood would be the next essential step in clarifying the predictive validity of this diagnosis, as so far, studies seem to only track into early adulthood. It would also be interesting to follow-up further those subject who appeared to do well, either in that their symptoms abated or disappeared in adolescence or early adulthood, or that they somehow adapted to their symptoms. Are there any positive aspects of having a diagnosis of ADHD in adulthood, once the restraints of classroom conformity and adult expectations of behaviour have ended? Issues of treatment efficacy and appropriateness require further research, and
unravelling the impact of the multiple aetiological pathways is complex and will possibly only become clearer as neuroscience provides us with more accurate assessments of the brain and its functioning. Until such time as such advances in the research have taken place, caution in diagnosis is preferable, but outright denial of the disorder seems inappropriate based on the currently available evidence.

References:


From early-onset childhood disruptive behaviour disorders to adult antisocial and criminal behaviour: How can attachment theory inform understanding of early risk and intervention?

"It is plausible to argue that events occurring between conception and 3 years of age are the first steps in a developmental sequence leading to childhood conduct disorder and eventually to juvenile delinquency and adult crime".

David Farrington (1994, p.85)

1. Introduction

This paper explores the phenomenon of challenging childhood behaviours such as significant and frequent temper outbursts, aggression, defiance and impulsive behaviours that are potentially dangerous. These behaviours frequently occur initially in interactions with primary caregivers and are the most common presenting problems referred to child mental health services, (DeKlyen, 1996; Fonagy, 1998; Hill & Maughan 2001). The management and treatment of aggression in children has emphasised behavioural approaches that entail teaching parenting techniques (e.g. Webster-Stratton, 1991, Barkley, 1997). Such approaches have a tendency not to focus on the emotional components of the parent-child relationship (Landy & Menna (2001). If the quality of the parent-child relationship is fundamentally poor, it is possible that these behavioural approaches might fail to bring about or maintain any improvements made in treatment. It is therefore proposed that the quality of the parent-child relationship is a crucial factor in the success of treatment approaches. In order to explore this proposal in greater detail, childhood behavioural problems will be viewed through the lens of attachment theory (Bowlby, 1969), where the quality of the parent-child relationship will be evaluated as a possible risk factor in the development and maintenance of childhood conduct problems. The reason for focusing on attachment theory is that it claims that the security of attachment relationships in early life potentially influences future relationships, including those of the next generation. Therefore, parental attachment behaviour may influence parent-
child closeness and the infant's developing sense of security and trust, which may in turn impact on emotional development and social learning.

In order to assess its clinical usefulness, attachment theory would need to provide evidence of the effect of child and adult attachment on the development of a child's emotional and social development, particularly with respect to behavioural difficulties. Furthermore it would need to inform understanding about the possible mechanisms involved between attachment status and treatment outcome. In other words does attachment theory tell us anything about treatment outcome for childhood conduct problems?

The literature to be reviewed covers mainly the past ten years by authors identified by an electronic search as being at the forefront of this subject. Certain studies cited by these authors will also be included. Most studies have males as the subject group as they outnumber female clinical referrals for behaviour problems, 4:1 (Cohen, et al., 1993). The literature on the developmental pathways to antisocial behaviour in girls is relatively unexplored (Silverthorn & Frick, 1999) and will not specifically be addressed in this paper due to constraints of space. The term Disruptive Behaviour Disorders (DBD), (Abikoff & Klein, 1992) will be used throughout this paper as it encompasses the recognised challenging childhood behaviours such as Attention Deficit Hyperactivity Disorder (ADHD), Oppositional Defiant Disorder (ODD) and Conduct Disorder (CD) (APA, 1994). This review will firstly give an account of the background literature to childhood behaviour problems, with specific emphasis on the implications of early-onset difficulties, in order to set the scene for exploring attachment theory and DBD.

2. DBD: issues of early-onset and adult outcome

Disruptive childhood behaviours may be transient, but there is an extensive body of literature that consistently links the early onset of DBD to juvenile antisocial and criminal behaviour (Patterson, Forgatch, Yoerger & Stollmiller, 1998; Holmes, Slaughter & Kashani, 2001; Vitelli, 1996; Farrington, 1994 & 1995; Loeber & Hay, 1997) and criminal behaviour and antisocial personality disorder (APD) in adult life (Moffit, 1993; Robins, 1991; Zoccolillo, Pickles, Quinton, & Rutttner, 1992). APD has
been identified in 50-85% of convicted felons (Hare 1985) and is understood as pervasive socially deviant and criminal behaviour (Black & Braun, 1998). Farrington (1995) concluded from his longitudinal study where 411 children were followed-up from age 8 to 32 that there was evidence of antisocial children tending to become antisocial adults who produced antisocial children. This gives a sobering message for the intergenerational impact of conduct problems, not only to the individual concerned, but also to their families and society as a whole.

