ADHD, a social construct?

The experience of families who have a child diagnosed with Attention Deficit Hyperactivity Disorder.

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Abstract
The diagnosis of children with Attention Deficit Hyperactivity Disorder (ADHD) has increased over the last few years in Australia. ADHD is currently understood largely through a medical perspective, and in that context, the treatment recommended is stimulant medication. ADHD is a mental health label given to children who exhibit challenging behaviour. These children are diagnosed according to the categories stated in the Diagnostic Statistical Manual (DSM) – IV.

To date, there is no medical test children can undertake to show that they ‘have’ ADHD. This research focuses on an alternative view of ADHD. Focussing upon families’ experience of ADHD, and the medicalisation of children’s behaviour, it argues that behaviour is socially influenced and constructed.

It is because insufficient attention has been given to the family experience and the social implications of ADHD, that the child is often seen as ‘the problem’. The gap in our understanding of ADHD is situated in our understanding of the broader social context. To challenge this I will explore perceptions of the ‘good child’, ‘good mothers’ and the social consequences of inappropriate behaviour.

Each family was interviewed five times every three months over a two-year period. Their stories and experiences are presented in this thesis.
Chapter One
Introduction

This thesis is concerned with the medicalisation of children’s behaviour. The number of children diagnosed with Attention Deficit Hyperactivity Disorder (ADHD) has increased over the last decade. These children have been diagnosed by medical practitioners and treated with stimulant medication. Parents anticipate that once their child is diagnosed with ADHD and prescribed medication, the behavioural difficulties will no longer persist. Some parents continue to experience difficulties, however, not only with their child’s behaviour, but also as a result of the diagnosis and accompanying criticism of their parenting abilities. Furthermore, the social stigma associated with the diagnosis—that is, children are seen as being mentally abnormal—affects the child and the whole family.

ADHD is categorised within the broader context of mental health disorders. The diagnostic categories were first set down in the Diagnostic and Statistical Manual of Mental Disorders (DSM) III in the late 1980’s. This publication is the official guideline for the clinical assessment and diagnosis of mental health disorders. Today the diagnostic criteria of ADHD are based on the categories updated in the DSM-IV (Barkley, 1990). According to the DSM-IV, for children below the age of twelve to be diagnosed as having ADHD, they must show six of nine inattention items and/or six of nine hyperactive-impulsive items. The behaviour exhibited must not be age appropriate and must commence before the age of seven. The difficulties must be evident in at least two settings (school, home), and there needs to be clear evidence of impairment in social or academic performance (Barkley, 1990; DuPaul & Stoner, 1994; Ingersoll, 1988).

It is not this thesis’ goal to disprove the existence of ADHD, but to propose an alternative way of thinking about the ADHD behavioural symptoms. As the categorisation of ADHD is based upon an analysis of behaviour, the diagnosis is subjective to some degree and therefore imprecise. There is a fine line between those who actually have ADHD and those who exhibit
the symptoms either as a way of gaining attention or as a result of emotional or behavioural difficulties. In this sense, the label may be appropriate to some cases and not to others. This thesis will consider the effect of labelling children with ADHD. By letting the parents and the children tell their story, it provides a fresh perspective on these issues. That is, the process of labelling a child with ADHD can be examined and the behaviour exhibited by the child can be understood as actions, events and consequences, rather than an internal biological process. Medication may well decrease the inappropriate behaviour of children who are either aptly or inaptly labelled with ADHD, however, if the root cause is not biological, it will not treat the underlying emotional or behavioural difficulties. Furthermore, there are negative side effects to taking the medication. It results in the child losing some of his/her spontaneity and the essence of his/her personality.

A medical understanding of ADHD does not appear to adequately explain the continuing difficulties experienced by children and their families following the diagnosis of ADHD. Some children who exhibit extreme behavioural difficulties have a psychiatric illness that can be effectively treated by medical remedies. However, many children who exhibit unacceptable behaviours do not fit into this category. Placing all these children together under the diagnosis of ADHD may be more harmful than useful. Insufficient attention to the broader social context limits the usefulness of intervention strategies for families and may perpetuate difficulties within families.

The research component of this thesis explores families who have a child diagnosed with ADHD. The focus is on their understanding of the child’s behaviour, their experiences of seeking and receiving an ADHD diagnosis and how this has impacted on the family and child diagnosed. Narratives are the primary embodiment of our understanding of the world, of experience and ultimately of ourselves. The specific ways people tell their story are, influenced by their idiosyncratic experience, but are also informed by their set of dispositions and values formed through their enculturation. In other words the socialisation, participation in certain
communities, culture, education (formal and informal) and upbringing a person encounters throughout life are formative (Bourdieu, 1991). Accordingly, the structure of reality as perceived by people is reflected in the way they tell their story. This research project attends to narrative structure as a most important way in which experiences are given meaning. A story is influenced by an individual’s idiosyncratic experiences but it is also shaped by social norms and from the views of significant others (eg. doctors and psychiatrists), as well as the wider society. Unravelling these patterns in respect to parents of children diagnosed with ADHD forms part of this study. In this way, the broader social structures in which the families live, and the ways that these structures influence families and individuals (and vice versa) are taken into account.

**Background to the Research Project**

When I first embarked on this research some six years ago, there was not as much information available for families, professionals and other interested parties on the topic of ADHD, and the information available was largely medically based. Today there are many books and professional groups who have begun to question the medical model, the validity of the diagnosis, and the notion of prescribing medication to children.

I was curious about ADHD and wanted to find out more about the experiences of families, who take their child to be assessed and receive a mental health diagnosis of ADHD. I was interested in finding out more about what this experience was like for them, how their family circumstances and interactions had changed, if at all, after a diagnosis.

When I commenced talking with families, they described the difficulties they were experiencing managing their child’s challenging behaviour. The parents talked about feeling confused, angry, frustrated and powerless to change the situation. School often further exasperated parents’ concerns about their child, as teachers often focus on the difficult behaviour of their child, particularly in the classroom, but in the playground, the fights with
other children, and the few, if any, friends they had. Their child was the focus of much
discussion with school staff and this made parents feel inadequate. In some ways parents
wanted to protect their child from all this negative attention, but in other ways, they were
angry with their child for acting out at school.

Social gatherings are very stressful for these parents. Their child often would receive negative
attention from extended family and friends. Their child was often singled out as the ‘trouble
maker’, the one who led all the other children astray. Parents once again were left feeling like
they wanted to protect their child from other people’s negative comments and but at the same
time they were angry that their child would draw negative attention to themselves. Parents felt
blamed, their parenting abilities were being scrutinized. At the same time, they felt that in
some ways they had contributed to their child’s ‘bad’ behaviour. Extended family and friends
took it upon themselves to discipline the child, or provide unwanted and unwarranted
parenting advice to parents, this often left them feeling angry both at their child for not ‘being
like other children’ and at the family member or friend for making them feel like they were a
‘bad’ parent or that their child was ‘naughty’.

All this negative attention, negative feelings, difficult and challenging behaviour, stress,
frustration, anger, advice, and the desire to improve the situation led the parents to seek a
psychiatric assessment to determine whether there was something wrong with their child, as
many people often suggested. Moreover, they were made to feel that their child was naughty
or that their parenting was inadequate even if they were not told that there was something
wrong with their child. I was left wondering whether these parents would have had their child
assessed if it had not been for the social pressures they and their child were experiencing. Did
their family, friends and school community contribute to the labelling process of this child
because they did not behave like other children? Trying to answer these and other questions
led me to embark on this research project.
The research question that this thesis addresses is:

What is the effect of the mental health diagnosis, of Attention Deficit Hyperactivity Disorder on children and their family and what are the social implications of this for the family?

Research Aim

The aims of the research project are to explore and to examine:

1. The varieties of personal and family experiences of parents of a child diagnosed with ADHD and how they understand these experiences;

2. The impact the diagnosis of ADHD has on a family’s daily lives, taking into consideration the broader social implications for families and individual members.

Since beginning this thesis in 2000, there has been new debate about the diagnosis and treatment of ADHD. The medical model, however, continues to dominate the current diagnosis, treatment and definition of ADHD. ADHD is a diagnostic label given to children who seem to be experiencing difficulties in attention, impulsivity and hyperactivity. ADHD has become the most common issue for children referred to mental health professionals today (Barkley, 1990; Shaywitz, Fletcher & Shaywitz, 1994). It is estimated that ADHD affects up to ten per cent of all children in Australia today, approximately two per cent being severely disadvantaged (Green & Chee, 1994; Hazell, 2000). The treatment generally prescribed is stimulant medication. Between 1990 and 1998 the prescription of Ritalin has increased remarkably in Australia, from just over 13,000 to 96,000 (ABC, 7.30 report, 22/3/00).

To better understand the issues faced by families with a child diagnosed with ADHD, two theoretical approaches will be explored. The first is the medical perspective that continues to dominate the understanding of ADHD and is being seriously challenged by some researchers (Barkley, 1990; Woods & Ploof, 1997). The second is to interpret the experiences of day-to-day
living and behaviour as socially constructed. The latter is an alternative perspective that warrants further investigation.

The central focus of this study therefore is to recognise the importance of the interface between people and the social structures in which they live. The issues faced by children and families are defined not only in psychological terms, but also in the context of these broader social structures, and the belief systems that maintain their existence (Ife, 1997; Mullaly, 1993). Hence when exploring a specific issue, such as the experiences of families with a child diagnosed with ADHD from within a broader social framework, these various broader social factors need to be delineated. These include experiences the child has at school, the way powerful social discourses impact on children and their families, the reactions of extended family members and how these reactions affect the parents and the child. Information that comes from family members and significant others is valuable because it is derived from their everyday experiences. It gives professionals and others insight into the lives of children and families living with ADHD, it is first hand experience that people cannot gain through surveys or even from books.

**Methods**

The approach used in this research utilizes a case study methodology. The participants of this study were families who had a child recently diagnosed with ADHD. Three families in total were interviewed five times each at three-monthly intervals over an eighteen-month period. The classroom teacher of each child diagnosed with ADHD was also interviewed. A semi-structured interview format was developed to explore participants’ experiences of everyday life. The interview schedules were constructed with specific topics related to ADHD. The interview design was flexible, with interviews conducted in a non-threatening manner. The project utilised a longitudinal design, allowing time to explore any changes, improvements and/or continuing concerns relating to the diagnosis of ADHD and the intervention plan established by psychiatrists and paediatricians.
Structure of Thesis

The thesis consists of eight chapters. The theoretical framework for the research project is developed over two chapters. Chapter two presents the medical and biological viewpoint that has come to be influential in explaining ADHD, its historical developments and current theory concerned with the diagnostic criteria of ADHD. The medical and other remedies available for children and their families are also delineated. An overview of current practices indicates that treatment is based almost entirely on medical practice that focuses on specific diagnosis and prescription of medication for the treatment of the child’s behavioural symptoms.

A review of other relevant literature indicates that there are some health professionals who are questioning this medical approach to the issue. Recent analyses indicates that while the predominant treatment and medication model appears to lessen the symptoms, families can still continue to experience a range of difficulties.

In chapter three the implications of this phenomenon are examined by exploring the impact and influences social factors have on individuals. Consideration is given to acceptable and non-acceptable behavioural expectations within society and the implications of this for individuals and families. In the literature review it is argued that it is important to examine how behavioural standards impact on the whole family.

In chapter four the methodology and procedures adopted in the research are presented. This was a longitudinal study drawing on case study methodology that allowed the interpretations and experiences of the families involved in the study to be captured and examined within the context of broader structures and discourses (Grbich, 1999; Strauss & Corbin, 1994).

The data analysis is presented in discussion format in the proceeding three chapters. In these chapters the families’ experiences, interpretations, daily triumphs, defeats and celebrations are
presented. In all three chapters the powerful effect of social beliefs on the parents’ expectations of their children’s behaviour and their own parenting, as well as on the attitudes of the parents and children towards the diagnosis and treatment of ADHD are demonstrated.

Chapter five explores the families’ experiences, their feelings and events that resulted in the family seeking a diagnosis of ADHD for their child. The strategies the families used to manage their child before a diagnosis was made are described. It explores their daily struggles to make sense of why their child was so ‘naughty’, and their questioning and self-doubt of their own ability be ‘good’ parents.

Chapter six explores the families’ experiences after diagnosis. A number of highly significant issues are discussed including: the use of medication; the parent’s ambivalent attitude towards diagnosis and medication; the reaction of extended family and friends; the families’ experiences and their reaction to the diagnosis; and what the children have to say about being diagnosed with ADHD.

Chapter seven is the exploration of the families’ experience of change and the knowledge they have obtained along the road from pre-diagnosis to post-diagnosis and their future aspirations for their children. The families reflect on the eighteen months gone by, the service provided and what, if any, other support they may have required.

In conclusion, chapter eight presents implications of the study and makes important suggestions for future exploration in the areas of policy, practice and research.
Chapter Two
ADHD & the Medical Perspective

Currently ADHD is understood largely within a medical context. Consequently the use of stimulant medication is recommended. ADHD is a mental health diagnostic label for individual behaviour that does not conform to expected standards.

In western society, in particular Australian and American culture, there has been a significant increase in the number of children being diagnosed with ADHD and prescribed medication to manage behavioural difficulties (DeGrandpre, 1999). In this chapter, first I present the current medical explanation for ADHD. Then I discuss the history and the development of ADHD, and examine the argument for the use of stimulant medication, the recommended treatment for children diagnosed with ADHD. Also discussed are the side effects the medication is known to have on children. As the medical profession has dominated the understanding and treatment of ADHD, stimulant medication has been the recommended means of lessening symptomatic behaviours. However, the use of stimulant medication introduces a new set of behavioural and social difficulties. Finally, I explore other forms of managing the behavioural and social difficulties that may be experienced by the family and the child diagnosed with ADHD.

[PRIVATE ]What is ADHD?

Knowledge of ADHD is not a recent phenomenon as families and individuals are led to believe. Scientific papers first appeared on this disorder very early in the twentieth century. They were medical in nature, often describing ADHD as, “residual cognitive and behavioural effects of various central nervous system injuries” in children (Barkley, 1990, p.3).

More recently ADHD is described as a developmental disorder of self-control, that is, problems with attention span, impulse control and hyperactivity (Barkley, 1995).
History of ADHD

The examination, observation and explanation of children’s behaviour has occurred for many years. It is important to present the history of how ADHD has developed and come to be known as ADHD and how the understanding of ADHD has been influenced and shaped. From the earliest understandings of behavioural difficulties to present day understanding, the definition of ADHD has changed according to medical understanding of the issues affecting the child.

One of the earliest recorded writings on children’s behaviour was by George Still from the Royal College of Physicians in 1902. Still conducted a series of lectures describing children he saw as being ‘aggressive, defiant and resistant to discipline; excessively emotional or passionate’ (p.1009); ‘and show[ing] little inhibitory volition’ (p. 1008). ‘Lawlessness, spitefulness and cruelty, and dishonesty were also associated with this disorder’ (Still, 1902, p. 1009). Most of these children were described as being impaired in attention and were overactive. Still believed these children displayed a major ‘defect in moral control’ (p. 1009), in their behaviour and in most cases it was chronic.

Still (1902) was one of the first to note that symptoms of this disorder were ‘unnatural’, relative to the behaviour of ‘normal’ children of the same age group. He proposed a biological predisposition to this behavioural condition, suggesting it may be hereditary in some children and the result of pre- or postnatal injury in other children (Barkley, 1990).

Tredgold (1908) found that alterations in the environment and medication temporarily improved behaviour. For instance, it was suggested at this time that these children needed a strong educational environment. Levin (1938) postulated that severe restlessness in children was likely to be the result of pathological defects in the forebrain structures.
These early understandings of ADHD highlight a moral overtone. Not only was the focus on the physical or biological factors, the child was also seen to be physically and mentally weak, or defective in some way.

Between 1937 and 1941 a series of papers marked the beginning of medication therapy, for children diagnosed with behavioural disorders (Bradley, 1937; Bradley & Bowen, 1940; Molitch & Eccles, 1937). It was reported that the use of amphetamines reduced disruptive behaviour and improved academic performance of children hospitalised at the Emma Pendleton Bradley Home in Providence, Rhode Island. Studies by Laufer, Denhoff and Solomons (1957) also confirmed the positive results of drug use. This paved the way for medication to become the preferred treatment for children with characteristics, which could be interpreted as ADHD, in the 1970's.

In the 1950's, however, a number of studies were conducted involving neurological mechanisms underlying the behavioural symptoms (Laufer, Denhoff & Solomons, 1957). Writers referred to children as having 'hyperkinetic impulse disorder' and stated that the central nervous system deficit occurred in the thalamic area (Barkley, 1990). They argued that it was due to poor filtering of stimulation, allowing an excess of stimulation to reach the brain.

During the 1960's and 1970's the term 'hyperactivity' came to be used more frequently. By the late 1960's the popular terminology was 'hyperactive child syndrome'. Chess (1960) defined the hyperactive child as:

PRIVATE one who carries out activities at a higher than normal rate of speed than the average child, or who is constantly in motion, or both (p.2379)

PRIVATE The definition of 'hyperactivity' or 'hyperkinetic' by the early 1970's, was broadened to include impulsivity, short attention span, low frustration tolerance, destructibility and aggressiveness (Marwitt & Stenner, 1972; Safer & Allen, 1976).
Addressing the Canadian Psychological Association, Virginia Douglas (1972) argued that the deficit in sustaining attention and impulse control is more likely to be the reason children experience difficulties, not hyperactivity. Douglas (along with Susan Campbell) found that hyperactive children were not more destructive than normal children and that sustaining attention was the difficulty and that this could emerge in conditions where no significant distraction existed (Douglas, 1972).

This theory was to guide research over the next fifteen years. So influential was Douglas, that by the 1980's, McGill University named the disorder Attention Deficit Disorder (ADD). This was significant, as it was to appear in the DSM-III as a diagnostic label. Later the DSM-III further revised the criteria for diagnosing this disorder and changed its name to ADHD, to include the presence of hyperactivity. This later change significantly changed the diagnosing procedure of children, and now DSM-IV presents the criteria in two categories, one dealing with attention and the other with hyperactivity or impulsivity.

**ADHD Today**

The most recent studies carried out within a bio-medical framework suggest that ADHD is linked to a brain deficiency, that is, a delay in the development of the response inhibition. It is argued that ADHD is the disturbance of the self-regulation and organisation of behaviour across time and that it is a function of the frontal region of the brain (Barkley, 1995).
Russell Barkley, a prominent psychiatrist working with children in the field of ADHD has conducted numerous studies and has written extensively on this topic. In 1994 he developed a medical paradigm for understanding ADHD. He suggested that the link to the delay in the development of the response inhibition has a number of implications that need to be addressed if ADHD is to be fully understood (Barkley, 1995). To summarise:

1. ADHD is a disorder in performance, not in skill. As human beings develop and mature, so does their behaviour. As children grow and develop they experience a shift of control, that is, behaviour that was once controlled by the immediate environment is now controlled by an internal source of information, and the consequences of behaviour are taken into consideration. Barkley (1995) argues that ADHD disrupts all this, with impairment in the normal development of inhibition. There is a decrease of self-control, behaviour is regulated by the immediate events, and future influences on behaviour (Barkley, 1995).

2. ADHD has a profound effect on "adaptive functioning" - that is, it interferes with self-regulating behaviour that must be organised over time to meet day-to-day living (Barkley, 1995);

3. ADHD is not likely to be detected by traditional academic, intellectual, or other psychometric tests (Barkley, 1995);

4. If ADHD is to be diagnosed it is to be over a period of time, with the child's behaviour observed daily (Barkley, 1995);

5. [PRIVATE ]For the treatment to be most successful it must occur where the behaviour needs to be modified (Barkley, 1995).

Barkley has presented a more comprehensive argument supporting the notion that ADHD is a "developmental disorder of the ability to regulate one’s behaviour with an eye towards the future" (Barkley 1995, p.19). He maintains that ADHD stems from underactivity in an area of the brain that, as it matures 'normally', provides us with an "ever-greater means for behavioural inhibition,
self-organisation, self-regulation and foresight" (Barkley, 1995, p.19). He claims that the behaviour induced by the underactivity of the brain can be detrimental in its impact on the person's ability to manage his/her day-to-day behaviour. He argues that ADHD is more than inattention, impulsivity and hyperactivity. Its complexities increase over time, and it varies in degree in all humans, it is not pathological in most cases and it is not temporary.

Barkley concludes:

ADHD is a disorder of performance, not of skills; one of dysregulation not of deficit; one of not doing what you know rather than of not knowing what to do. It is an impairment on the execution of behaviour as it is organised over time and directed towards future goals rather than in comprehending what those behaviours should be. Hence, it is at the point of performance where the failure of self-regulation rests and it is the consequences of inadequate response inhibition (Barkley, 1995).

These recent explanations emphasise that behaviour inhibition is a major factor in ADHD, and provide a new framework for examining behavioural issues. For instance children may have difficulty focusing on the task at hand. These children are easily distracted, more likely to be disruptive in a classroom situation, and in fact resist undertaking part in activities that they feel are uninteresting. Sustaining attention in many activities is more likely and this may lead teachers and parents to think that the child is being difficult and simply refusing to do the given tasks.

This has led to a recognition by prominent health professionals, such as Green and Chee (1994), Barkley (1995), and Ingersoll (1998), that difficult behaviour is not brought about by poor parenting or any other social factors but is a result of the child experiencing difficulty with inhibition. Nevertheless, how to respond to these behaviours can be a challenge for all those relating to the child.
Medication

Currently the recommended management for children who are diagnosed with ADHD is stimulant medication. Although giving young children stimulant medication to improve their behaviour is controversial, it is argued by those subscribing to the use of stimulant medication, that to date there does not appear to be any other form of management that works as effectively to improve children’s behaviour and academic performance (Barkley, 1990, 1995; DuPaul & Stoner, 1994; Green & Chee, 1994; Ingersoll, 1988; Tannock, Schachar & Logan, 1993).

Many studies have been conducted examining the effects of medication on children who have been diagnosed with ADHD. The number of studies conducted on medication and ADHD is endless. Many explore the effects medication has had on the child’s behaviour and academic performance (Alto & Frankenberger, 1995; Jenson, 1996). It is widely accepted by medical and psychiatric professions that stimulant medication is effective and beneficial to the quality of daily life and interaction of children diagnosed with ADHD. Doctors at the other end of the spectrum, however, argue that stimulant medication may be addictive, and that there are associated side effects. If a child is diagnosed with ADHD and medication is prescribed, the medication does appear to improve behavioural difficulties. However, once the medication has worn off, the difficult behaviour reappears and is once again an issue.

The sole purpose of stimulant medication is to increase the level of activity or arousal in the brain (Woods & Ploof, 1997). There are three commonly recommended stimulants for the treatment of ADHD in the USA: d-amphetamine (Dexedrine), methylphenidate (Ritalin), and pemoline (Clyert). However in Australia Ritalin and Dexedrine are most commonly used (Green & Chee, 1994).

