

**RAISING A CHILD WITH ATTENTION DEFICIT HYPERACTIVITY
DISORDER: A PARENTS' PERSPECTIVE**

by

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**This thesis is dedicated to my son
Stephen Farrer**

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SUMMARY

According to DSM-IV criteria a child has attention-deficit hyperactivity disorder (ADHD) if the child consistently shows one or more of the following characteristics over a period of time, and to a degree that is maladaptive and inconsistent with the child's developmental level: (1) inattention, (2) hyperactivity, and (3) impulsivity (Santrock, 2002).

Despite the years of research and the advances in understanding and treating children with ADHD, the disorder continues to be a serious educational and social impairment (Weiss & Hechtman, 1993). When examining the literature on ADHD, what is very clear is the scarcity of published literature that draws from parental perceptions on the disorder. If we are to fully understand ADHD and the effect that it has upon our society it is vital that a candid examination of parents' perceptions occur.

This qualitative, phenomenological study used in-depth interviews to explore parents' perceptions of raising a child with ADHD. The present study focused on parents' perceptions regarding five aspects of raising children with ADHD, namely: 1) parents' perceptions regarding their interaction with health professionals and the child's use of medication, 2) parents' perceptions regarding the effects of ADHD on family life, 3) parents' perceptions about their ADHD child and the school experience, 4) parents' concerns and hopes for their ADHD child, and 5) getting through the day and advice for other parents of ADHD children.

A number of implications for health and educational professionals arose from the current study's examination of parents' experiences, insights, and strategies for dealing with the ADHD child. Parents also discussed their concerns for the future for their ADHD child and offered valuable advice for other parents whose child has just been diagnosed with ADHD.

How parents view the experience of raising a child with ADHD, their feelings about the experience, the actions that they take, and the strategies that they use to cope is important information that will assist in understanding and interacting with families who have a child with ADHD.

Key terms: Attention Deficit Hyperactivity Disorder, parents' perspective, phenomenology, in-depth interviews, health professionals, school, family, concerns, coping, advice.

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CHAPTER ONE: INTRODUCTION

“They can’t sit still; they don’t pay attention to the teacher; they mess around and get into trouble; they try to get others into trouble; they are rude; they get mad when they don’t get their own way” (Henker & Whalen , 1989, p216).

When it was first identified, hyperactivity was defined principally as a problem of excess motor activity, and the term was used to describe children who could not sit still and were continually on the go (Sigelman & Rider, 2003). Now hyperactivity is viewed as first and foremost a problem of attention. According to DSM-IV criteria a child has attention-deficit hyperactivity disorder (ADHD) if the child consistently shows one or more of the following characteristics for at least six months, and to a degree that is maladaptive and inconsistent with the child’s developmental level: (1) inattention, (2) hyperactivity, and (3) impulsivity (Santrock, 2002).

Children who are **inattentive** frequently fail to listen, have difficulty focusing on any one thing, and display an inability to finish tasks, often getting bored with a task after only a few minutes. Children who are **hyperactive** show high levels of physical activity, almost always seeming to be in motion, perpetually fidgeting, finger tapping and chattering. Children who are **impulsive** have difficulty curbing their reactions and don’t do a good job of thinking before they act. The impulsive child cannot inhibit an urge to blurt out something in class and has difficulty waiting for a turn during group activities (Santrock, 2002).

Depending on the specific characteristics which children with ADHD display, they can be diagnosed as: (1) ADHD with predominantly inattention, (2) ADHD with predominantly hyperactivity/impulsivity, or (3) ADHD with both inattention and hyperactivity/impulsivity (Whalen, 2000). Those children with attention-deficit hyperactivity disorder who are mainly inattentive, but not hyperactive and impulsive, tend not to be disruptive, but often have difficulty in the school context (Weyandt, 2001). Those children with ADHD who are predominantly hyperactive and impulsive as well as inattentive are often diagnosed as having conduct disorders or other externalising problems as well. They are likely to irritate adults and become locked in coercive power struggles with their parents, interactions that only aggravate their problems (Barkley, Fischer, Edelbrock & Smallish, 1991; Buhrmester, Camparo, Christensen, Gonzales & Hinshaw, 1992). Because their behaviour is so disruptive,

they are also rejected by peers, which can have its own damaging effects on their adjustment and later development (Deater-Deckard, 2001; Whalen, Henker, Buhrmester, Hinshaw, Huber & Laski, 1989).

Not only do many children with ADHD have conduct disorders and behave aggressively, but many also have diagnosable learning disabilities and some suffer from depression or anxiety disorders.

Despite the years of research and the advances in understanding and treating children with ADHD, the disorder continues to be a serious educational and social impairment (Weiss & Hechtman, 1993). When examining the literature on ADHD, what is very clear is the scarcity of published literature that draws from parental perceptions on the disorder (Fowler, 1990; Hughes, 1990). There has been some research on family interactions, but none where parents discussed **their** perceptions of raising a child with ADHD and how it affected their whole family. If we are to fully understand ADHD and the effect that it has upon our society it is vital that a candid examination of parents' perceptions occur. A sense of the concrete day-to-day life of the parents as they go about the work of parenting a child with ADHD is needed. Also needed is a sense of the inner perceptions of the parents as they interact with their children and the medical and educational professionals.

The purpose of the present study was to explore, through in-depth interviewing, parents' perceptions of raising a child with ADHD. The present study focused on parents' perceptions regarding five aspects of raising children with ADHD, namely:

- Parents' perceptions regarding their interaction with health professionals and the child's use of medication
- Parents' perceptions regarding the effects of ADHD on family life
- Parents' perceptions about their ADHD child and the school experience
- Parents' concerns and hopes for their ADHD child
- Getting through the day and advice for other parents of ADHD children

How parents view the experience of raising a child with ADHD, their feelings about the experience, the actions that they take, and the strategies that they use to cope is important information that will assist in understanding and interacting with families who have a child with ADHD. Parents of children who have been diagnosed with ADHD need the services of both the educational and medical communities. Once professionals have a better understanding of the experiences of parenting a child

with ADHD, effective partnerships between parents and professionals can be developed. Insights and information obtained can, for example, assist professionals to:

- Provide education for parents and families on issues in which they demonstrate a lack of knowledge
- Establish family counselling systems that address the issues and concerns of highest priority that extend throughout the years of parenting a child with ADHD
- Make better use of pharmacological interventions for children with ADHD by carefully considering parental perceptions and needs.

Another important consideration is that today experts in the field, such as Russell Barkley, are recommending a multidimensional treatment programme when ADHD has been diagnosed in a child (Barkley, 1990). They recommend that the treatment should include: medication, behaviour management, educational interventions, and family training and counselling. If these treatment programmes are to be successful it is imperative that special educators, medical professionals, psychological practitioners, and parents work together to provide the most effective treatment programme. It is necessary for parents and professionals to understand each other if they are to effectively work together. For this reason, it is vital to examine parents' experiences, insights and strategies for coping with an ADHD child.

As stated, the focus of this study was to examine parents' experience of raising an ADHD child. However, in order to do this, it is necessary to first gain an understanding of Attention Deficit Hyperactivity Disorder (ADHD). The following chapter will provide an overview of the disorder.

CHAPTER TWO: ADHD: AN OVERVIEW

2.1 The changing face of ADHD

Attention-Deficit/Hyperactivity disorder (ADHD) is the most recent diagnostic label for children presenting with significant problems with attention, impulsiveness and overactivity (Barkley, 1998). Children with ADHD represent a heterogeneous population who display considerable variation in the degree of their symptoms, and in the extent to which other disorders occur in association with it.

The history of ADHD spans nearly a century of clinical and scientific publications on the disorder. An overview of this history is vital as it within this history that the concepts reside that serve as the foundation for the current conceptualisations of the disorder and its treatment. This chapter will discuss the history of ADHD as outlined by Barkley (1998).

2.1.1 The period 1900 to the late 1950s

According to Barkley (1998), credit is awarded to George Still and Alfred Tredgold as being the first authors to focus scientific attention on the behavioural condition in children that most closely approximates what is today known as ADHD.

2.1.1.1 Still's view

In a series of three published lectures, Still in 1902 described 43 children in his clinical practice who were often aggressive, defiant, resistant to discipline, excessively emotional, and who showed little inhibitory volition. Still was particularly impressed by the serious problems with sustained attention that these cases often manifested. Most were also quite overactive. Still believed these children displayed a major deficit in moral control in their behaviour, that was relatively chronic in most cases. Much as today, a greater proportion of males than females existed in Still's cases (3:1) and their disorder appeared to arise in most cases before eight years of age and frequently in early childhood (two to six years of age).

Still proposed a biological predisposition to this behavioural condition that was probably hereditary in some children, while the result of prenatal or postnatal injury in others. Still hypothesized that the deficits in inhibitory volition, moral control, and sustained attention were causally related to each other, and to the same underlying neurological deficiency. He speculated on the possibility of either a decreased

threshold for inhibition of responding to stimuli or a cortical disconnection syndrome where intellect was dissociated from will, which may be due to neuronal cell modification or brain damage. Later Tredgold (1908) would also subscribe to this theory of early, mild and undetected brain damage to account for the disorder. Temporary improvements in conduct might be achieved by alterations in the environment or by medications, both Still and Tredgold found, but they stressed the relative permanence of the defect even in these cases. The need for special educational environments for these children was strongly emphasized.

2.1.1.2 North American interest in ADHD

According to Barkley (1998) the history of interest in ADHD in North America is frequently traced to the outbreak of an encephalitis epidemic in 1917-1918. Clinicians were presented with a number of children who survived this brain infection, yet were left with significant behavioural and cognitive sequelae. Numerous papers reported these sequelae and they included many of the characteristics that are now incorporated into the concept of ADHD. Such children were described as being impaired in attention, regulation of activity, and impulsivity, as well as other cognitive abilities, including memory, and were often noted to be socially disruptive. Symptoms of oppositional and defiant behaviour, as well as delinquency and conduct disorder, also arose in some cases. Postencephalitic Behaviour Disorder, as it was called, was seen as clearly the result of brain damage. The large number of children affected resulted in significant professional and educational interest.

2.1.1.3 The origins of a brain-damage syndrome

The association of a brain disease with behavioural pathology led early investigators to study other potential causes of brain injury in children and their behavioural manifestations. Birth trauma (Shirley, 1939); other infections such as measles (Meyers & Byers, 1952); lead toxicity (Byers & Lord, 1943); epilepsy (Levin, 1938); and head injury (Werner & Strauss, 1941) were studied in children and were found to be associated with numerous cognitive and behavioural impairments, including the triad of ADHD symptoms. Other terms introduced during this era for children displaying these behavioural characteristics were organic drivenness (Kahn & Cohen, 1934) and restlessness syndrome (Levin, 1938).

Notable during this era was also the recognition of the striking similarity between hyperactive children and the behavioural sequelae of frontal lobe lesions in primates (Levin, 1938). Frontal lobe lesions in monkeys were known to result in excessive

restlessness, poor ability to sustain interest in activities, aimless wandering, and excessive appetite, among other behavioural changes. Several investigators, such as Levin (1938), would use these similarities to speculate that severe restlessness in children was likely the result of pathological defects in the fore-brain structures. Later investigators (e.g., Chelune, Ferguson, Koon & Dickey, 1986; Lou, Henriksen, Bruhn, Borner & Nielsen, 1989; Mattes, 1980) would return to this notion, but with greater evidence to substantiate their claims.

Milder forms of hyperactivity, in contrast, were attributed in this era to psychological causes such as spoiling the child or delinquent family environments. This theme would also get resurrected again in the 1970s and beyond.

In the 1940s it became fashionable to consider most children hospitalised in psychiatric facilities with hyperactive symptoms to have suffered from some type of brain damage, such as encephalitis or pre/perinatal trauma, whether or not the clinical history of the case contained evidence of such. The concept of the brain-injured child was to be born in this decade (Strauss & Lehtinen, 1947). This term would later evolve into the concept of minimal brain damage and, eventually minimal brain dysfunction (MBD) by the 1950s and 1960s.

Substantial recommendations for educating these brain-damaged children were made by Strauss and Lehtinen (1947), which included placement in smaller, more regulated classrooms and reducing the amount of distracting stimulation in the environment.

2.1.1.4 Beginnings of child psychopharmacology with ADHD

A significant series of papers on the treatment of hyperactive children appeared in 1937-1941. These papers were to mark the beginning of medication therapy for behaviourally disordered children (Bradley, 1937; Bradley & Bowen, 1940; Molitch & Eccles, 1937). They revealed the efficacy of amphetamines in reducing the disruptive behaviour and improving the academic performance of behaviourally disordered children hospitalised at the Emma Pendleton Bradley Home in Providence, Rhode Island. Later studies would also confirm such a positive drug response in half or more of hyperactive children (Laufer, Denhoff & Solomons, 1957). As a result, by the 1970s, stimulant medications had become the treatment of choice for ADHD; and they remain so today.

2.1.1.5 The emergence of a hyperkinetic syndrome

In the 1950s investigators began a number of investigations into the neurological mechanisms underlying the behavioural symptoms of ADHD, the most famous of which was probably that by Laufer et al. (1957). These writers referred to ADHD children as having Hyperkinetic Impulse Disorder, and reasoned that the central nervous system deficit occurred in the thalamic area. Here, poor filtering of stimulation occurred, allowing an excess of stimulation to reach the brain. Their evidence was based on a study of the effects of the photo-Metrozol method in which the drug Metrozol is administered while flashes of light are presented to the child. The amount of drug required to induce a muscle jerk of the forearms, along with a spike-wave pattern on the electroencephalogram, serves as the measure of interest.

Laufer et al. (1957) found that hyperactive inpatient children required less Metrozol than nonhyperactive children to induce this pattern of response. This finding suggested that hyperactive children have a lower threshold for stimulation in the thalamic area. The study would never be replicated, and it is unlikely that such research would pass today's standards of ethical conduct in research. Nevertheless, it remains a milestone in the history of the disorder for its delineation of a more specific mechanism that might give rise to hyperactivity (cortical overstimulation).

Others at the time also conjectured that an imbalance between cortical and subcortical areas existed, such that there was diminished control of subcortical areas responsible for sensory filtering, which permitted excess stimulation to reach the cortex (Knobel, Wolman & Mason, 1959).

2.1.2 The period 1960 to 1969

2.1.2.1 The decline of Minimal Brain Dysfunction

In the late 1950s and early 1960s, critical reviews began appearing questioning the concept of a unitary syndrome of brain damage in children. Chief among these critical reviews were those of Birch (1964), Herbert (1964), and Rapin (1964), who questioned the validity of applying the concept of brain damage to children who had only equivocal signs of neurological involvement, not necessarily damage.

The concept of MBD would die a slow death as it eventually became recognised as vague, overinclusive, of little or no prescriptive value, and without much neurological evidence (Kirk, 1963). Its value remained in its emphasis on neurological mechanisms over the often convoluted environmental mechanisms proposed at the

time, particularly those etiological hypotheses stemming from psychoanalytical theory, which blamed parental and family factors entirely for these problems (Hertzig, Bortner & Birch, 1969; Kessler, 1980). The term MBD would eventually be replaced by more specific labels applying to somewhat more homogenous populations of cognitive, learning, and behavioural disorders, such as dyslexia, language disorders, learning disabilities, and hyperactivity. These new labels were based on the observable and descriptive deficits of the child, rather than on some underlying, unobservable etiological mechanism in the brain.

2.1.2.2 The hyperactive child syndrome

At the same time that dissatisfaction with the term MBD was occurring, the concept of a hyperactive child syndrome arose, described in papers by Laufer and Denhoff (1957) and Chess (1960).

Chess (1960, p. 2379) defined hyperactivity as follows: “The hyperactive child is 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”. Chess’s article was historically significant because: (1) it emphasized activity as the defining feature of the disorder, as other scientists of the time would also do, (2) it stressed the need to consider objective evidence of the symptom beyond the subjective reports of parents or teachers, (3) it took the blame for the child’s problems away from the parents, and (4) it separated the syndrome of hyperactivity from the concept of a brain-damaged syndrome. It would now be recognised that hyperactivity was a behavioural syndrome that could arise from organic pathology, but could also occur in its absence. Even so, it would continue to be viewed as a result of some biological difficulty, rather than solely due to environmental causes.

Unlike early writers like Still, Chess (1960) and other writers in this era stressed the relatively benign nature of ADHD symptoms and claimed that in most cases it resolved by puberty (Laufer & Denhoff, 1957; Solomons, 1965).

Also noteworthy in this era (1960-1969) was the definition of hyperactivity given in the second edition of the *Diagnostic and Statistical Manual of Mental Disorders* (DSM-II, American Psychiatric Association, 1968). It employed only a single sentence describing the disorder and, following the lead of Chess (1960), stressed the view that the disorder was developmentally benign: “The disorder is characterized by overactivity, restlessness, distractibility, and short attention span, especially in young

children; the behaviour usually diminishes by adolescence” (DSM-II, American Psychiatric Association, 1968, p.50).

2.1.2.3 Europe and North America disagree

In this period, the perspective of hyperactivity in North America began to diverge from that in Europe, and particularly Great Britain. In North America, hyperactivity would become a behavioural syndrome recognised chiefly by greater-than-normal levels of activity, would be viewed as a relatively common disturbance of childhood, would not necessarily be associated with demonstrable brain pathology or mental retardation, and would be viewed as more of an extreme degree in the normal variation of temperament in children.

In Great Britain, the narrower view would continue into the 1970s that hyperactivity or hyperkinesis was an extreme state of excessive activity of almost driven quality, was highly uncommon, and usually occurred in conjunction with other signs of brain damage, such as epilepsy, hemiplegias, retardation, or a clearer history of brain insult such as trauma or infection (Taylor, 1988).

The divergence in views would lead to large discrepancies between North America and Europe in their estimations of the prevalence of the disorder, their diagnostic criteria, and the preferred treatment modalities. Reconciliation between these views would not occur until well into the 1980s (Rutter, 1988, 1989; Taylor, 1986, 1988).

2.1.3 The period 1970 to 1979

By the early 1970s the defining features of the hyperactive or hyperkinetic child syndrome were broadened to include what investigators previously felt to be only associated characteristics, including impulsivity, short attention span, low frustration tolerance, distractibility and aggressiveness (Marwitt & Stenner, 1972; Safer & Allen, 1976).

Others (Wender, 1971, 1973) persisted with the excessively inclusive concept of MBD in which even more features, such as motor clumsiness, cognitive impairments, and parent-child conflict were viewed as hallmarks of the syndrome, and in which hyperactivity not necessary for the diagnosis.

The diagnostic term MBD would fade from clinical and scientific usage by the end of this decade, due to critical reviews by authors such as Rutter (1977). These writings

emphasized the lack of evidence for such a broad syndrome in that the symptoms were not well defined, did not correlate significantly among themselves, had no well-specified etiology, and displayed no common course and outcome. The heterogeneity of the disorder was overwhelming and many took note of the apparent hypocrisy of defining an MBD syndrome with statements that there was often little or no evidence of neurological abnormality. Moreover, even in cases of well-established cerebral damage, the behavioural sequelae were not uniform across cases and hyperactivity was seen only in a minority. Hence, contrary to 25 years of theorising to this point, hyperactivity was not a common sequelae of brain damage. Truly brain-damaged children did not display a uniform pattern of behavioural deficits, and children with hyperactivity rarely had substantiated evidence of neurological damage (Rutter, 1989).

2.1.3.1 Wender's theory of MBD

This decade (1970-1979) was notable for the development of two different models of the nature of ADHD: Wender's theory of MBD, and Douglas's model of attention and impulse control in hyperactive children.

Wender (1971) described the essential psychological characteristics of children with MBD as consisting of six clusters of symptoms: (1) motor behaviour, (2) attentional-perceptual cognitive function, (3) learning difficulties, (4) impulse control, (5) interpersonal relations, and (6) emotion.

Within the realm of motor behaviour, the essential features were noted to be hyperactivity and poor motor coordination. Excessive speech, colic, and sleeping difficulties were thought to be related to the hyperactivity. Foreshadowing the later official designation of a group of children with attentional problems who would not be hyperactive (ADD without Hyperactivity; American Psychiatric Association, 1980), Wender expressed the opinion that some of these children were hypoactive and listless while still demonstrating attentional disturbance. He argued that they should be included within this syndrome because of their manifestation of many of the other difficulties thought to characterize it.