Children who are at highest risk of persistent antisocial behaviour problems appear to be those that have significant behavioural problems that manifest during the preschool years (under 5 years) (Hill, 2001 p.103) and that there is some evidence of childhood antisocial behaviour at age 5 being associated with convictions for violence at 18 years (Bartusch, Lynam & Moffitt, 1997) and behaviour as early as 3 years being associated with adult criminality (Stevenson & Goodman, 2001) with temper tantrums, high activity levels and management difficulties being identified as indications of long-term risk (Fonagy, 1998). Those children whose behavioural problems develop in later childhood and adolescence (late-onset) have been found to have a more favourable prognosis, with antisocial behaviour often tailing off as early adulthood is entered (Moffitt, Caspi, Dickson, Silva & Stanton, 1996).

The aetiology of DBD is thought to involve multiple interacting risk factors of a biopsychosocial nature (Greenberg, Speltz & DeKlyen, 1993; Speltz, deKlyen & Greenberg, 1999; Hill & Maughan, 2001). The influence of the family environment, peers, teachers, and wider social processes such as the law, economics and political processes are not directly addressed in this paper, but would all have a possible role in causing and/or maintaining conduct problems particularly as a child enters school and wider social environments. However, as the preschool early-onset of DBD has been suggested as potentially having the poorest prognosis, the focus of this review will now be on the early parent-child relationship within the framework of attachment theory (Lyons-Ruth, 1996).
3. Individual and relational development in the young child – the influence of attachment on DBD.

3.1 Attachment theory

There is an extensive literature on Attachment Theory and its implications on child development and clinical practice (see Goldberg, Muir & Kerr, 1995; Lyons-Ruth, 1996). There are two main methods of measuring attachment in the literature. The Strange Situation (SS) (Ainsworth, Blehar, Water & Wall, 1978) assesses child-to-parent attachment, and the Adult Attachment Interview (AAI) developed by George, Kaplan & Main, (1985), which assesses the parent’s state of mind with respect to their own childhood attachment experiences.

The SS is a well-replicated behavioural observation methodology (Ainsworth et al., 1978). Categories of infant-to-parent attachment were initially described in three main groups (Wilson, 2001): secure, which describes the young child actively seeking proximity with the carer after a separation, is easily comforted and will continue with play and explore once reassured. There are two insecure categories, insecure/avoidant, where a child tends to avoid proximity, ignore or casually acknowledge reunion but does not actively seek reassurance and comforting, and insecure/resistant, where the child will resist contact with the carer after a separation. Ambivalence and lack of exploratory behaviour when with the carer is characteristic of this group. A fourth group, who displayed a mixed profile of insecure behaviour was later classified as disorganized/disoriented (Main & Solomon, 1986). A recent meta-analysis of attachment studies, including the disorganized group showed a distribution of 55% secure, 23% avoidant, 8% ambivalent and 15% disorganized (van IJzendoorn, 1995). The key determinant for the transmission of secure/insecure attachment, according to this theory, is the degree to which a parent is able to sensitively and consistently respond to the infant’s needs in order to establish an experience of safety and trust for the child (Fonagy, Steele, Steele, Higgitt & Target, 1994). Should this process not occur, it is thought that an insecure attachment pattern
will be established whereby the child will be compromised in achieving secure and satisfactory close relationships in the future.

The Adult Attachment Interview (AAI) is a semi-structured interview assessment that yields four classifications of attachment style: *autonomous* — secure, giving coherent accounts of attachment related experiences; *dismissing* — tend to minimize their descriptions of childhood attachments; *preoccupied* — confused, angry or passive preoccupation with childhood attachment figures. Both dismissing and preoccupied groups are considered to be insecure. Finally *unresolved/disorganised* classification suggests traumatic experiences related to loss or abuse with descriptions being chaotic, or with lapses in their discourses of childhood experiences. The AAI has been shown to predict associations with parental responsiveness and infant attachment, and its predictive validity has been supported in clinical studies (van Ijzendoorn, 1995). These two measures, or adaptations of them, have formed the bedrock of the research on attachment, but have limitations. For example the measures were initially developed on normative, low risk samples and the SS is an early childhood measure (12–18 months). Both procedures are time consuming, development specific and costly, and therefore do not lend themselves to large-scale longitudinal studies, nor day-to-day clinical use. Nevertheless their use has generated many studies exploring the influence of parents’ responsiveness to the child’s attachment signals and the impact of this on the child’s social and emotional development (van Ijzendoorn, 1995).