The use of Ritalin appears to have rapidly increased over recent years. For example in the United States alone during the 1980’s, one million children used it regularly. By 1989 there were many professionals, books and support groups supporting the use of Ritalin. Just a few years later, by the early to mid 1990’s the numbers of children using Ritalin doubled to more than two million (DeGrandpre, 1999).
Effects of Medication

Barkley (1995) argues that stimulant medication produces positive effects on sustained attention and persistence of effort to work, and that it reduces restlessness and gross motor activity. Stimulant medication is recommended for children aged four years and older. Once it has been determined that medication will be prescribed, Ritalin is usually the first choice by physicians. This appears to be because more research has been undertaken on Ritalin than any other stimulant medication. Ritalin has a proven efficiency across a wide range of ages (Barkley 1990). The usual practice is to begin a child on a small dosage, twice a day, usually once in the morning and once in the afternoon (Wood & Ploof, 1997). There is also variation in dosage depending on which stimulant medication the child is prescribed. For example the dosage of Dexedrine is typically half that of Ritalin, due to the potency of Dexedrine (Barkley 1990; Wood & Ploof, 1997).

In the classroom setting, it is widely reported that the child’s behaviour improves whilst taking the medication. The behaviour is no longer as disruptive as prior to medication, the children are more focused and able to stay on task, and their academic achievements improve (Cunningham & Barkley 1979; DuPaul & Rapport, 1993; DuPaul & Stoner, 1994; Ingersoll, 1998; Pelham et al, 1993). It is reported that in a social setting, children generally behave in more socially appropriate ways after commencing medication. Their level of frustration is reduced, their outbursts and aggressive behaviour is greatly reduced and they are likely to deal with disappointment better (Ialongo et al, 1994; Milich, Carlson, Pelham & Licht, 1991).

There is also the suggestion that the child’s language and relationship with family and peers improve (Ingersoll, 1998; Tannock, Fine, Heintz & Schachar, 1995). Many studies conducted in this area report significant improvements in the quality of social interactions between the child diagnosed with ADHD and their family and peers (DuPaul & Barkley, 1992). These studies show that children are less aggressive and behave more appropriately with their peers (Hinshaw, 1991; Pelham & Hoza 1987; Whalen et al, 1989).
Despite the findings of marked improvements in the child’s behaviour when taking the stimulant medication, there is also growing evidence of a number of associated side effects.

**Side Effects**

Medical and psychiatric professionals have been investigating the side effects of stimulant medication. The side effects associated with stimulant medication are widely acknowledged by professionals, and by parents. The most serious side effect of using stimulant medication is death (Jacobs, 2002). There have been some reported cases of children dying as a result of taking stimulant medication and more information needs to be given to parents when making the decision to allow their children to be prescribed stimulant medication.

A long-term side effect associated with the use of stimulant medication is withdrawal effects. Research indicates that children may suffer from withdrawal after discontinuing stimulant medication (Jacobs, 2002). Other reported long term side effects of using stimulant mediation are the effects on growth, development and the brain. Breggin (1998) states:

> There is now a mountain of evidence that stimulants disrupt growth hormone production on a daily basis and that they also can reduce the child’s overall growth, including height and weight…It is hard to imagine a more serious warning flag than growth inhibition, since it affects the overall growth of the body and all its organs, including the brain (p. 25).

Studies have shown that children taking the stimulant medication may have a decreased appetite, insomnia, anxiousness, irritability, or proneness to crying (Barkley, 1995; Ialongo et al., 1994). Children often complain of stomach aches and headaches, and in extreme situations children may develop tics (Barkley, 1993).

Another side effect associated with taking the medication is the potential psychological impact on the child (Campbell, Green & Deutsch, 1985). An increasing number of writers suggest that stimulant medication may undermine self-competence and self-concept in children diagnosed with ADHD.
These children may come to see themselves as lacking control over positive outcomes, or lacking the ability to control and improve their own behaviour. Researchers argue that this lack of control may create feelings of inadequacy and helplessness, and that it may cause subsequent failure to even attempt to achieve positive behaviour (Abramson, Seligman & Teasdale, 1978; Ialongo et al, 1994).

Ialongo et al, (1994) suggest that children on stimulant medication may lack motivation to improve their social problem-solving and academic behaviour despite the need to do so, due to the limited effectiveness of the medication. Furthermore, it is reported that the benefit of stimulant medication ceases to continue once the dosage is withdrawn (DeGrandpre, 1999).

Relying too heavily on stimulant medication to address the social, academic, familial and psychological issues which may result from ADHD symptoms, is to "deny the impact these secondary symptoms have had and continue to have on ADHD children and those around them" (Burte & Burte, 1994:2).

As indicated in chapter one, children diagnosed with ADHD generally have low self-esteem, poor self-image and lack confidence in their abilities (Brooks, 1994). The low self-esteem and poor self image may be related to the fact that once the medication is withdrawn any benefits it may have quickly disappear (Campbell, Green & Deutsch 1985; Ialongo et al, 1994). The child may come to see any improvements or positive outcomes as being associated with the medication, and feel that they have little control over any positive outcomes (Henker & Whalen, 1980).
Once on the medication the child’s inattentiveness, restlessness, and lack of concentrations does appear to improve (Barkley, 1995). However, if parents do not respond positively and appropriately to the changes incurred by the medication, this could result in lost opportunity to reinforce positive social and academic behavioural and personal growth (Ialongo et al., 1994).

[PRIVATE ]There is also a danger that parents, school staff and the child's peers, have too many unrealistically high expectations of the child on stimulant medication, which could distort their perception of progress or gains made in improving social behaviour. Stimulant medication does not provide the child with the necessary skill to improve social and behaviour patterns (Burte & Burte, 1994). If this is not acknowledged and rectified, the fact that the medication does not improve all aspects of the child’s behaviour could lead the child diagnosed with ADHD to further conduct disturbances, depression, academic under-achievement, aggression and oppositional defiant behaviour (Burte and Burte, 1994).

In the family home parents may find managing their child’s behaviour difficult and challenging. Children often violate household rules, refuse to do their chores and home work, and may fight with and disrupt their siblings. Often medication may be inadequate in improving behaviour in terms of relationships and social situations, and professionals may suggest other forms of behaviour management for parents to develop strategies on how to best handle their child’s difficult behaviour.

**Behaviour management approaches**

Over the last decade or so, health professionals have developed alternative forms of behaviour management strategies for parents, to assist in managing the child’s difficult behaviour. The assumption is that parents may need to be skilled in parenting to improve their child’s behaviour, to be more appropriate and socially acceptable (Barkley, 1995).
Although stimulant medication is the most widely used ‘treatment’ for children diagnosed with ADHD, clinicians argue that medication alone cannot meet the clinical management needs of families and children (Barkley, 1990). Using stimulant medication does not automatically provide parents with improved parenting skills, nor do the behavioural improvements continue as the effects of medication begin to wear off (Barkley, 1990; DeGrandpre, 1999). Hence parents may find it difficult to manage their child’s behaviour especially in the early evenings, on school holidays and on weekends. Due to the side effects, parents do not give children the medication all the time. When parents spend time with their children when medication is not being used, it becomes necessary for parents to rely on other forms of behaviour management strategies to handle difficult behaviour. They are not always well equipped to do this.

Clinicians recommend parenting training and counselling because the difficulties of children diagnosed with ADHD are seldom limited to the core ADHD symptoms themselves. Children quite often exhibit difficulties, such as low self-esteem, underachievement at school, depression, poor peer relationships, and aggression, that are not alleviated by the medication (Barkley, 1990). As medication is inadequate in addressing these difficulties, they need to be addressed by other means. Behaviour management programs are sometimes recommended to the family by the psychiatrist involved (Barkley, 1990, 1995; Edwards, 1995; Green & Chee, 1994; Ingersoll, 1998; Pelham & Gnagy, 1995; DuPaul & Stoner, 1994). For instance Barkley (1995) developed a program called Eight Steps to Better Behaviour for parents to use with children diagnosed with ADHD. The aim is to improve the child’s behaviour, so that they are more cooperative and less defiant or oppositional. Barkley (1995) outlines the eight steps for achieving a more positive outcome for the whole family, which he argues, will take at least eight weeks to complete. There are many such programs that aim to assist parents in improving the child’s behaviour. The implications of such parenting programs are that the child is identified as the central difficulty. The focus is on changing his or her behaviour. This is a very individualistic approach.
Family counselling is another form of assistance. Traditional family counselling models such as those developed by Minuchin (1974), Haley (1976) and the Milan group (Selvini Palazzoli, Boscolo, Cecchin & Prata, 1974, translated into English 1978), are all well-established and respected within the family counselling realm. These models however, have been criticised for their failure to consider the cultural and social structures that impact on families. Family counselling is not an approach usually recommended by the medical professionals involved with family who have a child diagnosed with ADHD; the medical professionals’ primary focus is behaviour management for the child.

Like the behaviour management programs, the models of family counselling tends to pathologize and medicalize family difficulties through notions of ‘healthy’ and ‘dysfunctional’ families (Greenspan, 1993; Marchant & Wearing, 1986). The main focus of these traditional perspectives is to maintain the status quo and to reinforce social norms. They do not challenge the social structures that maintain the expectations placed on families and individuals, in particular on those diagnosed with a mental health ‘disorder’.

**Conclusion**

ADHD has been constructed as a bio-medical phenomenon by the medical discourse for children’s behavioural difficulties. Historically ADHD was seen as a set of behavioural difficulties. Today psychiatrists continue to explore the causes of ADHD and now suggest that ADHD is a frontal lobe impairment, which affects children’s ability to sustain attention, impulsivity and hyperactivity. The medical profession has recommended stimulant medication for the treatment of ADHD. The medication appears to alleviate the symptomatic behaviours whilst it is in the child’s blood stream (i.e. while it is administered daily). I have discussed both the benefits and side effects of using stimulant medication. Studies of the benefits and long term and short term side effects of medication continue to be conducted.
The medication does wear off, and if there is a break from taking it the symptoms do appear to
continue and a new set of difficulties may arise for the families and children. To address these
new difficulties families are often referred to behaviour management and parenting skilling
courses. These suggested behaviour management strategies are limited, however, because they
do not explore the behavioural difficulties and family circumstances from a holistic perspective.
They do not attempt to understand the family, the difficulties they encounter or the impact of
the social and cultural expectations placed on the family and children. In the next chapter I will
discuss the cultural and social structures that impact on and influence the family.
In the previous chapter I discussed the medical explanation of ADHD, outlining the link between behavioural symptoms, classification and medical treatment. In this chapter, however, I provide an alternative view of the phenomenon known as ADHD. I argue that behaviour is socially constructed and defined as ‘normal’ or ‘not normal’ and that as a consequence medical labels are given to those who stand outside the ‘normal’ realm of acceptable behaviour.

**Critiquing the Medical Model**

The medical profession has spent a lot time and money on research into the question of what causes ADHD, and the best treatment for it. Today there is a plethora of studies and books published discussing the cause, treatment and diagnosis of ADHD. There is still no proven medical test, however, that children can take to establish whether they have ADHD. Diagnosis is based on subjective interpretations of the child’s behaviour. If a child exhibits a certain number of those behaviours listed in the DSM IV then they are diagnosed with ADHD. These categories are arbitrary. At one point or another all children exhibit those behaviours, albeit to a greater or lesser degree. To a large extent these behaviours are influenced by the capacity of parents or teachers to cope with the behaviour. When the behaviour becomes a ‘problem’ for adults it then becomes a ‘problem’ for the child. By giving the behaviour a label that classifies it as the result of medical factors, then the need for further analysis of the social or psychological context, or the influence of other systems, or subsystems, on the child is negated.

The medical profession is very influential in the diagnosis and treatment of children diagnosed with ADHD. Foucault (1967) argues that the power of knowledge held by the medical profession has the biggest influence over the general public. According to Foucault the
influence of the medical profession on mental health categorization is achieved in three ways. First, through ‘scientific discourse’, that objectifies human behaviour and labels it as in the case of ‘insane’ or ‘deviance’. In the case of ADHD, the behaviour children exhibit is objectified, then defined and finally labelled according to the classifications stated in the DSM-IV. Second, power is extorted through ‘dividing practices’, which view people as either sane/insane or sick/healthy. Once diagnosed with ADHD children may then be perceived by others as different or as having something wrong with them. The final influencing factor is the way individuals may identify with the label, they internalize it, defining themselves with the label. That is, they have a medical label, which defines, who they are and how they will be treated and seen by others. (Crinall, 1999; Foucault, 1967).

Let us examine the dominance of the medical model in our daily lives, with particular focus on Foucault’s theory of mental illness/health. The origins of the modern understanding of mental illness can be traced back to classical medicine, where both mental and organic illnesses were regarded as autonomous and unified botanical species, which existed independently of the individual bodies (McNay 1994). During the late eighteenth century, however, this notion of mental and organic illnesses being autonomous and self-sustaining phenomena was gradually rejected in favour of a synthetic view of illness, which adhered to the ‘psychosomatic totality’ of the sick individual. Thus the personality becomes the element in which the illness develops and the criterion by which it can be judged; it is both the reality and the measure of the illness (Foucault, 1976).

Mental illness is usually seen and defined in terms of failure or suppression of normal psychological functions (Foucault, 1976). In the case of children diagnosed with ADHD, medical practitioners hold that the child’s ‘normal’ psychological functions are underdeveloped; this ‘makes them’ hyperactive, impulsive, unable to sit still or stay on task, have learning difficulties, and find it difficult to play amicably with other children without.
Foucault argues that the notion of mental health is not a self-evident behavioural or biological fact but a product of various socio-cultural practices (Foucault, 1967; McNay, 1994). Madness, he argues, has no pre-social essence but acquires its “density of being” in relation to the needs and demands of a given culture (Foucault, 1967; McNay, 1994). The modern treatment for those diagnosed with a mental illness is a process of ‘normalisation’ and ‘medicalisation’ (Foucault, 1967; McNay, 1994). That is, the aim of the treatment is to ensure wellness, prescribe a treatment for the individual to ensure that their symptoms slowly disappear and they are able to function as ‘normal’ members of society. Modern psychiatry, he argues, alienates the insane from themselves by imposing moral categories on them under the guise of an ostensible objective medical knowledge (Foucault, 1967; McNay, 1994). The experience of madness is internalised, people may begin to believe that there is something wrong with them, that they are not ‘normal’, and they begin to feel ashamed.

Let us examine more carefully the DSM-IV criteria used to diagnose ADHD, which classifies it as a mental illness. As mentioned in chapter two, the criteria for the diagnosis of ADHD first appeared in the DSM-III as a result of research conducted by Douglas (1972), which found that hyperactive children performed badly in standardised tests of attention when compared to other children. Before we look specifically at the DSM-IV criteria on ADHD, it is important to briefly discuss the purpose of the DSM. As previously stated the medical profession gains its power and social standing as a profession through scientific knowledge and technology, which involves classification, diagnosis, and treatment. In psychiatry, the process of agreed diagnosis criteria in mental health illnesses, has been a particularly difficult journey.

Although the DSM first appeared in America in 1952, it was not until the 1970’s that it gained professional standing. Today it is a widely used professional tool in the psychiatric profession for diagnosis of individual mental health illnesses. Today, the psychiatric profession argues that the DSM is based on scientific research evidence. The medical assumption is that “planning a treatment program must begin with an accurate diagnostic assessment” (Tomm,
1990). The DSM is a powerful tool for the psychiatric profession, which fails to mention other possible contributing factors to the individual such as social influences on human behaviour. There is widespread criticism of the DSM’s narrow view of human behaviour. The most highly contested category in the DSM was homosexuality, which has now been removed and is no longer seen as a mental health illness. Today the highly contested issue is ADHD.

The DSM criteria’s medicalisation of children’s behaviour, based on subjective interpretation, is highly controversial. Currently there are three core criteria of ADHD, and in order for a child (or adult) to be diagnosed he or she needs to present six or more symptoms for at least six months. The first criterion is

*hyperactivity*; a child who “often fidgets with hands or feet or squirms in seat” and “often leaves seat in classroom or, in other situations which remaining seated is expected” is defined as hyperactive. The second criterion is *impulsivity*; a child who “often blurts out answers before questions have been completed” and “often has difficulty awaiting turn” is given this label. The last criterion is *inattention*; a child who “often fails to give close attention to details, or makes careless mistakes in school work, work or other activities” is inattentive (Breggin, 2001, p.51; DSM-IV, 1994). None of these criteria explore with the child and/or their parent/s circumstances in the child’s life that may contribute to the behaviour exhibited. These criteria do not consider the emotional health of the child when assessing his or her behaviour and considering a diagnosis, nor do they allow for cultural difference. For instance it is well documented that there are more children diagnosed with ADHD in America and Australia than there are in Western Europe. Does this mean that children in Western Europe are better behaved, or that their behaviour is more acceptable and less under the gaze of professionals? There would need to be greater research conducted in this area to compare geographical differences and explore possible contributing factors. A recent newspaper article reported that
a recent study conducted by the Alfred hospital, in Melbourne, led by child psychiatrist Dr Vance found that children who are exhibiting behaviour difficulties maybe suffering from depression (The Age, 04/08/03). This finding suggests that all aspects of a child’s life need to be explored before a diagnosis is confirmed. The finding also leaves the following questions unanswered: which comes first, the depression or the ADHD diagnosis? at what point is it decided that this child has a ‘problem’? who makes that decision?

In *Rethinking ADHD*, Schmidt-Neven, Anderson and Godber, (2002), criticise the medical approach to ADHD describing it as “entirely focused on the individual’s physical status and on physiological processes within the body that can be directly observed or measured” (p.4). They argue, with some justification, that the subjective diagnosis and treatment process restricts the medical model. It fails to take into account the interrelationships between the mind and the body, the impact that emotional and social experiences have on the physical health and well-being of human beings (Schmidt-Neven, Anderson & Godber. 2002).

These are behavioural, not strictly medical, thus the test for this illness are restricted to behavioural observations which could have many different causes other than medical ones.

The medical model encourages mental health professionals to biological pathology at the expense of social considerations, and to make distinctions between ‘normal’ and ‘pathological’ behaviour, and to rely on biomedical treatment (Breggin, 2001; DeGrandpre, 1999; Foucault, 1973; McNay, 1994; Schmidt Neven, Anderson & Godber, 2002). In Australia, the ADHD phenomenon increased 25-fold, between 1988 and 1993. This has resulted in increasing criticism of the medical model’s effectiveness and appropriateness in the diagnosis and treatment of ADHD (Breggin, 2001; Hazell, 2000; Schmidt Neven, Anderson & Godber, 2002). The symptoms of ADHD are behavioural, not strictly medical; thus the tests for this illness are restricted to observations of behaviour, which could be the result of many other non-medical causes.
An Alternative View

Children’s behaviour can be extremely disruptive and wearing for parents and other significant adults. It is seen as a problem that needs a quick solution. The personality of children is another factor that determines the way children respond to rules and behavioural expectations. This is often overlooked in the search for quick explanations. One solution that has gained credence over the last ten or more years is to explain such behaviour in medical terms that posit medical treatment as the best option. This is particularly attractive because the labelling of a problem provides the key players (parents and teachers) with some assurance that the problem can be controlled. Then the child is propelled along a path from which there is little chance of escape. Once the label is given, reversal of the label becomes unlikely. This is not to deny that mental illness can affect behaviour nor that medical treatment may contain the symptoms.

I argue that most of these children do not have a mental illness. They do exhibit behaviour which society finds unacceptable. So do criminals, but we do not force them to take medicines to control their behaviour. The child is seen as the ‘problem’ and is labelled, given medication and the other emotional or environment factors contributing to the child’s behaviour are not taken into consideration. Giving children a pill to improve their behaviour does not alleviate the ‘problem’; it just shifts the responsibility from adult to child. The behaviour may be reduced, but it does not go away. Parents and teachers continue to experience difficulties with children’s behaviour and underlying psychological issues are still present. One might well ask, what the purpose of the medication is if the medication and diagnosis do not ‘fix’ the ‘problem’, for which the doctor was consulted. Wilkinson states that “Ritalin has no healing or curative power – it is purely symptomatic management, and not very successful at that either” (cited Jacobs, 2002, p.9).

In Queensland Children at Risk, Jacobs (2002) quotes author Beverly Eakman: “these drugs make children more manageable, not necessarily better. ADHD is a phenomenon, not a ‘brain disease’ ” (p. 21) in support if his view that virtually any child who has been a ‘problem’ for
any adult, may be eligible for the diagnosis and declared ‘sick’ (p.8). Hacking (1998) argues that we are currently inundated with mental illnesses more neurotic than psychotic; he questions which ones are based on affectations, cultural-artefacts, clinician-enhanced, or copy cat syndromes (p. 8). He argues that although fidgety children have always existed, this is currently labelled a mental illness requiring the prescription of stimulant medication. He asks whether this is a real mental disorder or an artefact of psychiatry demanded by a culture that wants to medicalise every annoyance that troubles parents, teachers and other powerful people (Hacking, 1998, p.8).

Behaviour is socially constructed and children learn what society deems correct and incorrect behaviour. They also learn that there are perceived benefits for non-compliance to these expectations eg. attention, revenge. Children who have been mistreated or traumatized may choose not to conform and may need psychological assistance to help them through their trauma. They do not necessarily need medical treatment to control their symptoms. In today’s society there is a lot of social pressure to make children conform to certain behavioural expectations. The range of what is acceptable and what is not appears to have narrowed, and strangeness is less tolerated (Richards, 1978). Children are expected to be ‘good’, well behaved, sit still, not talk, not run around, not fight, not argue, and not be disruptive. If a child does not conform to these expectations, then adults seek causes and solutions. They want desperately to find easy explanations for the child’s behaviour and ones that do not imply what they have done to contribute to the child’s non-conformity. Social pressure to be seen as good parents is very strong and the desire to seek explanations outside the immediate systems and subsystems in which the child operates, is compelling (Wearing, 1984). It is much more comforting to blame the behaviour on a medical problem than to accept and then address often quite complex explanations for the child’s behaviour. This process allows parents and teachers to shift the responsibly on to the child and away from the family, the school or even the wider society.
Examining ADHD from a social constructionist perspective challenges fundamental beliefs about behaviour, diagnosis, and treatment. Human behaviour is seen as socially constructed, influenced, and defined by the broader social structures in society. Constructionism views “all knowledge and therefore all meaningful reality as such, [as] contingent upon human practices, being constructed in and out of interaction between human beings and their world, and developed and transmitted within an essentially social context” (Crotty, 1998, p.42). As a Sociological explanation constructionism focuses on how the social world shapes and defines human behaviour. The medical perspective argues that children’s development is in stages and milestones can be ticked off at prescribed intervals. Social constructionist theorists challenge these stages arguing that human development cannot be measured by universal standards. Individual circumstances, family situations, changes in environment, the interactions between nature and nurture, further complicated by social forces, all influence human development and behaviour (Gergen, 1982; Gould, 1980; McNamee & Gergen, 1994).