With regard to attentional and perceptual-cognitive functioning, short attention span and poor concentration were described as the most striking deficit. Distractibility and daydreaming were also included with these attentional disturbances, as was poor organization of ideas or concepts.

Learning difficulties were the third domain of dysfunction, with most of these children observed to be doing poorly in their academic performance. A large percentage was described as having specific difficulties with learning to read, with handwriting, and with reading comprehension and arithmetic.

Impulse control problems, or a decreased ability to inhibit behaviour, were identified as a fourth cluster. Within this general category, Wender included low frustration tolerance; an inability to delay gratification; antisocial behaviour; lack of planning, forethought or judgement; and poor sphincter control leading to enuresis and encopresis. Disorderliness, or lack of organization, and recklessness, particularly with regard to bodily safety, was also listed.

In the area of interpersonal relations, unresponsiveness to social demands was singled out as the most serious deficit. Extroversion, excessive independence, obstinence, stubbornness, negativism, disobedience, non-compliance, sassiness, and an imperviousness were some of the characteristics that instantiated the problem with interpersonal relations.

Finally, within the domain of emotional difficulties, Wender included increased lability of mood, altered reactivity, increased anger, aggressiveness, and temper outbursts, as well as dysphoria. The dysphoria of these children involved the specific difficulties of adhedonia, depression, low self-esteem, and anxiety. A diminished sensitivity to both pain and punishment were also felt to typify this area of dysfunction in children with MBD.

Wender theorised that these six domains of dysfunction could be best accounted for by three primary deficits: (1) a decreased experience of pleasure and pain, (2) a generally high and poorly modulated level of activation, and (3) extroversion. A consequence of the first deficit is that MBD children would prove less sensitive to both rewards and punishments, making them less susceptible to social influence. The generally high and poorly modulated levels of activation were thought to be aspects of poor inhibition. Hyperactivity, of course, was the consummate demonstration of this high level of activation. The problems with poor sustained attention and distractibility were conjectured to be secondary aspects of high activation. Emotional overreactivity, low frustration tolerance, quickness to anger, and temper outbursts resulted from the poor modulation of activation. These three

primary deficits affected the larger social ecology of the child, resulting in numerous interpersonal problems and academic performance difficulties.

From the advantage of hindsight and subsequent research it is evident that Wender is combining the symptoms of Oppositional Defiance Disorder (and even Conduct Disorder) with those of ADHD to form a single disorder (Barkley, 1998). This is likely due to clinic-referred cases being the starting point for his theory, as many clinic-referred cases are comorbid for both disorders. Research (for example Hinshaw, 1987) now shows that these are not the same disorder.

2.1.3.2 The emergence of attention deficits

In this decade, disenchantment developed with the exclusive focus on hyperactivity as the main feature of the disorder. Significant at this time was the presidential address of Virginia Douglas to the Canadian Psychological Association (Douglas, 1972), in which she argued that deficits in sustained attention and impulse control were more likely to account for the difficulties seen in these children than just hyperactivity. These other symptoms were also seen as the major areas of impact of the stimulant medications used to treat the disorder. Douglas's paper is also significant in other ways. Her extensive and thorough battery of objective measures of various behavioural and cognitive domains allowed her to rule in, or out, various characteristics felt to be typical for these children in earlier scientific lore. For instance, Douglas found that hyperactive children were not necessarily more reading or learning disabled, did not perseverate on concept learning tasks, did not manifest auditory or right-left discrimination problems, and had no difficulty with short-term memory. Most important, hyperactive children were not more distractible than normal children, and that the sustained attention problems could emerge in conditions in which no significant distractions existed.

Douglas and her colleagues at McGill University repeatedly demonstrated that hyperactive children had some of their greatest difficulties on tasks assessing vigilance, or sustained attention, such as the continuous performance test (CPT). These findings would be repeatedly reconfirmed over the next 20 years of research using CPTs (Corkum & Siegel, 1993). This test would eventually be standardised and commercially marketed for diagnosis of the disorder (Conners, 1995; Gordon, 1983; Greenberg & Waldman, 1992). Douglas remarked on the extreme degree of variability demonstrated during task performance by these children – a characteristic that would later be advanced as one of the defining features of the disorder.

The McGill team (Freibergs & Douglas, 1969) also found that hyperactive children could perform at normal or near normal levels of sustained attention under conditions of continuous and immediate reinforcement, but their performance deteriorated dramatically when partial reinforcement was introduced, particularly at schedules below 50% reinforcement. Campbell (Campbell, Douglas & Morgenstern, 1971) further demonstrated substantial problems with impulse control and field dependence in the cognitive styles of hyperactive children. Douglas commented on the probable association between deficits in attention/impulse control and deficiencies in moral control that were plaguing her subjects, particularly in their adolescent years.

The research of the McGill team showed dramatic improvements in these attention deficiencies during stimulant medication treatment, as did other laboratories at the time (Conners & Rothschild, 1968; Sprague, Barnes & Werry, 1970). Finally, of substantial significance were the observations of Douglas's colleague, Gabrielle Weiss, from her follow-up studies (see Weiss & Hechtman, 1986) that although the hyperactivity of these children often diminished by adolescence, their problems with poor sustained attention and impulsivity persisted.

Douglas (1980a, 1980b, 1983; Douglas & Peters, 1979) later elaborated, refined, and further substantiated her model of hyperactivity; thus her model culminated in the view that four major deficits could account for symptoms of ADHD: (1) the investment, organisation, and maintenance of attention and effort; (2) the inhibition of impulsive responding; (3) the modulation of arousal levels to meet situational demands; and (4) an unusually strong inclination to seek immediate reinforcement.

Douglas's work and that of her colleagues at McGill University was so influential that they were probably the major reason the disorder was renamed Attention-Deficit Disorder (ADD) in 1980 with the publication of the DSM-III (DSM-III, American Psychiatric Association, 1980). In this revised official taxonomy, deficits in sustained attention and impulse control were formally recognised as of greater significance in the diagnosis than hyperactivity. The shift to attention deficits rather than hyperactivity as the major difficulty of these children was useful, because of the growing evidence that hyperactivity was not specific to this particular condition but could be noted in other psychiatric disorders (anxiety, autism etc.), that there was no clear delineation between normal and abnormal levels of activity, that activity was in fact a multidimensional construct, and that the symptoms of hyperactivity were quite situational in nature in many children (Rutter, 1989). But this approach only corrected

the problem of definition for little over a decade before these same concerns also began to be raised about the construct of attention.

2.1.3.3 Other historical developments

The period 1970-1979 also saw the rapid increase of use of stimulant medication with school-age hyperactive children. This use was no doubt spawned by the significant increase in research on the effects of stimulants on hyperactive children. Despite the proven efficacy of this approach, public and professional misgivings about its increasing use with children emerged. At the same time as the use of medication was increasing, the claim was being advanced that hyperactivity was a “myth” arising from intolerant teachers and parents and an inadequate educational system (Conrad, 1975; Schrag & Divorky, 1975).

Another significant development in this decade was a growing belief that hyperactivity was a result of environmental causes. An extremely popular view was that allergic or toxic reaction to food additives, such as dyes, preservatives, and salicylates (Feingold, 1975) caused hyperactive behaviour. It was claimed that more than half of all hyperactive children had developed their difficulties because of their diet. It was believed that effective treatment could be had if families of these children would buy or make foods that did not contain the offending substances.

Research has, however, failed to substantiate any link between ADHD and food additives, such as artificial colourings and flavourings and the sugar substitute aspartame – or, for that matter, sugar itself (Barkley, 1998). Although a minority of children with ADHD have allergic reactions to food additives, carefully controlled studies in which children and their families do not know whether they are getting a diet with food additives or a diet without them show that food additives have little effect on most children with ADHD (Bradley & Golden, 2001; Harley, Ray, Tomasi, Eichman, Matthews & Chun, 1978). Similarly, having hyperactive boys drink sugary drinks, as compared to drinks containing the sugar substitute aspartame, has no effect on their behaviour or learning performance (Milich & Pelham, 1986).

Schools of psychology/psychiatry at opposite poles advanced a different environmental view – that poor child rearing generally and child behaviour management specifically lead to hyperactivity. Both psychoanalysts (Hartcollis, 1968) and behaviourists (Willis & Lovaas, 1977) promulgated this view. The psychoanalytic view claimed that parents who are intolerant of negative or

hyperactive temperament in their infants would react with excessively negative, demanding parental responses giving rise to clinical levels of hyperactivity. The behaviourist view stressed poor conditioning of children to stimulus control by commands and instructions that would give rise to noncompliant and hyperactive behaviour.

This decade also saw a plethora of research on the use of behaviour modification techniques in the management of disruptive classroom behaviour, particularly as an alternative to stimulant medication (Allyon, Layman & Kandel, 1975; O'Leary, Pelham, Rosenbaum & Price, 1976). Although the studies demonstrated considerable efficacy of these techniques in the management of inattentive and hyperactive behaviour, they were not found to achieve the same degree of behavioural improvements as the stimulants (Gittelman-Klein, Klein, Abikoff, Katz, Gloisten & Kates, 1976) and so did not replace them as treatment of choice. Nevertheless, a growing opinion would be that stimulant drugs should never be used as a sole intervention, but should be combined with parent training and behavioural intervention in the classroom (Barkley, 1998).

Another hallmark of this era was the widespread adoption of the parent and teacher rating scale developed by Conners (1969) for the assessment of the symptoms of hyperactivity, particularly during trials on stimulant medication. The adoption of these rating scales marked a turning point towards the use of more structured, quantitative assessment methods, rather than merely relying on clinical impression.

The 1970s were also noteworthy for an explosion in the number of research studies on the psychophysiology of hyperactivity in children. Many were investigating the theories of over- or underarousal of the central nervous system in hyperactivity, which grew out of the speculations in the 1950s on cortical overstimulation. Two influential reviews at the time (Hastings & Barkley, 1978; Rosenthal & Allen, 1978) were highly critical of most investigations but concluded that if there was any consistency across findings, it might be that hyperactive children showed a sluggish or underreactive electrophysiological response to stimulation. This view laid to rest the belief in an overstimulated cerebral cortex as the cause of symptoms in hyperactive children, but did little to suggest a specific neurophysiological mechanism for this underactivity.

Some recognition was also seen in this decade that there are adult equivalents of childhood hyperactivity, and that these cases responded to the same medication treatments that had earlier been suggested for childhood ADHD (Barkley, 1998).

2.1.4 The period 1980 to 1989

The exponential increase in research on hyperactivity, characteristic of the 1970s, continued unabated into the 1980s, making hyperactivity the most well-studied childhood psychiatric disorder in existence (Barkley, 1998). This decade would become known for its emphasis on attempts to develop more specific diagnostic criteria, the differential conceptualisation and diagnosis of hyperactivity from other psychiatric disorders, and, later in the decade, critical attacks on the notion that inability to sustain attention was the core behavioural deficit in ADHD (Barkley, 1998).

2.1.4.1 The creation of an ADD syndrome

Marking the beginning of this decade was the publication of the DSM-III (American Psychiatric Association, 1980) with its radical reconceptualisation (from that in DSM-II) of Hyperkinetic Reaction of Childhood to Attention-Deficit Disorder (with or without hyperactivity). The new diagnostic criteria not only placed greater emphasis on inattention and impulsivity as defining features of the disorder, but also provided much more specific symptom lists, numerical cut-off scores for symptoms, guidelines for age of onset and duration of symptoms, and the exclusion of other childhood psychiatric conditions as being essential to defining the disorder.

Even more controversial was the creation of subtypes of ADD based on the presence or absence of hyperactivity (+H/-H) in the DSM-III criteria. Little, if any, empirical research had existed at the time these subtypes were formulated. Their creation would, by the end of the 80s, initiate numerous research studies into the validity and usefulness of the subtyping approach, along with a search for other useful ways to subtype ADD (situational pervasiveness, presence of aggression, stimulant drug responses etcetera) (Barkley, 1998).

2.1.4.2 The creation of research diagnostic criteria

At the same time that the DSM-III criteria for ADD (+/-H) were gaining in recognition, others attempted to specify research diagnostic criteria (Barkley, 1982; Loney, 1983). Barkley set up a more operational definition of hyperactivity, or ADD+H, which not only required the usual parent and/or teacher complaints of inattention, impulsivity

and overactivity, but also stipulated that these symptoms had to: (1) be deviant for the child's mental age as measured by well-standardised child behaviour rating scales, (2) be relatively pervasive within the jurisdiction of the major caregivers in the child's life (parent/home and teacher/school), (3) have developed by 6 years of age, and (4) have lasted at least 12 months (Barkley, 1982).

Loney (1983) and her colleagues had been engaged in a series of studies that would differentiate the symptoms of hyperactivity, or ADD+H, from those of aggression or conduct problems (Loney, Langhorne & Peternite, 1978; Loney & Milich, 1982). Loney demonstrated that a relatively short list of symptoms of hyperactivity could be empirically separated from a similarly short list of aggression symptoms. Empirically derived cut-off scores on these symptom ratings by teachers could create these two semi-independent constructs. These constructs would prove highly useful in accounting for much of the heterogeneity and disagreement across studies in their findings. Among other things, it would become well established that many of the negative outcomes of hyperactivity in adolescence and early adulthood were actually due to the presence and degree of aggression that coexisted with the hyperactivity. Purely hyperactive children would be shown to display substantial cognitive problems with attention and overactivity, whereas purely aggressive children did not. Previous findings of greater family psychopathology in hyperactive children would also be shown to be primarily a function of the degree of aggression or conduct disorder in these children (August & Stewart, 1983; Lahey, Pelham, Schaughency, Atkins, Murphy, Hynd, Russo, Hartdagen & Lorys-Vernon, 1988). Furthermore, hyperactivity would be found to be associated with signs of developmental and neurological delay or immaturity, whereas aggression was more likely to be associated with environmental disadvantage and family dysfunction (Hinshaw, 1987; Milich & Loney, 1979; Paternite & Loney, 1980; Rutter, 1989; Weiss & Hechtman, 1986; Werry, 1988).

Eric Taylor (1986) and colleagues in Great Britain made notable advances in further refining the criteria for ADHD, and their measurement along more empirical lines. Taylor's (1989) statistical approach to studying clusters of behavioural disorders resulted in the recommendation that a syndrome of hyperactivity could be valid and distinctive from other disorders, particularly conduct problems. This distinction required that the symptoms of hyperactivity and inattention be excessive and handicapping to the children, occur in two of three broadly defined settings (for example home, school, and clinic), be objectively measured rather than subjectively

rated by parents and teachers, develop before age 6, last at least 6 months, and exclude children with autism, psychosis, or affective disorders (depression, anxiety, mania etc.).

Efforts to develop research diagnostic criteria for ADHD eventually led to an international symposium on the subject (Sergeant, 1988) and a general consensus that subjects selected for research on ADHD should at least meet the following criteria: (1) reports of problems with activity and attention by at least two independent sources (home, school, clinic), (2) at least three of four difficulties with activity, and three of four with attention being endorsed, (3) onset before 7 years of age, (4) duration of 2 years, (5) significantly elevated scores on parent/teacher ratings of these ADHD symptoms, and (6) exclusion of autism and psychosis.

2.1.4.3 Subtyping of ADD

Also important in the decade 1980 to 1989 was the attempt to identify useful approaches to subtyping other than those just based on the degree of hyperactivity (+H/-H) or aggression associated with ADD. Research by Dykman and Ackerman (Ackerman, Dykman & Oglesby, 1983; Dykman, Ackerman & Holcomb, 1985) distinguished between ADD children with and without learning disabilities, particularly reading impairments. Their research and that of others (McGee, Williams, Moffit & Anderson, 1989) showed that some of the cognitive deficits (verbal memory, intelligence etc.) formerly attributed to ADHD were actually more a function of the presence and degree of language/reading difficulties than ADHD.

Others in this era attempted to distinguish between pervasive and situational hyperactivity, where the former was determined by the presence of hyperactivity at home and school, and the latter referred to hyperactivity in only one of these settings (Schachar, Rutter & Smith, 1981). It would be shown that pervasively hyperactive children were likely to have more severe behavioural symptoms, greater aggression and peer relationship problems, and poor academic achievement. A revision of the DSM-III (DSM III-R; American Psychiatric Association, 1987) incorporated this concept into an index of severity for ADHD. However, research appearing in the early 90s (Costello, Loeber & Stouthamer-Loeber, 1991) demonstrated that differences between situational and pervasive subgroups were more likely the result of differences in the source of information used to classify the children (parents versus teachers) than to actual behavioural differences.

A different approach was the subtypes of ADHD created by the presence or absence of significant anxiety/depression or affective disturbance. Several studies demonstrated that ADHD children with significant problems with anxiety or affective disturbance were likely to show poor or adverse responses to stimulant medication (Taylor, 1983; Voelker, Lachar & Gdowski, 1983) and would perhaps respond better to antidepressant medications (Pliszka, 1987).

2.1.4.4 ADD becomes ADHD

Later in the decade, in an effort to improve the criteria for defining this disorder, the DSM was revised (DSM-III-R, American Psychiatric Association, 1987), resulting in the renaming of the disorder to Attention-Deficit Hyperactivity Disorder. The revisions were significant in several aspects. First, a single list of symptoms and a single cut-off score replaced the three separate lists (inattention, impulsivity, and hyperactivity) and cut-off scores in DSM-III. Second, the item list was now based more on empirically derived dimensions of child behaviour from behaviour rating scales, and the items and cut-off score underwent a large field trial to determine their sensitivity, specificity, and discriminating power to distinguish ADHD from other psychiatric disorders and normal children (Spitzer, Davies & Barkley, 1990). Third, the need to establish the symptoms as developmentally inappropriate for the child's mental age was stressed more emphatically. Fourth, the coexistence of affective disorders with ADHD no longer excluded the diagnosis of ADHD. And, more controversially, the subtype of ADD without Hyperactivity was removed as a subtype and relegated to a vaguely defined category, Undifferentiated ADD, which was in need of greater research on its merits. ADHD was now classified with two other behavioural disorders (Oppositional Defiant Disorder and Conduct Disorder) in a supraordinate category known as the Disruptive Behaviour Disorders in view of their substantial overlap or comorbidity in clinic-referred populations of children.

2.1.4.5 ADHD as a Motivation Deficit Disorder

As more rigorous and technical studies of attention in ADHD children appeared in the 1980s, an increasing number failed to find evidence of problems with attention under some experimental conditions while observing them under others (see Douglas, 1983, 1988, for reviews; Draeger, Prior & Sanson, 1986; Sergeant, 1988; Sergeant & van der Meere, 1989). Moreover, if attention was conceptualised as involving the perception, filtering and processing of information, no substantial evidence could be found in these studies for any such deficits. These findings, coupled with the realisation that both instructional and motivational factors in an experiment played a

strong role in determining the presence and degree of ADHD symptoms, led some investigators to hypothesise that deficits in motivation may be a better model for explaining the symptoms seen in ADHD children (Glow & Glow, 1979; Rosenthal & Allen, 1978; Sroufe, 1975). Following this line of reasoning, others pursued a behavioural or functional analysis of these symptoms, resulting in hypothesised deficits in the stimulus control over behaviour - particularly by rule and instructions. Barkley (1988a) argued that such deficits arose from neurological factors, while others argued that they arose from poor training of the child by parents (Willis & Lovaas, 1977).

Barkley (1981; 1990) initially raised the possibility that rule-governed behaviour might account for many of the deficits in ADHD, but later amended this view to include the strong probability that response to behavioural consequences might also be impaired and could conceivably account for the problems with rule following. Others independently advanced the notion that a deficit in responding to behavioural consequences, not attention, was the difficulty in ADHD (Benninger, 1989; Haenlein & Caul, 1987; Quay, 1988; Sagvolden, Wultz, Moser & Morkrid, 1989; Sergeant, 1988; van der Meere & Sergeant, 1988). That is, ADHD arises out of an insensitivity to consequences, reinforcement, punishment, or both. This insensitivity was viewed as neurological in origin. Others continued to argue against the merits of a Skinnerian, or functional, analysis of the deficits in ADHD (Douglas, 1989) and for the continued explanatory value of cognitive models of attention in accounting for the deficits in ADHD children.