3.2 The development of secure and insecure attachment in the young child.

There are two often-cited studies by Fonagy, Steele & Steele, (1991) and Fonagy, Steele, Steele, Moran & Higgitt (1991) that aimed to illustrate how a pre-natal attachment interview could predict infant-mother attachment more than a year later. In these studies Fonagy et al. used the same cohort of 100 first-time mothers, and in the second paper, included the results of 82 fathers. The AAI was administered to the parents before the birth of their child, in order to discover if their attachment classification was related to the child’s attachment to them at ages 12 and 18 months respectively. Independent raters found that in 75% of cases, the mother’s attachment classification predicted the infant’s attachment status using the SS at 1 year. It should
be noted however that these studies used a non-clinical group of first-time parents. Therefore, although they demonstrated the potential usefulness of the AAI in identifying those infants who may develop insecure attachment, these results may not apply to a clinically referred group, nor did they address how this transgenerational pattern may impact in subsequent children.

Expanding the theory that attachment could be transmitted across generations, a study was carried out by Beniot & Parker (1994) where they examined attachment patterns across three generations. The authors predicted these patterns would be transmitted from maternal grandmother to mother to infant. To test within individual stability of the AAI, 96 expectant mothers, recruited from the community, were interviewed twice, once just before the birth of their child and once just before the SS procedure with their 1-year-old infant to assess if their attachment classification remained stable. Maternal grandmothers (N=81) were also interviewed using the AAI. 65% of the grandmother-mother-infant triads had corresponding attachment classifications. Limitations of this study were that the maternal sample were of high education and socio-economic status and therefore not representative of the general population nor of a clinical group.

Despite their limitations, the above studies illustrate the usefulness of the AAI and the SS in measuring attachment and the emotional security or insecurity of the young child in non-clinical groups of subjects. The impact of attachment with particular respect to DBD will now be examined.

3.3 DBD and attachment theory

The rationale for approaching DBD from an attachment perspective is that it highlights the possible interpersonal dynamics of the parent-child relationship as influencing the development of conduct problems (Campbell, 1995; Shaw & Bell, 1993). The term ‘attachment’ does not refer to all aspects of the parent-child relationship, but is understood as a behavioural system that is activated by stress (Lyons-Ruth, 1996). If early disruptive behaviour is considered to be the precursor to DBD, then tantrums, aggression and non-compliance may be understood as attachment generated strategies by the child to gain the attention and proximity of
carer who might be otherwise emotionally unavailable or unresponsive (Greenberg, 1999). A coercive pattern of parent-child interaction can develop as the child resorts to challenging behaviour as a way of controlling an unpredictable relationship, which may then evolve over time into early-onset chronic conduct problems (Main & Hesse, 1990; Lyons-Ruth, 1996).

4. Insecure attachment and the development of DBD.

One of the problems of studying the links between attachment and DBD is that it is difficult to identify an infant sample that is large enough to provide a significant number of disordered young children (DeKleyn & Speltz, 2001). One way of identifying a sample is by studying clinic-referred children meeting the criteria of DBD.

A study by Speltz, DeKlyen, Greenberg and Dryden, (1995) aimed to test attachment theory as a reliable framework to conceptualise children with DBD. The sample consisted of 25 consecutive clinic referrals with a primary diagnosis of oppositional behaviour, and 25 case-matched normal comparisons. The study sought to assess attachment and behavioural variables that might predict clinic and non-clinic status of oppositional defiant disorder. All participants were boys aged between 3.5 to 5.5 years. A videotaped mother-child separation-reunion, based on the SS procedure, was used to gather attachment data. A parent-child coded observational procedure was also carried out. The latter procedure was included to assess the usefulness of social learning theory in explaining DBD. Coders were blind to clinic and attachment status of all the parent-child dyads. It was found that the attachment measures provided the single best indicator in discriminating clinic and control groups (correct classification in 86% of cases). However, this study was limited by the relative small size and middle class status of the sample.

In a study that examined the relevance of maternal attachment classification to clinic status by DeKlyen (1996), the AAI was used to interview the mothers of 25 preschool boys referred to a clinic for behaviour problems, and 25 matched non-referred boys. Parent-child interaction was measured by a standardized observational
procedure similar to the SS and classified by a rater who was given no information on the participants. A diagnostic interview and questionnaires were also administered.

Results indicated that mothers of clinic-referred children and their child were more likely to be rated as insecure (24% of clinic mothers vs. 72% of comparison mothers, were classified as secure). Significant correspondence was found between child attachment and maternal representation of attachment (agreement for secure vs. insecure was 80%). This finding suggested implications for treatment; mothers classified as secure would possibly be good candidates for the regular therapeutic interventions in treating their child (e.g. parenting skills, contingency management, family therapy), whereas those rated as insecure may need specific intervention aimed at their own individual issues before engaging in parenting interventions. The study was limited by the use of low-risk subjects (despite being clinic-referred) and the conclusions may not hold for families who experience more severe psychosocial stressors.