The notion of milestones and developmental stages is perpetuated within everyday interpersonal interactions. A mother begins to interact with professionals, expectations surface. For instance a new mother with her new born child is expected to visit a maternal child nurse, the assessments nurses make of these children and mothers are based on formulas of ‘normal’ child milestones. Although there is a place for assessments of children who do not appear to be thriving, there are theories of child development that have played a major role in how we perceive the development of emotional and behavioural patterns, as well as the expected milestones in children. This knowledge has given rise to a new and increasingly dominant arena of professional expertise (Reiger, 1986). There are parenting courses available, which teach skills and techniques on how to best manage children’s behaviours, what the expected behaviour is and how to achieve it. Books, articles and training manuals guide parents on how to raise their children to behave in what these ‘experts’ consider to be socially acceptable.
Over the last several decades the flourishing market for parenting books and manuals has reinforced socially acceptable standards of behaviour. These manuals promote parenting techniques developed by professionals from their own knowledge base, such as the assertive discipline model, or the S.T.E.P. parenting program (Saunders, 1992). These parenting books and manuals argue that if the parent prescribes to the techniques outlined their child will in turn, react and behave in the prescribed fashion.

Although manuals and books are supposed to be user-friendly, some come across as parent blaming, placing a lot of pressure on the parent and their parenting skills. Alvy’s (1994) *Parent Training Today*, places expectations on parents right from the first page that reads:

Children are a nation’s greatest natural resource. Today’s children are tomorrow’s adults, workers, parents, and leaders. It is in the best interests of a nation to do everything it can to raise and nurture its children as effectively and humanely as possible.

Parents are the major persons involved in raising children. It is mainly through their efforts and abilities that children are socialised to become productive citizens. When parents possess the resources and skills to raise children effectively and enjoyably, the entire nation benefits. (Alvy, 1994, p.1).

In these two paragraphs Alvy (1994) is making some profound presumptions. He assumes that parents are the major influences on children. He is stating that parents, who find parenting enjoyable, will produce ‘productive citizens’. However, many parents at one time or another find parenting a difficult, unrewarding and frustrating task especially if unsupported in their role. Is he saying that parents who do not consistently enjoy parenting will not raise ‘productive citizens’? Is he placing more pressure on parents, and in particular mothers as the main caregivers, to enjoy parenting? What this may do is alienate mothers more from other
mothers and place an unnecessary burden on them to feel that they are not good enough parents if they do not consistently enjoy parenting.

Alvy (1994) adds that if parents are “unskilled, unprepared and unable to provide the necessary emotional and material resources, the opposite outcomes often result and we all suffer” (p.1). This statement needs much clarification. I question what he means by ‘unskilled, unprepared and unable’? Does he mean unskilled in child raising because this may be their first child? Does unskilled imply something about a parent’s educational and employment prospects? This statement has many connotations discriminating against well meaning parents.

What does it mean then to families, in particular mothers, who are generally the main caregivers, when their child is disruptive, challenging and attracts negative attention from other adults? Although the women’s movement has done a lot for the rights and equality of women, in today’s society, mothers are still viewed as mostly responsible for the care of their children, mother blaming continues to be notorious, the responsibility for children’s behaviour is placed squarely on the mother’s shoulders. As a consequence of this mother blaming, mothers begin to believe that it is their fault that their child is exhibiting challenging and difficult behaviour, and they seek solutions, to alleviate the stress this disruptive behaviour is causing them. Today there are more women in the workforce, women are more educated and financially more independent, and although in men take a greater role in parenting, women continue to take the primary role of raising children (Thurer, 1994). Feminist theories explore the complex issue of why women still have the prime parenting responsibility and take responsibility when their child is seen to behave badly. In this thesis I will side step this issue to focus on the responsibilities placed on women to raise happy, healthy, well-liked, well-behaved and socially successful children. How society determines the appropriate roles for women as mothers will be addressed later in the chapter.
At first glance it appears easier to give a child a pill rather than address a child’s loneliness or rejection by his or her peers. For the mother a medical diagnosis may have some positive effects. It confirms that her child’s behaviour is not her fault, and this will lessen the likelihood of people blaming her it.

Martell, Addis and Jacobson (2001) discuss why people seek medical explanations for behaviour, by finding a cause and seeking answers, while looking for cures. They argue that seeking a medical diagnosis assumes that the cause for the discomfort is an internal one, and that internal causes have implications on how to help those who suffer from the condition. In the case of children diagnosed with ADHD, internal causes are appealing because the symptoms, the disruptive behaviour, are due to a biological factor that can be treated with medication. It eases parents’ distress about possible causes for the child’s behaviour and reduces their feelings of blame. The medical model is based on research founded on a long standing tradition. Doctors and researchers are not part of the same malicious plot to bolster their professions, indeed they have sought and found evidence that suggests that ADHD has a biological component and that medication is shown to improve the behaviour (Martell, Addis & Jacobson, 2001). There is, however, competing data that suggests that these issues are not clear cut.

Internal causes are appealing to parents because our culture seeks rational explanations and families often are put under the spot light first. In looking for reasons for and solutions to the ‘problem’, blame can be easily ascribed. Parents’ motivation to find an explanation functions to reduce the sense of blame and increase sympathy (Martell, Addis & Jacobson, 2001). It is no surprise then that they enthusiastically embrace the medical model. People, it would, appear become more sympathetic and excusing of children’s behaviour after diagnosis, because children are now labelled as unwell, sick, unable to help themselves, born that way, whereas prior to diagnosis people are less tolerant, blaming and judgemental. Biological explanations support ‘illness-oriented’ theories of emotional ‘disorders’ (Martell, Addis & Jacobson, 2001).
In some ways medical explanations of children’s disruptive behaviour are straightforward and easily understood by the layperson. The medical perspective argues that ADHD is caused by chemical imbalance in the frontal lobe of the brain, which produces disruptive and challenging behaviour in children. This is the popular understanding widely accepted by the majority of the population. To argue that (with the exception of psychiatric illness eg, psychosis, schizophrenia) children’s behaviour is socially constructed and defined, controlled by social rules and norms, influenced by social, environmental and emotional circumstances of the child and their family, is much more complex, not so tangible or as straightforward to treat. Perhaps this is why it is not as widely accepted.

Breggin (1994) argues that:

….. bio-psychiatry appeals to people who feel so helpless that they want to give up responsibility for themselves, and to parents and teachers who feel so frustrated or baffled that they uncritically turn to the experts….but bio-psychiatry has no place in a world in which children need attention, love, improved parenting, better schooling, and more equal opportunity. It has no place in a society in which adults take responsibility as parents, teachers, or child advocates (cited in Jacobs, 2002, p.49).

It is this exacerbation of the child’s behaviour that leads the teacher to look to the mother to manage the child’s behaviour, and it is this exacerbation of the child’s behaviour and the pressure from external forces that leads the mother to seek medical assistance.

**A Feminist Perspective**

Let us now examine more closely the feminist perspective on mothering, children exhibiting difficult and challenging behaviour and medical diagnosis of ADHD. A feminist perspective argues that mothering is social constructed and challenges the dominant ideology that it is women’s primary role to care for and raise children and the notion of mother blaming
(Everingham, 1994; Rich, 1997). Feminist writers have challenged the notion that a mother’s success is represented by how successfully her children present in society (Ruddick, 1982; Wearing, 1984; Walkerdine & Lucey, 1989). Nancy Chodorow (1978) argues that mothering is a social construct, which needs to be understood not as a natural relation but as a problematic construction involving unconscious psychological processes.

It is a product neither of biology, nor of intentional role-training. I draw on the psychoanalytical account of male and female personality development, to demonstrate that women’s mothering reproduces itself cyclically. Women as mothers, reproduce daughters with mothering capacities and the desire to mother (Chodorow, 1978, p.7).

What is meant by the word mothering? Chodorow states, that unlike fathering, mothering means usually both bearing and caring for children. Like many feminists Chodorow disputes the notion that for women mothering is innate and biologically determined, she argues socialisation produces expectations about mothering.

Girls are taught to be mothers, trained for nurturance, and told that they ought to mother. They are wrapped in pink blankets, given dolls and have their brother’s trucks taken away…they are barraged from early childhood into adult life with books, magazines, ads, school courses and television programs, which put forth pro-natalist and pro-maternal sex-stereotypes. They ‘identify’ with their own mothers as they grow up and this identification produces the girl as a mother (Chodorow, 1978, p.34).

If we examine mothering briefly from an historical point of view we see that in the 1930’s there was a movement towards making motherhood more rational, efficient and modern (Reiger, 1986). Technological/scientific developments placed mothers under the influence of predominantly male ‘self-appointed’ experts (Thurer, 1994). Late 1940’s media began publicising messages about child guidance, and speeches were made by professionals
addressing the notion of child rearing based on psychological insights (Reiger, 1986). Mothers were encouraged to read books and take on methods of child rearing that the ‘experts’ were advocating. This shift was significant for mothers. It changed the way they were expected to mother their children. More pressure was placed on women to perform their motherhood role within standards prescribed by professionals (Reiger, 1986).

This shift in child rearing practices focused on raising well-behaved, polite children, and concentrated on avoiding psychological distress. Professionals, such as social workers and psychologists, began evaluating ‘mothering’. They assumed that the child’s state of mind largely determined the mothers’ state of mind (Reiger, 1986; Thurer, 1994). The focus shifted so that mothers were held responsible for the psychological development of their children. This caused some mothers to feel powerless, guilty and accused if their child was not conforming to the expected behavioural standard.

The focus of parenting literature at this time was on mothering, i.e. on mothers’ involvement with their children, and the dominant ideology was that mothers should be in control of their children’s behaviour (Wearing, 1984). Mothers faced a complicated bind: too much involvement was not good for their child’s psychological development, but neither was not enough involvement; too much discipline meant they were authoritarian and not enough discipline meant they were permissive and neglectful; too much love smothered a child’s growth and development and not enough meant the child would not be ‘well-adjusted’ and able to develop appropriate relationships; over-protectiveness was also frowned upon as was under-protectiveness. Psychological and theoretical approaches to child psychology and parenting brought all these complicating factors with each expert giving their advice on how to raise happy healthy children. It is no wonder mothers began to feel pressured by the wider community judging and scrutinising their every move.
Since then there has been a great deal of feminist literature arguing that women still continue to feel the pressure to be an ‘ideal good’ mother (Everingham, 1994; Greer, 1999; Peach, 1998; Richards, 1978; Wearing, 1984).

There is an ideal of the ‘good’ mother towards which all mothers should strive. A ‘good’ mother is one who is always available to her children; she gives time and attention to them, listens to their problems and questions and guides them where necessary. She cares for them, with adequate food and clothing, and emotionally by showing them love. She is calm and patient, does not scream or yell or continually smack her children......Mothers will be especially patient with children who have behavioural problems – naughty children do not really exist, they are the product of a ‘bad’ mother. At this point in the life-cycle, a mother’s main aim in life is to bring up her children to the very best of her ability, to be a ‘good’ mother to her children (Wearing, 1984; p.49).

This ideal of ‘good’ mothering is socially constructed, maintained and reinforced by the social supports and networks of women themselves. Wearing (1984), found that women’s own social networks support the values and beliefs about motherhood and the ‘ideal’ mother image to which they were encouraged to aspire. There was little room for questioning and challenging these ideals of motherhood, rather they accepted the very ideals that suppress any form of consciousness raising. Social networks encourage women to be at least as good as other mothers they know, and their children’s achievements and performance is a credit to their ‘good’ mothering. Hence the status and achievements of mothers can largely be judged by the broader community as being dependent on the performance of their children (Wearing, 1984).

A feminist analysis of child rearing identifies the dominant ideology as perceiving the mother’s primary role to be carer of children. The role of the mother as carer of children has been influenced by professional power and knowledge through parenting books and manuals, and professional intervention in the behaviour of children. Mothers also feel pressure to raise
happy, well behaved children by other women within their social supports and networks. If a child is exhibiting behavioural difficulties, the mother is often blamed (Everingham, 1994; Ladd-Taylor & Umansky, 1998; Peach, 1998; Wearing, 1984). The notion of blame and responsibility mothers feel in terms of child rearing, can be reduced through the analysis and deconstruction of dominant discourses in society.

Conclusion

In this chapter I argue that behaviour is socially constructed. When a child deviates from ‘normal’ standards of behaviour they are considered to need professional assistance. There is a need to find out what might be ‘wrong’ and to establish strategies to make the behaviour more acceptable and appropriate. Mothers are still viewed as the carers of children’s behaviour and they are blamed for their children’s inappropriate behaviour and expected to carry out strategies to improve the situation for their children in social settings. For a variety of reasons individuals behave and respond differently when confronted with similar situations. Interpretation of behaviour is subjective and open to misinterpretations. Children seek to obtain certain goals and attempt to have their needs met in a variety of ways that may be neither logical to others nor appropriate. This does not mean that they have a medical problem. The diagnosis of ADHD based on observation and interpretation of a child’s behaviour can sometimes result from over diagnosis or inappropriate diagnosis.
Chapter Four
Fieldwork

In the previous chapter I discussed the theoretical framework underpinning this study. I will now outline the methodological principles of this research. This will be followed by a description of the research design and finally the limitations of the project. The research project is exploratory; it is interested in understanding the experiences of families who have a child diagnosed with ADHD. This framework seeks to develop a greater understanding of behavioural patterns and how they may result in misunderstandings, which can lead to the pathologizing of behaviour (Ife, 1997) or of an individual. The methods used are qualitative, and incorporate case study methodology. This allows individuals and families to present their perspectives on their everyday life experience of living with a child diagnosed with ADHD.

Methodology
The primary aim of my research is to present the families’ own interpretation of their experience using an interpretative perspective, which seeks to understand the meanings, interpretations, beliefs, motives and intentions in people’s everyday lives (Blaikie, 1993). This research adheres to an interpretative methodology, which is respectful to the participants by allowing them the opportunity to express their meanings, actions, intentions and motives.

Qualitative Data
Qualitative data collection is the best approach to present people’s understanding of their everyday life experiences. It seeks to capture people’s meanings, definitions and descriptions of everyday life and situations. This emphasis of qualitative research’s emphasis is on understanding human nature through perceptions and interpretations.

I chose the qualitative approach over a quantitative research approach for a number of reasons. First, more traditional social research approaches do not acknowledge social structures such as gender, the family, and social networks (Abbott & Wallace, 1990). Second quantitative research
emphasises objectivity, validity and reliability (Sarantakos, 1993). Quantitative research aims to count and measure phenomena, and is concerned with discovering facts about social life (Berg, 1989; Minichiello, Aroni, Timewell & Alexander, 1990). I wanted to explore the experiences of each individual family with a child diagnosed with ADHD. With this focus in mind, the research approach had to compliment the subjective contribution of each family member, allowing for his or her interpretations, experiences and feelings to be included.

Developing a qualitative data approach allowed me to gain some insight into individual’s situations and experiences (Sarantakos, 1993). I believe that interviewing families makes research into the family experience of ADHD rich and true to life. These first hand experiences teach us about living with children diagnosed with ADHD.

The case study methodology adopted for this research is the type identified by Robert Stake (1995) as instrumental case study. This aim of instrumental case study is for greater understanding of the issues confronting Australian parents of children diagnosed with ADHD. The instrumental approach extends beyond individual cases and explores social context, joining micro with macro structures (Grbich, 1999, p. 189). This permits the identification of factors that concern parents and by extension policy makers An ethnographic approach to analysing data is taken as outlined in the aims. The emphasis is on ‘thick description’ to establish the uniqueness, particular context, issues and the story (Stake, 2000, p. 448).

I chose this method for a number of reasons. Firstly, from the social and cultural perspective, the client is seen as the expert on their lives (Ife, 1997; Mullaly, 1993; Walter & Peller, 1992). The families and the children in the study were seen as the experts on ADHD, able to provide and share their experiences on the complexities of ADHD and what this meant to them. Secondly, case study methodology is fluid and allows the researcher the flexibility to obtain as much information as possible about people’s lives and their everyday experiences. Importantly it gives an individual the opportunity to discuss what having a child diagnosed with ADHD
meant for their relationships and interactions with extra familial people and social groups. Finally, case study methodology is not about having a theory and then setting out to prove it, rather it begins with an area of study and allows what is relevant to emerge. This analytic process is used explain common patterns of social life (Chenitz & Swanson, 1986).

To allow information and conversations to flow between the participants and the researcher, a semi-structured in-depth interview approach was utilised. In-depth interviews are an important feature of grounded theory methods. They allow the development of a greater connection between researcher and participant. A greater understanding of people’s situation and experience is achieved, which could easily be missed if using more traditional methods such as questionnaires or surveys (Minichiello, Aroni, Timewell & Alexander, 1990; Sarantakos, 1993). In-depth interviewing also allows for greater flexibility, clarification, and gives the researcher the ability to be more inquisitive about a situation, experience or feeling. It is a way to gain access to private thoughts and interpretations of people’s social reality (Minichiello, Aroni, Timewell & Alexander, 1990; Taylor & Bogdan, 1984).

I also adopted a longitudinal approach to explore changes in the families’ interaction and relationships with each other and others outside the immediate family (Minichiello, Aroni, Timewell & Alexander, 1990; Sarantakos, 1993). This method allows for comparisons of social activities, events, behaviours and attitudes over time. The underlying assumption of a longitudinal approach is that the behaviour of children diagnosed with ADHD will improve over time, whilst on medication.

This research study began with the aim of learning about diagnosis of children with ADHD, their family’s and their day-to-day experiences. The information that emerged was information the family members thought to be important and relevant to their everyday life.
Methods

This research tries to capture people’s experiences by interacting with a small number of participants chosen because of their commonality, rather than by random sample. In qualitative research sampling is biased by the very nature of the underlying qualitative framework (Sarantakos, 1993). The qualitative researcher makes choices about the kind of people to be included in the study, particularly since the number of participants in the study is small (Sarantakos, 1993). The sample of this study was made up of families who had a primary school aged child recently diagnosed with ADHD.

I began by speaking to both the diagnosing psychiatrist and paediatrician from the Royal Children’s Hospital in Melbourne to outline the aims and purpose of my research project. Then the medical professionals involved with the families with a child diagnosed with ADHD, discussed the research project with the families and asked for their willingness to participate in the study. The family was then referred to the study. The doctor obtained the family’s permission for their details to be released to myself. To increase referrals to the project I rang the diagnosing doctor, every week or so to gather any possible new referrals.

I made the initial contact with parents by telephone to ensure their willingness to participate in the study and to arrange for an initial meeting. The purpose of this introductory meeting was to outline the purpose of my study, and give the parents the opportunity to meet the researcher, discuss the study, and clarify their questions. It was an opportunity to inform them that they could withdraw from the study at any time they liked. If the families agreed to participate in the study, written consent was attained (Appendix I).

Participants

Four families were interested in participating, and three of those families decided to partake in the research. The school had referred the three families to the Royal Children’s Hospital, in Melbourne, for an assessment for ADHD diagnosis. The children were of primary school age
and had not received a previous diagnosis of ADHD (see Table I). The small number of families who participated is an issue discussed in this chapter in the section on the research limitations. The three families were all interviewed five times, at three monthly intervals. I specified that all the family members should be present for the first interview, if at all possible. All the members of the family, living within the household, parents, the child diagnosed with ADHD and their siblings, did attend this first interview. Interviews thereafter were conducted predominantly with the mother and at times with other family members, the child diagnosed with ADHD, their siblings, step-parents, and fathers. On two occasions step-parents were also involved in the interview process. The child’s attendance was not always required or appropriate, mainly because of the issues discussed with parents about the child’s behaviour.

The duration of each family and school interview was approximately an hour to an hour and a half. All family members were encouraged to participate in the interviews because their contribution was seen as valuable. The interviews were conducted in a non-threatening way, more like conversations and at no time were the children interviewed by themselves, their mother was always present.

Five interview schedules were developed with some general topics already established. Although each interview had a specific focus, discussions were flexible and allowed to flow as non-intrusively as possible. For example the first interview concentrated on the experience that led the family to seek a diagnosis, and how it was at home prior to the child being diagnosed and prescribed medication. I had very general open-ended questions that were used mostly as a guide, the conversation was dictated by what the family members wanted to share with me (see Appendix II for the interview schedules).

The first interview with the families had two components. The first part was a general discussion with the whole family about behaviour and the diagnosis of ADHD. The second part concentrated on the parents, as I believed that issues might arise that may not have been
appropriate to discuss in front of the child. The purpose of the first interview with the family was to understand the diagnosis and the events leading up to the diagnosis, the difficulties they experienced and the strategies they used. Subsequent interviews varied according to who attended and who did not.

With parents’ signed consent, the principal of the school attended by the child diagnosed with ADHD was approached to participate in the study. I believed that interviewing the teacher was important because it added another perspective to the understanding of children diagnosed with ADHD. It also provided a broader picture of the impact social situations and peer group interactions have on the child diagnosed with ADHD. Children spend a lot of time at school, and there is an emphasis on both academic achievement and socially appropriate behaviour at school. School plays a major role in the lives of children diagnosed with ADHD.

First contact with the principal was a telephone conversation in which the aims and purpose of the research project were briefly outlined, and emphasising that the classroom teacher’s participation in the study would be most valued. The consent form (Appendix III) and the plain language statement (Appendix IV) were sent to the principal, for the classroom teacher’s information and a form to be signed before participating in the study. A semi-structured format, as used with the families, was used with the teachers (Appendix V). The school interviews aimed to gain knowledge about the child’s social interactions and to ascertain whether there had been any noticeable changes with the child’s behaviour since the time of diagnosis and the administration of medication.