According to Barkley (1998), the appeal of the motivational model came from several different sources: (1) its greater explanatory value in accounting for the more recent research findings on situational variability in attention in ADHD, (2) its consistency with neuroanatomical studies suggesting decreased activation of brain reward centres and their cortical-limbic regulating circuits, (3) its consistency with studies of the functions of dopamine pathways in regulating locomotor behaviour and incentive or operant learning, and (4) its greater prescriptive power in suggesting potential treatments for the ADHD symptoms. These new theories based on the construct of motivation would, according to Barkley (1998), alter the way in which the disorder is conceptualised and any future attempts at theory construction would need to incorporate some components and processes that dealt with motivation or effort.

2.1.4.6 Other developments in this era

This decade witnessed greater research into the social-ecological impact of ADHD symptoms on the children, their parents (Barkley, 1989; Barkley, Karlsson & Pollard, 1985; Mash & Johnston, 1982), teachers (Whalen, Henker & Dotemoto, 1980, 1981), siblings (Mash & Johnston, 1983) and peers (Cunningham, Siegel & Offord, 1985; Henker & Whalen, 1980). These investigations further explored the effects of stimulant medications on these social systems, as well as strengthening the conclusion that ADHD children elicit significant negative, controlling, and hostile or rejecting interactions from others, which can be greatly reduced by stimulant medication. From these studies emerged the view that handicaps associated with ADHD do not rest solely in the child, but in the interface between the child's capabilities and the environmental demands made within the social-ecological context in which that child must perform (Whalen & Henker, 1980). Changing the attitudes, behaviour, and expectations of caregivers, as well as the demands they make on ADHD children in their care, should result in changes in the degree to which ADHD children are disabled by their behavioural deficits.

Another development in this decade was further research to explore the unique features of ADHD relative to other psychiatric disorders of children (such as affective or anxiety disorders, learning disorders, and particularly conduct disorders) rather than just in comparison to normal functioning. These studies indicated that situational hyperactivity was not consistent in discriminating among psychiatric populations, but that difficulties with attention and pervasive (home and school) hyperactivity were more reliable in doing so, and were often associated with patterns of neurocognitive immaturity (Firestone & Martin, 1979; Gittelman, 1988; McGee, Williams & Silva, 1984a, 1984b; Rutter, 1989; Taylor, 1988; Werry, 1988).

The emerging interest in comparing ADD children with and without Hyperactivity (+/- H) furthered this line of inquiry by demonstrating relatively unique features of each disorder in contrast to each other, and to groups of learning-disabled and normal children (Barkley, DuPaul, & McMurray, 1990, 1991). Further strengthening the position of ADHD as a psychiatric syndrome was evidence from family aggregation studies that relatives of ADHD children had a different pattern of psychiatric disturbance from those children with Conduct Disorder or mixed ADHD and Conduct Disorder (Biederman, Munir & Knee, 1987; Lahey, Pelham et al., 1988). Purely ADHD children were more likely to have relatives with ADHD, academic achievement problems, and dysthymia, whereas those children with Conduct Disorder had a

greater prevalence of Conduct Disorder, antisocial behaviour, substance abuse, depression and marital dysfunction among their relatives. This finding led to speculation that ADHD had a different etiology than Conduct Disorder. The former is said to arise out of a biologically based disorder of temperament or a neurocognitive delay; the latter springs from inconsistent, coercive, and dysfunctional child rearing and management frequently associated with parental psychiatric impairment (Hinshaw, 1987; Loeber, 1990; Patterson, 1982, 1986).

Further research also emerged with regard to the potential etiologies of ADHD. Several studies on cerebral blood flow revealed patterns of underactivity in the prefrontal areas of the central nervous system and their rich connections to the limbic system via the stratum (Lou, Henriksen & Bruhn, 1984; Lou et al., 1989). Other studies (Hunt, Cohen, Anderson & Minderaa, 1988; Rapport & Zametkin, 1988; Shaywitz, Shaywitz, Cohen & Young, 1983; Shekim, Glaser, Horwitz, Javaid & Dylund, 1987; Zametkin & Rapoport, 1986) on brain neurotransmitters provided further evidence that deficiencies in dopamine, norepinephrine, or both may be involved in explaining these patterns of brain underactivity – patterns arising in precisely those brain areas in which dopamine and norepinephrine are most involved. Drawing these lines of evidence together even further was the fact that these brain areas are critically involved in response inhibition, motivational learning, and response to reinforcement. More rigorous studies on the hereditary transmission of ADHD were also published (Goodman & Stevenson, 1989), indicating a strong heritability for ADHD symptoms.

There was also a movement during this decade away from the strict reliance on clinic-referred samples of ADHD children to the use of community-derived samples. This change was prompted by the widely acknowledged bias that occurs among clinic samples of ADHD children as a consequence of the process of referral itself.

The 1980s also witnessed some advances in the tools of assessment. The Child Behaviour Checklist (CBCL; Achenbach & Edelbrock, 1983, 1986) emerged as a more comprehensive, more rigorously developed, and better-normed alternative to the Conner's Rating Scales. It would become widely adopted in research on child psychopathology in general, not just in ADHD. Other rating scales more specific to ADHD were also developed, such as the ACTeRS (Ullmann, Sleator & Sprague, 1984), the Home and Schools Situations Questionnaires (Barkley & Edelbrock, 1987; DuPaul & Barkley, 1992), the Child Attention Profile (see Barkley, 1987), and the

ADHD Rating Scale (DuPaul, 1991). Greater emphasis was also given to developing direct behavioural observation measures of ADHD symptoms that could be taken in the classroom or clinic and would be more objective and useful adjuncts to the parent and teacher rating scales in the diagnostic process.

Developments also continued in the realm of treatments for ADHD, for example the emergence of cognitive-behavioural modification (Camp, 1980; Douglas, 1980a; Kendall & Braswell, 1985; Meichenbaum, 1988). These approaches stressed the need to develop self-directed speech in impulsive children to guide their definitions of and attention to immediate problem situations, to generate solutions to these problems, and to guide their behaviour as the solutions were performed.

A second development in treatment was the development of a specific set of steps for training parents of ADHD children in child behaviour management skills (Barkley, 1981, 1987). This approach involves the use of differential attention and time-out procedures for treating oppositional behaviour in children – a behaviour frequently associated with ADHD.

This era also saw development in the area of social skills training for ADHD children. Hinshaw and his colleagues (Hinshaw, Henker & Whalen, 1984) developed a program for training ADHD children in anger-control techniques.

Finally, medication treatments for ADHD expanded to include the use of the tricyclic antidepressants, particularly for those ADHD children with characteristics that contraindicated using a stimulant medication or for ADHD children with anxiety/depression (Pliszka, 1987).

This era also saw the blossoming of parent support associations for families with ADHD. According to Barkley (1998) these associations offer the best hope that the general public can be provided with a more accurate depiction of ADHD and its treatment. Barkley believes these associations can help the public understand that hyperactive disruptive child behaviours can arise out of a biologically based disability rather than being entirely due to the simplistic yet pervasive societal view of bad parenting and diet as its cause.

2.1.5 The 1990s

The 1990s saw the increase in research on the neurological and genetic basis of the disorder, and on ADHD as it occurs in clinic referred adults.

2.1.5.1 Neuroimaging research

Researchers had long suspected that ADHD was associated in some way with abnormalities or developmental delays in brain functioning. In 1990, Alan Zametkin and his colleagues at the National Institute of Mental Health (NIMH; Zametkin, Nordahl, Gross, King, Semple, Rumsey, Hamburger & Cohen, 1990) published a landmark study. The authors evaluated brain metabolic activity in 25 adults with ADHD who had a childhood history of the disorder and who also had children with the disorder. The authors used positron emission tomography (PET), an exceptionally sensitive technique for detecting states of brain activity and its localisation within the cerebral hemispheres. The results of the study indicated significantly reduced brain metabolic activity in adults with ADHD relative to the control group, primarily in frontal and striatal regions. Such results were certainly consistent in many, though not all, respects with the earlier demonstrations of reduced cerebral blood flow in the frontal and striatal regions in children with ADHD (Lou et al., 1984, 1989). Significant in the Zametkin et al. (1990) study, however, was its use of a much better defined sample of ADHD patients and its focus on adults with ADHD. Although later attempts by this research team to replicate their original results using teenagers with ADHD were consistent with these results for girls with ADHD, no differences were found in boys with ADHD. Sample sizes in these studies were quite small, however, almost ensuring some difficulties with the reliable demonstration of the original findings. Despite these difficulties, the original report stands out as one of the clearest demonstrations to date of reduced brain activity, particularly in the frontal regions, in ADHD.

At the same time as the NIMH study using PET scans was appearing, other researchers were employing magnetic resonance imaging (MRI) to evaluate brain structures in children with ADHD. Hynd and his colleagues were the first to use this method and they focused on the total brain volume, as well as specific regions in the anterior and posterior brain sections. Children with ADHD were found to have abnormally smaller anterior cortical regions, especially on the right side, and they lacked the normal right-left frontal asymmetry (Hynd, Semrud-Clikeman, Lorys, Novey & Eliopoulos, 1990). Subsequent research by this team focused on the size of the corpus callosum, finding that both the anterior and posterior portions were

smaller in children with ADHD (Hynd, Semrud-Clikeman, Lorys, Novey, Eliopoulos & Lyytinen, 1991). However, in a later study, only the posterior region was found to be significantly smaller (Semrud-Clikeman, Filipek, Biederman, Steingard, Kennedy, Renshaw & Bekken, 1994).

Additional studies were reported by Hynd, Hern, Novey, Eliopoulos, Marshall, Gonzalez and Voeller (1993), who found a smaller left caudate region in children with ADHD, and Giedd, Castellanos, Casey, Kozuch, King, Hamburger and Rapoport (1994), who found smaller anterior regions of the corpus callosum.

More recently, two research teams published studies using MRI with considerably larger samples of ADHD children (Castellanos, Giedd, Eckburg, Marsh, Vaituzis, Kaysen, Hamburger & Rapoport, 1994; Castellanos, Giedd, Marsh, Hamburger, Vaituzis, Dickstein, Sarfatti, Vauss, Snell, Lange, Kaysen, Krain, Ritchie, Rajapakse & Rapoport, 1996; Filipek, Semrud-Clikeman, Steingard, Renshaw, Kennedy & Biederman, 1997). These studies documented significantly smaller right prefrontal lobe and striatal regions in children with ADHD. Castellanos et al. (1996) also found smaller right-sided regions of structures in the basal ganglia, such as the striatum, as well as the right cerebellum. Filipek et al. (1997) observed the left striatal region to be smaller than the right. Despite some inconsistencies across these studies, most have implicated the prefrontal-striatal network as being smaller in children with ADHD, with the right prefrontal region being smaller than the left. Such studies have placed on a considerably firmer foundation the view that ADHD does, indeed, involve impairments in the development of the brain, particularly in the prefrontal-striatal regions, and that the origin of these differences from normal are likely to have occurred in embryological development (Castellanos et al., 1996). Advances in neuroimaging technology will continue to provide exciting and revealing new developments in the search for the structural differences in the brain that underlie this disorder.

2.1.5.2 Genetic research

In the 1990s a number of studies, particularly those by Biederman and colleagues strengthened the evidence of the familial nature of ADHD. Between 10% and 35% of the immediate family members of children with ADHD were found to have the disorder, with the risk to siblings of the ADHD children being approximately 32% (Biederman, Faraone & Lapey, 1992; Biederman, Keenan & Faraone, 1990; Pauls, 1991; Welner, Welner, Stewart, Palkes & Wish, 1977). Even more striking, recent

research shows that if a parent has ADHD, the risk to the offspring is 57% (Biederman, Faraone, Mick, Spencer, Wilens, Kiely, Guite, Ablon, Reed & Warburton, 1995). Thus, family aggregation studies find that ADHD clusters among biological relatives of children or adults with the disorder, strongly implying a hereditary basis to this condition.

At the same time these studies were appearing, a number of twin studies were being reported that focused on the heritability of the dimension(s) of behaviour underlying ADHD, that being hyperactive-impulsive-inattentive behaviour, or on the clinical diagnosis of ADHD itself. Large-scale twin studies on this issue have been quite consistent in their findings of a high heritability for this trait or for the clinical diagnosis with minimal or no contribution made by the shared environment (Edelbrock, Rende, Plomin & Thompson, 1995; Levy & Hay, 1992). For instance, Gilger, Pennington and DeFries (1992) found that if one twin was diagnosed as ADHD, the concordance of the disorder was 81% in monozygotic twins and 29% in dizygotic twins. Recent large scale studies with twins demonstrate that the majority of variance (70-90%) in the trait of hyperactivity-impulsivity is due to genetic factors (averaging approximately 80%) and that such a genetic contribution may increase the more extreme the scores along this trait happen to be, although this latter point is debatable (Faraone, 1996; Gjone, Stevenson & Sundet, 1996; Gjone, Stevenson, Sundet & Eilertsen, 1996; Rhee, Waldman, Hay & Levy, 1995, Silberg, Rutter, Meyer, Maes, Hewitt, Simonoff, Pickles, Loeber & Eaves, 1996; Thapar, Hervas & McGuffin, 1995; van den Oord, Verhulst & Boomsma, 1996). Thus twin studies add substantially more evidence to that already found in family aggregation studies, supporting a strong genetic basis to ADHD and its behavioural symptoms.

Also in this decade, a few studies began to be published that used molecular genetic techniques to analyse DNA taken from ADHD children and their family members to identify genes that may be associated with the disorder. The focus of research initially was on the dopamine type 2 gene, given findings of its increased association with alcoholism, Tourette syndrome and ADHD (Blum, Cull, Braverman & Comings, 1996; Comings, Comings, Muhleman, Dietz, Shahbahrani, Tast, Knell, Koesis, Baumgarten, Kovacs, Levy, Smith, Borison, Evans, Klein, MacMurray, Tosk, Sverd, Gysin & Flanagan, 1991).

More recently, the dopamine transporter gene was implicated in ADHD (Cook, Stein, Krasowski, Cox, Olkon, Kieffer & Leventhal, 1995; Cook, Stein & Leventhal, 1997).

Dopamine, a chemical in the brain that relays messages, is typically broken down quickly after it is released in the body. If for some reason the breakdown and reabsorption is delayed, it is theorized that high levels of hyperactivity, inattention, and impulsivity result. Due to the success of medications that regulate the reabsorption of dopamine in patients with ADHD, the authors of this study were interested in the part dopamine plays in the disorder. Coming from the perspective that ADHD is familial, they designed their study with a focus on families with ADHD and administered intelligence tests, behaviour rating scales, and DNA testing. The family units consisted of the mother, father, and the affected child or children. Cook and his colleagues concluded that, although these results need to be replicated to determine if there are any defective gene patterns, there appears to be some association between mutations in the dopamine transporter gene and the manifestation of ADHD within families. This is an indication of a difference in brain chemistry among individuals with ADHD and those without the disorder, and it reinforces the theory of heritability.

Another gene related to dopamine, the D4RD (repeater gene) was recently found to be overrepresented in the seven-repetition form of the gene in children with ADHD (Lahoste, Swanson, Wigal, Glabe, Wigal, King & Kennedy, 1996).

Research into the molecular genetics involved in the transmission of ADHD across generations offers the promise of the eventual development of genetic tests for, and subtyping of, ADHD into potentially more homogenous and useful genotypes, as well as the promise of developing more specific pharmacological agents for treating ADHD (Barkley, 1998).

2.1.5.3 Essential fatty acid research

The nineties have also seen an interest in the role that essential fatty acid (EFA) plays in ADHD. EFA plays an important part in the structure and function of the cells in the human body. Stevens and colleagues (Stevens, Zentall, Deck, Abate, Watkins, Lipp & Burgess, 1995) conducted a study to determine if essential fatty acid (EFA) is associated with ADHD in boys. Subjects included in the study consisted of boys with ADHD and a control group of healthy boys (all between the ages of 6 and 12 years). The ADHD diagnosis was confirmed through parent and teacher completion of behaviour rating scales. EFA levels were determined by blood tests.

ADHD subjects were found to have lower levels of EFA than controls. In addition, they had some of the symptoms of EFA deficiency, such as thirst (greater fluid intake), more frequent urination, and drier skin than the control group.

Some studies have indicated a possible association between deficiencies in zinc and EFA and hyperactivity or maladjusted behaviour. There has also been a great deal in the press in recent years about serotonin and melatonin and their effects on mood and behaviour. Zinc and fatty acids are believed to influence the production of serotonin and melatonin, which in turn affect dopamine function. So it seems reasonable to study deficiencies in zinc and EFA in relationship to ADHD. Bekaroglu, Aslan, Gedik, Deger, Mocan, Erduran, and Karahan (1996) looked at the levels of both elements in patients with ADHD. The research was conducted by establishing a diagnosis of ADHD for the target group and by analysing free fatty acid (FFA) and zinc levels from blood samples. The subjects included boys and girls between the ages of six-and-a-half and 12 years.

The authors found that children with ADHD had significantly lower levels of zinc and FFA than the control group. It is not clear whether the zinc deficiency is responsible for the lowered FFA levels; further studies are needed to establish FFA as a primary or perhaps secondary cause of ADHD.

2.1.5.4 ADHD in adults

The 1990s saw a broader acceptance of ADHD in adults. According to Barkley (1998) this is in part due to studies that documented the persistence of the disorder into adolescence in up to 70%, and into adulthood in up to as many as 66% of childhood cases (Barkley, Fischer, Edelbrock & Smallish, 1990; Fischer, 1997; Mannuzza, Gittelman-Klein, Bessler, Malloy & LaPadula, 1993; Weiss & Hechtman, 1993). It can also be attributed to published studies on clinically referred adults diagnosed with the disorder (for example Biederman, Faraone, Spencer, Wilens, Norman, Lapey, Mick, Lehman & Doyle, 1993; Murphy & Barkley, 1996).

Also notable in this decade was the publication of more rigorous studies that demonstrated the efficacy of the stimulants (Spencer, Wilens, Biederman, Faraone, Ablon & Lapey, 1995) and the antidepressants (Wilens, Biederman, Prince, Spencer, Faraone, Warburton, Schleifer, Harding, Linehan & Geller, 1996) in the management of adult ADHD. Thus, the adult form of the disorder was found to not only share many

of the same patterns of symptoms and comorbid disorders as did the childhood form, but also to respond just as well to the same medications (Barkley, 1998).

2.1.5.5 Other developments in the 1990s

In 1994, new diagnostic criteria for the disorder were set forth in DSM-IV (DSM-IV, American Psychiatric Association, 1994). These criteria contained several improvements over those in the DSM III-R. They reintroduced criteria for the diagnosis of a purely inattentive form of ADHD, similar to ADD without hyperactivity which first appeared in DSM-III. The diagnostic criteria also now required evidence of symptom pervasiveness across settings, as well as the demonstration of impairment in a major domain of life functioning (home, school, work). Based on a much larger field trial than any of its predecessors, the DSM-IV criteria are the most empirically based in the history of this disorder (Barkley, 1998).

A further development in this decade was the undertaking of the NIMH multisite study of ADHD that focused on various combinations of long-term treatments (Arnold, Abikoff, Cantwell, Connors, Elliot, Greenhill, Hechtman, Hinshaw, Hoza, Jensen, Kraemer, March, Newcorn, Pelham, Richters, Schiller, Severe, Swanson, Vereen & Wells, 1997). The Swedish government also commissioned the longest treatment study of stimulant medication ever undertaken, the results of which indicated that amphetamine treatment remained effective for the entire 15 months of the investigation. More sobering was a report that a year-long intensive treatment programme using primarily cognitive-behavioural treatment produced no substantial treatment effects either at post-treatment or at follow-up (Braswell, August, Bloomquist, Realmuto, Skare & Crosby, 1997). Barkley (1998) reports a year-long intensive early intervention programme for hyperactive-aggressive children that found no significant impact of training either at post-treatment or at a two-year follow-up. The school-based portion of this multimethod programme produced some immediate gains, but by two-year follow-up these had dissipated. Finally, a multisite study of stimulant medication with and without intensive behavioural and psychosocial interventions was reported to have found that the psychosocial interventions added little or nothing to treatment outcome beyond that achieved by stimulant medication alone (Abikoff & Hechtman, 1995). According to Barkley (1998), these studies do not so much undermine the earlier studies on the effectiveness of behavioural interventions with ADHD children, as suggest that some of those interventions produce minimal or no improvements when used on a large-scale basis, that the extent of improvement is difficult to detect when adjunctive stimulant medication is

also used, and that treatment effects may not be able to be maintained over time following treatment termination.