In order to expand understanding of attachment theory and DBD, Speltz, DeKlyen and Greenberg, (1999) sought to assess specific aspects of attachment variables and their influence on clinical status and outcome. For example, what contribution to clinic status does separation and reunion behaviour have, and are attachment variables related to concurrent or future problem severity? They compared a group of 80 boys referred for early childhood behaviour problems with a group of 80 normally developing boys (mean age 57.1-57.5 months) using a parent-child separation procedure (based on the SS) as well as questionnaires scored by parents and teachers. Follow-up was arranged 1 and 2 years later. Results indicated that the clinic and comparison boys differed significantly: over half of the boys with early onset conduct problems exhibited insecure attachment strategies during reunion (comparison group – 18%). It should be noted that this study did not assess their subjects in infancy, therefore were unable to establish a causal link between attachment status and the behaviour problems that resulted in a clinic referral at ages 4-5 years. The authors concluded that although their study replicated findings from other studies, they were doubtful that attachment as a single construct was of value in predicting the course and severity of the problems over the two-year follow-up period. They suggested that other factors might explain ongoing insecure attachment and behaviour problems,
such as harsh discipline or difficult child temperament. Future research is needed to
determine whether preschool attachment measures have prognostic value as this
cohort approach their middle school years.

In an earlier paper, Greenberg et al., (1993) presents insecure attachment as risk
factors for the development DBD in the context of other variables including child
biology, parent management and socialization practices. Here the emphasis was on
maternal attachment. Maternal representations of attachment were considered to have
an indirect effect on disruptive behaviour. For example, mothers with insecure
representations of attachment reported difficulties such as dissatisfaction with social
supports, psychopathologies (e.g., depression), and were less likely to remain in long-
term relationships or provide a stable living environment for their child. Also, the
study commented that a parent might be warm and responsive with an infant but
laissez-faire with the same child as a toddler. This highlighted one of the main
weaknesses of attachment theory in explaining stability in interpersonal behaviour i.e.
the lack of measures that track attachment behaviour along the developmental
pathway once a child moves from infancy and toddlerhood. Greenberg further points
out that it would be important to chart the trajectories of individuals and families who
share different levels of risk, and that a variety of interactions may best be studied
using a within-subject analysis.

Lyons-Ruth’s review (1996), which investigated attachment-related studies of early
aggression, concluded that the understanding of the trajectory leading to early-onset
aggressive behaviour disorders was extended by the attachment literature. Maternal
hostile-intrusive behaviours and behaviours associated with disorganized infant
attachment in high-risk samples were understood as having a significant role in the
development of DBD, especially those children who displayed disorganized
attachment behaviour together with pronounced avoidant behaviour. Lyons-Ruth
pointed out the importance of extending the understanding of the trajectory of DBD
from early childhood onwards by conducting longitudinal studies of high-risk
populations and encouraged investigators to include both theory-driven and
exploratory descriptive analyses in these studies. This author called to question the
current analytic methods that tend to use variables as units of analysis rather than
individuals, and linear causal relations among variables to explain effects. It is
suggested that this methodology may not be well suited to identify and describe intergenerational continuity and organizational coherence in individual behaviour.

In summary, the literature suggests that attachment theory does have some useful concepts when considering DBD in early childhood, but its usefulness becomes less valid as children progress beyond toddlerhood. When considering the evidence for parent-child attachment status, studies were limited by the use of normative, low risk samples to develop and test measures. Furthermore, in order establish a link between attachment and a disorder such as DBD, longitudinal studies with large sample size and/or high risk groups as well as post infancy measure of attachment are needed. However, larger sample sizes and longitudinal methodologies would be difficult to conduct using the AAI/SS models of measurement. Well validated measures that track attachment relations from infancy through to early adulthood do not yet exist.

We might therefore state that although attachment theory may not fully explain the development and maintenance of DBD, it does provide some evidence of insecure attachment being a risk factor in early development, and may be a useful framework for understanding how a parent’s pervasive state of mind may influence a very young child’s developing sense of security and safety.

5. Treatment implications

van Ijzendoorn, Juffer & Duyvesteyn (1995) recommend the need for intervention studies that focus on corrective and preventative approaches. These may be at the behavioural level or at the representational level, i.e., parents’ mental representations of attachment. The overall aim, however, is to improve the quality of the infant-parent relationship.