With the permission of parents and school staff, each interview was taped. The family and school’s written consent was obtained for the documenting and publishing of information collected and their identity was protected at all times. All participants were told that they had the right to withdraw at anytime.
The responses to the questions were coded and categorised before the next interview, allowing questions to arise from information gathered.
### Table 1 – Characteristics of Families involved in the study

<table>
<thead>
<tr>
<th>Child’s Name</th>
<th>Green Family</th>
<th>Jones Family</th>
<th>Peters Family</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Peter</td>
<td>Matt</td>
<td>Billy</td>
</tr>
<tr>
<td>Date of Birth</td>
<td>19.7.87</td>
<td>21.11.88</td>
<td>19.5.87</td>
</tr>
<tr>
<td>Date of diagnosis</td>
<td>September 1996</td>
<td>January 1996</td>
<td>February 1996</td>
</tr>
<tr>
<td>Family/household</td>
<td>Mother – Joanne</td>
<td>Mother – Sally</td>
<td>Mother – Stephanie</td>
</tr>
<tr>
<td></td>
<td>Stepfather – David</td>
<td>Grandfather - Steve</td>
<td>Sister – Karen</td>
</tr>
<tr>
<td></td>
<td>Stepbrother - Paul</td>
<td></td>
<td>Stepsister – Kylie</td>
</tr>
<tr>
<td>Significant others</td>
<td>Father – John</td>
<td>Father – William</td>
<td>Father - Fred</td>
</tr>
<tr>
<td></td>
<td>Stepmother - Amy</td>
<td>Stepmother - Pam</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Stepsiblings - Mary &amp;</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Tom</td>
<td></td>
</tr>
<tr>
<td>Type of treatment</td>
<td>Ritalin</td>
<td>Ritalin</td>
<td>Ritalin</td>
</tr>
<tr>
<td>Interview dates:</td>
<td>First interview</td>
<td>Second interview</td>
<td>Third interview</td>
</tr>
<tr>
<td></td>
<td>21.11.96</td>
<td>26.02.97</td>
<td>03.06.97</td>
</tr>
<tr>
<td></td>
<td>26.02.97</td>
<td>26.05.97</td>
<td>04.08.97</td>
</tr>
<tr>
<td></td>
<td>03.06.97</td>
<td>04.08.97</td>
<td>17.11.7</td>
</tr>
<tr>
<td></td>
<td>01.09.97</td>
<td>24.03.97</td>
<td>23.06.97</td>
</tr>
<tr>
<td></td>
<td>28.11.97</td>
<td>06.10.97</td>
<td>31.10.97</td>
</tr>
</tbody>
</table>

All the names used above are pseudonyms to protect the privacy of the families who participated in this study. The Anglo-Celtic names reflect the ethnicity of the families involved in the study. All those mentioned participated in the interview process; the only people not interviewed were Matt’s father, grandfather, his stepmother and stepsiblings. All members were interviewed as a family group, although on most occasions the interview was conducted with the mother and sometimes the child diagnosed with ADHD only.

In all three families the parents were separated and the mother was the main carer. The mothers were all full time carers at home, and their ages ranged from late 20’s to early 30’s. All the children had contact with their fathers. However the relationships were all very different. Peter saw his father very regularly, as they lived close by and his parents remained good friends. Billy and Matt’s contact with their father was not always consistent.

The families all lived in very different suburbs of Melbourne, ranging from outer eastern to western and outer western. Only one of the families owned their own home; the other two
families were renting. One of the mothers was married during the time of the interviewing. The other two mothers were single at the time of the interviews. All family members welcomed the researcher into their home and were very willing to share information about the impact of ADHD on their lives (for more detailed information about the families see appendix VII).

Role of the Researcher

I enjoyed my time with the families involved. I found them very open to sharing their experiences, disappointments and thoughts. I admired the strength and commitment of the mothers to their families even during the most difficult and trying times.

I began this research with my own opinions and ideas about ADHD, families and children. During my time with the families I learnt much more than I could have reading literature on the topic. There is another side to the story presented by professionals. Professionals view ADHD from their own theoretical beliefs, some believe it is biological, others believe it is due to the child’s diet, others believe that it is environmental, influenced by social and emotional relationships and interactions. What I gained from my contact with these families was that ADHD is more than professional theories and debates, it is about people’s lives, and their daily interactions not just with each other, but with extend family, friends, schools and society at large. The families’ contribution is the most valuable experience brought to this research.

Data Analysis

Qualitative data analysis attempts to capture the meanings and relationships involved in the complexities of individual’s experiences of everyday life (Alston & Bowles, 1998). The first task of data analysis is to make comparisons and asking questions about the issues discussed in the interviewing process and identifying general categories or themes (Alston & Bowles, 1998; Strauss & Corbin, 1990). For example, in transcribing the interviews the issue of mother blaming and ‘good’ mother arose frequently. Transcribing interviews prior to subsequent interviews allowed further questions to be developed to address how mothers perceived their
role and what their experiences were when discussing their child who was diagnosed with ADHD. Information was then separated into general themes.

The next phase of data analysis is a more intensive and concrete coding of categories. It involves making connections between categories and sub-categories (Alston & Bowles, 1998; Strauss & Corbin, 1990). Once the data was separated into general themes I began to group the themes together under subcategories such as ‘what is a good parent?’; ‘what is a good child?’

**Ethical Issues**

Ethics approval was obtained from R.M.I.T., the Royal Children’s Hospital and the Department of Education and the Australian Catholic University. No issues remained unresolved. The only ethical concern was that the consistent interviewing of the families and the issues discussed with the families ran the risk of families becoming attached to the researcher. However this was resolved because the families were aware from the onset of the interviews that the interviews were for the purpose of the research project and would occur over a specified time frame. I was careful to maintain professional boundaries.

**Home interviewing**

All interviews conducted were planned to take place in the family home. Some families may find having a stranger come into their home difficult. It was emphasised from the onset that participation in the study was voluntary, so any family who had a difficulty with interviews being conducted in their home could withdraw from the study. All family members were willing participants in the interviews at home.

**Emotional Reactions**

I was aware of the possibility that my interviews may raise emotional reactions from family members. As a trained social worker I have worked with many families in a counselling role
and felt sure that I would be able to ease the family members and refer them to appropriate services if necessary. I did not experience this during any of the interviews with the families or the school teachers.

**Inclusion of Minors**

Another ethical issue with which I was confronted was the consent from the child. Written consent was obtained from the parents to protect the interests of the children. All children were interviewed within the family group interview. At no time were children interviewed on their own. However, there were also interviews conducted without the child diagnosed with ADHD present.

**Confidentiality**

Confidentiality was an important factor in this research project for a number of reasons. All participants signed consent forms on Royal Children’s Hospital letter head. First to participate in the study consent forms needed to be signed. Second, all interviews were taped so the parents and teachers permission was needed for this. Third, the parents’ permission was needed for the interviewing of teachers. And finally, to inform them that the information they were willing to share would be documented and possibly published. All the families and teachers were willing participants in this process.

Another important confidentiality issue was the assurance that everyone who participated in this study would remain anonymous, and his or her identities protected at all times. This was successfully achieved. All participants’ responses were coded and numbered, and all the names used in this report are pseudonyms.

The tapes and transcripts of the interviews have been safely secured, I am the only person with access to them. They remain confidential.
**Limitations**

A particular limitation of this study was the number of participants. There were unfortunately only three families involved, initially it was intended that between 5 – 7 families would be involved.

It was difficult to get families to commit to participating in the research. This could be due to a number of factors. First, families who have a child diagnosed with ADHD may feel very stressed, and generally just wanted to ease the conflict and difficulties they have been experiencing. Families usually hesitate to talk to people outside the family about family issues and difficulties, they fear the possible involvement of welfare services involvement, or being judged as a ‘bad’ mother. There is immense pressure by society, to have well-behaved children. This is usually seen as the responsibility of the mother (Everingham, 1994). The role of the mother, as the primary carer, is still defined in terms meeting all her children’s needs first and foremost, and the behaviour of the child is associated with whether she is a ‘good’ or ‘bad’ mother (Brown, Lumley, Small & Astbury, 1994; Everingham, 1994; Ladd-Taylor & Umansky, 1998). For these reasons parents may not have been keen to talk to someone they did not know about personal issues such as their feelings concerning their child’s behaviour and their own issues around the parenting of their child.

I was very appreciative of the doctor’s willingness to meet with me and for me to explain my research project. I appreciate how busy the doctors were and the pressure of the public health system, and the demands placed on them to see patients. The doctors were very busy and often would forget to refer families. My constant ringing and reminding them often fell on deaf ears, as it was difficult to even speak to them. Often my messages were not returned. I devised a chart that was placed in one of the consulting rooms, mainly as a prompt but also as a process of referral. This, too, was unsuccessful in ensuring that additional families were referred to the study.
On reflection, the fact that I was employed outside the hospital may have made referral more difficult. Perhaps if I had been a hospital employee I could have made myself more visible to the doctors on their clinic days. I could have made more of an effort to seek out the doctors, rather than relying on phone calls or leaving messages. If I were to conduct a similar project again, I would make myself present on clinic days, purely to be visible and a constant reminder to the doctors for referrals.

Families from different ethnic backgrounds were difficult to engage with because of the language and cultural barriers. The one family who was referred but decided not to participate was a family of non-English speaking background. Their assumption about my first meeting with them was that I would be more like a counsellor and assist them in the behaviour of their child and explain what ADHD was. After I explained to them that I was not there for that reason but I could maybe link them into a welfare/counselling service, and outlined the purpose of my visit they declined the invitation to participate in the study.

**Conclusion**

Qualitative research data collected for this research was oral rather than statistically based. Participant reality was studied from the inside, with the aim of interpreting meaningful human action and interaction. Overall, qualitative research aims to understand people, rather than measure them. Data is presented in a descriptive manner, in the participants’ own words about their views and experiences (Sarantakos, 1993). Qualitative data is used to obtain fresh ways of looking at things, and give intricate details about the subject under investigation, that may be difficult to obtain through quantitative methods (Strauss & Corbin, 1990). This suited the aims of my study, as I wanted gain an insight into the family experience of, and ideas about, ADHD.
Chapter Five Pre-Diagnosis

‘I’m at my wit’s end’

Chapter five presents the families’ experiences leading up to seeking professional assistance for their child’s behaviour. Prior to the diagnosis of ADHD, home life for the three families was often stressful and at times unpredictable, chaotic and frustrating. In the first section of this chapter a number of issues around the experiences of family members are discussed including, the feelings of family members around the time of seeking diagnosis and the set of circumstances that led them to pursue a medical assessment of their child. This is followed by a discussion of the broader social implications of the diagnosis of ADHD including the pressure the mothers felt to live up to the image of ‘good mother’ and the child to live up to the image of the ‘good child’.

Events Leading Up To The Diagnosis

To understand why the parents in this study sought an assessment for an ADHD diagnosis, it is important to develop insight into what contributed to their decision in the first instance by illustrating the difficulties and stresses that the family members experienced in the home.

The parents indicated that at times they felt stressed and confused, and did not understand why they were having so many difficulties managing their child’s behaviour. They were constantly being called up to the school to listen to yet another incident and/or complaint involving their child’s behaviour. At family gatherings they were told that their parenting was not ‘good’ enough and were blamed for their child’s disruptive behaviour. They were often given unwanted advice on how to discipline their child. They observed extended family members chastise their child. These parents were at their wit’s end. They did not know what to do anymore. They wanted solutions to make life easier and less stressful for the whole family.
I start by exploring the three participating families’ experiences and feelings in regards to their child’s behaviour. How did they feel about the behaviour? What issues did the difficult behaviour exhibited by their child raise for them?

“He was just a naughty boy”

The parents in this study stated that their child’s behaviour had always been difficult to manage and was often a source of stress for them, but they had been resigned to managing it as best as they could.

_I think I was going along thinking this was him, and that this was it, that somewhere along the line I went wrong, and too I think I started to think that he just didn’t love me anymore, he didn’t have any respect for me anymore, that he didn’t care_ (Sally, interview 1, 11.3.97)

The parents described feelings of confusion, embarrassment and self doubt in their parenting abilities, and the powerlessness of being unable to ‘control’ the child’s behaviour. As Joanne despondently stated:

_It was getting to the point where it was very confusing because I was either a really bad mother or he was a really naughty boy_ (Joanne, interview 1, 21.11.96)

The mothers’ view of themselves as parents was very much intertwined with their child’s behaviour. They blamed themselves for the child’s behaviour and felt that they were not “good enough” parents because their children were not “well-behaved” or did not do as they were told, as the following statements illustrate:
I think we weren’t sure what as parents we were meant to do. We really didn’t know, we thought maybe we weren’t that good a parent (Joanne, interview 2, 26.2.97)

I thought where did I go wrong (Sally, interview 1, 11.3.97)

As already discussed, it is a commonly held belief that if a child is misbehaving or is defiant, then it is the mothers’ fault (Garcia-Coll, Surrey & Weingarten, 1998; Ladd-Taylor & Umansky, 1998). The mothers felt that people around them blamed them for their child’s difficult behaviour. According to the mothers some people went as far as suggesting to the parents that there may be something wrong with their child. The assumptions of others placed pressure on the parents to look for possible explanations for their child’s ‘naughtiness’. The parents concluded that there must be either something wrong with the child or with them as parents.

I used to think it was me because I am the stepmother. I used to think he was just rebelling at the fact that mum and dad weren’t together and you’re in dad’s life (Amy, interview 2, 26.2.97)

The parents seemed to begin to question their child’s behaviour and their own ability to parent their child after friends, extended family and school staff brought the behaviour to their attention making assumptions about the child’s behaviour. This questioning and uncertainty regarding their parenting ability resulted in feelings of self doubt, which in turn focused their attention on their parenting styles and on the child.

Social Situations
Prior to diagnosis of the child with ADHD and the prescription of medication, social events were often a difficult time for the parents of this study. They experienced many conflicting emotions. They felt hurt by others’ attitudes towards their child. They also felt that they needed
to protect their child from other people’s reactions, and at the same time they felt embarrassed and frustrated by their child’s behaviour.

I dreaded going to any family dos, because I knew that people just didn’t like him…I know that everyone would jump on him…I dreaded it, I used to think of lies to get out of it (Sally, interview 1, 11.3.97)

It’s like everyone yells at him, first thing you hear is someone yelling at him. There are places he won’t go because he’s spoken to like a piece of ‘shit (Joanne, interview 1, 21.11.96)

The behaviour an individual exhibits is an important factor in the way others relate to and perceive him or her. All children are expected to perform to a particular standard. The children of this study however did not often adhere to these standards. The child who finds sitting still for long periods of time difficult, or the child who likes to daydream, or the child who does not concentrate as well as others, may find school an unfriendly and even hostile environment (DeGrandpre, 1999). Children’s interaction with other children seems to depend on how they are perceived by their peer group. The parents of this study believed that children are expected to do well at school, to always be well-behaved, to want to do their homework and chores, to play in a socially acceptable way, to not get into ‘trouble’. When a child who is not conforming, parents may also feel the pressure that their child was not behaving according to appropriate standards of acceptable behaviour.

The expectations of child behaviour and performance place immense pressure on families, and in particular, mothers (Allan, 1997). As socialising agents, parents are often told that they have a special influence on the early experience of acceptable and non-acceptable behaviour of their children. It is no wonder that parents often feel the pressure to have well-behaved children. In
this study the parents experienced the constant reminder that their children were misbehaving
as can be seen in the following excerpts:

I spoke to lots of different teachers about him and every school report was something
about his behaviour (Joanne, interview 1, 21.11.96)

He was having so much trouble at school, fighting, no one would have anything to
do with him, the kids were scared of him, I was getting called up there all the time,
he’s been suspended, everything (Stephanie, interview 1, 23.9.96)

In social settings, in particular schools settings, children learn not only academic concepts but
also social concepts, that is, appropriate standards of behaviour (Neuville, 1995). Children with
difficult behaviour find it hard to fit in to the social structures of society. This often means that
they may not have friends at school, or they will spend a lot of time being punished (Neuville,
1995). The tensions and contradictions that exist for these families, in particular for the child
exhibiting behavioural difficulties are extensive.

Overall the period prior to diagnosis was a difficult and trying time for these families. The
parents recognized the difficult behaviour their child was exhibiting but continued to persist
with their own discipline and coping strategies. They tried to protect their child from people
outside the family who may have responded to the child negatively. At this stage the parents in
this study asked many questions of themselves. They questioned their ability to parent their
children, they thought that their parenting abilities were inadequate because they could not
manage their child’s behaviour. They felt in some way alone and defeated because they were
constantly being called up to the school to hear what trouble their child was in again. They also
isolated themselves from social gatherings to avoid the constant negative responses from other
people, and to protect both their child and themselves.
The parents of this study received a lot of attention from friends, extended family and the school in regards to their child’s behaviour. They often wished that their child would be (good) like every other child. I decided to explore what the parents of this study image of a ‘good’ child was and what it meant for them.

A ‘good’ child

A good child is what you see on the telly…they’re never grumpy, they are usually pretty well dressed…. they speak very politely to everyone, they are usually quiet, not too rough or loud, they don’t annoy the other children in the playground, or they don’t jump all over Nanna, that’s pretty much a good kid (Joanne, interview 3, 3.6.97)

Much focus has been on children behaving ‘inappropriately’ by society’s standard, and on professionals’ quest to find solutions for the child’s behavioural ‘problems’ (Okagaki & Divecha, 1993; Moreau, 1979). The parents in this study all talked about the pressures placed on children and in particular on their own child by today’s society. They defined ‘good children’ by behaviour. They firmly believed that ‘good’ children are children who listen to their parents, do their chores and behave appropriately in school. These ideas and notions are reinforced by the rise in ‘expert’ knowledge and the professionalization of parenting and child development, of what is ‘normal’ and what is problematic.

Over the years there has been a growing market in parenting manuals. These manuals discuss age appropriate behaviour. According to parenting manuals and other literature advising on parenting strategies, a good child (for example, Chernosfsky & Gage, 1996; Linke, 1994; Saunders, 1992; Taylor, 1994;), goes to bed quietly when they are told to do so, does not fight with siblings, always eats their greens, follows instructions, is well-mannered, behaves when shopping, does not whine or throw tantrums. Do these behaviours occur everyday? When parents and experts expect children to be perfectly well behaved at all times, in every situation,
are they expecting too much of children today? Problematically these manuals assume that all children develop at the same rate. They do so without considering individual variations. Many variables impact on child development, such as home environment, race, colour, wealth, poverty, employment, unemployment, housing, health, separation, and ethnicity.

Children’s sense of self-worth is nearly always learnt within the family environment. The way families treat children as they grow up plays a significant part in their sense of self-worth and self-esteem (Berne & Savary, 1996; West, 1992). Parents feel they are bad parents when their child misbehaves, as behaviour is usually associated with self-esteem and self-worth, and a child who feels good about themselves is a loved child. “Healthy self-esteem is related to loving” (Berne & Savary, 1996). To many parents such a statement assumes that children with behavioural difficulties are in some ways neglected. Literature on the topic of self-esteem and children’s behaviour reinforces this assumption (Berne & Savary, 1996; West, 1992). With so many people reinforcing this assumption, it is very hard for families and children not to feel some kind of blame, guilt and rejection.

People outside the family, such as teachers, extended family members, friends, grandparents, and significant others play an important part in the child’s life. The way they respond, react or, speak to the child may also have some impact on the child. Children need to feel that they are good people and that they are liked and loved. Children exhibiting behavioural difficulties generally receive negative responses from their parents, extended family members, school teachers or peers. The constant negative responses these children receive eventually take their toll on children’s sense of self-worth and self-esteem (Berne & Savary, 1996). Sometimes all that is needed for change to occur is for individuals who interact with children, to realise the impact their behaviour has on the child. One of the parents described her experience of this very situation, as follows:
I didn’t realise what, just how shattered he would have been or was, and it wasn’t until I recognised just myself. We’d be somewhere and I would lecture him for half an hour about how he behaved afterwards. I cringe at it now. But just not knowing at the time, because you want a good kid, and they’re just not being this good kid. Just the things I said to him (Joanne, interview 3, 3.6.97)

It wasn’t until I started picking up on just how constantly he was always saying ‘isn’t that good mum?’, ‘I’m a good boy aren’t I mum?’ Like he was looking for it the whole time and I never ever knew until his diagnosis and reading about it. Now I constantly, I want to make sure everyday that I tell him something positive about himself and the teachers follow through at school which is just great. (Joanne, interview 3, 3.6.97)

Joanne described her feelings about her child taking medication to make him a ‘good’ or more socially acceptable child:

Watching him pop this little white pill in his mouth twice a day, just so he could be good and be acceptable and people will like him more, its pretty hard (Joanne, interview 1, 21.11.96)

Having a well-behaved child may be something expected by the society in which the family live, however, it is not always possible. Children do at times exhibit unacceptable behaviour.

The expectation of having ‘good’ children also raised questions and concerns about how parents see their role as parents, in particular as mothers. Many writers have documented studies exploring the role of mothering. Mothers are expected by society to be perfect in all ways. If they do not live up to this expectation, then it is their fault, and they have failed in some way (Ladd-Taylor & Umansky, 1998).
What is a ‘good’ mother?

Throughout my family interviewing, I spoke with the mothers of the children most, because they were the primary carers of the children. This was also because the fathers of the children involved in this study were either not living with them, or at work during the day when the interviews were held. Only on two occasions did I actually spoke to one of the fathers, and this is discussed later in the chapter.

The mothers in this study stated how they experienced a lot of pressure in relation to their child’s behaviour and their parenting abilities. At one point or another, they felt that they were not ‘good’ enough parents, and that it was their fault that their child was misbehaving. One mother sums it up:

*You’re judged by your offspring, you’re judged by what you parent*” (Joanne, interview 2, 26.2.97)

The mothers of this study discussed the pressures on parents today, coming from many sources of everyday life, such as the media, other parents, the school community, and extended family and friends. They felt they were constantly being judged on the way their child behaved or misbehaved.

These experiences are consistent with those documented in numerous studies conducted discussing the issue of ‘good’ mothering and of expectations placed on mothers today (for example Everingham, 1994; Richards, 1978; Wearing, 1984). Wearing (1984) interviewed a number of women on their views of mothering and found a range of strong values associated with mothering and what was expected of a mother. The women believed that ‘good’ mothers were always available for their children, and put their children’s needs first, before their own. Supporting, loving and caring for their children’s physical needs were overwhelmingly
important tasks. Overall, the women in Wearing’s study believed that taking care of their children full-time was the most important task for them.

Somewhat surprisingly, in spite of the passage of time since Wearing’s study was undertaken, the mothers’ beliefs and values in my study were consistent with those of the mothers in Wearing’s study. Joanne sums up the feeling of the mothers, by stating that in general people expect mothers to raise ‘good’ children and if this does not occur then mothers have failed in some way.

….everyone is expected to have good children, naughty children are still frowned upon (Joanne, interview 3, 3.6.97).