This decade also witnessed the emergence of new trends such as renewed interest in theory development related to ADHD. There was a recognition that deficits in behavioural inhibition may be the most distinguishing characteristic of this disorder from other mental and developmental disorders. Russell Barkley put forth the view that the frontal lobes of individuals with ADHD do not function properly, resulting in deficiencies in the executive functions that allow us to plan and control our behaviour and to inhibit unwise responses (Barkley, 1997a, 2000). There was also recognition that the subtype of ADHD comprising chiefly inattention without impulsive-hyperactive behaviour may possibly be a qualitatively distinct disorder entirely from those children who have hyperactive-impulsive behaviour (Barkley, Grodzinsky & DuPaul, 1992; Goodyear & Hynd, 1992; Lahey & Carlson, 1992).

A new stimulant medication, Adderall, appeared on the market in this decade that shows promise as being as effective for ADHD as the other stimulants. The 1990s also saw an increasing interest in the use of peers as treatment agents for academic performance and peer conflict in school settings in several new behavioural intervention programmes (Cunningham & Cunningham, 1998; DuPaul & Henningson, 1993).

Although the 90s saw a shift to viewing ADHD as far more influenced by neurological and genetic factors than by social or environmental ones, some critics still regard it as a label. The year 1999 saw the publication of the book **The Indigo Children** (Caroll & Tober, 1999). The authors describe the Indigo child as a new kind of child who comes into the world "knowing" who they are. According to them these children:

- Come into the world with a feeling of royalty (and often act like it)
- Have a feeling of "deserving to be here," and are surprised when others don't share that.
- Have no problem with self-worth. They often tell the parents "who they are."
- Have difficulty with absolute authority (authority without explanation or choice).
- Simply will not do certain things; for example, waiting in line is difficult for them.

- Get frustrated with systems that are ritually oriented and don't require creative thought.
- Often see better ways of doing things, both at home and in school, which makes them seem like "system busters" (nonconforming to any system).
- Seem antisocial unless they are with their own kind. If there are no others of like consciousness around them, they often turn inward; feeling like no other human understands them. School is often extremely difficult for them socially.
- Will not respond to "guilt" discipline ("Wait till your father gets home and finds out what you did").
- Are not shy in letting you know what they need.

The authors believe that society copes with this new kind of child by diagnosing him/her with ADHD and legally drugging the child. According to the authors, these unusually bright and active children must be recognised and celebrated for their exceptional qualities and must be guided with love and care.

2.1.6 Beyond 2000

A landmark article recently appeared in the November 22, 2003, edition of the British medical journal *The Lancet*. The article reports results of a US study that provides details of the underlying physical causes of attention-deficit hyperactivity syndrome (Sowell, Thompson, Welcome, Henkenius, Toga & Peterson, 2003).

Elizabeth Sowell, Assistant Professor of Neurology from the Laboratory of Neuro Imaging at the University of California Los Angeles, USA, and colleagues undertook the first detailed morphological study using high-resolution magnetic resonance imaging (MRI) and sophisticated computational image analytical techniques to more accurately determine the specific areas of the brain underlying ADHD. Brain assessment of 27 children (11 girls, 16 boys) and adolescents with ADHD was compared with that of 46 control children without ADHD who were group-matched by age and sex.

Abnormal brain structure was observed in the frontal cortices (on both sides of the brain) of children with ADHD, with reduced regional brain size localised mainly to small areas of the dorsal prefrontal cortices. Children with ADHD also had reduced brain size in anterior temporal areas, also on both sides of the brain. Substantial increases in grey matter were recorded in large portions of the posterior temporal

and inferior parietal cortices in children with ADHD. The changes are not only in brain regions controlling attention, but also in regions that subserve impulse control. Disordered impulse control is often the most clinically debilitating symptom in children with ADHD.

The authors believe that these findings may help us understand the sites of action of the medications used to treat ADHD, particularly stimulant medications. They believe that, in conjunction with other imaging techniques, the findings may help them to develop new therapeutic agents given their knowledge of the cellular and neurochemical make-up of brain regions where they have detected the greatest abnormalities.

This chapter has provided an overview of the history of Attention Deficit Hyperactivity Disorder. The following chapter will go on to examine incidence of the disorder and the developmental course of ADHD.

CHAPTER THREE: ADHD - INCIDENCE AND DEVELOPMENTAL COURSE

3.1 The incidence of ADHD

Attention deficit hyperactivity disorder (ADHD) affects an estimated 2 to 11 percent, or more, of school-age children worldwide (Zametkin & Ernst, 1999). Boys are three to four times more likely to be diagnosed as girls (Zametkin & Ernst, 1999).

The relationship between gender differences and ADHD has been identified as an area needing more research. There may be variations in the manifestation of ADHD between males and females, which could influence the selection of interventions.

Gaub and Carlson (1997) conducted a meta-analysis of research on gender differences in ADHD. Due to the limited amount of research that has been done on gender and ADHD, the authors were only able to find 18 studies that met their criteria for size and selected variables. The analysis showed that there are distinct differences between girls with ADHD who have been clinically referred and girls with ADHD who have not been clinically referred when compared to boys with ADHD. Clinically referred girls with ADHD, compared to boys, had lower levels of hyperactivity, fewer were diagnosed with conduct disorders, had a lower rate of externalising behaviour (acting out behaviours), had greater intellectual impairment, and greater severity of inattention. Clinically referred girls with ADHD, compared to boys, had similar levels of internalising behaviour, aggression toward peers, and disliking peers.

Non-referred girls with ADHD showed less impairment than boys on inattention, internalising behaviours, aggression toward peers, and disliking peers. Both boys and girls with ADHD were characteristically of a lower SES than non-ADHD children, but girls with ADHD were of a lower SES than boys with ADHD, or, in other words, they were found to be at a greater social disadvantage.

The results of this analysis suggest that girls with ADHD are more likely to have learning problems while boys with ADHD are more likely to exhibit behaviour problems. Within a structured learning environment, behaviour problems probably lead to more referrals, whereas learning problems are probably addressed within the context of the school setting. This may partially account for a lower referral rate of

girls for clinic-based treatment. The authors identified some limitations in their study, including the small number of studies available addressing gender differences and ADHD. There was also the constraint of having primarily clinically referred populations from which to draw results. Since girls are less likely to be referred to a clinic, those females included in the research are probably more severe, atypical cases.

The number of children diagnosed and treated for ADHD has increased substantially, by some estimates doubling in the 1990s (Santrock, 2002). There is controversy about the increased diagnosis of ADHD; however, some experts attribute the increase mainly to heightened awareness of the disorder. Others are concerned that many children are being diagnosed without undergoing extensive professional evaluation based on input from multiple sources (Santrock, 2002). Some critics who claim that ADHD is over-diagnosed believe that ADHD may represent more of an adaptational problem than a disorder (Jensen, Mrazek, Knapp, Steinberg, Pfeffer, Swalter & Shapiro, 1997; Luk, 1996). From this perspective, many children diagnosed as having ADHD are simply highly active and playful youngsters whose impulsiveness and heightened motor activity may once have been advantages, but simply do not mesh with the focused attention that is required for success in modern schools.

Other authorities contend that a pseudo ADHD accounts for 50-60% of the diagnosed cases (Hallowel & Ratey, 1994). By pseudo Hallowel and Ratey mean the manifestation of a set of behaviours that mimic ADHD, but are actually the result of environmental influences such as fast food, fast-paced media and video games, and a pervasive societal attitude toward immediate gratification.

3.2 Comorbidity of ADHD with other disorders

Comorbidity is found in as many as two thirds of the clinically referred children with ADHD (Dulcan, Dunne, Ayres, Arnold, Benson & Bernet, 1997). The frequency of co-occurrence is highest for Conduct Disorder and Oppositional Defiant Disorder, followed by Learning Disabilities, then affective disorders (e.g., Major Depressive Disorder, Bipolar Disorder, Mood Disorder, and Anxiety Disorder), and Tourette's syndrome with the lowest frequency of comorbidity (Barkley, 1997b; Biederman, Newcorn, & Sprich, 1991). Allergies have also been found to co-occur with ADHD (Lensch, 2000).

The study by Biederman, Newcorn and Sprich (1991) reviewed the literature on comorbidity and findings on the co-occurrence with ADHD were as follows:

- Conduct Disorder co-occurs with ADHD in 30-50% of cases.
- There is limited research on co-occurrence of Oppositional Defiant Disorder, but it is frequently combined with Conduct Disorder.
- Mood Disorders, across studies, were found to co-occur with ADHD in 15-75% of cases.
- Anxiety Disorders have about 25% co-occurrence with ADHD and there is a higher incidence of ADHD in offspring of parents with Anxiety Disorder.
- There is a 10-92% reported co-occurrence of Learning Disabilities with ADHD.
- About 60% of youth with Tourette's syndrome also have ADHD. Conversely, only a small percentage of youth with ADHD have Tourette's syndrome.

Eiraldi, Power and Nezu (1997) investigated patterns of comorbidity associated with two of the subtypes of ADHD as defined by the DSM-IV (DSM-IV, American Psychiatric Association, 1994), namely the Predominantly Inattentive Type and the Combined Type. A normal control group also formed part of the study. As the authors hypothesized, the co-occurrence of disorders with externalising behaviours was significantly more prevalent among subjects with ADHD Combined Type. Specifically Conduct Disorder and Oppositional Defiant Disorder had a much higher incidence in the ADHD Combined Type group than in the ADHD Inattentive Type group. Both ADHD groups were at equal risk for internalising disorders such as anxiety or depression.

According to Lensch (2000) there have over the years been reports of the co-occurrence of allergies in individuals with ADHD, indicating that there may be a relationship between the two conditions. There appears to be some overlap in the neurotransmitters involved in the nervous system (operant in behaviour problems) and the immune system (involved with allergies). Norbert Roth and his colleagues (Roth, Beyreiss, Schienzka & Beyer, 1991) compared a group of children with allergies and control group of children without allergies, to see subjects with allergies had a higher percentage of ADHD diagnoses. The study showed that a significantly higher number of subjects with allergies exhibited characteristics of ADHD than control subjects.

3.3 The developmental course of ADHD

The symptoms of ADHD appear to arise relatively early in childhood, with the mean age of onset being between three and four years old (Barkley, Fischer, Edelbrock & Smallish, 1990; Barkley, Fischer, Newby & Breen, 1988). Although most cases may develop before age seven years, in a sizable minority of cases the children may have had their ADHD characteristics for quite some time, but they did not interfere with their academic or social functioning until later childhood (Barkley, 1998). Thus, the onset of impairment may succeed the onset of symptoms by several years or more. The latter seems to occur in very bright or gifted ADHD children whose superior intellect appears to allow them to pass through the early grades of school without difficulty because they do not need to apply much effort to be successful. As the work at home and school increases in length and complexity, and greater demands for responsibility and self-control are made in later childhood, such ADHD children are now handicapped by their deficits. This interface between environmental demands and child capabilities seems important in determining the degree to which a child's ADHD characteristics will prove socially disabling throughout their development.

3.3.1 Early childhood through to preschool

“Normal” development

According to Hughes (2000), with regard to **physical development**, by about age 2 most children have shown a preference for using either their right or left hand. Between the ages of 4 and 7, improvements in visual acuity result in a greater ability to identify the finer distinctions between stimuli. Towards the end of the preschool years visual abilities have advanced well enough for the child to begin learning to read. Co-ordination of abilities controlled by more than one part of the brain is also learned. Preschoolers learn and master a number of new gross motor skills, such as climbing stairs, riding tricycles, running, jumping and hopping. Fine motor improvements in their hands and fingers enable them to dress themselves and to manipulate objects such as scissors, puzzle pieces, and other small toys. They also begin to express themselves through drawings.

With regard to **cognitive development**, the stage of preoperational thought, occurring between the ages of 2 and 7, introduces more systematic use of mental representations as children create an understanding of the world around them. Pre-school aged children are, however, not yet able to apply more sophisticated mental operations such as logic as they develop these understandings. Preschoolers have short attention spans, are easily distracted, and tend to organise their focus on

factors with interest value rather than pragmatic value. Their short-term memory is limited early on, but by the end of the preschool years its capacity is almost as large as an adult's. Their long-term memory storage and retrieval are limited by their lack of practice at remembering, not knowing what is important to commit to memory, and having a smaller pool of general knowledge and language networks to supply retrieval cues. Preschoolers' intelligence test scores begin to approximate their long-term IQ scores. Language skills advance more during the preschool years than at any other stage of development, and preschoolers learn as many as 20 new words a day. Preschoolers learn a number of the basic rules of grammar as well as the rules of conversation, although their conversation skills are limited in part by their immature theories of mind.

With regard to **social and emotional development**, the preschool years are a significant window for development of a sense of conscience and gender identity. Relationships with peers provide substantial social and emotional training and practice. Preschoolers begin experiencing in themselves, and recognising in others, more complex, socially based emotions such as pride, shame, guilt, envy and embarrassment. They also begin learning how to regulate emotions and express them appropriately. Moral development can be influenced more during the preschool years than at any other stage of development. At first, preschoolers see moral rules as absolute, applying to the consequences of the act, and inevitably intertwined with punishment. As children mature to school age, they learn that rules are actually created and enforced by people, and that moral judgements address a person's intent rather than the actual behaviour. Preschoolers' self-concepts are at first based in their roles and behaviours, then progress towards recognising that aspects of their inner character are constant. Their self-esteem at first overestimates their abilities, then is shaped by feedback from their environment

ADHD children

ADHD often reveals itself first in infancy. As infants, children with ADHD are often very active, have difficult temperaments, or show irregular feeding and sleeping patterns (Teeter, 1998).

As preschool children, they are in perpetual motion, quickly moving from one activity to another (Sigelman & Rider, 2003). Since most young children are energetic and have short attention spans, behaviour must be evaluated in terms of developmental norms. The appearance of significantly inattentive and overactive behaviour by age

three to four years by itself is not indicative of a persistent pattern of ADHD into later childhood or adolescence in at least 50-90% of children so categorised (Barkley, 1998). Palfrey, Levine, Walker and Sullivan (1985), in a follow-up study of preschool-age children from birth to second grade, found that approximately 5% of their total sample of children, or about 10% of those with concerns about inattention, eventually developed a pattern of persistent inattention to be predictive of behaviour problems, low academic achievement and need for special education services by second grade. Campbell (1990) also showed that among difficult-to-manage three-year olds, those whose problems still existed by age four years were much more likely to be considered clinically hyperactive and to have difficulties with their hyperactivity as well as conduct problems by ages six and nine years. Therefore, both the degree of ADHD symptoms and their duration determine which children are likely to show a chronic course of their ADHD symptoms throughout later development.

Parents of children with this durable pattern of ADHD in this age group describe them as restless, always up and on the go, acting as if driven by a motor, and frequently climbing on and getting into things (Barkley, 1998). They are more likely to encounter accidental injuries as a result of their overactive, inattentive, impulsive and often fearless pattern of behaviour. "Childproofing" the home at this age becomes essential to reduce the risk of injury, as well as to protect family valuables. Persistent in their wants, demanding of parental attention, and often insatiable in their curiosity of their environment, ADHD preschoolers pose a challenge to the child-rearing skills of their parents (Barkley, 1998). Such children require far more frequent and closer monitoring of their ongoing conduct than do normal preschoolers. Although temper tantrums may be common instances even for normal preschoolers, their frequency and intensity are often exacerbated in ADHD children. Mothers of these children are likely to find themselves giving far more commands, directions, criticisms, supervision and punishment than do mothers of normal preschoolers (Barkley, 1988b; Battle & Lacey, 1972; Campbell, 1990; Cohen & Minde, 1981). Although the mothers of ADHD preschoolers are likely to report feeling competent in their sense of knowing how to manage children, this finding will progressively decline as these children grow older and parents find that the typical techniques used to manage normal children are less effective with ADHD children (Mash & Johnston, 1983). The coexistence of additional difficulties such as sleep problems, toilet training difficulties, and/or motor and speech delays in a small percentage of ADHD children is likely to further tax the patience and competence of many of their parents.

Should such a child happen to have a mother whose own mental health is compromised by psychiatric problems, such as depression, anxiety or hysteria, or whose marriage is in trouble, the combination of negative child temperament with a psychologically distressed caregiver could be potentially explosive and increase the risk of physical abuse to the child (Barkley, 1998). This same situation may also arise when the father of this child is alcoholic, antisocial, or highly aggressive within the family.

Placement of these children in day care, a progressively increasing practice for preschool children in our society, is likely to bring additional distress as day-care personnel complain about the child's disruptive behaviour, aggression toward others in many cases, and difficulties in being managed (Barkley, 1998). Such children are often noted to be out of their seats, wandering the classroom inappropriately, disrupting the play activities of other children, excessively demanding peer interactions, and being especially vocally noisy and talkative (Campbell, Endman & Bernfield, 1977; Campbell, Schleifer & Weiss, 1978; Schleifer, Weiss, Cohen, Elman, Cvejic & Kruger, 1975). It is not uncommon to find the more active and aggressive among these ADHD children to actually be kicked out of preschool (Reebye, 1997) - so begins the course of school adjustment problems that afflict many of these children throughout their compulsory educational careers. Other ADHD children, especially those who are not oppositional or aggressive, who are milder in their level of ADHD, or who are intellectually brighter, may have little or no difficulties with the demands of a typical day-care or pre-school program.

Difficulties in obtaining babysitters for their ADHD children, especially the more severely ADHD and oppositional among them, is reported by mothers of children at this age during clinical interviews (Barkley, 1998). This may result in a greater restriction of both socialisation with other adults and the ability to carry out the typical and necessary errands within the community needed to care for a household. For single parents of ADHD children, these limitations may prove more frequent and distressing, as there is no other adult with whom to share the burden of raising such children.

As ADHD preschool children approach entry into formal schooling, research suggests they are already at high risk for academic failure. Not only does their symptom picture predispose them to be less ready to learn in school, but also they are more likely to be behind in basic academic readiness skills (e.g. pre-reading

abilities, simple mathematics concepts, and fine motor skills) (Mariani & Barkley, 1997; Shelton, Barkley, Crosswait, Moorehouse, Fletcher, Barrett, Jenkins & Metevia, 1998).

3.3.2 Middle childhood

“Normal” development

According to Hughes (2000) with regard to **physical development**, children in middle childhood become stronger and faster, as well as more coordinated, agile, and flexible. They show improvements in endurance, reaction time, and ability to coordinate perceptual and motor skills. Comparing handwriting samples of children at the beginning and end of middle childhood gives evidence of improvement in fine motor skills. Play activity also becomes more organised and complex.

With regard to **cognitive development**, during the middle childhood phase of concrete operations, children are now able to perform mental operations on pieces of information and draw correct conclusions. These new abilities contribute towards increased organisation of, and flexibility in, thinking. Early in middle childhood, the preschooler's piecemeal information-processing methods begin to be replaced by methods of making interconnections. The child more effectively integrates new knowledge with what he or she already knows. Likewise the child's current knowledge influences his or her likely choice of new information to process and integrate. The ability to pay attention improves dramatically during middle childhood. Some improvements emerge as the child's personal experiences and growing knowledge base indicate to the child what needs to be attended to and what should be ignored. The school-age child's selective attention becomes increasingly better controlled, more sensitive to the social context within which stimuli are presented, and better able to take in the distinctive or relevant characteristics of new information. Memory becomes enhanced as children learn to use memorization strategies such as rehearsal, categorization and imagery. Children double their vocabulary during middle childhood, develop more complex understandings of the words they know, learn and use more sophisticated forms of syntax, and apply all of the above as they learn to read.