Is there evidence that attachment concepts influence treatment for DBD? Interventions for pre-school children are largely parent focused (Speltz, 1990; Fonagy, 1998; Kazdin, 2001; van den Boom, 1994). Hanish, Tolan and Guerra, (1996) state that parents or main carers are the main agents of change with young children as their behaviour is largely governed by external sanctions that are imposed by adults. Recent reviews of effective interventions for childhood behavioural
problems appear to identify parent-focused behavioural training programmes as being the most effective form of intervention for early-onset problems (Behan & Carr, 2000; Nolan & Carr, 2000). Parent training is an umbrella term for either intensive individual or group-based parent focused behavioural coaching, and rests on the assumption that if parents can be trained to use specific behavioural skills in managing their children on a day-to-day basis, behaviour will change. Addressing other parental difficulties such as marital discord and single parenthood with poor social support is also recommended. It is suggested that parents need to be motivated and consistent with these methods in order to become confident and for change to occur. Such a commitment might be difficult for an insecurely attached dyad (Routh et al., 1995). The high incidence of parental insecure attachment in clinic children would suggest that the parent’s own working model of responsiveness and availability may need addressing as well. For example, Routh, Hill, Steele, Elliott & Dewey, (1995) identified unresolved attachment issues, as measured by the AAI, as resulting in a poor outcome to a parent training course for conduct disordered children when assessed at 13 and 43 months post-treatment.

Studies reviewed by Behan and Carr and Nolan and Carr (in Carr, 2001) identified parent-based problems such as low social support, marital stress and single parenting as needing attention in order that interventions were effective. However, the emphasis on behavioural strategies meant that relationship issues between the main carer and child were not addressed (Speltz, 1990). This may account to some extent with the high dropout rates in treatment studies generally (up to 20-50%, Fonagy, 1998; Rutter 2001). For example, a parent who may have been classified as dismissing, preoccupied or unresolved may find the demands of behavioural treatment very challenging and might possibly either drop-out of treatment or fail to carry out the strategies effectively. It therefore does appear that maternal attachment variables could negatively influence the effectiveness of interventions for DBD.

An interesting area of development might be within the realms of cognitive-behavioural therapy (CBT). For instance, the “internal working model” of the mother might be amenable to a cognitive approach i.e. addressing the negative attributional biases of the mother towards her child and introducing a more flexible, non-pathologising narrative for how she perceives and experiences that child (Dallos,
Neale & Strouthos, 1997) might be an important part of the intervention. Positive reframing and behavioural experiments e.g. "catching your child out being good", Herbert (1996) may be an effective way of both addressing parent and child issues at the early stages of development, before coercive patterns of interaction become ingrained in the relationship. Hanish, Tolan and Guerra, (1996) demonstrate a cognitive therapy approach to parent management training. This work was reported in the form of a case discussion which illustrated a cognitive behavioural approach which focused primarily on the parent's beliefs about discipline which had roots in her own childhood. This intervention resulted in a successful outcome for a 4-year-old child with aggression, swearing, tantrums and defiance. No follow-up was reported, but this approach could be carried out with attachment theory principles informing a cognitive behavioural approach. This case study method for investigating treatment efficacy is an example of findings from actual clinical conditions. Further studies using this methodology would be useful in learning more about the components of treatment of efficacy (or not) that are potentially unreported in more traditional quantitative studies.

A possible future development for attachment-focused interventions would be in perhaps identifying a parent's attachment status as a way of allocating to different treatment modalities (DeKlyen, 1996). Parents with secure working models of attachment may benefit more from a standard parent training programme with the focus on behaviour management, whereas dismissing, preoccupied or unresolved attachment (closely linked with disorganized child status) may require a different approach e.g. by engaging in conversations with the parent on possible links between the parent-child relationship and the parent's other close relationships (Speltz, 1990; Routh et al., 1995). The use of the AAI in this way has not been systematically investigated and it would be challenging for the general child clinician to carry out the complex analysis of individually recorded parent interviews, in order to formulate different parent interventions. The development of more 'user-friendly' assessment instruments would be essential in order to progress with this line of investigation. In their review of attachment and conduct disorders, DeKlyen and Speltz (2001) state that overall the clinical application of attachment theory to conduct problems is at a very early stage and the issue of how best to engage high risk clients in user-friendly interventions that they would be willing to engage with and persevere with needs
further investigation. However, there continues to be a substantial problem with findings from research conditions that do not necessarily represent treatment efficacy in everyday clinical practice (van der Wiel, Matthys, Cohen-Kettenis & van Engeland, 2002), and a challenge for future studies would be to bridge mental health research and clinical practice.

5. Conclusions

The studies in this review indicated that insecure attachment might lead to a child developing internal working models in which relationships are generally viewed as characterised by anger, mistrust, chaos and insecurity. The indications are that attachment is best viewed as a risk factor, rather than a main effect. Research studies in the future would need to use more representative samples e.g. those with more complex risk factors in infancy (family adversity, difficult temperament, socio-economic difficulties) in order to clarify further what specific role attachment may have in influencing behaviour problems, and which combination of factors might be most harmful (Greenberg et al., 1993). Larger samples and longitudinal studies, and the development of suitable measures for this task have been recommended. Clinical case studies of individual pathways associated with DBD could also potentially further develop theoretical and clinical understanding of the potential links between attachment and DBD.