…a good parent is just a saint…. they just seem to naturally know what to do, they have all the answers, they have good children…. (Joanne interview 3, 3.6.97)

Even today with the influences of the feminist movement, new parenting styles, dual working parent families, the role of parenting falls mainly with women’ (Greer, 1999). The ideology of the ‘good’ mother was picked up in Lyn Richard’s (1978) seminal work on mothers in a new housing estate in Melbourne in the 1970’s. Today society still sees it as the mother’s responsibility to raise the children (Garcia-Coll, Surrey & Weingarten, 1998; Ladd-Taylor & Umansky, 1998). There is enormous pressure on women to be the ‘perfect’ mother who meets the needs of her children, who is there for them, who raises well behaved, well mannered children. When children are not well behaved or well mannered, particularly in public, this is frowned upon causing the mother much distress. Mother blaming is an accepted part of our society (Brown, Lumley, Small & Astbury, 1994; Garcia-Coll, Surrey & Weingarten, 1998; Ladd-Taylor & Umansky, 1998). One of the mothers in my study vividly described an incident she had with her child in a public place, her lack of control over her son’s behaviour in the situation and how this made her feel:
He actually chucked a tantrum on the floor and was kicking and punching and crying and this was all over a video game. He was kicking the machine and because I couldn’t stop him and he was just screaming and yelling like at the top of his voice, he was kicking dad, and going on and on. I mean really! And I was really embarrassed because some of the other parents came to pick their kids up, and like the guy who owns it was there as well, and I was so embarrassed I got frustrated too. Like he had to get out of my sight too, otherwise I would have hit him and I don’t like that, I mean I think he’s old enough now that he shouldn’t need to be hit but I was totally embarrassed. And I was even shocked looking at him, thinking ‘my God what are you doing?’ (Sally, interview 4, 17.11.97)

This is a scenario parents of a child diagnosed with ADHD typically confront. Caplan (1998) conducted a study examining 125 mental health journals exploring the association between mothering and children’s behaviour. She found that in the journal articles mothers were blamed for 72 different ‘problems’ their children had, ranging from bedwetting to schizophrenia, aggressive behaviour and learning difficulties. Mother blaming is ‘well nourished’ by what health professionals say and publish. They are seen in society as the experts on human behaviour (Caplan, cited in Ladd-Taylor & Umansky, 1998). The ‘expert’ is so highly regarded in society that it is often forgotten that their theories and research influence and perpetuate mother blaming, yet their theories are also influenced by this very notion of blaming mothers (Ladd-Taylor & Umansky, 1998). Values inherent in concepts such as the ‘good mother’ and ‘mother blaming’ are maintained within society.

The mothers in this study felt that they were blamed in some way for their child’s difficult behaviour. These feelings of blame raised concerns and questions for them about the decisions they had made during their lives. As Joanne stated:
You do blame it on the marriage break up and things. I don’t know maybe if we were still together it may be different for a non-separated family (Joanne, interview 2, 26.2.97)

Not only did the mothers blame themselves but people around them also contributed to the feeling of blame by giving unwanted advice regarding the parenting of their child, and opinions on the child’s behaviour. The mothers described feeling depressed by the reactions of other people towards them. They often felt that it was their fault that their child was misbehaving, that they had done something ‘wrong’, and that their motherhood was in question. What other people thought of the family was very important to both mother and child. The mothers were very sensitive to how family friends, neighbours and relatives saw them and how they felt about their child. It also left them with the feeling of self-doubt:

[I was] sick of hearing it, sick of it. It’s a bit depressing…. (Joanne, interview 1, 21.11.96)

It would upset me but then I’d think ‘I wonder if they’re right’ (Stephanie, interview 1, 23.9.96)

The expectations of the mothers in this study, brought about feelings of blame and guilt. They often wondered what might be the reason for their child’s behavioural difficulties, which in turn made them question their ability to parent their children.

I wondered about my parenting, that I’ve been too strict this whole time and that I caused this badly behaved child (Joanne, interview 3, 3.6.97)
How other people react to parents and children plays a significant role in parents’ self-perception. The mothers of this study often felt that they were not ‘good’ enough because their child would misbehave, which they believed reflected on their abilities as mothers. They felt the pressure to have well-behaved and successful children. In all three instances this pressure prompted the school to suggest that the mothers to seek professional assistance to aid in the improvement of their child’s behaviour. People’s reaction to the child was increasingly becoming an issue for both the parents and the child.

**Seeking a diagnosis**

A longstanding belief in our society is that children who behave outside the norm of acceptable behaviour need professional assistance as there may be ‘something wrong’ (McCallum & Lang, 1989; Napier & Whitaker, 1978). Medical professionals seek to diagnose and ‘cure’ inappropriate behaviour through the process of identifying objective causes, objective explanations, and objective diagnosis and cures (Pease & Fook, 1999). They rely heavily on diagnostic criteria and chemical therapies. Professionals and experts in the mental health field would probably argue that there is usually a reason for a child’s difficult behaviour, whether that is refusing to go to school, displaying aggressive behaviour in the playground, or not having any friends. If a child is not conforming to the socially accepted standards of behaviour, why should we assume that there is ‘something wrong’? Perhaps we should consider whether the behavioural expectations are problematic. A critical theoretical perspective on behaviour suggests that there is no one meaning or objective explanation. Meaning occurs through events in the social environment (Pease & Fook, 1999). Individual behaviour is influenced by the people and social environment around them. People respond to situations differently and their behaviour is a reaction to the different situations they encounter in everyday life.
The diagnosis of ADHD is based on individual behaviour without taking into consideration the individual within their social environment and how that environment influences the individual’s reactions, responses and behaviour. Although there is little known about the causes of ADHD, or what it actually is and how to ‘cure’ it, people are very quick to labelling children with it (Pease & Fook, 1999).

As the focus is on behaviour, particularly that which stands out from the norm, the children in this study were referred to health professionals for an assessment of, and possible causes for, their behaviour. The school staff were aware of the difficulties faced by the families in the home; they were also aware of the difficulties the child was experiencing at school. In the next section I explore the school staff’s experiences of the child’s behaviour, their concerns, and their contact with the family.

The Role of the School

The parents’ only support prior to the diagnosis of their child, was the school staff. Although at times, the relationship with school staff was stressful, with parents having to attend meetings (sometimes daily) to discuss their child’s misbehaviour, the parents felt that school staff were most supportive, in a world where they felt unsupportive, misunderstood and judged.

It was the school staff who suggested the parents in this study have their children seen by a health professional. It is widely documented that usually the school makes the first suggestion to families about having a child see a health professional to explore the possibility of ADHD (Ingersoll, 1998).

In each case it was the classroom teacher who advocated that the child be seen by a health professional, such as a psychiatrist or paediatrician, as they thought that the child’s behaviour was cause for concern. Medical discourse dominates the viewpoint of the classroom teachers who first mention to the parents that the child’s difficult behaviour could be due to biological
factors. The school teachers suggested the families seek professional assistance, because they were aware of the difficulties the parents had been experiencing at home, and acknowledged the stress parents were under. School staff felt that the parental stress combined with the difficulties the children were experiencing at school, made professional support the most appropriate action. The school played a critical role in linking families with resources to assist them in managing their child’s difficult behaviour.

*He’s at risk, he’s at risk in all areas, from what his mother tells me, and from what I see she has no control over him, though she tries and tries and tries. We’re going through a pattern at the moment where he doesn’t get to school ‘till 10am (teacher interview, re: Billy, 31.10.97,)*

Other than the stress of the parents, the other main factor contributing to the classroom teacher’s recommendation that the parents seek professional assistance was the child’s poor academic performance. The parents did not automatically take up the teacher’s suggestion for a psychiatric assessment for their child. All three parents stated that they had seen current affair programs on television discussing ADHD and showing the families and the extreme behaviour exhibited by the children. The mothers in this study did not believe that their children were as extreme as the children they saw on television. One mother talked about this very issue:

*I have seen on telly about ADHD, they I suppose seemed worse than Matt and I thought that’s what ADHD children are like, like the ones on telly. So I went along to rule that [ADHD] out and then I could figure out what it was (Sally, interview one, 11.3.97).*

However, the teachers strongly advocated that the parents to have their child assessed because they were not only concerned about the child’s behaviour, but also about the learning
difficulties the child appeared to be having. The child was neither able to stay on task in the classroom, nor to produce any kind of schoolwork.

There has been much documentation of the difficulties children diagnosed with ADHD have in regards to their academic achievements (Barkley, 1990; DuPaul & Stoner, 1994). Poor academic performance was an important issue for the teachers participating in this study, as they felt that the children were not reaching their full educational potential. When I asked the teachers what was actually different about these children compared to other children in their classroom, they stated that there was not that much of a difference until someone paid close attention to their schoolwork.

*If someone came into this room who didn’t know a soul they wouldn’t pick him, I’m sure they wouldn’t, but they are a bunch of rowdy children in this grade, so he doesn’t stand out. They might not notice him until they check up on the work and then they would notice that he hadn’t actually done any* (Matt’s school teacher, 4.8.97)

*What stood out was that he had, for one, learning difficulties and the other, he didn’t stay on task* (Billy’s school teacher, 31.10.97)

The school teachers all believed that the diagnosis of ADHD and the medication was positive for the child. They believed it was good on a number of levels. First, after the commencement of the medication life in the classroom was much easier for the teacher, as they had one less student with behavioural difficulties to be concerned about. Second, the diagnosis alleviated some of the stress and pressure felt by parents who, before diagnosis they were continuously being called up to the school to discuss the concerns the school had about their child. Finally, the medication assisted the child concentrate in the classroom, stay focused on tasks at hand and improve their academic performance.
It [the behaviour] just changed when the medication started. He’s quiet, he concentrates, he does his work. He doesn’t always finish things but he does sit and do it. He seems to really stick at his task and get his work done, which is a big change
(teacher interview re: Matt, 4.8.97)

One teacher expressed some reservations about the medication:

I guess I have mixed feelings in a way. I wonder whether the medication suppresses his personality a little bit. That worries me to a degree but I guess if you off-set that with the advantages of it…….my reservation that his personality was squashed a little bit even if it was a bit annoying, that was him and what we are seeing isn’t really Matt (teacher interview re: Matt, 4.8.97)

Overall though, the school teachers who were interviewed claimed that the diagnosis and medication was positive for the child. Prior to the diagnosis the child was too frequently reprimanded for difficult behaviour. As already mentioned, the parents were called up to the school on a regular basis to talk about their child’s behaviour and to discuss what could be done to improve the situation. The child was not performing academically to an appropriate level and there were many behavioural difficulties at school. The diagnosis introduced the medication which, on the surface, appeared to improve the situation somewhat for all concerned.

**Conclusion**

The families endured many stressful and confusing times. In some ways the mothers did feel responsible for the behaviour exhibited by their child, and this was reinforced by the reactions and advice of extended family and friends. The families in my study linked the behavioural difficulties exhibited by their child to the realm of the social discourse, i.e. with social or psychological factors, without giving a thought to biological causes. It was not until the
teachers from the school the child attended, suggested assessment, and the parents considered whether it may be something other than their child’s naughtiness or their parenting abilities that was contributing to the difficult behaviour, that there was a shift to medical discourse.

In the next section I will discuss events experienced by the child and family members after a diagnosis of ADHD has been established. I explore the parents’ and the child’s reactions to the diagnosis. I also discuss the kinds of stimulant medication and what impact it had on the child and the parents, as well as the perceived benefits and drawbacks.
Chapter Six
“He’s ADHD....”

It would appear that the behaviour individual exhibit is linked to all aspects of their daily lives. Individuals are judged, accepted and even stigmatised as a result of their inability to conform to normative expectations of behaviour patterns. Children who exhibit serious behavioural difficulties are often diagnosed with ADHD, as has been already mentioned. What does it mean to these children to have a label such as ADHD and to be given medication to control their behaviour? In this chapter, I describe the parents’ stories of what life was like for them after their child had been diagnosed with ADHD. I discuss the reactions of family members to the diagnosis. Both the parents and the child experienced the diagnosis quite differently, which meant that their experiences and perceptions changed hereafter. I discuss the medication, the impact it had on the family and the child, and whether taking it made a difference to the child’s daily living. I explore what the parents and other significant adults in the child’s life thought about the diagnosis.

The families in this study experienced many feelings, changes, uncertainties, and difficulties as well as good times during the course of the interviewing. For each family, there was improvement in child’s behaviour and family interaction and then there was relapse. Overall, the families did experience change. They learnt more about their child and the impact people outside the family have on their perceptions of themselves as parents.

The families discussed their difficulties and issues with the process of labelling, diagnosis and prescription of medication. On the one hand, this process was positive. It enabled them to work with their child to improve the behavioural difficulties. On the other hand, the process was also a negative experience. The families, and especially the children diagnosed with ADHD, neither liked the idea of having a mental health label with an associated stigma, nor the
medication prescribed. The parents feared that these factors might have long-term psychological effects on their child’s development.

How broader social factors impacted on the family’s day-to-day living was another important aspect of this study. As members of society, individuals learn the values, norms and belief systems of their culture through many facets of daily life. These are learnt first and foremost through the family as primary socialisation agents. Parents teach their children about behaviour, manners (what is considered to be appropriate and what is not) and appropriate use of language. Then the child attends school and learns more about social norms and beliefs through interaction with their peers and school teachers. The reactions of other members of society to the individual’s behaviour influence learning. People understand their lives through socially constructed narrative realities, which giving meaning and order to their experience (McNamee & Gergen, 1992). The idea that reality is socially constructed has never been more evident than with the push for mental health professionals to ‘define treatable conditions, establish ways of treating them and invent newer and better outcome studies’ (Hoffman, 1992). The families felt that overall the diagnosis was positive for both the child and the whole family. Nevertheless, at times the parents struggled with what diagnosis meant for their child, in particular having a medical/psychiatric label, and being given medication at such a young age.

The insight parents of this study gained as a result of the diagnosis and the medication, influenced and changed their ways of interacting with the child. The interaction between parent and child became less hostile and less authoritarian, which in turn seemed to change the way the child responded to the parent. The parents found that when their behaviour towards the child was more positive, the child’s behaviour also changed and improved. This may be indirectly related to the knowledge of the diagnosis and medication, or directly related to the change in the social context of the individual’s life, where people react to the child in a more positive way or both (DeGrandpre, 1999).
The Diagnosis of ADHD

At one time or another prior to the diagnosis, all three mothers had sought some kind of professional assistance to try and ascertain the causes of their child’s behaviour and to find ways to better manage their child’s behaviour.

Seeking professional assistance is generally a significant decision for parents. The parents in this study agreed to seek professional support when both the family and the school felt that they could no longer manage the behaviour of the child, and the parental stress was at its peak. The parents were confused and frustrated that no matter what they tried, their child’s behaviour was difficult. They could not understand why their child behaved so badly. By the time the parents sought professional assistance the stress in coping with the child and his/her behaviour, with the school demands, and the social pressures associated with the child’s behaviour, they were desperately looking for of answers and solutions.

_I was at the end of the line I s’pose you call it, wits end, had enough of not knowing what it was_ (Joanne, interview 1, 21.11.96)

_I just couldn’t take it anymore, I’d had enough, I told the doctors that they either had to do something or I’m going to have to put him in a home for a while because I can’t take much more. I needed help with him_ (Stephanie, interview 1, 23.9.96)

The parents involved in this study had made attempts to seek professional assistance prior to the school teachers’ suggestion. The parents were looking for possible guidance to manage their child’s behaviour. However, their first experience with professionals was not very positive. One of the mothers involved in the study visited her general practitioner on a number of occasions. The general practitioner always focused on physical health issues rather than discussing the behavioural difficulties the family was experiencing. This experience left the mother feeling unsupported and powerless to implement change or alleviate the stress being
dealt with in the family home. Another mother went to see a naturopath for some advice in
regards to her son’s behaviour and found the whole experience to be quite negative and
judgmental. She reported that the naturopath suggested that it was her fault and that she
needed to learn how to handle her child. This left her feeling blamed for the child’s difficult
behaviour.

_The naturopath told me that I didn’t know how to control my son (Sally, interview 1,
11.3.97)_

The mothers found very little support from people outside the immediate family in regards to
their child’s difficult behaviour and negative experiences with professionals reinforced their
feelings of blame, helplessness and self-doubt.

The parent’s interaction with their child at times became negative and authoritarian. This often
spilt over to relationships with other children in the family. The relationship the child had with
their extended family was also under pressure and at times quite negative, as people often
became impatient and frustrated with the child.

Seeking the diagnosis was important to the mothers of this study in order to answer their
questions about managing the child’s difficult behaviour, to get resolution and to find out what
they could do to improve the situation at home and school. Here one parent expressed her
powerlessness over trying to manage her child’s required behaviour, and the empowering
feeling the questionnaire that she had to complete as part of the assessment process for ADHD
had had on her.

_We were given a questionnaire to take home by the doctor, so I’m going through this
questionnaire and I’m ticking, ticking, ticking, and I’m thinking, I hope he is, I really_
Once the diagnosis is made, parents commonly experience mixed feelings (Green & Chee, 1994; Ingersoll, 1998). The parents of this study experienced the diagnosis quite differently from the children. The parents talked about initial feelings of relief that there was now a reason for their child’s difficult behaviour. They felt empowered, as they no longer felt responsible and did not blame themselves for not bringing up this child in the ‘right’ way. They also felt that others would no longer blame them for the child’s behaviour. Here parents describe their feelings after diagnosis:

You finally have someone telling you, we know what’s wrong with your child, and its not him and its not this and its not that, this is what it is, is really good. I was hoping and then I felt guilty for hoping but at least you know what it is and you’re not fighting this hidden enemy (Joanne, interview 1, 21.11.96)

….. there’s a reason and the relief has been when we were told that’s the problem, you feel the grief just washing away and now we know why (David, interview 1, 21.11.96)

Before people would say that it was my fault and because he’s just a spoilt little ‘bastard’, they’d say to me. Now it’s not my fault, there is a reason for it, a medical reason, or something he can’t help, they don’t worry about it, if its something he can’t help (Stephanie, interview 1, 23.9.96)

The child’s experience of the diagnosis on the other hand differed from their parents’. For the parents it was positive and empowering, for the children diagnosis was negative and
disempowering. They internalised the diagnosis and now felt that there was something ‘wrong’ with them. The children lost their sense of self-worth and saw themselves differently.

*He [Peter] thought he was mental, ‘but mum I don’t want to be mental’ (Joanne, interview 1, 21.11.96)*

*It sucks….because its classed as a mental problem (Peter, interview 3, 3.6.97)*

One of the children described how he felt when he was told by the doctor that he had been diagnosed with ADHD:

*I cried, and I cracked it. I just wanted to get out of the hospital. I don’t like it (Peter, interview 1, 21.11.96)*

Another issue that surfaced through talking to the children was that the stigma associated with having a psychiatric label appeared to have an impact how the children saw themselves. The children began to doubt themselves; the longer they had the diagnosis, the harder it became for them. They began to put themselves down and lose confidence in their abilities. When an individual is labelled, not only do they begin to see themselves differently, but others see them differently as well (Tomm, 1990). People may in turn feel stigmatised; they may feel self-hate and/or self-derogation (Goffman, 1963). Goffman (1963) argues that people will do anything to become more acceptable and to no longer feel stigmatised. This supports Ingersoll’s (1998) argument that children fear taking the medication and labelled because they fear being teased and humiliated by their peers and stigmatised as ‘crazy’ or ‘weird’.

Two of the mothers explained how their children felt about themselves after the diagnosis was established. These are important insights into children’s perception of themselves in a world
that seems to be concerned with telling children how they feel, rather than asking children how they are feeling.

_I’m an idiot that’s why I’ve got to go and see a psychiatrist; I’m an idiot I can’t do it_

_(this is what Billy said to Stephanie, interview 3, 24.3.97)_

_….he was saying that he was stupid and he’s even saying that people don’t like him and don’t love him and he’s only really started saying that in the last say month, putting himself down (Sally, interview 4, 17.11.97)_

The stigma associated with a psychiatric label, coupled with the individual’s own emotional reactions to the diagnosis of ADHD, had a number of implications for the families. On the one hand, parents/family members did not want to tell people that their child had been diagnosed with ADHD, as it is a psychiatric label with certain connotations. On the other hand, they wanted to tell people so that others could understand their child better and not view him or her as ‘bad’ when he or she exhibited difficult behaviour, and not blame them for being incapable parents unable to ‘control’ their child.

_I don’t go around telling everybody that that’s what he’s got [ADHD] and sometimes when they are being naughty like at the football and people are looking at him like ‘you naughty little boy’, you do want to turn around and say leave him alone he has got a problem or something but in other ways you don’t, its frustrating because its I suppose embarrassing, not to have an ADHD child, but when they do misbehave and they do go to extremes that it does get embarrassing (Sally, interview 5, 10.3.98)_

Overall, despite their reservations the parents saw the diagnosis as a positive contribution to their lives. They stated that they learnt to deal with continual behavioural difficulties more patiently; they no longer ‘flew off the handle’ as they had prior to diagnosis. The parents felt
empowered; they no longer blamed themselves for their child’s behavioural difficulties; there was a medical reason, beyond their control, for their child’s behaviour.

It was empowering for the parents to regain faith in their ability to manage their child who was difficult to discipline and who had caused much stress and anxiety. Nevertheless, for the child is was a disempowering process which left them feeling powerless because there was something wrong with them that meant they needed to take medication and see a Psychiatrist.

Medication - “it calms him down”

You really are encouraged to medicate them. And I don’t know anyone who has an ADHD kid and is not medicated, and knowing that it does help them, you tend to go with it. There’s nothing else out there that can physically help them. There’s no operation they can have (Joanne, interview 1, 21.11.96)

Generally the prescription of stimulant medication follows the diagnosis. Parents are encouraged by the health professionals to give their children stimulant medication to foster their child’s day-to-day well-being (Barkley, 1995). The use of stimulant medication is a topical issue. As noted in chapter two, there are both positive and negative attitudes towards using medication for the management of children with behavioural difficulties. Stimulant medication, it can be argued has a ‘prosthetic function’, that is, it eliminates the immediate behaviour for as long as the medication lasts in the persons’ body (DeGrandpre, 1999).

DeGrandpre (1999) argues that stimulant medication not only has a prosthetic function. The stimulant medication, he continues, maintains the status quo of acceptable behaviour, by which children are expected to abide. The parents in this study all stated that they would have preferred their child not to take this kind of medication but they felt their child benefited from using the medication. Their improved behaviour meant they were more accepted by their peers.
in social settings such as school. It also helps their child improve their academic achievements. The benefits to the whole family when the child took the medication were also important to the parents. In social gatherings and family get-togethers the child’s behaviour was much more appropriate, making other people’s reaction more positive, which in turn made the parents’ experience more positive. As Joanne emphasized (cited page 58), parents tend to have mixed feelings about the medication.

The parents believed that if their child took the medication, then the situation at home and at school would be likely to improve, that the behavioural difficulties would no longer be an issue, and that the child would do well at school and be a ‘good’ boy/girl. The parents stated that the medication did appear to work, in that their child seemed calmer, more compliant and less disruptive. It became quite obvious to the parents, that once the children took the medication their behaviour immediately improved. They were more successful at school, academically and socially. One of the children described this transformation as follows:

I hardly ever had friends, now I’ve got some, heaps now (Billy, interview 2, 9.12.96)

The parents also reinforced this:

He was considered one of the naughty boys, so he was playing with the naughty boys and since his medication, he’s that bit more patient and he’s not annoying everyone in the class, the other children have got time for him. His circle of friends has just doubled (Joanne, interview 1, 21.11.96)

He’s able to learn and become more involved (School teacher, - Matt, 4.8.97)
The parents all stated that they used the medication mainly for academic reasons, to assist the child to improve their academic standards at school. Although they found the medication successful in some ways they were ambivalent about their child taking medication to manage their behaviour. They stated that they would prefer to use other more natural products, if they were to become available. However, they did continue to use the medication. The interviews suggested that the families continued to use the stimulant medication for the following reasons. It made their child ‘good’; he was now more accepted by his peers, teachers and extended family and friends, which resulted in an increased friendship group. He was more obedient and compliant both at school and at home. There was less disruptive behaviour, not as much tension or stress that was previously related to the child’s behavioural difficulties. Overall, the child was what they would call ‘normal’ i.e. he behaved as well, as a child not diagnosed with ADHD would.