With regard to **social and emotional development**, during middle childhood, children develop skills and personal attributes relevant to succeeding in their culture. They develop competence in the areas of adjusting to the school milieu, establishing peer relationships, learning to play by the rules, and achieving academically. Children develop a greater capacity for emotional regulation. Increasing cognitive ability and

more varied independent life experiences results in more complex emotional states, as well as greater understanding of others emotions. Moral reasoning progresses from being self-focussed and concrete to other focussed and abstract, fuelled during middle childhood by increasing sociocentrism and advancing cognitive abilities. During middle childhood, children's self-concepts become increasingly less behaviourally oriented and more abstract, incorporating psychological traits, beliefs and values. Social comparison helps them establish and develop a working relationship between their real and ideal selves. Self-esteem becomes more realistic as children recognise their shortcomings yet learn to value their strengths.

ADHD children

Studies suggest that formal, compulsory education is the area of greatest impact on the child's ADHD (Barkley, Fischer et al., 1990; Biederman, 1997) and will create the greatest source of distress for many of them and their parents. Almost all clinic-referred ADHD children are doing poorly at school, typically under-performing relative to their known levels of ability as determined by intelligence and academic achievement tests. According to Barkley (1998) such performance is believed to be the result of their inattentive, impulsive and restless behaviour in the classroom. Evidence supporting this interpretation comes from numerous studies of stimulant medication with ADHD children that demonstrate significant improvements in academic productivity and sometimes accuracy when the children are on their medication (Barkley, 1977; Pelham, Bender, Caddell, Booth & Moorner, 1985; Rapport, DuPaul, Stoner & Jones, 1986).

The ability to sit still, attend, listen, obey, inhibit impulsive behaviour, cooperate, organise actions, and follow through on instructions as well as share, play well, and interact pleasantly with other children is essential to negotiating a successful academic career, beyond those cognitive and achievement skills needed to master the curriculum itself (Barkley, 1998). It is not surprising that the vast majority of ADHD children will have been identified as deviant in their behaviour by entry into formal schooling, particularly first grade.

Parents not only have to contend with the ongoing behavioural problems at home noted during the preschool years, but now have the additional burden of helping their children adjust to the academic and social demands of school. These parents must also tolerate the complaints of some teachers who see the child's problems at school

as stemming entirely from home problems, or poor child-rearing abilities in the parents (Barkley, 1998).

The fact that many schools now assign homework, even to first-graders, adds an additional demand on both the parent and the child to accomplish these tasks together (Barkley, 1998). It is not surprising that homework time at home becomes another area in which conflict arises in the family.

It is presumed that ADHD children are also more likely than normal children to have learning disabilities (Safer & Allen, 1976). A learning disability is typically defined as a significant discrepancy between one's intelligence, or general mental abilities, and academic achievement, such as reading, mathematics, spelling, handwriting or language. Both intelligence and achievement must be assessed by well-standardised tests.

Barkley, DuPaul and McMurray (1990) investigated the prevalence of ADHD children who had a learning disability using the criterion of a 15-point IQ-achievement discrepancy. They found rates of 40% in reading, nearly 60% in spelling, and nearly 60% in mathematics. However, the rates in the normal control group were 20%, 38%, and 35%, respectively, being defined as learning disabled.

Using a somewhat larger discrepancy (20 points), Frick, Kamphaus, Lahey, Loeber, Christ, Hart and Tannenbaum (1991) estimated that 16% of ADHD children had a reading disability, whereas 21% had a mathematics disability. The corresponding prevalence in their normal control group was 5% and 7% respectively. Likewise, when Semrud-Clikeman, Biederman, Sprich-Buckminster, Lehman, Faraone and Norman (1992) increased the desired discrepancy to 20 points, 23% of the ADHD children could be considered reading disabled and 30% mathematically disabled, versus 2% and 22% of normal children, respectively.

An alternative approach is to define learning disabled as a score falling below 1.5 standard deviations from the normal mean on an achievement test, regardless of the child's IQ. This approach is far less likely to diagnose normal children as learning disabled. Using this approach, Barkley (1990) found the following prevalence of learning disability in ADHD children: 21% in reading, 26% in spelling, and over 28% in mathematics. For the normal children, these rates were 0%, 2.9% and 2.9% respectively.

A more intricate approach to calculating a discrepancy formula involves first converting the standard scores on the IQ and achievement tests to Z scores and then estimating the expected achievement score with a regression equation that takes into consideration both the correlation between the IQ and achievement test and the standard error of estimate for the achievement test. To be learning disabled, the child must have a discrepancy that exceeds a Z score of -1.65 (the $p < .05$ confidence level). Using this approach, Frick et al. (1991) reported a prevalence of 13% for reading disability and 14% for mathematics disability. Using this same approach, Faraone, Biederman, Lehman, Keenan, Norman, Seidman, Kolodny, Kraus, Perrin and Chen (1993) found that 18% of their ADHD group had a reading disability and 21% had a mathematics disability.

A different approach being used is to combine several of the previously discussed methods. In this case, learning disabled is defined as both a score below some level on an achievement test, say one standard deviation, *and* a significant discrepancy between IQ and achievement on that test, say 20 points. August and Garfinkel (1990) defined a learning disability as a 15-point IQ-achievement discrepancy and a standard score below 85 (1 standard deviation) on a reading test and found that 39% of their ADHD children were reading disabled. Using the same formula, Semrud-Clikeman et al. (1992) found that 15% were reading disabled and 33% were mathematically disabled (compared to none of the control group). Again using this same formula, Casey, Rourke and Del Dotto (1996) found that nearly 31% of children with Attention-Deficit Disorder with Hyperactivity had a reading disorder, 27% had a spelling disorder, and nearly 13% had a mathematics disorder.

In conclusion, if the more rigorous approaches to defining learning disability are employed (i.e. Frick et al.'s regression equation or the combined approach mentioned above) then approximately 8-39% of ADHD children are likely to have a reading disability, 12-30% a mathematics disability, and approximately 12-27% a spelling disorder.

For those ADHD children who have a reading disorder, it will soon be noted as the child tries to master the early reading tasks at school. Among those who will develop mathematics and writing disorders, these problems often go undetected until several years into formal schooling (Barkley, 1998). Even for those without comorbid learning disabilities, almost all ADHD children are haunted by highly erratic educational performance - some days performing at or near normal levels of ability and

accomplishing all assignments, other days failing tests and not completing assigned work. Disorganised desks and notebooks are highly characteristic of these children, forcing others to step in periodically and reorganise their materials to try to facilitate better academic performance.

At home, parents often complain that their ADHD children do not accept household chores and responsibilities as well as do other children their age (Barkley, 1998). Greater supervision of and assistance with these daily chores and self-help activities (dressing, bathing etc.) are common and lead to the perception that these children are quite immature. Although temper tantrums are likely to decline, as they do in normal children, ADHD children are still more likely to emit such behaviour when frustrated than do normal children (Barkley, 1998). Relations with siblings may be tense, as the sibling grows tired and exasperated at trying to understand and live with so disruptive a force as their ADHD brother or sister. Some siblings develop resentment over the greater burden of work they carry compared to their hyperactive siblings. Certainly, siblings are often jealous of the greater amount of time these ADHD children receive from their parents. At an age when other children are entering extracurricular community and social activities (such as clubs, music lessons, sports and scouts) ADHD children are likely to find themselves barely tolerated in these group activities or outright ejected from them in some cases. Parents frequently find that they must intervene on behalf of their children to explain and apologise for their behaviour and transgressions to others, to try to aid the children in coping better with the social demands, or to defend their children against sanctions that may be applied for their unacceptable conduct (Barkley, 1998).

An emerging pattern of social rejection will have appeared by now, if not earlier, in over half of all ADHD children because of their poor social skills. Even when the ADHD child displays appropriate or pro-social behaviour toward others, it may be at such a high rate of intensity that it elicits rejection and avoidance of the child in subsequent situations, or even punitive responses from his or her peers (Hinshaw, 1992; Ross & Ross, 1982). This rejection can present a confusing picture to the ADHD child attempting to learn appropriate social skills. The high rate of behaviour, vocal noisiness, and tendency to touch and manipulate objects more than is normal for age, combine to make the ADHD child overwhelming, intrusive and even aversive to others. By late childhood many ADHD children commonly develop feelings of depression and a sense of inadequate competence (Diener & Milich, 1997).

By late childhood and preadolescence, these patterns of academic, familial and social conflicts have become well established for many ADHD children. At least 40-60% have developed Oppositional Defiant Disorder (ODD) and as many as 25-40% are likely to develop symptoms of Conduct Disorder (CD) and antisocial behaviour between 7 and 10 years of age (Barkley, Fischer et al., 1990; Biederman, Faraone, Taylor, Sienna, Williamson & Fine, 1997). The most common symptoms are lying, petty thievery, and resistance to the authority of others. At least 25% or more may have problems with fighting with other children. It is the minority of ADHD children who have not developed some comorbid psychiatric (ODD/CD), academic (learning disability and underachievement), or social disorder by this time. Those who remain purely ADHD whose attention problems are most prominent are likely to have the best adolescent outcomes, experiencing problems mainly with academic performance and eventual attainment (Fergusson, Lynskey & Horwood, 1997; Weiss & Hechtman, 1993). For others, an increasing pattern of familial conflict and antisocial behaviour in the community may begin to appear or worsen where it already existed. Such family conflicts often prove particularly recalcitrant to treatment (Barkley, Guevremont, Anastopoulos & Fletcher, 1992).

The majority of ADHD children (60-80%) have by this time been placed on a trial of stimulant medication, and over half have participated in some type of individual and family therapy (Barkley, DuPaul & McMurray, 1990; Barkley, Fischer et al., 1990; Faraone et al., 1993; Munir, Biederman & Knee, 1987; Semrud-Clikeman et al., 1992). Approximately 30-45% will also be receiving formal special educational assistance for their academic difficulties by the time they enter adolescence. Some gains in scholastic performance have been achieved through cognitive-behavioural programmes that teach ADHD children how to set academic goals that require sustained attention, while allowing these youngsters to reinforce their success with tokens that can be exchanged for prizes (Shaffer, 2002).

3.3.3 Adolescence

“Normal” development

According to Hughes (2000), with regard to **physical development**, adolescents experience a growth spurt during which they not only approach their adult size, but also develop gender-specific differences in physique. Athletic skill and physical endurance and power increase for both genders. Normal adolescent risk-taking occurs as teenagers attempt to gain peer acceptance, fortify their self-esteem, and establish their independent identities. Tobacco use typically begins during

adolescence, and substance use is relatively common among teenagers, in spite of their knowledge of the potential risks.

With regard to **cognitive development**, formal operational reasoning introduces thinking in terms of abstractions, rather than relying upon concrete representations. Adolescents now have the capacity to integrate abstract concepts and co-ordinate a number of mental processes. Improvements in deductive reasoning allow adolescents to apply logic more effectively. Discovery of their newfound independent reasoning ability contributes to a new egocentric phase, during which they perceive themselves as special, invincible and under extreme public scrutiny.

The increasing independence and breadth of choices confronting adolescents necessitates that they capitalise upon their ability to learn formal decision-making and problem-solving techniques. Information-processing ability improves as adolescents work with increasingly more familiar material, experience opportunities to practice information-processing skills, build larger knowledge bases, and develop new information processing skills. New skill attainment is affected both by direct instruction and developmental maturity. Language ability is enhanced by ongoing improvements in grammar and vocabulary. Adolescents' experience of reading begins touching upon more abstract, hypothetical notions such as possible motives and symbolism. The ability to perform more complex mathematical manipulations is supported by adolescent improvements in attending and ability to consider multiple variables. Children's earliest career fantasies involve jobs that sound exciting or have high visibility. At adolescence, they begin assessing their interests and abilities realistically as they consider potential careers.

With regard to **social and emotional development**, identity formation requires independent adolescent self-exploration, often resulting in considerable oppositional or rebellious behaviour. Adolescents need to sort out multiple and conflicting facets of selfhood as they establish an independent self-concept. Cultural gender expectations affect their identity formation.

During adolescent individuation, relationships with parents become more conflictual, especially with mothers; and less cohesive, particularly with fathers. However, teenagers continue to benefit emotionally and cognitively from secure attachments to parents, even though this attachment may be more aloofly expressed. Peer relationships become more influential during adolescence, providing more emotional

supportiveness that they do for younger children. Academic achievement, identity formation and emotional adjustment are associated with an adolescent's choices of crowds, cliques and individual friendships. Younger adolescents are more influenced by peers than are older ones, and girls place more importance on social relationships than do boys. Dating during adolescence provides a means of practicing couplehood, both personally and socially. Adolescents are easily susceptible to excessive social influence.

Increases in emotionality during adolescence are in part associated with hormonal changes and adjustment to more complex cognitive processing. Children invest the greatest amount of energy in regulation of emotional expressiveness during the early teen years. Adolescents commonly experience normal depressive moods as they sort out and react to developmental issues. Depression reaches clinical levels twice as often in adolescent girls as in boys, and adolescents attempt suicide more than any other age group. Adolescents' advances in moral reasoning correspond with their greater understanding and ability to manipulate abstractions

ADHD children

It was once believed that hyperactive children simply outgrew their problems after reaching puberty. As a result, parents sometimes delayed getting help, expecting their children's difficulties to go away by adolescence (Kendall, 2000). Although there is generally a decline in their levels of hyperactivity and an improvement in their attention span and impulse control (Hart et al., 1995), 70-80% of ADHD children are likely to continue to display these symptoms into adolescence to an extent inappropriate for their age group (Barkley, Anastopoulos, Guevremont & Fletcher, 1991; Barkley, Fischer et al., 1990). As many as 25-45% of the adolescents display oppositional or antisocial behaviour or CD (Biederman et al., 1997), and 30-58% have failed at least one grade in school (Barkley, Anastopoulos et al., 1991; Barkley, Fischer et al., 1990; Brown & Borden, 1986). Other studies clearly show these children to be significantly behind matched control groups in academic performance at follow-up (Fischer, Barkley, Edelbrock & Smallish, 1990; Lambert, Hartsough, Sassone & Sandoval, 1987; Weiss & Hechtman, 1993).

As Ross and Ross (1976) have indicated, the adolescent years of ADHD individuals may be some of the most difficult because of the increasing demands for independent, responsible conduct, as well as the emerging social and physical changes inherent in puberty. Issues of identity, peer group acceptance, dating, and

physical development and appearance erupt as a source of demands and distress with which the ADHD adolescent must now cope. Sadness, major depression in as many as 25% of cases, poor self-confidence, diminished hopes of future success, and concerns about school completion may develop.

A detailed picture of the adolescent outcome of ADHD children has emerged from a study by Barkley and his colleagues (Barkley, Fischer et al., 1990). The study consisted of a large sample of ADHD and normal children followed prospectively eight years after their initial evaluation. Unlike past studies, the clinic referred children diagnosed as hyperactive fulfilled a set of rigorous research criteria designed to select a sample of children who were truly developmentally deviant in their symptoms relative to same-age normal children.

The initial sample in Barkley's study consisted of 158 hyperactive children and 81 normal children between four and 12 years of age. A total of 123 hyperactive children and 66 normal children were located and agreed to be interviewed and complete the questionnaires. This represents a total of 78% of the original sample for hyperactive children and 81% for the normal group. In the hyperactive group, 12 of the subjects (9.7%) were female and 111 were male, whereas in the normal group four of the subjects (6.1%) were female and 62 were male.

With regard to comorbidity for other disruptive behaviour disorders, 59% of the hyperactive group met DSM-III-R criteria for a diagnosis of ODD, as compared to 11% of the control group. Approximately 43% of the hyperactive group qualified for a diagnosis of CD using DSM-III-R criteria, as compared to only 1.6% of the control group. The mean age of onset for ODD was 6.7 years and for CD was six years.

Previous research has been equivocal concerning whether the rates of substance use and abuse among hyperactive adolescents differ from that of normal adolescents. Barkley's study (Barkley, Fischer et al., 1990) found that cigarette and alcohol use are the only categories of substance use that significantly differentiate the hyperactive and normal teenagers, according to teens' self-reports. A previous follow-up study by Gittelman, Mannuzza, Shenker and Bonagura (1985) found that the differences between clinically diagnosed hyperactive children and the control group in substance use at adolescent outcome were primarily accounted for by those hyperactive teens that received a diagnosis of CD. In agreement, a study by Lynskey and Fergusson (1995) found that rates of adolescent substance use and abuse were

elevated only in ADHD children having comorbid conduct problems as children. Barkley's study (Barkley, Fischer et al., 1990) separated subjects into those who were purely hyperactive and, in agreement with the above studies, found no greater use of cigarettes, alcohol or marijuana than did normal subjects. However, the mixed hyperactive/CD subjects displayed two to five times the rate of use of these substances than the pure hyperactive or normal subjects.

With regard to academic outcome, Barkley's study (Barkley, Fischer et al., 1990) showed that the academic outcome of the hyperactive adolescents was considerably poorer than that of the normal adolescents, with at least three times as many hyperactive subjects having failed a grade (29.3% versus 10%), been suspended (46.3% versus 15.2%), or been expelled (10.6% versus 1.5%). Almost 10% of the hyperactive sample followed into adolescence had quit school at this follow-up point, compared to none of the normal sample. Levels of academic achievement on standard tests were also significantly below normal on tests of mathematics, reading and spelling. Barkley and his colleagues (Barkley, Fischer et al., 1990) again examined whether the presence of CD at follow-up within the hyperactive group accounted for these greater than normal rates of academic failure. The results indicated that, although hyperactivity alone increases the risk of suspension and dropping out of school, the additional diagnosis of CD greatly increases these risks. Moreover, the presence of CD accounts almost entirely for the increased risk of expulsion within the hyperactive group, in that the pure hyperactive group does not differ from normal in expulsion rate (1.6 versus 1.5%), whereas 21.7% of the mixed hyperactive/CD group had been expelled from school. In contrast, the increased risk of grade retention in the hyperactive group is entirely accounted for by their hyperactivity with no further risk occurring among the mixed hyperactive/CD group.

Barkley and his colleagues also examined the extent of various interventions received in the ensuing eight years since initial evaluation and their durations for both groups. Not surprisingly, more ADHD children had received medication and individual and group therapy as well as special educational services than had normal children. Similar results were found in a later study by Barkley (Barkley, Anastopoulos et al., 1991) involving clinic-referred adolescents having ADHD. In terms of the duration of treatment among those receiving it, the hyperactive children had received a substantial period of stimulant medication treatment (mean of 36 months) and individual and family therapy (16 and 17 months respectively), as well as special educational assistance for learning, behavioural and speech disorders during the

past eight years (65, 59, and 40 months respectively) (Barkley, Fischer et al., 1990). This pattern is similar to that found in Barkley's study of clinic-referred ADHD teens (Barkley, Anastopoulos et al., 1991) and Lambert's follow-up study of 58 hyperactives and controls (Lambert et al. 1987).

With regard to automobile accidents, a later study by Barkley and colleagues (Barkley, Guevremont, Anastopoulos, DuPaul & Shelton, 1993) confirms prior research (Weiss & Hechtman, 1993) that suggested that hyperactive adolescents have a higher incidence of automobile accidents than do normal adolescents. Barkley's study followed ADHD teens prospectively for three to five years and found that they were significantly likely to have had more crashes, to have more bodily injuries associated with such accidents, and to be at fault more often for such accidents. They were also more likely to receive traffic citations, particularly for speeding.

3.3.4 Adult outcome

Only a few studies have followed samples of hyperactive children into adulthood. The results of research to date, based largely on North American samples, suggest that problems with behaviour in general, and ADHD symptoms specifically, continue for 50-65% of these children as they achieve adulthood (Weiss & Hechtman, 1993). Persistence of ADHD into adulthood is very much a matter of the source of information and the diagnostic criteria being employed (Fischer, 1997). If DSM criteria are applied to the subject's own self-reports, low rates of persistence of ADHD are likely to be found. But if parent reports of the subjects are used, persistence of the disorder is much greater. According to Barkley (1998) this suggests that DSM criteria become increasingly less sensitive to the disorder with age. This information also implies that subjects with ADHD may be prone to seriously under-report their symptoms of the disorder, relative to what others may say about them.