Attachment theory therefore can be viewed as adding a further dimension to the more conventional methods of assessment and intervention of DBD, specifically in interpreting the quality of the parent-child relationship. Conventional parent skills interventions may rely on relatively secure autonomous parents for efficacy, whereas parents who have an insecure attachment style may need help in recognising and monitoring their representations of relationships and how that may influence their response to their child. Alternative interventions utilising attachment theory were explored, but this is still a relatively new approach and further research is needed.

Finally, the issue of early prevention interventions with an attachment theory focus is emerging in the literature (Fonagy, 1998; van den Boom, 1994), and where future research needs to focus. With the possibility of establishing more secure parent-child
attachment in at-risk families in the early months of an infant's life, secure attachment may then act as a protective factor that may ameliorate other adverse biopsychosocial risk factors and promote a more resilient response by the child. Introducing early preventative interventions might then reduce the likelihood of a substantial number of pre-school children with DBD developing into antisocial and criminal adults. The issue of bringing together empirically supported approaches into actual clinical practice remains a challenge for future studies to address.

References:


Personal Study Plan

Name: Ann Colborn
Date of registration: November 1999
End of registration: September 2002
Registration number: 3917665
Personal Tutor: Dr Lorraine Nanke

Overview of portfolio:

The main subjects to be covered in this portfolio are linked to the difficulties of childhood behaviour problems that form the main reason for referral of children in our Psychology Department, and are often the most clinically challenging in terms of being able to offer helpful interventions. Particular focus will be on the condition Attention Deficit Hyperactivity Disorder as this was a service I was personally involved in developing. The question of this condition being a legitimate diagnosis in adulthood has also become the centre of some controversy with colleagues working in the Adult Mental Health Services. The trajectory from childhood behaviour problems to adulthood is also of interest, especially the possible impact of attachment and the parent-child relationship in early life. These issues will be incorporated in a qualitative study involving the client group who are on the treatment list for ADHD.

My personal study plan is as follows:

Academic dossier:
Two critical reviews
1) Is ADHD a legitimate diagnosis in adulthood?
2) Does attachment theory inform clinical understanding of the trajectory from early childhood behaviour problems to adult anti-social behaviour?

Word limit: 4,500 each

Professional dossier:
An account of the development of a service for the assessment and treatment of ADHD in children.

Word limit: 5,000

An account of my professional practice since qualification in the form of a CV to include further training and CPD.

Research dossier:

A qualitative study of mothers who have a child with ADHD. There are several issues of clinical interest. Many children do seem to benefit from medical treatment of this condition (Ritalin) but there are a significant number who continue to experience problems in all areas of their lives; home, school and socially. This group is the most challenging to help from a clinical point of view. There is also a great deal of controversy surrounding the legitimacy of this diagnosis that influences clinical understanding, but less is known about how this might affect the families of children with ADHD. An exploratory study would perhaps illuminate some of the issues as well as deepen understanding about the actual experience of these families.

Methodology: Qualitative study

   Interpretative analysis
   Small sample of individual cases

Anticipated hurdles: *Finding appropriate supervision
                  *Ethics approval
                  *Dealing with an extensive amount of data
                  *Using techniques that I am unfamiliar with and that are considered somewhat controversial

Word limit: 20,000
Reflective epilogue - February 2003

Compiling this portfolio has taken three years and looking back to the first two pieces of work that I wrote, the ADHD service development and the dilemmas of diagnosis of ADHD for adults, I am aware that these were written at a particular point in time (over two years ago) and both the service and the issue of diagnosis in adulthood continue to develop.

The ADHD service is now considered a well-established service in the South West and we are consulting with other child and adolescent services that wish to develop a service along similar lines to our model. Children and families have a comprehensive service that is now integrated into the school system where school doctors, nurses, teachers, children and parents have regular opportunities to monitor and discuss progress. Children's own views are an important part of these meetings. Many children (figures of most recent audit not yet available) have discontinued medication because of improvement in their all-round functioning; others have left the child and adolescent service, and we have no way of knowing how they are managing in their young adult life, or if they continue to have significant problems, or, indeed if they continue to take medication for ADHD. It is unusual to be able to conduct long-term outcome studies in the context of clinical services, but this would provide data that could possibly answer some of the more fundamental questions that these uncertainties raise. In particular, do the means justify the ends, i.e., do current treatment protocols, for all their uncertainties and limitations, produce acceptable outcomes. There still remain certain rather disjointed communication links between some professionals, but with the help of the specialist community nurse, who fulfils the role of key liaison person between the families and other services, this difficulty has been largely overcome. We have also been very concerned that recently two children were found selling their Ritalin to peers, which touches on one of the complex implications of prescribing; that of misuse of medication. This also brings to the forefront the importance of parental supervision, which again links back to those families where there are multiple problems, the child has a significant co-occurring conduct problem, and our service does not have sufficient resources to monitor and adequately support such complex family situations. Even when offered extra support we have had experience of families not accepting this support and being very difficult
to engage with. Sometimes the only way to stay in touch with these families is through the school-based review process.