*It calms him down, and keeps him calm whereas before he just, there was not a thing you could do, you could bribe him, you could do anything, he seems to think more before he does things now (Stephanie, interview 3, 24.3.97)*

*It just seems that there is an automatic change. It’s like he is Dr. Jekyll and Mr Hyde. One minute he’s a really nasty little boy, and then you give him his tablet and he turns round, he’s just completely different, he’s a loving little boy, who would do anything for you (Sally, interview 2, 26.5.97)*

The mainstream belief is that stimulant medication has long-term positive effects on children’s academic performance and psychological well being (DeGrandpre, 1999). The viewpoint that the benefits of stimulant medication do not go beyond masking the child’s difficulties and controlling their behaviour is gaining credence (DeGrandpre, 1999). This issue also became apparent to the parents who participated in this study. They noticed an improvement in their child whilst taking the medication. Once the medication began to wear off the picture was very
different, however, the behavioural difficulties persisted. This was most evident during the
times when the child returned home from school or on the weekends and holidays when the
child was not on the medication at all:

As the night wears on, he can get more obnoxious and a real smart arse (Sally,
interview 5, 10.3.97)

In the evenings, where you see the effects of the medication wearing off, he starts to
revert back to his old ways, you can really see the difference the medication makes, it’s
phenomenal (Joanne, interview 1, 21.11.96)

Well at first it was really good but the last 6 months it’s like the tablets aren’t even
working (Stephanie, interview 5, 6.10.97)

The prescribing doctors often inform parents that the child does not necessarily have to take the
medication on weekends or holidays. Parents in this study did decide to have breaks from the
medication as they felt that it would be better that their child was not medicated all the time.
However when the child desisted the medication, the parents found his behaviour quite
stressful and difficult to manage. One parent describes her experience:

I won’t be doing that again. The only time he’s had a break is because he’s forgotten
to take it. Last time [during the break from the medication] he wouldn’t do as I said,
he was being a real smart arse, remarks coming back to you. Like you would tell him
to do something and he’d look straight at you and say ‘no’ (Sally, interview 4,
24.10.97).
Unpredictability

Having a child diagnosed with ADHD and then given medication to improve their behaviour is not always smooth sailing. The parents of this study discussed how unpredictable life with a child diagnosed with ADHD could be. Life was often quite changeable for the family. The child could be playing and being quite good and then suddenly become completely uncontrollable, fighting with friends or siblings, throwing a temper tantrum. Often the family was unable to explain what caused such drastic changes in the child’s behaviour.

Heaps of unpredictability, it can even be second to second some days, minute to minute; you can have calmness, wonderful and then bang for 5 minutes and then back to [original behaviour] (Joanne, interview 2, 26.2.97)

Even with the medication he can still...some days unexplainably he’s angel, I just love having him around, other days he’s a devil and I don’t love having him around and that’s exactly same medication same dosage and same time (Joanne, interview 2, 26.2.97)

Social outings

Some of the parents in this study made a conscious decision to take a break from using the medication on weekends, keeping the use to a minimum. However, they did find themselves using the medication on weekends when they were attending family gatherings or going on outings. They did this for a number of reasons, first, so that the child would be able to deal with the situation better. They recognised that going to parties and social gatherings was often a difficult situation for their child, so medication allowed him have a good time and enjoy himself, rather than finding the whole situation difficult and stressful. Second, they did not want their child to be the focus of everyone’s attention because of his ‘naughty’ behaviour. As Joanne explained:
I guess it depends on the event. The event I’m thinking of is a large family gathering with lots of children. I already know that that’s a terrible situation to bring him into without the medication, and weighing up the pros and cons I would rather have him with medication and still know that he’ll have to be spoken to (Joanne, interview 3, 3.6.97)

Family have noticed a changed in him, especially when we do go off to like family parties or whatever, you don’t hear anyone yelling at him anymore, or Matt getting into trouble (Sally, interview 5, 10.3.97)

**Side Effects**

The parents acknowledged that the medication did improve the quality of life for the child both at school and at home. Nevertheless, they were also concerned about the side effects. This is consistent with documented evidence that children do suffer the side effects of stimulant medication (Barkley, 1990, 1995; Green & Chee 1994; Ingersoll, 1998; Woods & Ploof, 1997). As the side effects are part and parcel of taking the medication, parents must find ways to handle them.

_Huge side effects, he’d never sleep, weight loss too (Joanne, interview 2, 26.2.97)_

_That’s the one thing I have noticed since he’s been on the tablets, is his appetite has just, I couldn’t believe it, how it sort of went down. Normally it’s I’m hungry, can I have something to eat, can I have something to drink, can I have something, constantly. Now with the medication it’s like, ‘are you hungry Peter, its lunch time’; ‘oh not yet’. But without the medication he ate so much (Amy, interview 3, 3.6.97)_
Child’s say

One of the parents talked about how her child described his experience of taking the medication:

> He said that it narrows his thoughts, he might only have one idea or one thought at the time, whereas without the medication he has lots of things going on in his head, he has lots of ideas coming into his brain all the time. He said that he preferred the times without the medication (Joanne, interview 3, 3.6.97)

> It’s almost as if you can see his brain slowing down (Joanne, interview 2, 26.5.97)

Positive changes

The same parent also talked about the positive changes that occurred within the family, what they had learnt during this time and their thoughts on the use of the medication.

> It didn’t just affect Peter, it affected Paul [stepbrother] too. David [stepfather] had his own thoughts and whatever on it and I’ve slowly seen a change of that in the year, because he’s seen that the medication has made a difference. And he has had time with him without the medication and I think he can see that no Peter’s not just a naughty kid, he can see that there is something definitely there and he really came to change his attitude too a lot (Joanne, interview 5, 28.11.97)

Overall, the parents did notice an improvement in their child’s behaviour and academic performance. They believed that the medication assisted their children to perform much better socially. They could now attend social gatherings without being concerned that their child would misbehave and be the focus of everyone’s attention. In spite of some ambivalence,
parents continued to give their child the medication as long as it continued to improve the circumstances for the child at home, at school and in public situations.

**What others think of ADHD: “there’s something wrong with them”**

The families were most troubled by what other people thought of their child, them as parents, and the diagnosis. The parents struggled to reconcile their feelings about how people perceived them and what was actually happening in the family.

If deviant behaviour is behaviour outside the social order, is ADHD then a form of deviant behaviour rather than a medically related illness? People who exhibit deviant behaviour are perceived as lacking in ‘piety’ (respect and consideration). They are generally seen by others as failing to make use of the opportunities available to them, and as showing disrespect for those who are behaving within the accepted social order. They represent “failures in the motivational scheme of society” (Goffman, 1963:171).

People look for reasons for the inappropriate behaviour exhibited. One parent summed up what they were all feeling about the judgements made about their children’s behaviour:

> I think everyone analyses children a hell of a lot these days, like kids were just kids years ago, and kids were, oh just a naughty kid, or he’s just a cheeky kid, or something like that, but now its like ‘something must have happened at birth’, or have they had a bad experience….. (Joanne, interview 3, 3.6.97)

Once the families received the diagnosis the reaction from extended family and friends varied greatly. The reactions were both positive and negative.
Before it was known, people would say, ‘we don’t like the way he goes on or the way he talks or his tantrums’ and all this sort of thing, ‘we don’t want our kids picking it up’. But now its ‘just come over anytime’ (Stephanie, interview 2, 9.12.96)

It is commonly believed ADHD is a label which gives the child an excuse to get away with what they have been doing (Neuville, 1995). As the social pressure to have ‘good’ children is so strong in our community, when children do not meet appropriate standards of behaviour, they are viewed with scepticism. Some families thought that ADHD let ‘naughty’ children ‘off the hook’. The mothers of this study described this as a “catch 22” situation. Joanne identified this on several occasions:

A lot of people don’t consider it as a real diagnosis. But an excuse, a very big one, to label naughty children, and let them get away with it, that’s a hard one to sort of cope with because as much as not wanting to label him myself, you end up doing it and end up falling back on it a bit sometimes (Joanne, interview 3, 3.6.97)

I think as soon as Peter’s grandmother heard ‘brain’, I think she just thought ‘spastic’ or something, he’s slow, he’s not mentally quite there (Joanne, interview 3, 3.6.97)

And again:

Once we told some friends that he was ADHD, they spoke to him like he was three years old again, people don’t know what it is. We don’t exactly know what it is, so they were just trying to help but later Peter mentioned to me ‘why was she talking to me like I was silly or something’, so he noticed too (Joanne, interview 3, 3.6.97)
Similarly, Stephanie said:

*Oh they thought retarded, that they’re mentally retarded because they’ve got this label. They think that there is something wrong with them, they’re stupid and all this*  
(Stephanie, interview 4, 23.6.97)

So while the diagnosis can alleviate some pressures and expectations, making people more understanding, it is also viewed with some scepticism. In particular the diagnosis did not seem to stop people from drawing inaccurate conclusions about the child; so pressure continued to be experienced by the family members.

The changes in the child’s behaviour can be seen in both positive and negative terms. Although the child is now receiving positive reinforcement and having positive interactions with peers and family, having a diagnosis of ADHD reinforces socially appropriate standards of behaviour and the view that if people do not conform then they will be pressured to do so.

**Conclusion**

It is known that using stimulant medication does alleviate some of the behavioural difficulties associated with ADHD (Barkley, 1990, 1995; Green & Chee, 1994; Woods & Ploof, 1997). However, there is also evidence that the medication does not diminish a large proportion of difficulties experienced by the family. In other words, stimulant medication, in particular Ritalin, can be seen as having a ‘prosthetic function’ much like methadone – “it does not eliminate the addiction but rather maintains it in a less destructive fashion” (DeGrandpre, 1999:33).
The three families interviewed for this study became aware that there were some improvements with family interaction and the child’s behaviour appeared to be less disruptive. However, the families and the school continued to experience behavioural difficulties even while the child was taking the medication. The medication does not ‘cure’ the illness attacking the impairment of the brain (DeGrandpre, 1999). Although the benefits of the medication are immediately noticeable, long-term effects are not sustained. Once the medication is removed the behavioural difficulties continue. Stimulant medication maintains the status quo rather than changing the situation or circumstances (DeGrandpre, 1999).
Chapter Seven
Living with ADHD

“Peter’s made me roar, I’ve had to roar for him or because of him”

In this chapter, I look at the joys, and trials and tribulations experienced by the family living with a child diagnosed with ADHD. A special interview with one of the families will be used to provide a more complete picture of what is like for parents of a child diagnosed with ADHD. This family was particularly interesting because the parents had to stop giving the medication to the child, because the drugs were temporarily unavailable. This gave the family a unique insight into their child, the medication and the diagnosis of ADHD.

A separate section on the fathers of the children is included because the fathers’ role emerged as an important theme during the interviews with the mothers. An interesting phenomenon emerged in respect to the different ways in which the children related to each parent. Possible reasons for this are explored.

In the concluding interviews with the families covered the changes that occurred over time, issues for the future and the educational needs they saw for their child diagnosed with ADHD. They described many emotions and experiences; it was like a roller coaster ride with improvements and disappointments. Overall they had the strength to continue even during the most difficult and trying times. They described the feeling of frustration, and the limitations they believed the diagnosis placed on the family’s movements. They also described feelings of self-doubt and self-blame in relation to their ability to parent their child, and the difficulties they experienced when others judged their child’s behaviour and their parenting abilities.

_It’s a learning experience with ADHD because you think ‘oh my God’ what next are they going to do_ (Stephanie, interview 4, 23.6.97)
It just makes it a little bit harder when they’re ADHD because you really don’t know how in the hell to handle it and what’s going to work (Stephanie, interview 4, 23.6.97)

They experienced times of confusion, because they were never quite sure what was going to happen next, nor how to handle the unpredictability of their child’s behaviour.

It can be very frightening, very confusing, you don’t know what in the hell is going on (Stephanie, interview 5, 10.3.97)

One parent described living with ADHD as heartbreaking, watching her child struggle to cope with difficult times, school and the need to be accepted by their peers.

It’s heartbreaking at times watching your kid struggle through and then its wonderful very rewarding. I think their achievements are like triple to a ‘normal’ kid’s achievements I guess (Joanne, interview 5, 28.11.97)

Having the diagnosis was the catalyst for these parents to review their parenting style; the change resulted in more positive experiences with their children. The parents in this study all stated that they changed the way they interacted and reacted to their child.

Praise, praise, and praise, and you can see he’s got flashes of happiness. He recognises that he’s done well and I think he’s recognising that he’s doing better (Joanne, interview 1, 21.11.96)
**Aggressive Behaviour**

One parent described her child as becoming more aggressive after the diagnosis was established. It was the period between the first and second interview that she noticed the aggressive behaviour starting to appear and by the fourth interview, twelve or so months into the study, it was getting much worse. She could not account for the sudden rise in aggressive behaviour. She was puzzled that it was happening in spite of the diagnosis and medication given to the child to modify his behaviour. If anything she thought that the diagnosis and medication should have improved his behaviour.

*His anger has gotten quite bad actually and he gets angry like at himself (Sally, interview 4, 17.11.97)*

**Fathers**

The differing relationship the boys had with their fathers in comparison to those they had with their mothers became quite apparent throughout the course of the interviews. The mothers often complained about the fact that the boys were better behaved and less disruptive with their fathers. Interestingly, the mothers stated that the boys tried very hard to be good for their fathers; they wanted acceptance not rejection from their fathers. There are many possible reasons for this fact but perhaps the most obvious was the fact that the fathers did not live with the child. Tallmadge and Barkley compared videotapes of children diagnosed with ADHD interacting with both their mother and their father. They found that the children were much more likely to be less negative with their fathers than their mothers (Barkley, 1995).

Psychological research provides us with another explanation for the boys wanting to be better behaved for their fathers than their mothers. Between the ages of five and eight, the son moves from primary identification with his mother to his father recognizing that he is a male like his father (Elium & Elium, 1992). It is during this time that the relationship with the mother becomes defiant. The child will often defy the mother, saying things like “I hate you mummy”
(Ilg, Ames & Baker, 1981). It is at this stage that the child is at his worst with his mother and often at his best with his father. It is argued that this is partly due to the fact that the child does not feel that he have the same power struggles with his father as he does with his mother (Ilg, Ames & Baker, 1981). It is also partly due to the fact during this stage children have more respect for the father’s authority than their mother’s, and would not dare be as bad with him as they are with her (Ilg, Ames & Baker, 1981). At the age of eight to ten the son will try his hardest to please his father. He will go to almost any length, and any cost to please his father. He craves his father’s approval and any positive response from his father does wonders for his sense of self-worth and self-acceptance (Elium & Elium, 1992). At this time the son will also question his mother’s authority. This theory deserves more attention in future work. The perception of the mothers in this study illustrates this notion of sons wanting to please their fathers.

*It seems to me that he wants to show Daddy that he’s a good boy and he’s not going to do anything wrong (Amy, interview 4, 1.9.97)*

*I can see it, he’ll just put in that 1% more with his Dad than he would with anyone else. They are best friends, best buddy, adores him (Joanne, interview 1, 21.11.96)*

*It gets hard when he thinks that the sun shines out of his father and I’m just a monster (Sally, interview 1, 11.3.97)*

*I’ve noticed it too, he really seems to dwell on his acceptance from Dad…he like really thrives on that acceptance from Dad (Joanne, interview 4, 1.9.97)*

*All I have to say is ‘shower now!’ and he’s in there (John, interview 4, 1.9.97)*
This one night Peter had been fighting with Paul, I’d had enough, it’s been full on all
day and I got on the phone to John and said ‘I’ve had enough, I’ve had it, you talk to
him’. And just a few words from Dad and it ‘ok yep, that’s fine’ and off he went
(Joanne, interview 4, 1.9.97)

At the time the boys of this study were all aged between eight and ten, which if taking the
explanation offered in the literature, could explain why they were more compliant with their
fathers than their mothers.

Another explanation put forward in the literature is that at times mothers, as the primary care
giver, feels worn down by constantly dealing with the difficult behaviour exhibited by their
child. As the father is not the primary carer he may not be so worn down and may be able to
deliver instructions to the child in a more convincing tone (Porter, 1994). There is much
speculation over why children behave better for their fathers, but to date there is not a
substantiated rationale offered in the literature.

The issue that the boys try harder to be better behaved for their fathers raises many questions
in regards to behaviour, diagnosis, gender issues, and family. These issues need to be
considered when making a diagnosis.

School
Interviewing the classroom teacher was important as it takes the focus away from family and
onto the social sphere. The teachers are with the child for six hours a day. They observe the
child’s interaction with their peers, and their peers interacting with the child. In the early
stages, the school is usually the first contact with professionals that parents have to talk about their child’s behaviour.

The school staff suggested that to the parents seek professional intervention primarily because these children could not concentrate on their work. They were lagging behind the other children in terms of academic performance and were often in trouble.

All three teachers stated that once the child was taking medication, there was a remarkable difference in behaviour. One teacher summed it up:

He’s quiet, he concentrated on his work still is below average, but he sits and does his work. He seem to really stick at his task and get his work done, which is a big change

The teachers had also noticed a change in the child’s social interactions with their peers both in the playground and the classroom. The medication prevents the children from overreacting in certain situations, allows them to stop and think. Before the medication the children were quite disruptive in the classroom. They moved around and bothered other children, were more fidgety and less likely to be co-operative when playing games with the other children in the grade. The medication curbed such behaviour, allowing the child to be more co-operative with their peers but also more productive in the classroom.

He has been able to control, I guess have more control over his behaviour, which would make him get along with the other children better.

His behaviour in the playground was the first to improve. The other kids would notice that he his not in trouble as often.
In spite of the improvements that had occurred at school for the child, there continued to be some areas of concern for the teachers.

At the moment he refuses to come to school. He’s at risk of becoming a child that doesn’t want to be at school.

Sometimes he won’t take his tablet. He says, “I did”, but a couple of times he threw it away, because he wanted to prove that he could be good without the tablet.

One of the teachers raised her concerns about the medication specifically. She expresses:

I guess I have got mixed feelings in a way. I wonder whether the medication suppresses his personality a little bit, that worries me to a degree. But I guess if you offset that with the advantages of it [the medication] but I don’t know. That was my reservation that his personality was squashed a little bit even if it was a bit annoying, that was him and what we are seeing isn’t really him.

Although all the teachers involved had some reservations about the medication overall they thought it was positive in assisting the child to improve concentration, behaviour and peer relations.

Sibling relationships
One parent talked about how the child, diagnosed with ADHD, continuous behavioural difficulties had affected his siblings. It is suggested that the relationships between children diagnosed with ADHD and their siblings differs from that of other families (Barkley, 1995). Children diagnosed with ADHD tend to be more argumentative, and more disruptive; they yell at their siblings, and generally have more difficulties getting along. Siblings of a child
diagnosed with ADHD often grow tired and exasperated with living in such disruptive, unpredictable and baffling circumstances (Barkley, 1995). As one parent observed:

*its very confusing for [Karen], she’s getting a bit upset with him and confused because one minute they’ll be playing and then he’ll hurt her for no reason* (Stephanie, interview 5, 6.10.97)

“I wish I could recognise between what is ADHD and just him being a child”

Today health professionals increasingly question the reliability of the diagnosis process of ADHD, which generally occurs, in the doctor’s surgery. For example a study published in the *Journal of Paediatrics* found that there were major disagreements between parents, teachers, and clinicians about the diagnosis. It found that 80% of children, who were thought to be hyperactive by parents and teachers, showed no signs of hyperactive or behavioural difficulties in the clinician’s office (DeGrandpre, 1999). This is an issue because on occasions children who are hyperactive sometimes present as ‘normal’ in doctor surgeries, and children whose behaviour is usually acceptable can sometimes seem hyperactive (DeGrandpre, 1999).

Since the symptoms are the basis for diagnosis, this issue of differing opinion between parents and clinicians raises concerns about the medical phenomenon ADHD (DeGrandpre, 1999). Critics have found that there is a higher incidence of ADHD in some countries than in others; this could be due to the difficulty of drawing the line between ‘normal’ and ‘abnormal’ behaviour, and the many shades of grey in-between (DeGrandpre, 1999). For example in Western Europe, even among health professionals who support the diagnosis of ADHD, there is a remarkably lower incidence of ADHD diagnosis. Studies conclude that this maybe related to Europeans’ view that difficult behaviour is developmental and psychological, rather than medical and biological (DeGrandpre, 1999).
For the parents of this study it was important to distinguish between what they called ‘ADHD’
behaviour and ‘normal’ behaviour. Knowing this difference, they argued, would play a major
role in the way they disciplined and related to their children. Working out the difference,
however, would be very difficult. The mothers explain:

I need to learn to distinguish between the ADHD and when he is actually being
naughty, and he’s just being a boy. I fly off the handle too quick and after I sort of
yelled at him and told him off, I sit back and think was that something he could help
or was that ADHD, surely he has been a normal boy in there somewhere (Sally,
interview 2, 26.5.97)

If he’s playing up and I’ve been trying to determine what’s ADHD and what’s him
being a kid. I wish I could know, recognise between what is ADHD and just being a
child and it’s very hard to know, like he’s playing up or doing something that, like yep
that’s ok that’s the ADHD coming out in him, then I could handle it different to
when he’s just being a naughty boy, disciplining him in a different way I suppose if
he’s doing something whereas with the ADHD you can’t really jump on him like you
would if he was being naughty (Sally, interview 3, 4.8.97)

I think a lot of it is a boy this age. I don’t know that much about it, the mouth I s’pose
is a lot the age, and I s’pose it’s normal teasing his sister… (Stephanie, interview 4,
23.6.97)

Although towards the end of the interviewing process parents began to feel more confident
about ADHD, the medication and the child’s behaviour, they expressed the concern that they
may be focusing too much on the ADHD diagnosis and not on the actual behaviour exhibited
by the child. A study was conducted exploring the issue of ADHD and difficult behaviour
(Barkley, Spitzer & Costello, 1990). It investigated the correlation between ADHD and ‘antisocial’ behaviour, and concluded that ADHD alone is not associated with ‘antisocial’ behaviour. It suggested other factors which need to be taken into consideration, such as the social environment, and the child’s relationship with peers, family and school.