Antisocial behaviour is likely to be troublesome for a sizable minority of ADHD children as adults, with at least 18-28% having Antisocial Personality Disorder (Gittelman et al., 1985; Mannuzza, Klein, Bonagura, Malloy, Giampino & Addalli, 1991; Mannuzza et al., 1993; Weiss & Hechtman, 1993) – a pattern of repetitive antisocial behaviour beginning in early adolescence. These cases of antisocial conduct overlap considerably with the 10-20% who are likely to have a Substance Abuse Disorder (Gittelman et al., 1985; Mannuzza, Klein, Bonagura et al., 1991;

Mannuzza et al., 1993). However, in both the Canadian study of Weiss and Hechtman (1993) and the Milwaukee follow-up study of Fischer (1997), the rates of specific forms of substance abuse or dependence were not found to be significantly higher than those found in the control groups.

The Milwaukee follow-up study (Fischer, 1997) documented a significantly higher rate of Major Depression among the hyperactive subjects in young adulthood compared to the control subjects (28% versus 12%). This has not been documented in the other follow-up studies that employed DSM criteria for assessing psychiatric disorders at adult outcome (Mannuzza et al., 1993).

Some research shows that approximately 79% of ADHD children, as adults, complain of difficulties with neurotic symptoms, such as anxiety, sadness, somatic complaints, or other internalising features, and 75% report interpersonal problems versus about 51% and 54%, respectively, of control subjects (Weiss & Hechtman, 1993). The incidence of psychotic disorders in ADHD children at adulthood is no greater than that for the normal control group. The results of the Weiss and Hechtman (1993) study suggest that almost 10% will have attempted suicide within the past three years and about 5% will die from either suicide or accidental injury. Both percentages are considerably greater than those seen in control groups.

With regard to antisocial activities, as adults, individuals with a prior history of ADHD were found to have a greater likelihood of contact with the police and courts, primarily for traffic offences (18% versus 5% for controls) (Weiss & Hechtman, 1993). However, problems with theft and non-prescription sale of drugs may occur in a significant minority of subjects. In the Canadian follow-up study, approximately 20% of ADHD children committed acts of physical aggression toward others in adulthood within the past three years, compared to 5% of control children (Weiss & Hechtman, 1993). In the Milwaukee young adult follow-up study, several forms of antisocial activity were more common among the hyperactive than the control subjects: theft of property (85% versus 66%), breaking and entering (20% versus 8%), disorderly conduct (68% versus 54%), assault with fists (74% versus 53%), carrying a weapon (39% versus 11%), assault with a weapon (22% versus 7%), intentionally setting fires (16% versus 5%), and running away from home as a teenager (31% versus 16%) (Fischer, 1997). Overall, 22% of the formerly hyperactive subjects had been arrested for a felony compared to only 3% of the control group. Satterfield, Satterfield and Cantwell (1981) found that between 36% and 52% of their hyperactive subjects had

been arrested at least once. Similarly, Mannuzza, Gittelman, Konig and Giampino (1989) found that 39% of their hyperactive subjects had been arrested (versus 20% of the control group) and 23% had been arrested more than once (versus 8% of the control group). Consequently, rates of incarceration were also higher in the hyperactive group (9% versus 1%). Only the Weiss and Hechtman (1993) study did not find higher rates of arrest among the sample of Canadian hyperactive children followed into adulthood. It is fair to say that the vast majority of ADHD individuals are not antisocial in adulthood, but that a small number, perhaps 25%, are so and display a persistent pattern of such conduct over time. Klein and Mannuzza (1991) found in their study that the greater arrest and incarceration rates were exclusively among those hyperactive subjects who had Antisocial Personality Disorder in adulthood.

With regard to academic attainment, the trends toward lower academic achievement and ability and greater grade retentions, suspensions, and expulsions evident in the adolescent years increase such that by adulthood, the percentage of ADHD children having difficulties in these areas is even greater than those percentages noted in adolescence and, of course, greater than those of control groups. The Milwaukee study found that by 19-27 years of age, more than 60% of ADHD subjects reported having been suspended from school (versus 18% of the control group) and more than 13% had been expelled (versus 5% of the control group). Although many ADHD children who are now adults will be employed and self-supporting, their general level of educational attainment and socio-economic status is less than that of control children or even their siblings (Mannuzza et al., 1993). Up to 30% will drop out of and never complete high school as compared to less than 10% of control children (Weiss & Hechtman, 1993). In the Milwaukee follow-up study, the rate of failure to graduate from high school was 32%. Inspection of high school transcripts obtained from these subjects indicated a significantly lower high school grade point average, and their average class ranking in high school was significantly lower. In the Canadian follow-up study, approximately 20% attempted a college programme, yet only 5% completed a university degree programme as compared to over 41% of control children (Weiss & Hechtman, 1993).

With regard to employment functioning, results from past studies suggest that as adolescents, ADHD individuals are no different in their functioning in their jobs than are normal adolescents (Weiss & Hechtman, 1993). However, these findings need to be qualified by the fact that most jobs taken by adolescents are unskilled or only semi-skilled and are usually part time. As ADHD children enter adulthood and take

on full-time jobs that require skilled labour, independence of supervision, acceptance of responsibility, and periodic training in new knowledge or skills, their deficits in attention, impulse control, and regulating activity level, as well as their poor organizational and self-control skills, could begin to handicap them on the job. The findings from the few outcome studies that have examined job functioning suggest this may be the case. Although ADHD adults are likely to be employed full time, are completely self-sufficient of their families, and are upwardly mobile (increasing in economic status with time), the quality of their work adjustment differs significantly from that of normal control subjects in adulthood (Weiss & Hechtman, 1993). The Milwaukee follow-up study obtained employer ratings of work performance at the young adult assessment and found that hyperactive subjects are rated as performing significantly more poorly at work than are control subjects. ADHD adults are likely to have lower socio-economic statuses than their brothers or control subjects in these studies and to move and change jobs more often, but also to have more part-time jobs outside their full-time employment. Employers have been found to rate ADHD adults as less adequate in fulfilling work demands, less likely to be working independently and to complete tasks, and less likely to be getting along well with supervisors. They also do more poorly at job interviews than do normal individuals. ADHD adults report that they are more likely to find certain tasks at work too difficult for them. Finally, ADHD adults appear to have a poorer work record and lower job status than normal adults (Weiss & Hechtman, 1993).

Weiss and Hechtman (1993) are the only investigators to date to have studied the social skills of ADHD adults followed prospectively from childhood. Their findings indicate greater social skills and interaction problems for ADHD adults, particularly in the areas of hetero-social skills (male-female interactions) and assertion.

With regard to sexual activity, the Canadian follow-up study (Weiss & Hechtman, 1993) found that sexual adjustment problems were described by as many as 20% of the ADHD group in adulthood, a figure greater than that of the control group (2.4%). The Milwaukee follow-up study questioned subjects about their sexual activities as part of the evaluation at the young adult follow-up point. Preliminary results indicate that the hyperactive subjects began having sexual intercourse at an earlier age than the control group (15 versus 16 years), have had more sexual partners in their lives (19 versus 7), are more likely to have conceived a pregnancy (38% versus 4%), are less likely to employ birth control methods, are more likely to have contracted a sexually transmitted disease (17% versus 4%), and are more likely to have been

tested for HIV/AIDS (54% versus 21%). Such findings indicate a high-risk sexual lifestyle among the formerly hyperactive subjects on reaching early adulthood, in comparison to the control subjects.

With regard to driving, the study by Weiss and Hechtman (1993) found that significantly more of their hyperactive subjects as adults had been involved in motor vehicle crashes and had received speeding tickets compared to their control groups. The Milwaukee outcome study did not find a greater number of accidents or speeding tickets by self-report of the subjects at their young adult assessment. However, more hyperactive subjects than control subjects reported having had their licences suspended or revoked (42% versus 28%), having been involved in accidents in which the vehicle was totalled (49% versus 16%), and having been involved in a hit-and-run accident (14% versus 2%). Also, the number of total traffic citations and licence suspensions/revocations was significantly greater in the hyperactive subjects, as was the amount of damage done in their first vehicular crashes. During a behind-the-wheel driving evaluation, the hyperactive subjects were rated by a driving examiner as significantly more distractible and impulsive, and were rated by themselves and their parents as using significantly poorer driving skills.

This chapter has reviewed the literature and existing research regarding the incidence and developmental course of attention deficit hyperactivity disorder. The following chapter will examine the effects of ADHD on the family and will discuss treatment options for ADHD.

CHAPTER FOUR: ADHD - EFFECT ON FAMILY LIFE AND TREATMENT OPTIONS

4.1 ADHD and family life

4.1.1 Parent-child interactions

ADHD is classified in the DSM-IV (American Psychiatric Association, 1994) as a Disruptive Behaviour Disorder because of the significant difficulties it creates for children in disrupting their social conduct and general social adjustment. The interpersonal behaviours of those with ADHD are often characterised as more impulsive, intrusive, excessive, disorganised, engaging, aggressive, intense and emotional (Barkley, 1998). And so they are “disruptive” of the smoothness of the ongoing stream of social interactions, reciprocity and co-operation that may constitute the child’s daily life with others (Whalen & Henker, 1992).

Research finds that ADHD affects the interactions of children with their parents and, hence, the manner in which parents may respond to these children. Children with ADHD are more talkative, negative and defiant; less compliant and cooperative; sustain their compliance for shorter time periods; are less likely to remain in task; are more demanding of assistance from others; and are less able to play and work independently of their mothers (Barkley, 1985; Danforth, Barkley & Stokes, 1991; Gomez & Sanson, 1994; Mash & Johnston, 1982). In what Johnston (1996) recently labelled a "negative-reactive" response pattern, mothers and fathers of ADHD children display more directive and commanding behaviour, more disapproval, fewer rewards that are contingent on the child's prosocial and compliant behaviours, and more overall negative behaviour than the parents of normal children do (Barkley, Karlsson, & Pollard, 1985; Befera & Barkley, 1984; Cunningham & Barkley, 1979; Mash & Johnston, 1982; Tallmadge & Barkley, 1983).

Research has demonstrated that the primary direction of effects within these interactions is from child to parent (Fischer, 1990; Mash & Johnston, 1990) rather than the reverse. That is, much of the disturbance in the interaction seems to stem from the effects of the child’s excessive, impulsive, unruly, non-compliant and emotional behaviour on the parent rather than from the effects of the parent’s behaviour on the child. This finding was documented primarily through studies that evaluated the effect of stimulant medication on the behaviour of the children and their

interaction patterns with their mothers. Such research found that medication improves the compliance of those with ADHD and reduces their negative, talkative and generally excessive behaviour such that their parents reduce their levels of directive and negative behaviour as well (Barkley & Cunningham, 1979; Barkley, Cunningham & Karlsson, 1983; Danforth et al., 1991; Humphries, Kinsbourne & Swanson, 1978). These medication effects are noted even in the preschool age group of children with ADHD (Barkley, 1988b) as well as those in late childhood (Barkley, Karlsson, Pollard & Murphy, 1985) and in both sexes of ADHD children (Barkley, 1989). Besides a general reduction in the negative, disruptive, and conflictual interaction patterns of these children with parents resulting from stimulant medication, general family functioning also seems to improve when ADHD children are treated with stimulant medication (Schachar, Taylor, Weiselberg, Thorley & Rutter, 1987).

The interaction conflicts in families with ADHD children are not limited only to parent-child interactions. Increased conflicts have been observed between ADHD children and their siblings relative to normal child-sibling dyads (Mash & Johnston, 1983; Taylor, Sandberg, Thorley & Giles, 1991). These patterns of disruptive, intrusive, excessive, negative and emotional social interactions of ADHD children have also been found to occur in their interaction with teachers (Whalen et al., 1980). Like the interactions of ADHD children with their parents, the interactions of these children with their teachers have also been shown to be significantly improved by administration of stimulant medication (Whalen et al., 1980).

Interestingly, ADHD children appear to be more compliant and less disruptive with their fathers than their mothers (Tallmadge & Barkley, 1983). According to Tallmadge and Barkley, there are several possible reasons for this. For one, mothers are still the primary custodians of children within the family, even when they are employed outside the home, and may, therefore, be the ones who are most likely to tax or exceed the child's limitations in the areas of persistence of attention, activity regulation, impulse control, and rule-governed behaviour. Getting children to do chores and schoolwork, perform self-care routines, and control their behaviour in public remain predominantly maternal responsibilities; thus mothers may be more likely to witness ADHD symptoms than are fathers. Another reason may be that mothers and fathers tend to respond to inappropriate child behaviour somewhat differently. Mothers may be more likely to reason with children, repeat their instructions, and use affection as a means of governing child compliance. Fathers

seem to repeat their commands less, to reason less, and to be quicker to discipline children for misconduct or non-compliance. The larger size of fathers and their consequently greater strength may also be perceived as more threatening by children and hence more likely to elicit compliance to commands given by fathers.

Research demonstrates that mother-child conflicts may result in increased father-child conflict when mothers and fathers interact jointly with their hyperactive children, especially hyperactive boys (Buhrmester, Camparo, Christensen, Gonzalez & Hinshaw, 1992). These negative parent-child interaction patterns occur in the preschool age group (Cohen, Sullivan, Minde, Novak & Keens, 1983) and may be at their most negative and stressful (to the parent) in this age range (Mash & Johnston, 1982, 1990). With increasing age, the degree of conflict in these interactions lessens, but remains deviant from normal into later childhood (Barkley, Karlsson & Pollard, 1985; Mash & Johnston, 1982) and adolescence (Barkley, Anastopoulos, Guevremont & Fletcher, 1992; Barkley, Fischer, Edelbrock & Smallish, 1991). Negative parent-child interactions in childhood have been observed to be significantly predictive of continuing parent-child conflicts 8 to 10 years later in adolescence in families with ADHD children (Barkley, Fischer et al., 1991).

Important in this line of family research has been the discovery that it is the presence of comorbid Oppositional Defiant Disorder (ODD) that is associated with most of the conflicts noted in the mother-child interactions of ADHD children and adolescents (Barkley, Anastopoulos et al., 1992; Barkley, Fischer et al., 1991). In a sequential analysis of these parent-teen interaction sequences, investigators have noted that it is the immediate or first lag in the sequence that is most important in determining the behaviour of the other member of the dyad (Fletcher, Fischer, Barkley & Smallish, 1996). That is, the behaviour of each member is determined mainly by the immediately preceding behaviour of the other member and not by earlier behaviours of either member in the chain of interactions. The interactions of the comorbid ADHD/ODD group reflected a strategy best characterised as “tit for tat” in that the type of behaviour (positive, neutral or negative) of each member was most influenced by the same type of behaviour emitted preceding it. Mothers of ADHD only and normal teens were more likely to utilise positive and neutral behaviours regardless of the immediately preceding behaviour of their teens, characterised as a “be nice and forgive” strategy that is thought to be more mature and more socially successful for both parties in the long run (Fletcher et al., 1996). Even so, those with ADHD alone are still found to be deviant from normal in these interaction patterns even though

less so than the comorbid ADHD/ODD group. The presence of comorbid ODD has also been shown to be associated with greater maternal stress and psychopathology as well as marital difficulties (Barkley, Anastopoulos et al., 1992; Barkley, Fischer et al., 1991). Yet parents of ADHD children, more than parents of normal children, appear to sense that the disruptive behaviour children is internally rather than externally caused, less controllable by the child, and more stable over development (Johnston & Freeman, 1997). In contrast, they evaluate the pro-social behaviour of their ADHD children as less internal and less stable than do control parents.

4.1.2 Family functioning

Research on the larger domain of family functioning has also shown that parents of children with ADHD commonly experience considerable stress in their parenting roles (Anastopoulos, Guevremont, Shelton, & DuPaul, 1992; Fischer, 1990). Moreover, they often view themselves as less skilled and less knowledgeable as parents, and derive less value and comfort from their parenting efforts (Mash & Johnston, 1983). Parents of ADHD children are also at increased risk for increased alcohol consumption (Cunningham, Bennes & Siegel, 1988; Pelham & Lang, 1993). Pelham and Lang (1993) have shown that the increased alcohol consumption of these parents is, in part, directly a function of the stressful interactions they have with their ADHD children.

Decreased extended family contacts are also noted in families with an ADHD child (Cunningham et al., 1988). Parents may feel blamed for their children's behaviour by extended family members. Conflicting understandings of ADHD and its treatment may further isolate parents from their families, who might otherwise be a source of support (Alexander-Roberts, 1995). Increased marital conflict, separations, and divorce, as well as maternal depression is also prominent in parents of ADHD children (Befera & Barkley, 1984; Barkley, Fischer et al., 1990; Cunningham et al., 1988; Lahey, Piacentini, McBurnett, Stone, Hartdagen & Hynd, 1988; Taylor et al., 1991).

Again, the comorbid association of ADHD with ODD, or its later stage of Conduct Disorder (CD), is linked to even greater degrees of parenting stress, parental psychopathology, marital discord, and divorce than in ADHD-only children (Barkley, Fischer et al., 1990; Barkley, Fischer et al., 1991; Johnston, 1996; Lahey, Piacentini, et al., 1988; Taylor et al., 1991).

4.1.3 Peer relations

Pelham and Bender (1982) once estimated that more than 50% of ADHD children have significant problems in social relationships with other children. Mothers (Campbell & Paulauskas, 1979), teachers (Barkley, DuPaul & McMurray, 1990), and peers (Johnston, Pelham & Murphy, 1985; Pope, Bierman & Mumma, 1989) find hyperactive children to be significantly more aggressive, disruptive, domineering, intrusive, noisy and socially rejected in their social relations than normal children, especially if they are male hyperactives, and particularly if they are aggressive (Hinshaw & Melnick, 1995; Milich, Landau, Kilby & Whitten, 1982; Pelham & Bender, 1982).

Studies that have directly observed these peer interactions suggest that the inattentive, disruptive, off-task, immature, provocative, aggressive and non-compliant behaviours of ADHD children quickly elicit a pattern of controlling and directive behaviour from their peers when they must work together (Clark, Cheyne, Cunningham & Siegel, 1988; Cunningham & Siegel, 1987; Hinshaw, 1992; Hinshaw & Melnick, 1995; Whalen, Henker, Collins, Finck & Dotemoto, 1979; Whalen, Henker, Collins, McAuliffe & Vaux, 1979). There also seems to be a tendency for ADHD children to accept other ADHD children as playmates more than do normal children (Hinshaw & Melnick, 1995). In their communication patterns, ADHD children in these studies have been found to talk more, but to be less efficient in organizing and communicating information to peers with whom they are asked to work. Moreover, despite talking more, the ADHD children are less likely to respond to the questions or verbal interaction of their peers. Hence, there is clearly less reciprocity in the social exchanges of hyperactive children with their peers (Cunningham & Siegel, 1987; Landau & Milich, 1988). ADHD children have also been shown to have less knowledge about social skills and appropriate behaviour with others (Grenell, Glass & Katz, 1987). Among ADHD children, those who are the most sensation seeking, emotionally reactive, aggressive, and non-compliant received the greatest disapproval from their peers (Hinshaw & Melnick, 1995).

Those ADHD children who are also aggressive may display an additional tendency to over-interpret the actions of others toward them as having hostile intentions and are, therefore, likely to respond with aggressive counterattacks over minimal, if any, provocation (Milich & Dodge, 1984). Such communication problems, skills deficits, attribution biases, and interaction conflicts could easily lead to the ADHD children, especially those who are aggressive, being rejected as playmates by their

classmates and neighbourhood peers in very short order. Many have noted that it takes few social exchanges over a period of only 20 to 30 minutes between ADHD and normal children for normal children to find the ADHD children disruptive, unpredictable and aggressive and hence to react to them with aversion, criticism, and rejection, and sometimes even counter-aggression. Certainly they are likely to withdraw from the ADHD child when opportunities to do so arise (Milich et al., 1982; Pelham & Bender, 1982; Pelham & Milich, 1984).