As to the issue of adults with a diagnosis of ADHD, this debate has moved on to the Adult Mental Health Service and adult psychology practitioners, but in retrospect I feel that the diagnosis of ADHD in adults would be particularly difficult, especially retrospectively as, by adulthood, multiple and complex risk factors may explain why an adult may be struggling with the issues described in the article in this portfolio.

The two most recent pieces of work, completed in 2002, i.e., the qualitative study of mothers' experiences and the review of attachment theory and challenging childhood behaviours are more representative of my present thinking and practice.

Over the three years that I have been working on this portfolio, I have become fully aware of the controversies around conceptualising ADHD as a biological condition and thereby a legitimate medical diagnosis. I am also aware that this has become the leading formulation established in the minds of parents and most professionals. Many of the professionals, e.g., GPs, teachers, social workers, who initially challenged the diagnosing of ADHD in children, now seem to take this condition for granted as being legitimate. I consider an important part of my role as a clinical psychologist in this service is to maintain an open and critical debate concerning the continuing uncertainties that exist around this diagnosis and advocate for a continuing awareness of psychological dimensions to case formulation. I have become particularly aware of a number of unresolved questions: it seems that the construct of ADHD as a ‘disorder’ raises more questions than it answers (Hinshaw & Zalecki, 2001); where is the dividing point between normal childhood boisterousness or a lively disposition and a neurodevelopmental disorder that manifests as hyperactive, distractible and impulsive behaviour; has this disorder been overdiagnosed or has scientific recognition of its symptoms and impairments led to these higher rates of diagnosis; is ADHD a real condition or is it a label given by adults with unrealistic expectations of children; is medication a legitimate treatment option bearing in mind the fundamental nature of ADHD is still open to question? Whilst continuing to live and work with these unresolved conceptual and clinical tensions, there remains a need to take a pragmatic
clinical stance, and I have increasingly recognised the need to maintain a critical reflection on practice and the rationale underpinning an evolving treatment.

Currently agreed diagnostic guidelines recognise ADHD in a child on the basis of evidence of extremes of attention and impulsive, hyperactive behavioural problems of a persistent nature in multiple settings that severely compromise the key domains in a child’s life. The challenge to the clinician is to try to discern what else might be causing such behaviour; might it be disorganised classrooms, chaotic home environment, and abuse? These are not questions specific to assessing ADHD. Many childhood behavioural problems may be due to any or all of these factors. I am aware that a specific issue of great concern with ADHD is that by labelling the child’s behaviour as a ‘medical’ condition, we may miss important psychosocial causes, despite our best efforts to track all these possibilities during assessment, and the real reasons for a child’s distress may then go unrecognised. But there again, there is no guarantee that the ‘real’ reasons for a child’s distress are accurately identified (I am thinking here of more general referrals to CAMHS). The issue is, what sort of intervention is offered to these families. With most problems, medication is not part of a treatment package (there are some exceptions, for example, clinical depression, obsessive compulsive disorder, psychosis). As a clinical psychologist, I have needed to grapple with the implications of the current treatment guidelines by the National Institute for Clinical Excellence (NICE) recommending medication as part of a comprehensive treatment package which encompasses psycho-education, home and school-based behavioural interventions as well as specific psychological therapies as and when appropriate, but that “While this wider service is desirable, any shortfall in its provision should not be used as a reason for delaying the appropriate use of medication” (NICE, 2000) with psychosocial interventions having been found, in the literature, as being ineffective as a first line of intervention on their own with severe problems due to inattention, hyperactivity and impulsivity (MTA, 1999). When our local service was first set up, we had very little in the way of a ‘comprehensive treatment package to offer’, but with improvements to our service, when medication is recommended, the decision about this is facilitated by a school doctor who also coordinates the school-based medical checks, which include side-effect checklists as well as feedback from the child, family and teacher about a child’s progress. Parents have the choice about medication and can now be offered some help with behavioural
strategies at home with advice to school by the specialist nurse, and some do opt for this intervention instead of medication. Results of a recent audit are not yet available but the nurse reports that it is almost inevitable that parents eventually try medication (personal communication) after trying to manage with support and behavioural strategies. Equally, medication is discontinued if there is no improvement in the core symptoms of ADHD after appropriate dose adjustment and monitoring. Medication is also discontinued if there are persistent side effects.