Labelling behaviour is often a difficult task for parents and professionals. Many of the observed behaviours are to some extent subjective. Once individuals start looking for something ‘abnormal’ or different in relation to a person’s behaviour, they re-interpret behaviour that previously they did not question in a way that allows them to categorize the behaviour as non-normative. If disruptive behaviour is related in society today to psychological factors, then this behaviour is more likely to be noticed and brought to the forefront (DeGrandpre, 1999).

Too many people have an opinion about it [ADHD]. That’s … society, I suppose if it wasn’t that pressure to have a good kid or whatever you wouldn’t need it [medication], but society has a lot to do with everything especially when it is behavioural (Sally, interview 5, 10.3.98)

Having the diagnosis has to some extent been positive for these three families. It assisted them to understand their child better and to relate to them in less authoritarian manner.

“It was a hell of a month”
During the time of interviewing the Green family I was fortunate to share a unique event with the family. Between the third and fourth interviews medication was interrupted for reasons beyond the family’s control. It was an amazing time in which the family learnt a great deal about itself, the child diagnosed with ADHD, the medication and ADHD as a diagnostic ‘disorder’.
The family experienced a great deal of difficulty during this time and described Peter’s behaviour as ‘reverting back’. There were behavioural difficulties at home, at school and in social settings. Peter was:

- Hitting and kicking people and back chatting like there’s no tomorrow and totally just ignoring everything you said, it was frustrating, you remembered what it was like because it was here all of a sudden again….it was full on (Amy, interview 4, 1.9.97)

- Joanne rang ready to kill him (John, interview 4, 1.9.97)

The family faced a new challenge. They had to find ways to deal with the behavioural difficulties that they were now experiencing. They found that their interaction with the child changed during the time he was off the medication.

- I just dropped all levels of ….all expectations. I find I drop a lot more, in other words he gets away with a lot more otherwise I’m on his case 24 hours a day and I don’t have the time or mental patience for that (Joanne, interview 4, 1.9.97)

- I don’t care, that I’m on his back even though it’s frustrates me, I won’t stop I’ll just keep constant and I’ll just like hound him (Amy, interview 4, 1.9.97)

When Peter first went on the medication his parents were very sceptical about using it to alter his behaviour and make him more socially ‘acceptable’. I asked them what they had learnt about the medication during the month off it, and whether their views and opinions about the efficacy of medication had changed or whether they still felt ambivalent about its use. This whole experience changed the parents’ opinion of the use of the medication. The parents and
step-parents became aware of how powerful the medication was in altering their child’s behaviour and the impact it had on their day-to-day living as a family unit.

With the tablets it makes him like easy to be able to sit there and think. It makes our life, it make me feel better because I’m not yelling at him constantly (Amy, interview 4, 1.9.97)

While off the medication, the parents could see the change in the way in their child conducted his day-to-day activities. On the medication he seemed more focused and able to stay on task, whereas off the medication he was unsettled, disruptive and not able to sit still. They reported that:

It calms him I think so that he’s able to understand what you’re saying. You can actually see that he’s sorting it out and he comes out with the most strangest things at times, you can sort of see how his mind works when he was on the tablets, but when he was off them it was sort of like he wasn’t thinking (Amy, interview 4, 1.9.97)

It was hard for him when he was off it, it was really hard to keep focused (Joanne, interview 4, 1.9.97)

We need the medication for sanity. You can see that Peter has trouble and he needs it to cope and as long as it doesn’t seem to be doing anything really really bad that we can see, if it helps him, I mean its always at the back of your mind that its drugs that he’s taking but it its going to help him you want to do your best thing. It eases my mind because I know its doing something for him, hopefully there will be no long term effects but at the moment he’s coping a lot better with life and that will make him a better person (Amy, interview 4, 1.9.97)
It was an incredible learning experience for this family. They learnt to appreciate when the child was behaving appropriately and not to take it for granted. They understood more about the medication than they had before. They had the opportunity to see its effects. For example when Peter was first on medication, they went from a very stressful time of major behaviour difficulties to improved behaviour. The improvement in Peter’s behaviour was what they were seeking and wanting, and with the medication that is what they got. Nevertheless, they over looked how much he had actually improved because he was still exhibiting some difficulties. This time they went back to the difficulties experienced earlier and realised the stress that everyone had been under prior to diagnosis and appreciated the situation more. They became more understanding of the difficulties experienced both by Peter and themselves. Even though they found it a stressful time, the experience taught them some valuable knowledge which will assist them in the future.

“I think of him differently now”

On the fifth and final interview (conducted a year and a half after the first interview) I wanted to reflect back to when the child was first diagnosed with ADHD and discuss any other issues that may have been raised in the previous four interviews. This was the parents’ final opportunity to discuss their concerns about and desires for greater or different assistance from professionals, other family members and friends. In particular, it was an opportunity to discuss what sort of advice they would give to other people in similar situations and whether they had any strategies and insights they wanted to share. It was a time to look back on the eighteen months gone by and evaluate the changes, if any, they had experienced. It was an opportunity for the families to reflect on what they had learnt about their child, ADHD and about themselves.

All three mothers interviewed for this study stated that they had learnt a lot about their child and their own parenting. They learnt that changing their approach assisted them in managing their child’s difficult behaviour and stressful situations. Although each child was different, as
was each family experience, what they had in common was that they developed new parenting
techniques along the way.

For example:

The Green Family: Joanne learnt to be less negative and more supportive of her son. She learnt
to be more patient and more accepting of the behaviour, and did not see her child as “just a
naughty boy” anymore. Now it is “Peter with ADHD”. Joanne reflected on how she now tries to
manage Peter’s difficult behaviour. “I tend to try and pin point when the worst of it is and act
differently. We really encourage the good and try to ignore the bad”

The Jones Family: Sally was a sole parent who lives with own father. She had a lot of difficulty
with her relationship with her son. Over the eighteen months, however, she managed to
become calmer, and to relate to her son in a less angry and frustrated manner. A significant
shift for this family was that Sally found part-time work. This not only meant that she was out
of the home, she was also able to afford to do more things with her son without being
concerned about the cost. She believed that once she started working her interaction with her
son improved. “I see so much improvement in both of us and an easier life for both of us.”

Sally, like Joanne, accepted the diagnosis and learnt to modify her reactions to her son’s
behaviour, which in turn assisted her in his management. “I think just knowing that this [ADHD]
is part of his problem is like so much easier. You don’t tend to be more lenient on them but you tend to
deal with the problem in a different way. That’s the key to it, just to figure out how you do actually go
round about it”.

The Peters Family: During the time of my involvement, the family had experienced many
behavioural difficulties with Billy, and this continued. Stephanie was a sole parent who had a
younger daughter and her grandson living in the house with her. She experienced many
stressful times in terms of Billy’s behaviour, which not only affected Billy but also the other
children in the house. Stephanie learnt her own way of managing Billy’s behaviour. She learnt that if she let him go, let him yell and scream, it would not increase the aggravation in the house and he would calm down quicker. Then she would be able to address the difficulty.

These women were resourceful and had the initiative to manage their child’s difficult behaviour in ways that were most suitable for the family. I was interested to reflect on what the three mothers would say to other families with a child diagnosed with ADHD facing continual behavioural difficulties even after diagnosis and the prescription of medication. Joanne summed it up for mothers:

*At the start be very patient. It does take time to learn what you’re doing. It’s such a personal thing, and it changes so much from family to family. Basically be patient with them and try not to force too many things on them at the start, which is what we tried to do. Let them go their own way, keep an eye on the medication, don’t be told by doctors like I was, they are wonderful, but I think don’t be afraid to say I’m not really happy with this* (interview 5, 28.11.97).

Sally went one step further to advise families who were undecided about seeking professional assessment:

*If they hadn’t made up their minds or gone to see about it or hadn’t had their kids on the medication I would definitely tell them to try it. Because I mean there is no harm in trying it, because…it’s been so much of a weight lifted off my shoulders* (interview 5, 10.3.98).

**Access to more Information**

In some of the initial interviews I asked families what they thought ADHD was and whether it had been adequately explained to them. All three mothers stated that they felt they were not
given adequate information about ADHD and the medication their children had been prescribed. I now asked them what, in hindsight, they would have liked, or needed, especially at the initial stages of the diagnosis.

All three women stated that they would have liked more accessible information about the causes and treatment of ADHD. They even stated that they would like their own general practitioner to be better informed about ADHD. They wanted more access to doctors who had a greater degree of expertise in dealing with children diagnosed with ADHD, in particular to the diagnosing doctor:

> It’s like you go, then it’s I’ll see you in a month, or in three months, here you go have your tablet and be good (Joanne, interview 5, 28.11.97).

Access to more information was an important factor for all three mothers. They all talked about more seminars on the topics of ADHD, behaviour and medication. Stephanie summed up the difficulty accessing information:

> You need a lot more help than what you get. They don’t cater for people like for seminars or anything about ADHD. Like they [seminars] are always at night, and I can’t get to them (interview 5, 6.1.97).

Access to information is an important factor in empowering people to move forward and meet the challenges of daily life. These mothers lack of access to this reinforced their feelings powerlessness and of isolation.

The families involved in this study, in particular the mothers, felt unsupported and on their own. They would have liked more access to professional assistance and helpful feedback; “having someone to ring” (Sally, interview 5, 10.3.98), would have helped.
Having someone to talk to was important to these mothers, because it alleviated feelings of isolation and validated their experiences. All three mothers talked about attending support groups for parents who have children diagnosed with ADHD.

*I've been to a few of those [support groups] and just talking to other parents who have these kids, it's so good just knowing that I'm not such a terrible mum and other people have these problems too. They have solutions that you may not have thought of for their kids that might work for your kids* (Joanne, interview 5, 28.11.97).

**The Future**

In hindsight there are many elements that these families needed from professionals but for one reason or another lacked. I spent a lot of time discussing what the mothers needed, what they did not receive. I was also interested in their perceptions of the future for their child. I asked the mothers how they imagined the next five years and whether they thought their child would still be taking the medication? Each mother’s response differed and are presented below:

**The Green Family:** “no idea. I want to see him happy, every parent does. He seems to have a bit of determination so I’d like to think that that will lead him somewhere I guess. Educated hopefully.”
*(interview 5, 28.11.97)*

And about the medication:

*I’ve never really been comfortable with it, it’s a huge problem for me. Even though I feel like I’m doping him up, I still give it to him, because I see it works. I would hate to think that in five years down the track I’m still giving him this medication. But I guess in five years if he’s still the same I probably will still give it to him because it works. I would like to think that in five years time that because we have at least done something that has helped Peter, so there will be a difference, so maybe he won’t need*
as much medication, or he might not need any at all, which would be a wonderful thing. But I guess in five years time I just want Peter to be happy (interview 5, 28.11.97)

The Jones Family about the medication: “I don’t think he will be taking the medication because he seems to have grown up and caught up to his age, and I think he’s a lot happier too” (interview 5, 10.3.98)

The Peters Family: “I think Billy is going to have a hard life because with the ADHD, his temper. I really think that Billy is going to have a hard life because he’s not interested in learning anything, he’s going really backwards lately” (interview 5, 6.10.97).

All three mothers expressed the sentiment that they just wanted their child to be happy and to succeed at school.

**Conclusion**

There were many complex factors associated with the diagnosis and medication for families. Prior to the diagnosis of the children, the mothers of this study tried to manage the behaviour of their child as best as they could. They often felt blamed and responsible for the child’s misbehaviour. Extended family and friends, school personnel, and associates were all in some way indirectly responsible for the mothers’ feeling that they were ‘bad’ mothers because their child was exhibiting behavioural difficulties. Some people went as far as to inform the mothers that it was their fault that their child was ‘playing up’; others would just give friendly advice how to treat their child.

The families found themselves avoiding social gatherings because they caused stress for the child and the parents. These feelings of blame, self-doubt and the sense of isolations compounded the difficulties the families were experiencing. The child is judged according to
the behaviour he exhibits. This pressure to be a ‘good’ child was felt by children and parents alike.

At the time the only support for the family came from the school, although the parents also found the relationship with the school quite stressful at times. Their child was constantly in trouble, and the parents were called up to the school regularly. The support and advice the school provided was well received and appreciated by parents. The school first suggested that the parents pursue professional guidance.

Prior to the diagnosis of their child, the family faced many difficult times and much uncertainty. After diagnosis this did not diminish. The parents did feel a sense of relief that their child’s inappropriate behaviour was not their fault, but at the same time they were uncertain about the medication and the reactions to their child’s diagnosis with ADHD. The families searched for other causes of their child’s behaviour. All three mothers stated that they thought the child’s father also had ADHD; others wondered whether family separation was a contributing factor.

In spite of uncertainties, the families decided to give their children the recommended medication. The medication did improve the situation at school slightly. The children performed better academically, their peer relations improved, their behaviour calmed down and was less disruptive. The family began to attend social outings and gatherings more often with less concern about how others would react to their child, as with the medication the children behaved appropriately.

Although the situation seemed to improve at school whilst the child was taking his medication, the situation at home for the child and the family did not improve a great deal. The child continued to exhibit difficult behaviour, and the family continued to feel confused and frustrated about the child’s behaviour. The diagnosis brought about feelings of self-doubt.
within the child that did not appear to be present prior to diagnosis. The children thought that there was something wrong with them, and thought they were ‘mental’. This had a negative impact on the children in that it created uncertainty about their own normality and undermined their feelings of self-worth.

Not only was the diagnosis confusing for the children it was also confusing for the parents. Although the parents’ first reaction was relief, later this relief was replaced by uncertainty and protectiveness. Some people outside the immediate family reacted in quite negative ways, stating that the diagnosis was just an excuse given to ‘naughty’ children, so they can get away with their behaviour. Others thought that there was something wrong with the child, that they had ‘mental’ health problems. Such reactions contributed to the parents and child’s feelings of uncertainty.

The families of this study persisted in their efforts to develop their own methods to manage their child’s difficult behaviour, and to avoid feeling blamed or to doubt about themselves. Overall, the diagnosis was a precipitating factor in assisting the parents and children to alter their interactions and improve a stressful and difficult situation.

What emerged from the data collected was the presence of two dominant and influencing discourses, that is, the social discourse and the medical discourse. These two discourses had very different effects on the parents and the children diagnosed with ADHD (see diagrams 1, II, III).

The social discourse reinforced notions such as the ‘good’ child, ‘good’ parent, appropriate behaviour, roles and responsibilities, and placed social and cultural expectations on parents and children. The values and assumptions inherent in these notions were expressed by people outside the family situation such as extended family, friends, teachers, and neighbours. The families in this study obtained medical assessment because of the dominant social discourse. Their social
interactions and networks influenced the way they saw themselves as parents and the way they perceived their child’s behaviour.

The medical discourse eliminated any connection between the behaviour and the social discourse and placed the behaviour, the cause and treatment in the domain of the child as defined by biological and medical factors. The medical discourse took away the sense of responsibility and blame from the parents. The medical discourse gave the parents a feeling of relief and made the children feel disempowered.

These two dominant discourses, social and medical, had profound impacts on these three families. The parents used the medication to assist their children participate in school activities and to complete necessary school work. The medication was used during school hours, so by the time the children arrived home the medication was beginning to wear off and the difficult behaviour once again surfaced. The parents chose not to give the children medication after school as it keeps the child alert and therefore inhibits sleep.

On the weekends, however, the parents chose to medicate the children only on when they were to attend social gatherings. They did this to enable their child to behave more appropriately without drawing unnecessary negative attention.

The social and medical discourses influenced the family’s ideas, perceptions and actions. Being part of a society means that it is difficult to appear different or individual; these families chose to ‘fit in’ into their environment rather than to challenge the structures imposed on them.
DIAGRAM 1

SOCIAL DISCOURSE
- GOOD MOTHERING
- GOOD CHILD
- BLAME
- RESPONSIBILITY
- SELF-DOUBT
- CONFUSION
- FRUSTRATION

MEDICAL DISCOURSE
- NO BLAME
- NO RESPONSIBILITY
- BIOLOGICAL CAUSE
- MEDICATION
- RELIEF
- EMPOWERMENT

THE FAMILY

SOCIAL DISCOURSE
- NAUGHTY
- DISRUPTIVE
- LOUD
- CAN'T SIT STILL

MEDICAL DISCOURSE
- LABEL
- STIGMA
- 'MENTAL'
- MEDICATION
- CONFUSION
- DISEMPOWERMENT

THE CHILD
DIAGRAM II

SOCIAL DISCOURSE
- GOOD MOTHERING
- GOOD CHILD
- BLAME
- RESPONSIBILITY
- SELF-DOUBT
- CONFUSION
- FRICTION

MEDICAL DISCOURSE
- NO BLAME
- NO RESPONSIBILITY
- BIOLOGICAL CAUSE
- MEDICATION
- RELIEF
- EMPOWERMENT

THE FAMILY

THE CHILD

NAUGHTY
- DISRUPTIVE
- LOUD
- CAN'T SIT STILL

LABEL
- STIGMA
- 'MENTAL'
- MEDICATION
- CONFUSION
- DISEMPOWERMENT
Diagram III

THE HOME

THE CHILD

PARENT/S

CONTINUOUS BEHAVIOURAL DIFFICULTIES

FRIENDS

THE SCHOOL

SIBLINGS

EXTENDED FAMILY

SOCIAL GROUPS

THE CHILD

PARENT/S

CONTINUOUS BEHAVIOURAL DIFFICULTIES

FRIENDS

THE SCHOOL

SIBLINGS

EXTENDED FAMILY

SOCIAL GROUPS

THE HOME
Chapter Eight

Conclusion

Chapter one outlined my own assumptions about ADHD and the diagnosis of children who exhibit certain behavioural patterns. The research has answered some of the questions I posed then and raised others. This chapter explores some of the findings and posits explanations of how the families managed their children’s extreme behaviour, their experiences with medical and school personnel and with the subsequent treatment regime. The findings give tentative support to the view that while the children’s behaviour is outside the bounds of what is considered acceptable by their social milieu, it may well have resulted from social and ecological factors rather than medical ones. It also gives credence to the view that behaviour is socially constructed and socially defined and may change over time and between contexts. While the medical model offered some relief for parents and children, it raised new problems for them. It does not differentiate between those who exhibit the behaviour because of medical factors and those who do so because of emotional or ecological factors. The chance of misdiagnosis is increased when the diagnosis is only based on behavioural indicators. Once a child receives a diagnosis then the family is on a train that is hard to get off and which is driven by a member of the medical fraternity. For some, this is reassuring, for others it may be inappropriate.

Receiving a diagnosis raised particular dilemmas for the families involved in this study. It was viewed by some people as an excuse to let a naughty child off the hook, and by others as an excuse for inadequate parenting. Other people again perceived it as a psychiatric illness, with which they had sympathy and compassion, thinking that it was a kind of intellectual delay.
The child and parents experienced the diagnosis differently. Although the parents were ambivalent about the diagnosis, their first reaction was one of relief. They were relieved to have a label for their child’s difficulties, as it seemed it was no longer the child or parents’ fault. Consequently they felt empowered.

On the other hand, they were reluctant to tell people of the diagnosis because of the stigma associated with having a psychiatric label which made it seem there was ‘something wrong’ with their child or that made him different from other children. They felt that the medication changed their child, made them into someone else. They asked themselves, “Isn’t this the point of the medication, that the child will act differently, ‘not like all other children’?”

On the other hand, the children seemed to be disempowered by the diagnosis, and for them there was no obvious advantage to the diagnosis. They saw themselves as different; they had to take a pill every morning and lunch time, and see a ‘doctor’. Prior to diagnosis the children did not seem to think that they were different, or that there was something wrong with them. This is an example of Foucault’s three stage problematizing of behaviour put into practice. The behaviour is firstly identified and defined, diagnosed and then treated.

After spending time with the three families I came to understand why they chose to have their child diagnosed. The diagnosis meant that they received support they would not otherwise receive. The school staff, other family members and friends now responded to the child with more compassion and understanding.

For these three children, the medication had the expected effect. It assisted them to remain seated in the classroom, stay focused on the task at hand; they became calmer in some ways, and to some extent it altered their personalities. They were no longer the extraverted classroom clowns; it slowed them down to a more acceptable level of interaction. Although the medication assisted at school, the behavioural difficulties persisted at home. The parents’
experience at home did not seem to change; they still had to find ways to manage the child’s
difficult behaviour. The medication was useful when attending social gatherings, parents
would often give the child medication to make him calm and well behaved. I argue that this
does not necessarily ‘fix’ the situation; is merely a band-aid approach which is worse for the
child. It gives children the message that they need a pill to be good and that their parents don’t
trust them to behave without the assistance of the medication. I question who benefits from
such circumstances.

This study highlights that for me there are more questions than answers. Would the families
have sought a diagnosis if the social pressures were not so prominent in their day-to-day
interactions with other people? The issues the families were experiencing prior to diagnosis
with their child’s behaviour continued to persisted. Why did the situation not improve at home
for the child and their parents?

I ask why the child’s personal situation was never explored by the diagnosing medical
professional? Although the family situation was not the focus of this study, in conversation
with the researcher family members disclosed personal and private information about family
circumstances. There may have been some correlation between the family situation and the
child’s behaviour but this was not explored. The focus was on the behaviour and improving
behaviour rather than an attempt to determine other contributing factors. In one family there
was violence; the father was abusive psychically and verbally to both the children and mother,
and this was not explored in relation to the child’s aggressive behaviour. This child was
diagnosed with ADHD and prescribed medication without any acknowledgement of the
aggressive and difficult behaviour which continued to be problematic at school and home.

In another family there were separation issues. The child had little contact with his father, lived
with his mother and extended family member. There were often inconsistent limit settings due
to the differing parenting styles of the parent and extended family member. The child’s parents
did not have a close relationship; they were hostile and often verbally abused each other in front of their son. The father had a new family that the child infrequently visited. This may have contributed to his behavioural issues, but the professionals assessing the child for ADHD did not explore this possibility with the child or parents.

The other family also had issues of separation. The mother was to be remarried, the father was in a new relationship; these issues were not considered when assessing the child.

I am not suggesting that the children in this study exhibited difficult and challenging behaviour because of their family circumstances but I am raising the possibility that these circumstances may have contributed to the child’s feelings and behaviour. Since there were only three families involved in this study, generalizations are vertically impossible. Nevertheless, the findings do have significant implications in relation to the link between social and medical discourses and the phenomenon of ADHD and the family as mentioned in chapter seven and illustrated in diagrams I, II, & III. This connection requires further investigation.