4.2 Treatment of ADHD

4.2.1 Medical Intervention

The medications most frequently used in the treatment of ADHD children are the stimulant drugs. It is estimated that about 85 to 90 percent of learners with ADHD are taking stimulant medication such as Ritalin to control their behaviour (Santrock, 2002). Seventy percent or so are helped by these drugs (Cantwell, 1996). Because Ritalin is a stimulant, in most individuals it speeds up the nervous system and behaviour. However, in many children with ADHD it has the opposite effect, slowing down their nervous system and behaviour, although scientists are still not sure why these drugs work in such opposite ways for children with ADHD and those who do not have the disorder (Johnston & Leung, 2001). Ritalin enables ADHD children to better focus their attention and makes them less distractible and disruptive (Gilberg, Melander, von Knorring, Janols, Thernlund, Hagglof, Eidevall-Wallin, Gustafson & Kopp, 1997). Important side benefits of this increased attentional focusing are that both academic and peer relations are likely to improve (Pelham, Carlson, Sams, Vallano, Dixon, Hoza, 1993).

The use of Ritalin and other stimulants to treat ADHD continues to be controversial. Critics of this approach argue that stimulants do little more than suppress ADHD symptoms while possibly producing such serious side effects as curbing appetites, disrupting sleep cycles, and reducing children's desire to play and to acquire any number of important skills that are not taught at school (Panksepp, 1998; Schachar, Tannock, Cunningham & Corkum, 1997). Critics argue that physicians are too quick to prescribe Ritalin, especially for mild cases of ADHD, and that long-term studies of the effects of Ritalin on children with ADHD have not been conducted to determine possible negative effects (Santrock, 2002). It is true that stimulants improve functioning only temporarily until their effect wears off at the end of the day (Schachar, Tannock, Cunningham & Corkum, 1997). And so far there is not much

evidence that individuals who took stimulants as children are better off as adolescents or adults than those who did not (Hart et al., 1995).

Papalia, Gross and Feldman (2003) note that a disturbing trend is the increasing use of drugs such as Ritalin with preschoolers, even though their effectiveness in children that young has not been shown, and despite concern about effects on the developing brain. A recent study suggests that up to 1.5 percent of two to four year olds are on stimulants, antidepressants, or antipsychotic medications (Coyle, 2000; Zito, Safer, dosReis, Gardner, Boles & Lynch, 2000).

A further concern with regard to Ritalin is that medication treatments may lead children with ADHD to attribute their successes to the medication. Such an attributional style of seeing success as due to external factors might be considered consistent with a helpless or depressogenic attributional style (Milich, 1994). Reflecting this concern over the possible negative effects of medication on children's self-perceptions, several studies have examined the effects of stimulant medication on children's attribution for their performance on academic-type tasks. In general, these studies have failed to find any evidence of deleterious effects of medication on children's attributions for their own behaviour (e.g. Carlson, Pelham, Milich & Hoza, 1993; Jalongo, Lopez, Horn, Pascoe & Greenberg, 1994; Milich, Light, Murphy & Pelham, 1989; Pelham, Murphy, Vannatta, Milich, Light, Gnagy, Greenslade, Greiner & Vodde-Hamilton, 1992; Pelham, Hoza, Kipp, Gnagy & Trane, 1997). Children do not appear to attribute their successes to the medication and instead generally attribute their successes to effort and their failures to external causes such as test difficulty.

The Ritalin debate rages just as strongly in South Africa and has been prominent in the popular media again of late. *Reader's Digest* (Reid, 2003) carried an article in May 2003 entitled "Making sense of Ritalin". *You* magazine carried an article in July with the headline: "Misbehaving kids? Blame the parents" (Louw & Barnes, 2003). The article highlights the work of British behavioural consultant Warwick Dyer. Dyer believes that over-active children shouldn't be put on Ritalin when the fault lies in parents being unable to control the child. According to Dyer, the answer lies in parents curbing their anger and learning to control their children's behaviour. The magazine published an article the following week entitled "Ritalin gave us a new child" – a reply from a parent's viewpoint (Coetzee, 2003). The use of Ritalin with ADHD children has also enjoyed attention on television and radio in recent months.

While it is probably true that Ritalin and other stimulants are overprescribed in some communities, other evidence suggests that many ADHD children who could benefit from drug treatment go untreated (Jensen, 2000). With regard to the South African situation, the article that appeared in the Reader's Digest in May of 2003 quotes Dr Billy Levin, whose Gauteng-based practice has focused exclusively on ADHD for the past 20 years (Reid, 2003). Levin insists that there is no evidence of overprescription. He also contends that underprescription may, in fact, be more of a problem than overprescription. A small study conducted in 30 schools in Gauteng in 2001 revealed that fewer than two percent of children were on stimulant medication, whereas the prevalence of ADHD in the population is somewhere in the region of 5%. According to Levin, this suggests that many children who could benefit from medication aren't getting it. Although no countrywide survey has been conducted in South Africa, experts agree that the average number of prescriptions across all provinces is likely to be much lower than in Gauteng (Reid, 2003). This is because knowledge about ADHD – and therefore identification of the condition – is much lower in rural schools with their poor infrastructure than in urban centres.

4.2.2 Educational Interventions

4.2.2.1 Behaviour Modification

Behaviour modification, particularly the use of consequences, is the most commonly practiced classroom intervention for students with ADHD (Pfiffner & Barkley, 1990). Contingency management (or the use of consequences) may take the form of a token economy in which the student is rewarded for the desired behaviour with a token that can later be exchanged for a reward (positive reinforcement). Another contingency system, response cost, involves the loss of a token (punishment) if the subject does not display the appropriate behaviour (Bos & Vaughn, 1998; Lewis & Doorlag, 1995; Pfiffner & Barkley, 1990). Time-out is a condition in which an individual is removed from a reinforcing situation to one that is not reinforcing, such as removing a child from the group to sit in the passage or in a quiet chair until he is ready to rejoin the group (Bos & Vaughn, 1998).

A study conducted by Robinson, Newby, and Ganzell (1981) using a token system with a group of hyperactive boys in a third-grade classroom showed positive results. All eighteen participants improved in academic performance. The emphasis of this study was on the accurate completion of reading and vocabulary tasks. However, inappropriate disruptive and hyperactive behaviours were reduced because they were incompatible with the targeted behaviour (i.e., academic task completion).

Lee Rosén and colleagues (1984) conducted four experiments using various combinations of positive and negative consequences with a class of eight hyperactive boys. They found that negative consequences used prudently (delivered consistently and without delay) enhanced the effectiveness of the positive consequences. Negative consequences consisted of time-out (in the hall), verbal reprimands, and loss of free time. The positive consequences were social praise, hugs, and special privileges. Virginia Douglas (1985) pointed out that the balance between negative and positive consequences is crucial. Children with ADHD tend to become overly impulsive and distracted by rewards. This tendency may be tempered by the clear establishment of rules regarding the loss of a reinforcer (for example a token in response cost). However, care should be taken to prevent the frustration that might occur if a student loses more than he earns (Douglas, 1985; Rosén et al., 1984).

Mary Solanto (1990) compared the effects of positive reinforcement and punishment (response cost) on impulsivity rates of children with and without ADHD to see if there was a difference in response between the two groups of subjects. Included in the study were 20 children with ADHD and 18 normal controls between the ages of four-and-a-half and eleven years. The researcher found that both groups improved equally in performance, under both contingencies (reward and punishment). In other words, there were no differences in performance between groups under either condition.

DuPaul, Guevremont and Barkley (1992) conducted a study to examine the effects of response cost and directed rehearsal on academic performance and classroom behaviour. The subjects were two boys with ADHD, ages six and seven years, who were in a self-contained special education class. The response-cost intervention was implemented through the use of the Attention Training System (ATS), a battery operated device that provided positive and negative feedback to the subject. The teacher monitored student off-task behaviour and used a remote control to signal the child when he was off-task. The ATS included a module, which was placed on the student's desk, and that tallied and displayed the number of points earned. At the appropriate time the child could trade points for various rewards.

The directed-rehearsal procedure consisted of instruction or modelling of the academic activity by the teacher or aide, followed by additional seatwork for the student. This technique was used if the subject failed to earn a designated number of points for on-task behaviour during specific phases of the experiment.

Both students showed significant improvement over baselines in attending and completing classwork under the response-cost (ATS) condition. According to DuPaul, Guevremont and Barkley, the findings were unclear as to whether or not the addition of the directed-rehearsal contingency was an enhancement over the ATS alone. The teacher and the aide preferred the use of the ATS to the use of tokens due to the ease of monitoring student behaviour. They chose to continue using the program after the experiment was completed. The students also expressed an interest in the continued use of this approach.

Factors affecting the success or failure of contingency approaches are the specific characteristics of the individual for whom it is being designed. It is essential that the rewards be meaningful to the child in order for it to serve as an incentive to change. That is, what might be a reward for one child may not be a reward for another. For this reason teachers should elicit input from the students regarding a reward menu and frequently change the items included (DuPaul & Stoner, 1994; Goldstein & Goldstein, 1990; Pfiffner & Barkley, 1990).

Although contingency approaches may affect the target behaviours, there may not be a corresponding improvement in academic performance (Barkley, 1990, 1997b; Zentall, 1989). Additionally, because the teacher externally controls the intervention, it is usually effective only within that specific environment and as long as the teacher is using the procedure (Baumgaertel, Copeland, & Wolraich, 1996; Zentall, 1989).

4.2.2.2 Cognitive-Behavioural Therapy

In part, cognitive-behavioural therapies were developed based on the premise that some individuals needed direct instruction on skills (Schumaker & Sheldon, 1985) rather than learning intuitively by observing and imitating the behaviour of others (Bandura, 1969). According to Albert Bandura's theory of social learning, children learn behaviours, as well as values, through exposure to the models around them. An example of copied behaviour is an infant waving goodbye as someone leaves. This type of incidental learning is often an area of weakness for children with ADHD (Barkley, 1997b; Meichenbaum, 1977). Instead, the action must be specifically modelled with explicit directions (Copeland & Love, 1995; Meichenbaum, 1977; Schumaker & Sheldon, 1985). By using direct instruction along with the modelling of self-talk, it was hypothesized that individuals with ADHD would be able to develop the self-control necessary for successful learning that most people develop intuitively

(Bandura, 1969; Barkley, 1990; Goldstein & Goldstein, 1990; Keogh & Barkett, 1980; Schumaker & Sheldon, 1985).

Lev Vygotsky (1962) proposed a three-stage theory of language acquisition that fostered the development of cognitive-behavioural therapies. The first stage is external speech, which is the expression of thoughts in words. Children begin this process by saying words and then sentences in an attempt to control their environment and to communicate. Egocentric speech is the second stage and it consists of speaking aloud to oneself. When engaging in egocentric speech the child does not need an audience and in fact is often oblivious to the response or presence of others.

Whereas external speech is social and interactive, egocentric speech is more like thinking out loud and is functionally the same as the third stage, which is inner speech (Vygotsky, 1962). Vygotsky believed that egocentric speech served in the transition of speech from external to inner. Through the use of external tools or signs the student is able to solve internal problems. A cognitive example of this process is when children use mnemonics or counting on their fingers to solve problems, and then make the transition to counting and problem solving in their heads.

Inner speech represents the merging of thought and language and brings with it self-regulation. Behaviour of a young child is regulated externally through commands from adults and stimuli from the environment. The development of inner speech enables the child to plan and reflect before acting (Diaz, Neal, & Amaya-Williams, 1990). Self-regulation is a process involving the regulation of attention, memory, concentration, and problem solving through the use of a plan of action that the individual has formulated (Diaz, Neal, & Amaya-Williams, 1990). This cognitive process is also referred to as executive function (Castellanos, 1997). Executive dysfunction, that is, the inability to self-regulate impulsivity, attention, concentration, memory, and problem-solving strategies, is characteristic of individuals with ADHD (Castellanos, 1997).

If the natural progression of language, as described by Vygotsky, should proceed from external to internal (Goldstein & Goldstein, 1990; Goldstein, 1997), then some children with ADHD may have a deficit due to an inability to transfer, without assistance, from external to internal control through self-talk (Barkley, 1997; Goldstein & Goldstein, 1990; Goldstein, 1997; Meichenbaum, 1977).

A study was conducted by Meichenbaum (1977) of the egocentric speech of 16 four-year-olds in their preschool setting. Half of the children were impulsive, and the other

half was considered reflective. The amount of egocentric talk did not differ significantly in amount between the two groups, but the quality varied in essential ways. The impulsive subjects engaged in more self-stimulating private speech (for example chanting, animal noises, nonsense words), whereas the reflective children used self-regulatory speech and adjusted their self-talk to meet the demands of the task at hand. In conclusion, Meichenbaum believed the results suggested that impulsive children used inner speech with less maturity and regard for the specific nature of the situation than reflective preschoolers. These findings are supported by the work of Zentall (1989).

Typically, cognitive-behavioural therapies include strategies that are designed to enhance self-control through self-regulatory processes (Barkley, 1997b; DuPaul & Stoner, 1994; Meichenbaum, 1977; Zentall, 1989). Self-regulation includes actions taken by an individual for the purpose of altering one's own behaviour and consequently the outcome (Barkley, 1997b). Methods of accomplishing this change in outcome usually involve self-directed activities beginning with having the individual observe his or her own behaviour (DuPaul & Stoner, 1994; Zentall, 1989). It is essential to recognize the inappropriate behaviour before attempting to change it (Copeland & Love, 1995; Meichenbaum, 1977; Zentall, 1989).

Self-monitoring can be used to identify and record maladaptive behaviours when they occur. Usually, an external cue is implemented initially, as in behaviour modification, possibly in the form of a signal from the teacher or an electronic device such as a tape player. However, in cognitive-behavioural modification, the external cue is faded out after the subject has internalised the ability to self-monitor (DuPaul & Stoner, 1994; Meichenbaum, 1977; Zentall, 1989). Through the paired use of cuing and modelling, the responsibility for changing behaviour is transferred from an external source (for example teacher, parent, device) to the internal mechanisms of the student (Christie, Hiss, & Lozanoff, 1984; Meichenbaum, 1977; Zentall, 1989).

Self-monitoring can play a crucial part in this process by helping the individual develop the ability to recognize the inappropriate behaviour, as well as the frequency of its occurrence. By identifying the undesired behaviours, the teacher may begin to employ strategies to improve the subject's repertoire of reactions (Meichenbaum, 1977). Self-talk (verbalization of actions and thought) should be modelled and then rehearsed in order for most individuals with ADHD to successfully develop mature use of inner speech (Barkley, 1997b; Meichenbaum, 1977).

Christie, Hiss, and Lozanoff (1984) conducted a study on the use of self-monitoring procedures, along with teacher cuing, to modify the behaviour of a group of hyperactive children. The researchers intentionally selected a regular classroom setting to avoid the difficulty in transferring training procedures from the laboratory setting to the classroom, which has been noted as one of the drawbacks in the use of cognitive-behavioural therapies (Barkley, 1990, 1997; Christie, Hiss, & Lozanoff, 1984). According to Russell Barkley (1997b), "The most useful treatments will be those that are in place in natural settings at the point of performance where the desired behaviour is to occur" (p.338).

The results of the study by Christie, Hiss, and Lozanoff (1984) support Barkley's contention. The students involved in the experiment were trained to record and classify their off-task and inattentive behaviour as depicted on a previously videotaped recording. After training, the teacher observed and recorded the student's behaviour and signalled the student to do so as well. The findings indicated that this method of self-recording with teacher signalling led to an increase in on-task and appropriate behaviour.

Another benefit of self-monitoring is that it can actually cause a change in behaviour as a result of the process itself (Heins, Lloyd, & Hallahan, 1986; Reid & Harris, 1993). In other words, the undesirable behaviour may become modified without the need for further intervention.

The two main focuses of self-monitoring within educational research have been time-on-task (amount of time the student continues working on the task) and cognitive behaviour (actual time the student spends solving the problem or completing the task) (Goldstein & Goldstein, 1990; Reid & Harris, 1993). An example of time-on-task might be the amount of time a student remains seated at a desk working on a math worksheet rather than engaging in off-task behaviours such as getting a drink of water, sharpening a pencil, or staring out the window. How well the student completed the math problems on the worksheet reflects cognitive behaviour. Time-on-task is measured by quantity of time, as compared to cognitive behaviour, which is measured by quality of task performance.

Some researchers contend that as a result of more time and attention devoted to the task, academic performance will improve (Heins et al., 1986; McDougall & Brady, 1998), whereas others argue that an increase in awareness of cognitive behaviours will result in greater time-on-task (Reid & Harris, 1993).

Robert Reid and Karen Harris (1993) conducted a study comparing the differential effects of self-monitoring of attention and self-monitoring of academic performance with a group of 28 students with learning disabilities. Although the subjects of this study were identified as learning disabled, due to the high comorbidity of learning disabilities with ADHD (Biederman, Newcorn, & Sprich, 1991), the findings may have relevance to ADHD children.

Reid and Harris (1993) suggested that both forms of intervention increased on-task behaviour, but self-monitoring for performance yielded greater gains in accuracy and skill maintenance over time. However, the authors noted that there does not appear to be a best method of self-monitoring for all students on all tasks. As mentioned previously, the specific characteristics of the individual influence the effectiveness of the intervention.

McDougall and Brady (1998) conducted a study in a general education classroom, and the subjects were a combination of students with and without disabilities. The purpose of this research was to compare the effectiveness and generalization of skills with two different self-monitoring approaches. One software program focused on time-on-task and the other focused on increased academic performance (in math). There were five fourth-grade students who participated. Three were fulltime regular education students, one was an ADHD student in the regular classroom receiving only consultant special education services, and one was a learning disabled (LD) student who spent most of the day in the general education class with some time in the resource room. The method of implementation was self-directed by each student. The students self-monitored, self-recorded and graphed progress, self-cued (with audiotape), self-assessed, and self-rewarded. Participants earned tokens based on improvement over their own baseline scores, not through competing with peers. Gradually, the experimenters faded out the self-management system. When audio-cuing equipment was removed, the students were directed to ask themselves if they were on task. When recording forms were phased out, the students recorded directly on their math worksheets. Modifications had to be made for the student with ADHD because she was not improving quickly enough. Changes were made in the frequency and statement used for cuing with this student, due to her problems with inattention and distractibility.

Results of the study by McDougall and Brady (1998) were:

- Percentage of correct math problems increased for all participants during the intervention, and was maintained throughout fading, for all but the ADHD student.
- Engaged time increased for all five participants, even during the fading time.
- Engaged time was slightly higher when the students were monitoring academic performance than when they were monitoring attention to task.
- Generalization of math fluency improved for all participants except the one with ADHD. For her it remained stable.

Although the student with ADHD improved in math fluency and engaged time, her gains were not maintained during the fading-out phase, nor did the skills generalize. As noted, modifications were made for this student to enhance her rate of improvement. The authors suggested that researchers explore additional adaptations to self-monitoring methods that might be more effective for students with ADHD, as well as combining its uses with other techniques.

4.2.2.3 Academic Interventions

Academic interventions consist of modifications in methods of instruction, instructional materials, or the classroom environment (DuPaul & Eckert, 1997). Examples of modifications in instruction might include the teacher's use of direct instruction, co-operative learning teams (Fowler, 1994), or peer tutoring (Kohler & Strain, 1990). Materials can be enhanced for students with ADHD through an adjustment in the length of the assignment, the addition of colour cues or the element of novelty, and by providing structure to the task (Fowler, 1994).

Modifications to the classroom environment may take the form of the physical placement of a student's desk near the teacher or the establishment of organizational procedures and structured lessons (Fowler, 1994). Carol Lensch (2000) provides an example of a relatively simple intervention where the student with ADHD is allowed to select two seats within the classroom to be used at his discretion throughout the school day.

Although there are many sources of suggestions for academic modifications for use in the classroom, there is a dearth of empirical data regarding the effectiveness of such techniques.

Sydney Zentall and Susan Leib (1985) conducted a study to evaluate the effect of task structure on the academic performance of students with and without

hyperactivity. Hyperactivity was regarded as excessive activity that results in disruptive or off-task behaviours, thus inhibiting the student's ability to attend. The authors selected an art lesson in order to provide an activity that the hyperactive subjects would be able to perform as well as the non-hyperactive subjects. By selecting such an activity, they believed they could minimize the effects of the differing ability levels among the students. Individuals with ADHD were seen as more likely to have academic deficits.