The main thrust of current research is to extensively investigate biological, aetiological and treatment pathways and these are now being investigated with sophisticated neuroimaging techniques in an attempt to identify that people with a diagnosis of ADHD have different brain functioning than those without this condition. Although I am sceptical about the tremendous drive to find a biological cause for almost all human conditions, because of the emerging literature on severe trauma-based changes in brain neurological development, I follow the ADHD literature with interest as I believe it is very important to remain well-informed, and through my clinical role, to offer a creative challenge to my colleagues and keep these questions alive within the service.

Against the above uncertainties, I have to acknowledge the extensive body of research that I have explored during this study that identifies important features, such as coherence of the syndrome described as ADHD, cross-cultural manifestations and evidence of clear impairment for a child. These impairments have significant implications for a child’s development. For example, there is evidence of high levels of peer rejection, learning difficulties and academic underachievement, problems with adaptive life skills, such as self-care and overall independence as well as family disharmony and child and parent distress as well as longer-term adjustment problems that may be life-long. Improvements in many of these areas of impairment have been reported in the literature as well as in the research study in this portfolio.

However, I have also become aware that these improvements may have come at a cost. What has not yet been voiced in the literature but was also apparent in the study of mothers’ experiences, was the insidious effect of a diagnosis on the child and the family, and the narrowing of expectations as well as the long-terms stigmatising affect.
on the child. In addition, I aware of the concerns about the potential damage medication may do to a child and of the ethical dilemma involved in prescribing medication to a child for a condition where the validity of the diagnosis is still challenged. Indeed, some have linked this issue of the uncertainties about the validity of a diagnosis of ADHD and the question about using medication as a way of gaining compliance from children in line with post-industrial society's emphasis on achievement and cultural conformity. This line of argument suggests that parents' desire for their children to be successful within this competitive environment can be enhanced by the use of drugs to enable a restless inattentive child to achieve better academically and socially. However, having now met with many children and families worried about this condition, it is not my experience that this is the core reason for their request for assessment for ADHD. My own position on medication is that I try to keep up with the literature on this subject and trust my medical colleagues do the same. Thus far, medication treatment outcome studies for ADHD published in the leading mental health journals have not indicated that use of Ritalin has a long-term detrimental effect. By their nature, medication outcome studies do not tell the full story of efficacy and there are certainly some children who have adverse reactions to medication. I have not undertaken a critical review of this literature, but the recent extensive treatment review by Wolpert et al., (2002), commissioned by the Division of Clinical Psychology Faculty for Children and Young People states: "If diagnostic criteria for ADHD are met following a comprehensive assessment by a suitably qualified professional, and other reasons for the behaviour have been excluded, then a trial of medication is indicated as the first line of intervention" (p.14). The Strength of Clinical Implications, Criteria A (directly based on category 1 evidence – meta analysis of RCTs) informs this statement. I cannot therefore personally say that I know more about the possible outcome of the use of Ritalin than the published bodies of experts, and therefore have to be guided by those that have the time and expertise to undertake this work. In practice I have found that good communication and collaborative working have enabled the psychosocial issues to remain at the forefront of our thinking when asked to assess a child for ADHD and in accordance with the above statement’s requirements, I feel confident that we have a child's well-being in mind as the priority when assessing. This has been strengthened by employing a specialist community nurse to implement psychologically based interventions at a time when NHS resources are scarce.
In their report on ADHD, the British Psychological Society state: “Despite its limitations, the term ADHD appears to be here to stay” (BPS Working Party, 1996, p. 57), and whilst referrals continue to come in to our service for assessment for ADHD, we will continue to respond. As with most philosophical/ethical debates, for every standpoint there is a counter standpoint and it is this process that shapes meaning and keeps critical debate alive, but does not result in certainty, and as a clinician it necessary to tolerate the tension around these uncertainties and keep the conversations around them active but to also engage with the practicalities with needing to respond to the question “does this child have ADHD?” alongside an awareness of the limits and complexities inherent in ‘diagnosis’.

I have an increasing interest around the influence that having a diagnosis has on an interpersonal, intrapersonal and wider socio-cultural level. If language shapes our reality, then the deficit language that surrounds the traditional discourse of ADHD (or indeed diagnosis in general) may distort a child’s developing view of themselves (Nyland, 2000), and any benefit that may be derived from being able to focus better in the classroom or be less impulsive, that conventional treatment for ADHD is reported to bring, has little value to the overall wellbeing of the young person. My aim now, as a result of my study as well as having had the opportunity this doctoral portfolio has afforded me to reflect on the phenomena of ADHD, is to try to move towards a more solution focused way of helping children and families. To understand better which factors can be protective to young people with ADHD-type difficulties; to move away from the deficit model of understanding, towards a focus on a child’s strengths and areas of competence. This brings in my interest in attachment theory and how, by being sensitive to the actual possible underlying mechanisms that are maintaining negative patterns of interpersonal relationships, a more affirming and positive view of a hyperactive young person can develop.


NICE, 2000, nice.org.uk/article.asp?a=11667