Crotty (1998) states that meanings and reality are socially constructed and that there is no exception to the rule. This could be seen particularly in the education system in which these children are social members. In most schools today there are social expectations to which children need to adhere. There are rules such as the child must sit in class between certain times of the day, stay focused on tasks that are determined by the classroom teacher, participate in classroom activities appropriately, have good peer relations and complete all homework activities to a certain standard. These expectations are graded according to the expectations of both the school system and wider social values of what is age appropriate and what is not. There is one system in which children are expected to participate and succeed; this system is not flexible enough to cater for the individual differences of those children who do not fit in.
The ideology of ‘good’ children and ‘good’ mothering is socially constructed and perpetuated by our social systems and structures. Parenting manuals, books and professionals provide us with the ‘dos’ and ‘don’ts’ of raising well-behaved successful children (Biddulph, 1998; Brazelton, 1993; Saunder, 1994; Schmidt Neven, 1996). Parenting issues did impact on the mothers in this study’s view of themselves as ‘good’ mothers. They often wondered whether they had done something wrong, whether it was their fault, and the remarks of people close to them about their parenting styles reinforced this sense of blame. The automatic assumption in society today is that if a child is misbehaving, it is the parent’s fault; however this is not always correct. Social discourse supports the belief that mothers are the predominant carers for their children, that they will put their child’s needs before their own, and that they will love and nurture their child (Everingham, 1994; Greer; 1999; Wearing, 1984). So what happens when a mother does care for her child as best as she can, putting the child’s needs first, loving and nurturing the child but the child exhibits behavioural difficulties that are seen by others as unacceptable and inappropriate? The mothers in this study had a strong commitment to their family and their children. They persisted in their efforts to manage their child’s difficult behaviour even under very stressful, frustrating and confusing circumstances. The diagnosis of their child with ADHD was in some ways a relief, which removed responsibility and gave them more credibility as parents.

The children’s experience was similar. They were perceived to be ‘naughty’ children, who were always the one in trouble, leading other children astray, and the one with whom the other children did not want to play. The social expectation was for these children to be like other children. The diagnosis meant that they would be like other children by taking stimulant medication. This was not necessarily a positive experience for these children, they now thought that there was ‘something wrong’ with them and that they needed to take a pill to make them ‘normal’. Social theorists argue that socially imposed structures contribute to the oppression and disempowerment of individuals (Fay, 1975; Ife, 1997; Mullaly 1993). In the case of these three families social structures created better behaved children.
Foucault (1967, 1973, 1976) argues that the medicalisation of individual behaviour is about the power and social control of the dominant professional group. These children were sent to medical professionals, seen as the expert in this situation, to ‘help’ combat this difficult behaviour and to make them ‘normal’ like other children. They were diagnosed with ADHD and prescribed stimulant medication to alter their behaviour, and to make them like other children.

These particular issues have possible implications for the practice of professionals working with families who have a child diagnosed with ADHD. Professionals should be aware of the implications for the parents after their child is diagnosed with ADHD. They may require some counselling on the issue of blame and responsibility. Possible strategies to deal with issues that may arise in the family situation after diagnosis may include information sharing and information availability.

Professionals should take into account the experiences of the families when developing practice policies for the field of ADHD. This assumption is consistent with the theory that people are not only able define their needs but also the way their needs can be met (Ife, 1997). Within the social theory framework, people’s experiences need to be legitimized to connect the personal to the political.

I have argued that a social theoretical perspective provides a framework to explore the issues experienced by the families who have a child diagnosed with ADHD and to relate their experiences to the broader structures of contemporary society. The medical understanding of children’s behaviour and the diagnosis of ADHD is widely accepted and documented. There is little information on the experience of families living with a child diagnosed with ADHD or on the wider social implications for families.
Although children are being diagnosed and prescribed medication, nothing really changes for either those children or their families. It may be argued that the situation worsens for the children in terms of their self-image and beliefs about themselves. There is a need for a more thorough assessment to be included in the diagnosis process. Children’s own views, experiences and perceptions should also be considered. This is the missing link in the diagnosis process. Currently diagnosis relies mainly on the perceptions and interpretations of parents, school staff, and medical professional.
Appendix I

Consent forms for Participants in the Research Project

Family Members

Name of Participant

------------------------------------------------------------------------------

Project - Attention Deficit Hyperactivity Disorder

Name of Researcher – Koula Neophytou

1. I consent to participate in the above project, the particulars of which – including
details of interviews - have been explained to me and are appended hereto

2. I authorize the investigator to interview me

3. I acknowledge that:
   a) I have been informed that I am free to withdraw from the project at any time and
to withdraw any unprocessed data previously supplied
   b) the project is for the purpose of research not for treatment
   c) I have read and retained a copy of the plain language statement, and agree to the
genral purpose, methods and demands of the study
   d) the project may not be of direct benefit to me
   e) my involvement entails being interviewed, up to five times over two years, for no
   longer than two hours each time
   f) my anonymity is assured
g) confidentiality is assured, however, should information of a confidential nature need to be disclosed for moral, clinical or legal reasons, I will be given an opportunity to negotiate the terms of this disclosure.

h) the security of the data obtained is assured following completion of the study.

i) the research data collected during the study may be published, and a report of the project outcomes will be provided. Any data which may identify me will not be used.

4. I consent to the interviews being taped and later transcribed.

5. I consent to the investigator interviewing key school staff at my/our child’s school.

_____________________________
Signature

_____________________________
Date

(Participant)

_____________________________
Signature

_____________________________
Date

(Witness)
Where participants is under 18 years of age:

I consent to participation of ________________________________
in the above project.

Signature ________________________________  Date __________________

(Signature of parent/guardian)

Signature ________________________________  Date __________________

(Signature of consent)

Any queries or complaints about your participation in this project may be directed to the Secretary, Human Research Ethics Committee, RMIT, (03) 9660 1745, 124 La Trobe St Melbourne, 3000.¹

¹ This research project was commenced at RMIT, and intended to be completed at ACU. The consent forms are required by RMIT and not ACU. The research was conducted prior to commencing at ACU.
Appendix II

Interview schedule: First Interview

**Introduction** – explain the interview process and the tape recording of interview to families. Explain that there are no right or wrong answers to any questions; I am only interested in their opinions and experiences. Invite them to ask any questions at any time and to feel free to interrupt when they feel it necessary.

**Purpose** – to explore what the family’s experience has been to date, prior to the diagnosis of ADHD of their child; to explore what they know about ADHD and how the diagnosis has influenced their lives to date.

**Basic socio-demographic data** – see appendix VI

**Themes** – the family’s experience prior to the diagnosis of ADHD; the impact of the diagnosis of ADHD on the family’s daily lives

**Questions**

(Theme one)

1. What were the events leading up to receiving the diagnosis? (What was happening in the family home at that time?)

2. What is your understanding of ADHD? Where have these ideas come from?

3. Have you been to other places for assistance with your child’s behaviour, prior to going to the Children’s Hospital? If so, where, and what was that experience like for you?

4. What information did you have, if any, about ADHD to pursue a diagnosis?
(Theme two)

5. How does it feel now that the diagnosis has been made?
6. What does having the diagnosis mean to the whole family?
7. Have you noticed anything different within the home now that a diagnosis has been made?
8. How do you think ADHD has changed/influenced/impacted on the child, and the family interactions? As well as, interactions with friends, extended family, neighbours, school etc.?

Part two of interview with parents only –

(Theme one)

1. Could you describe the child’s behaviour?
2. What was your experience, prior to diagnosis, of the reaction of others such as extended family, friends, neighbours etc. to the child’s behaviour?

(Theme two)

3. Has the diagnosis made a difference how to the child and family are perceived by others, such as extended family and friends?
4. Can you describe the difference?
5. How do you think the child feels now that the diagnosis has been made?
6. How do you feel now that the diagnosis has been made?

Other issues – there any other things you would like to say or ask before we finish up?

Future Plan – arrange the next interview.
Interview Schedule – Second - Fifth Interview

**Purpose** – to explore any changes that may have occurred since diagnosis and last interview relating to:

- the family
- school
- contact with extended family and friends.

- and to explore the family’s experience of any such changes.

The questions for the next four interview schedules largely related to the information obtained from the previous interviews. Questions were formulated after the interviews had been transcribed and issues were clarified in the following interview.

The main goal of all the interviews was to explore with the families what had changed since the last time we met, what had remained the same, and to identify the current issues and stresses they were experiencing at the time.

The interviews always started by asking the interviewee(s) how they had been since the last time we met and whether their interactions had changed or remained the same.

In the second to fifth interviews there was also much discussion of the parent’s views on the medication, and the reactions of extended family and friends to the medication and diagnosis.

Every interview ended by asking the families whether they have any questions, whether they would like to say anything else and establishing that they were feeling okay about the information that they had shared.
Appendix III

Consent Forms for School Staff

Name of Participant

Name of School

Project – Attention Deficit Hyperactivity Disorder

Name of Researcher – Koula Neophytou

1. I consent to participate in the above project, the particulars of which – including details of interview - have been explained to me and are appended hereto

2. I authorize the investigator to interview me

3. I acknowledge that:
   a) I have been informed that I am free to withdraw from the project at any time and to withdraw any unprocessed data previously supplied
   b) the project is for the purpose of research not for treatment
   c) I have read and retained a copy of the plain language statement, and agree to the general purpose, methods and demands of the study
   d) the project may not be of direct benefit to me
   e) my involvement entails being interviewed, up to five times over two years, for no longer than two hours each time
   f) my anonymity is assured
   g) confidentiality is assured, however, should information of a confidential nature need to be disclosed for moral, clinical or legal reasons, I will be given an opportunity to negotiate the terms of this disclosure
   h) the security of the data obtained is assured following completion of the study
   i) the research data collected during the study may be published, and a report of the project outcomes will be provided. Any data which may identify me will not be used.
4. I consent to the interviews being taped and later transcribed.

Signature ___________________________ Date _______________________

(Participant)

Signature ___________________________ Date _______________________

(Witness)

Any queries or complaints about your participation in this project may be directed to the Secretary, Human Research Ethics Committee, RMIT, (03) 9660 1745, 124 La Trobe St Melbourne, 3000.

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2 This consent form was devised to meet RMIT requirements. Teachers were interviewed prior to commencement at ACU.
Appendix IV

Plain Language Statement for School Principals

Information on Research Project:
As part of a master’s degree, I am undertaking a research project involving children of primary school age who have been diagnosed with Attention Deficit Hyperactivity Disorder.

ADHD is a diagnostic label given to children presenting attention, hyperactivity and impulsivity difficulties. It is now the most common paediatric psychiatric disorder for referral to mental health professionals. To date there has been little, if any, research conducted which incorporates a social perspective, exploring the personal and social experiences of children diagnosed with ADHD, and the implications for them and their families.

The purpose of this project is to gain a broader understanding of the experiences of these children and their families after a diagnosis of ADHD has been made and a treatment plan commenced. Such an understanding will help foster the development of a more holistic approach to the management of this issue in our community. The specific aims of the study are:

- to conduct a long-term study exploring the individual, family and social factors involved in the diagnosis and treatment of ADHD
- to provide a social perspective upon ADHD and its impact on families with child/ren diagnosed with ADHD
- to understand within a social framework the changes that may occur for the family and child after diagnosis is made and an intervention plan introduced.

I plan to gather the information for the study two different sources over a period of two years. This will occur through interviews with families in which a child has been recently diagnosed with ADHD. With the permission of the families concerned, I will then interview key staff at
the school attended by the child diagnosed with ADHD. I hope to interview key staff at your school who you believe to be the most appropriate person/s with whom I can talk concerning the particular child diagnosed with ADHD.

The reason for involving staff from the school attended by the child is that they will be able to provide further information regarding the child’s social interactions, and any changed and difficulties that may have occurred since the diagnosis of ADHD and the commencement of medication, and any continuing concerns. Information from other key people in the child’s life apart from family members will provide important additional information on the experiences of the child which will broaden the understanding of ADHD. The staff concerned would be asked whether there have been any noticeable changes to the child’s behaviour since diagnosis and medication administered; what their understanding of ADHD is; and about their general observations of the child, and his social interactions with his/her peers.

I plan to conduct two interviews with the relevant staff member/s during the two year period. I estimate that each interview will take approximately one hour.

Interviews with staff will take place at the school, and I plan to audiotape them so that they can be transcribed for later analysis. I want to stress that staff participation in the study is entirely voluntary and that consent to participate or to use any unprocessed data from the study can be withdrawn at any time. I also want to make clear that confidentiality of the data will be maintained at all times. The identities of participants will be protected through a coding system, and the tapes and transcripts of the interviews will be kept in a locked filing cabinet. Data will be presented in the form of themes that emerge from the study, illustrated at times with non-identifiable quotes from the people involved in the study. To ensure that data is not identifiable, pseudonyms will be used, and any identifying details disguised. In addition, information provided in the interviews with school staff will not be passed on by me to the
child or members of his/her family. Similarly, information given to me by family members will not be passed on to the school.

Should you need further information on, or clarification of, the project, please feel free to contact me during work hours on 9465 0322. If you have any questions or concerns about the project at any time, please contact the secretary of the ethics committee.

Koula Neophytou (BSW)

Appendix V

Teacher Interview Schedule

(a guide)

How long has the student been in the teacher’s classroom?

How did the child behave prior to diagnosis?

How was his relationship with his peers?

What sort of things did he get into trouble for?

What are some of the positives about the child prior to diagnosis?

Since diagnosis what have you notice that is different?

Have there been any changes in the child’s behaviour? If so what are they?

Have you noticed any changes to the child’s relationships and social interactions with their peers, family and other significant others?

Have there been any noticeable differences in the child’s school work?

What is your understanding of ADHD?
Has the school made any adjustments to assist the child diagnosed with ADHD? If so, what were they/are they?

Would you like to add any further information or questions?
## Appendix VI

**Fact Sheet**

**Family members:**

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**Guardian/parent**

**Children**

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**Child diagnosed with ADHD**

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Date of diagnosis

Date of referral to study

Date of first interview

Date of second interview
Date of third interview

Date of fourth interview

Date of fifth interview

Significant others living in family home

Any other relevant information
The Green family was referred to the study by the Royal Children’s hospital, Melbourne. The immediate household consisted of Joanne and David who were to be married, and their children from previous relationships Peter and Paul. The family lived in the outer-eastern suburbs of Melbourne in semi-rural surroundings. At the time of the interviews Joanne was working part-time in country Victoria. This meant that Peter had to be up very early to be dropped off at school. David was a truck driver, which meant he was regularly away from home.

The first interview involved the whole family that is, Joanne, David, Peter and Paul. At the time of the interviews Peter was 9 years old; he attended the local primary school and was in grade 3. Peter’s experience at school had been overshadowed by his behavioural, social and academic difficulties. Joanne was often called up to the school to discuss Peter’s behaviour.
The family experienced a lot of difficulties with Peter’s behaviour and wanted the situation to improve. They were determined to make things better, as the school staff were also finding his behaviour difficult to manage. The school suggested that they have Peter assessed at the Children’s Hospital. Amy attended all doctor appointments with Joanne. This was significant in the long term as it led to a better understanding and co-operative relationship between the two families.

Prior to diagnosis Joanne and David experienced continual behaviour difficulties; the school stated that Peter was a bright boy but that his behaviour was an issue. The family had no knowledge of ADHD prior to the diagnosis. Although they had heard of it, they did not think Peter ‘had it’. They thought he was just a naughty boy and that they could somehow manage his behaviour. Joanne and David had different discipline strategies and would often disagree with each other. Joanne thought David was too hard on Peter, and David thought Joanne was too lenient.

The family learnt to deal with the behavioural difficulties in its own way; they found strategies that would work sometimes and other times not. After the teacher first suggested that they have Peter assessed, they did so because they wanted the situation to improve both at home and at school. Both Joanne and David described feelings of relief, because they now had a reason and an explanation for the behavioural difficulties Peter was exhibiting. Prior to the diagnosis they thought the behavioural difficulties might be due to their parenting, or the fact that Peter’s parents had separated and both were in new relationships now. The diagnosis absolved them from feelings of responsibility, guilt and failure.

However, the diagnosis bought other complications. They were encouraged to give Peter medication. They did so, and he experienced some side effects. He lost his appetite consequently lost weight; he was no longer sleeping, although prior to medication he was a good sleeper. People began treating Peter differently. Having a mental health label meant that
Peter felt he was ‘mental’ and that there was something wrong with him. He did not think this before.

Medication stimulated obvious changes in Peter’s behaviour. His behaviour at school improved; he concentrated more on the task at hand; he completed projects; other children started to play with him more often; he was more accepted at social gatherings and parties; and people did not yell at him anymore. Although his parents found the diagnosis beneficial in providing an explanation for his behaviour, some people thought that the diagnosis was an excuse for Peter to get away with behaving badly.

After some time on the medication Joanne and David decided not to give Peter medication when he was at home from school or on weekends. The medication was used mainly for the purposes of school and social events/outings. If the family was on an outing Peter would take a tablet beforehand.

Does this tell the child that he is not trusted to behave appropriately, that he might embarrass his family, that he might draw unnecessary attention to the family, or that his ‘normal’ self is not acceptable in public. Did it mean that the parents were seen as good parents because their child was well-behaved?

The family continued to give Peter his medication throughout the time I interviewed them. They had an ambivalent attitude towards the diagnosis and medication but continued to participate in the process as they felt they had little choice. If they wanted Peter to do well at school, be seen as a good boy, have friends, medication seemed to be the only option available.
The Jones Family was also referred to the study by the Royal Children’s Hospital, Melbourne. The immediate household consisted of Sally, Matt and Steve. At the time of the interviews Sally and Matt lived in the back of Steve’s house, which was being renovated at the time. It was a two bedroom flat attached to the main house separated by a door. This meant that Matt spent nearly all of his time in his grandfather’s home, which Sally found very frustrating. It meant she was unable to be consistent with her parenting and discipline strategies, Matt was able to get away with a lot more in his grandfather’s home. This resulted in arguments between Sally and her father over Matt’s behaviour and discipline methods.

All the interviews were with Sally, Matt did not want to participate although he knew about them and was present for the first interview only. Sally was in her late 20’s and Matt was a result of a relationship in her late teens. She would often express anger towards Matt’s father. It appears they did not have a very good relationship, even years on the relationship seemed to be conflicting.

Sally described her life with Matt, prior to diagnosis, as ‘absolute hell’. She stated that his behaviour was totally uncontrollable, nasty and rude. She seemed to take a lot of Matt’s behaviour as if it was a personal attack. She often stated that he hurt her feelings. Sally described Matt as a lovely little boy before he went to school, then something changed, and she was unable to understand why these changes took place.
Sally often attended meetings with the teacher and school principal about Matt’s behaviour. She found this stressful; she began to feel that she was failing as a mother. This resulted in her getting angrier at Matt’s father for not being around for Matt or her.

The classroom teacher first suggested having an ADHD assessment at the Children’s Hospital to Sally. Sally did not believe that Matt was ‘one of those children’. Sally had seen children on television who were diagnosed with ADHD, and Matt was not like them. Although he had tantrums and threw things around, she believed that he had learnt this from her. She also thought that the diagnosis was a ‘cop out’. However she did go to see the doctor at the Children’s Hospital, and they came away with an assessment and a recommendation that Matt take medication.

Being able to control Matt’s behaviour was important to Sally. She would frequently state that when he was younger she was able to control his behaviour, which meant that she was parenting appropriately. As he got older he became more difficult to control. Sally thought this showed she was not a good enough parent, that Matt did not love her and that was why he would not listen to her. Sally associated good behaviour with ‘good’ parenting. Other people’s opinions of her parenting abilities were important to her. She did not want people to think badly of her or Matt. Her relationships with her siblings were not always supportive; they thought that Matt was a naughty boy who needed to be disciplined.

The diagnosis has helped Sally to be more patient with Matt; she stopped yelling at him and fighting with him because she no longer believed that it was his fault. There was a shift in her interaction with Matt.

The medication was positive for Matt in terms of keeping him focused and on task although his teacher stated that she felt his personality changed, and that he was no longer spontaneous. Sally rarely got called up to the school for meetings to discuss Matt’s behaviour. In social situations Matt was no longer the focus of negative attention. Even Steve began to notice that Sally and Matt’s interactions had become more positive and that she did not yell as much anymore.

What made this situation more complicated was that Matt’s father did not believe in the diagnosis; Sally felt unsupported by him; he refused to read any material she gave him on ADHD; and he did not give Matt his medication when on access visits.
The Peters family was referred by the mental health service of the Royal Children’s Hospital, Melbourne. The family lived in the Western suburbs of Melbourne in a ministry of housing home. The house was very chaotic, with the entrance hall and lounge room stacked with boxes. This family appeared to experience many financial and relationship difficulties with other family members, friends and the school. Stephanie found trying to manage Billy’s behaviour extremely stressful and at times impossible. She talked about his aggressive outbursts. He would run off and she would not know where he had gone or when he would return. He engaged in risk taking behaviour which lead him to be known by the local police. Billy did not have many friendships. He found school unpleasant and refused to attend. Stephanie would often meet with the school to discuss either Billy’s inappropriate behaviour or strategies to get him to school.

There was a history of violence and abuse in this family. Fred was physically and verbally abusive to both the children and Stephanie. There had been times when the family had fled to a women’s refuge. At the time of the interviews Stephanie and Fred were separated although he visited the family home frequently. Kylie also visited the family home and Tony stayed with the family regularly.

The first family interview consisted of Stephanie, Billy and Karen. Both Stephanie and Karen took delight in recalling stories of Billy’s behaviour. Billy sat quietly and would only speak when directly asked a question.
Stephanie stated that it was the kindergarten teacher who first suggested she have Billy assessed by a professional because his behaviour was disruptive and aggressive. Billy’s behaviour was often very unpredictable. According to Stephanie Billy would sneak out of his bedroom window when he was sent to his room for punishment. If he could not get out through the window, he would destroy his room, kick or punch holes in the walls and doors, and he would scream at the top of his voice, raising concerns and the attention of the neighbours. Stephanie stated that once after one of Billy’s screaming incidents, child protection was notified, and the case was investigated and later closed.

Stephanie stopped going out to parties and social gatherings because Billy would play up so much that she was made to feel that it was her fault, because she was not parenting appropriately, and that Billy was a very naughty boy who needed discipline. Family and friends often advised Stephanie on what to do and how to do it, which she did not find helpful. Billy had few friends at school, and from a very young age, he fought with other children. Other children were frightened of him, and he had been suspended from school.

Stephanie sought a lot of professional advice about Billy’s behaviour; from the time he was 4 she began looking for assistance and help. She reached a point of desperation, where she considered putting him into ‘a home’, because she was unable to manage his behaviour and no one was able to help her. Professionals were reluctant to diagnose him as ADHD but in the end they thought they would try him on the medication and hoped that that would alleviate some of Stephanie’s stress and Billy’s behavioural difficulties.

Billy was diagnosed with ADHD and given the medication. The medication did assist Billy to be more compliant and calmer, and to be less aggressive, defiant and disruptive. Family and friends were pleasantly surprised by the change in Billy, and once there was a reason for his behaviour, people were much more tolerant and understanding. Medication improved things greatly for Billy and his family.
Key

- Male
- Female

- Married couple
- Couple living together
- Couple separated
- Couple divorced
- Couple separated
- Deceased

Deceased
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