The subjects included 15 boys with hyperactivity and 16 boys without hyperactivity between the ages of nine and 13 years in Grades 3 through 6. Eight boys from each type (with and without hyperactivity) were randomly assigned to the group that would first participate in a highly structured task, and then in a task with low structure. The remaining subjects were assigned to a second group that began with a low-structure task, and proceeded to a highly structured task. Within the high-structure activity, students were directed to copy or reproduce designs of two models using precut paper squares. In the low-structure task students were to create original designs with the same number of paper squares.

There was significantly more activity in the low-structure condition for all subjects (those with and without hyperactivity). The authors concluded that added structure to a task decreased student activity level.

Another study by Zentall (1989) was designed as an extension of previous research using colour cuing to increase sustained attention and improve the task performance of hyperactive children (Zentall, Falkenberg, & Smith, 1985). Whereas stimulation has been used to enhance attention to salient details, researchers have found that stimulation can also act as a distraction that interferes with task performance if attention is drawn to non-relevant details (Rosenthal & Allen, 1980; Zentall, Zentall, & Barack, 1978; Zentall, Zentall, & Booth, 1978). In other words, individuals with ADHD tend to seek stimulation regardless of whether it is associated with essential or nonessential details. The indiscriminate use of colour cuing may actually do more harm than good if it serves as a distraction from the learning task. In this context, a visual stimulus was used to draw a student's attention to a specific task (Zentall, 1989).

The purpose of this study was to define what constituted the effective use of novel stimuli to enhance task performance (i.e. spelling). For the experiment, 20

hyperactive and 26 non-hyperactive boys in Grades three through six were presented with spelling tasks with and without colour coding. The order of task presentation was varied between black letters first, then letters with colour added, and the reverse order of trials.

The investigators found that the hyperactive boys outperformed the control group when colour was added during practice, rather than in the beginning when initial learning was taking place. A spelling task was used because it required selective attention as compared to a simpler task such as handwriting. The implication for educators is to use non-distracting stimuli (for example black letters) during the introduction of new, difficult skills, and to add colour during the rote-practice phase of learning with hyperactive children.

DuPaul and Henningson (1993) presented a case study of the effects of a classwide peer-tutoring program on a student with ADHD. Students with ADHD benefit from direct instruction, immediate feedback, and individualized instruction (Piffner & Barkley, 1990). Teachers, however, have too many students and not enough time to meet the additional demands of students with this disorder (Kohler & Strain, 1990). Peer tutoring can be used to alleviate the pressure on a teacher to personally meet the individual needs of each student (DuPaul & Stoner, 1994; Kohler & Strain, 1990). Additionally, by using active response procedures, the excess energy of some ADHD students that might otherwise result in disruptive behaviour can be redirected (Zentall & Meyer, 1987). Peer tutors may provide the extra help needed to implement such procedures (DuPaul & Stoner, 1994). The intervention designed by DuPaul and Henningson (1993) was based on a program developed by Greenwood, Delquadri, and Carta (1988). The subject was a seven-year-old male in second grade, who had been diagnosed with ADHD. He was experiencing academic difficulties, particularly in mathematics. After a baseline was established for the target student, peer tutoring in mathematics was implemented.

The following results were reported by DuPaul and Henningson (1993):

- There was an increase in the subject's on-task behaviour with peer tutoring.
- The subject's math performance improved.
- The subject's attention to instruction more than doubled in frequency over the baseline.

The authors attributed the effectiveness of peer tutoring to the methods of instruction used. The one-on-one instruction was geared to the ability level and instructional pace of the student with ADHD, as compared to a traditional, didactic approach more typically used with whole-class instruction. Through the use of peer tutoring, the afore-mentioned modifications were put in place and were conducive to student learning. The implication is that through changes in method of delivery, the needs of all students can be met and peer tutoring can be used to facilitate those instructional adjustments (DuPaul & Henningson, 1993).

4.2.3 Social Skills Training

Most children with ADHD experience difficulty getting along with parents, peers, siblings and teachers (Frederick & Olmi, 1994). Upon entering the school setting, the student with ADHD is faced with a new set of demands to behave and interact appropriately with others (Barkley, 1990). High levels of activity and impulsivity that were tolerable in a less structured setting may become areas of concern for educators (Frederick & Olmi, 1994).

By first grade, parents of ADHD children often are confronted with complaints from teachers regarding the child's inappropriate and immature social behaviours, as well as emerging academic difficulties (Barkley, 1990). Thus, the introduction of the classroom environment and all of the problems inherent in homework may exacerbate an already difficult situation. As the ADHD behaviours begin to spill over into a number of settings, parents and educators may need to work together to develop techniques that are effective across situations (Barkley, 1990; Frederick & Olmi, 1994).

Fred Frankel and colleagues (1997) conducted a study to evaluate the effectiveness of a social skills training programme that involved parents. Although the training was not conducted in the classroom, the transfer of social skills to the educational setting was assessed through teacher ratings. It was hypothesized that by involving parents as a component of the social skills training program, there would be generalization of those skills by the children from school to home.

The treatment group was comprised of 35 children with ADHD, 14 children without ADHD, and 19 children with ODD. Two subjects with ODD were in the non-ADHD group. Twenty-four children (one-half with ADHD and one-half without ADHD) were in a control group that received no treatment. Within the control group, five were diagnosed with ODD. All subjects with ADHD were on medication. The treatment consisted of 12 sessions of social skills training for the children and concurrent

sessions for parents. The improvement in social skills was measured by parent and teacher rating scales.

The ADHD subjects who received social skills training showed comparable gains in social skills to those without ADHD, according to both parent and teacher ratings. Likewise, subjects with ODD who received social skills training had gains comparable to those without ODD. Children in the treatment group had outcomes better than the majority (83%) of the subjects not receiving treatment.

4.2.4 Psychotherapy

Psychotherapy might include therapy for the child on his/her own or with other children in a group. The purposes of psychotherapy are to enable a child to recognize and understand his feelings and learn to deal with them appropriately (Wender, 2000). Couple therapy, family therapy, and individual therapy for the parents also have been found helpful. Marital therapy is often recommended as it gives the parents an opportunity to air differences in parenting styles and approaches in dealing with the ADHD child.

According to Wender (2000) there are no data whatsoever supporting the usefulness of psychotherapy in the basic treatment of ADHD children. Nonetheless, many experienced psychiatrists have found that it is sometimes a useful auxiliary technique with some ADHD children (Wender, 2000). Wender states that because the basis of most ADHD children's problems is physiological they must be dealt with physiologically - that is, with the aid of medication. According to him, "medication goes to the root of the problem" (Wender, 2000, p.128). He states that psychotherapy "may help to deal with some of the branches that, so to speak, have grown in the wrong direction" (Wender, 2000, p.128).

4.2.5 Parent training

Parent training is often employed in the clinical management of ADHD, either alone or in combination with other intervention techniques (such as medication). Parent training may be done in the psychotherapy setting or the parents may be referred for parent education training. Various training programs exist, but all strive to promote more positive, compliant, and generally pro-social behaviour while decreasing negative, defiant, and disruptive behaviour in children. Typically, this is achieved by training parents in more positive, consistent, and predictable child management skills (Forehand & McMahon, 1981; Patterson, Dishion & Reid, 1992; Webster-Stratton & Spitzer, 1996). In some applications of parent training, counselling parents about ADHD is included as well (Barkley, 1990). This can aid in correcting misperceptions

about ADHD and improve parents' abilities to make treatment decisions and obtain treatments.

According to Wender (2000) changes in the relationship between the parents and the ADHD child are almost always helpful. Wender believes parents must be understanding and must remember three things. One, the child does have difficulties in doing and not doing certain things. Two, he will learn best how to compensate for his problems if he is treated as a responsible person who can gradually learn to control himself and his behaviour. Three, the degree to which his problems can be helped by particular child-rearing techniques varies. As Wender states, it is much easier to teach him how to control his temper or how to take responsibility for his chores than to teach him to have a longer attention span or to be less distractible. Both medicine and discipline will help the first kind of problem (for example temper, and chores). The second kind of problem (for example short attention span) for the most part can be helped only by medicine (Wender, 2000).

Wender states that the main problem of the ADHD child at home involves discipline. To help the child to function effectively in his home environment, he believes the parents must establish firm, consistent, explicit, predictable rules. By **firm** Wender means that rules or expectations for the child always have the same consequences. If he breaks a particular rule, he is always punished and always in the same way. If he does what he is asked, he always obtains acknowledgment or praise. **Consistent** means that the rules themselves do not change from day to day. **Explicit** means clearly defined and clearly understood by all parties. For example, with the cleaning-up rule, the definition of cleaning up must be explicit enough so that the child and the parents understand the rule the same way. **Predictable** means that the laws are made before, not after, the crime. Obviously, all parental expectations for the child cannot be stated beforehand. Some things can be dealt with only after they happen. In general, however, for most daily activities, rules can and should be made and then enforced.

While there certainly is evidence attesting to the efficacy of parent training for bringing about improvements in the home behaviour of children with ADHD (Dubey, O'Leary, & Kaufman, 1983; Gittelman-Klein, Abikoff, Pollack, Klein, Katz & Mattes, 1980; Horn, Jalongo, Popovich & Peradotto, 1987; Pelham, Schnedler, Bender, Nilsson, Miller, Budrow, Ronnel, Paluchowski & Marks, 1988; Pisterman, McGrath, Firestone & Goodman, 1989; Pollard, Ward, & Barkley, 1983), many questions remain as to its broader psychosocial impact. Of particular concern is that, in the vast majority of parent training studies, outcome has been defined almost exclusively in

terms of changes in child functioning, with attention to treatment-induced changes in parent and family functioning being the rare exception rather than the rule. What little evidence is available suggests that parent training can have a therapeutic impact on parents, at least in terms of self-reported increases in parenting self-esteem and reductions in overall parenting stress (Pisterman, McGrath, Firestone, Goodman, Webster, Mallory & Goffin, 1992).

Possible barriers to parent training are that compliance by parents in both attending the training meetings and following through on the recommended strategies can be problematic (Cunningham, Bremner, & Boyle, 1995; Kazdin, 1987; Offord & Bennett, 1994).

4.2.6 Dietary Intervention

Some physicians have suggested that ADHD may be due to bodily reactions to normal food constituents (Wender, 2000). One possibility is that some children may be allergic to certain foods and the allergy may produce behavioural problems. As mentioned in Chapter two, a second, and different, claim was made by a California physician, Dr. Ben Feingold (1975), who believes that many children develop ADHD as a reaction to artificial colourings, flavourings, some preservatives (which may be present in processed foods), and salicylates (a chemical related to aspirin) that are found naturally in some fruits and vegetables. A diet that eliminates these chemicals is called a food-additive-free or Feingold diet.

According to Wender (2000) the idea that food additives might cause ADHD is particularly appealing to those people who believe that food additives are "unnatural" (and therefore probably harmful), and that treatment with a special, healthful diet seems preferable to treatment with drugs. When children are put on these special diets without any attempt to disguise the treatment, some children do seem to show significant change in behaviour (Wender, 2000). Wender cautions, however, that it is important for parents to realize that at present there is little evidence that food allergies play any substantial role in the behaviour problems associated with hyperactivity.

Wender (2000) also discusses the role that coffee may play in treating ADHD. According to him, a few years ago someone proposed that ADHD might be less common in South American countries because children there drank coffee. Because coffee contains caffeine, a recognized stimulant of the brain, and because stimulants seem to help ADHD, it was inferred that caffeine might be useful in treating ADHD.

Leon (2000) reviewed studies examining caffeine's effects on cognitive, psychomotor, and affective functioning of children with ADHD. For children with ADHD, caffeine was more effective than no treatment in decreasing impulsivity, aggression, and parents' and teachers' perceptions of children's symptom severity, and more effective than the placebo in decreasing hyperactivity and teachers' perceptions of children's symptom severity, and in improving executive functioning/planning. Methylphenidate was more effective than caffeine in decreasing hyperactivity, aggression, and parents' and teachers' perceptions of children's symptom severity, and in improving executive functioning/planning and motor coordination. Amphetamines were more effective than caffeine in reducing hyperactivity, impulsivity, aggression, and teachers' perceptions of children's symptom severity. Leon concluded that combining caffeine and stimulants to produce moderate levels of arousal might produce better functioning than caffeine or stimulant drugs alone.

Wender (2000) acknowledges that when caffeine is combined with stimulant drug treatment, the overall response is better than with stimulant drugs alone, but states that the same good response can be obtained simply by increasing the amount of the stimulant drug.

4.2.7 Is there a best approach?

If Ritalin is so controversial, is there then a better approach to treatment? The recently completed National Institute of Mental Health Multimodal Treatment of Attention-Deficit Hyperactivity Disorder Study, a national study of 579 children with ADHD ranging from seven to nine years conducted in North America, is our best source of information about the pros and cons of medication and behavioural treatment for ADHD (Jensen, Hinshaw, Swanson, Greenhill, Conners, Arnold, Abikoff, Elliott, Hechtman, Hoza, March, Newcorn, Severe, Vitiello, Wells & Wigal, 2001). This study compared children who receive optimally delivered medication, state of the art behavioural treatment (a combination of parent training, child training through a summer programme, and a school intervention), a combination of the two approaches, or routine care in the community. The findings were quite clear: medication alone is more effective than behavioural treatment alone or routine care in reducing ADHD symptoms. However, a combination of medication and behavioural treatment was superior to medication alone when the goal was defined as not only reducing ADHD symptoms, but also improving academic performance, social adjustment, and parent-child relations. So, medication is indeed effective, but it can be even more so if supplemented by behavioural programmes designed to teach

children with ADHD to stay focused on tasks and to control their impulsiveness, and by parent training designed to help parents understand and manage the behaviour of these often-difficult youngsters.

This chapter has reviewed the literature regarding the effects of attention deficit hyperactivity disorder on family life and the possible treatment options for ADHD. As stated in the introduction, this study examined the experience of parents of hyperactive children from a phenomenological approach. The following chapter will provide an understanding of the phenomenological approach before going on to explain the research design employed in the current study.

CHAPTER FIVE: PHENOMENOLOGY

The early eighties marked the growth of an interest in qualitative methodology that paralleled the growing disillusionment with traditional logical-empirical research methods. Although quantitative methodological dominance continues, the degree of coexistence and complementarity between quantitative and qualitative research methods seems to be increasing (Osborne, 1994).

As Patton (2002) states, there is no definitive way to categorize the various philosophical and theoretical perspectives that have influenced and that distinguish the different types of qualitative inquiry. Lincoln and Guba (2000) identify five alternative inquiry paradigms: positivism, post-positivism, critical theory, constructivism and participatory. Schwandt (2000) discusses three epistemological stances for qualitative inquiry: interpretivism, hermeneutics and social constructionism. Crotty (1998) also offers three primary epistemological influences: objectivism, constructionism and subjectivism. Crotty posits that these three have, in varying degrees, influenced different theoretical perspectives: namely positivism (and post-positivism), interpretivism (symbolic interaction, phenomenology, and hermeneutics), critical inquiry, feminism, and post-modernism. Creswell (1998) distinguishes five qualitative traditions of inquiry: biography, phenomenology, grounded theory, ethnography, and case study.

How then does the researcher decide on a method of qualitative inquiry? Which qualitative method is the “best” one? According to Osborne (1994, p.186), the most important thing to remember when doing research is that the method that is chosen “should be a function of the question to be answered rather than allegiance to metatheoretical dogma”.

Patton (2002) too prefers to distinguish theoretical perspectives by their foundational questions. Patton (2002, p.104) phrases the foundational question for phenomenology as: “What is the meaning, structure and essence of the lived experience of this phenomenon for this person or group of people?”

Van Manen (1990, p.10) states that “phenomenology asks for the very nature of a phenomenon, for that which makes a some –‘thing’ what it is – and without which it could not be what it is”.

5.1 What is phenomenology?

According to Patton (2002) the term *phenomenology* has become so popular, and has been so widely embraced, that its meaning has become diluted and confused. Phenomenology can refer to philosophy (Husserl, 1967), an inquiry paradigm (Lincoln, 1990), an interpretive theory (Denzin & Lincoln, 2000), a social science analytical perspective or orientation (Harper, 2000; Schutz, 1967, 1970), a major qualitative tradition (Creswell, 1998), or a research methods framework (Moustakas, 1994). Varying forms complicate the picture even more: transcendental phenomenology (the essential meanings of individual experience), existential phenomenology (the social construction of group reality), and hermeneutic phenomenology (the language and structure of communication) offer different nuances of focus (Schwandt, 2001). Moustakas (1994) further distinguishes empirical phenomenological from transcendental phenomenology. Gubrium and Holstein (2000, p.488) add the label social phenomenology. Van Manen (1990) prefers hermeneutical phenomenological reflection. Harper (2000, p.727) talks of looking at images through “the phenomenological mode”, that is from the perspective of the self: “from the phenomenological perspective, photographs express the artistic, emotional, or experiential intent of the photographer.” Phenomenological traditions in sociology and psychology vary in unit of analysis, group or individual (Creswell, 1998). Adding further confusion to the mix, the term *phenomenography* was coined by Ulrich Sonnemann (1954) to emphasise “a descriptive recording of immediate subjective experience as reported” (p. 344).

Add to this confusion of terminology the difficulty of distinguishing phenomenological philosophy from phenomenological methods and phenomenological analysis, all of which adds to tensions and contradictions in qualitative inquiry (Gergen & Gergen, 2000).

The following section will attempt to distinguish the various phenomenological movements and traditions using the following descriptions as detailed by van Manen (2000):

- Transcendental phenomenology
- Existential phenomenology
- Hermeneutical phenomenology
- Linguistical phenomenology
- Ethical phenomenology
- Phenomenology in practice.

5.2 Movements in Phenomenology

5.2.1 Transcendental phenomenology

The founder of phenomenology, the German philosopher Edmund Husserl (1859-1938), introduced the term in his book Ideas: A General Introduction to Pure Phenomenology (1958). As formulated by Husserl after 1910, phenomenology is the study of the structures of consciousness that enable consciousness to refer to objects outside itself. This study requires reflection on the content of the mind to the exclusion of everything else. Husserl called this type of reflection the phenomenological reduction. Because the mind can be directed toward nonexistent as well as real objects, Husserl noted that phenomenological reflection does not presuppose that anything exists, but rather amounts to a “bracketing of existence,” that is, setting aside the question of the real existence of the contemplated object.

What Husserl discovered when he contemplated the content of his mind were such acts as remembering, desiring, and perceiving and the abstract content of these acts, which Husserl (1958) called meanings. These meanings, he claimed, enabled an act to be directed toward an object under a certain aspect; and such directedness, called intentionality, he held to be the essence of consciousness. Transcendental phenomenology, according to Husserl, was the study of the basic components of the meanings that make intentionality possible.

Husserl described phenomenology as the rigorous science of all conceivable transcendental phenomena. For Husserl, phenomenology is a rigorous, human science precisely because it investigates the way that knowledge comes into being and clarifies the assumptions upon which all human understandings are grounded.

A contemporary exponent of Husserl's transcendental phenomenology is Amedeo Giorgi (1986,1989, 1994). He too speaks about phenomenology as a rigorous science. Giorgi criticizes the interpretive approaches to phenomenology. In his view, phenomenological inquiry should be a descriptive method, since it is through analysis and description of how things are constituted in and by consciousness that we can grasp the phenomena of our world.

5.2.2 Existential phenomenology

All phenomenologists follow Husserl in attempting to use pure description. Thus, they all subscribe to Husserl's idea of keeping to the things themselves. They differ among themselves, however, as to whether the phenomenological reduction can be

performed, and as to what is manifest to the philosopher giving a pure description of experience.

The German philosopher Martin Heidegger (1889-1976), Husserl's colleague and critic, claimed that phenomenology should make manifest what is hidden in ordinary, everyday experience. He thus attempted in Being and Time (1927; trans. 1962) to describe what he called the structure of everydayness, or being-in-the-world, which he found to be an interconnected system of equipment, social roles, and purposes.

Because, for Heidegger (1962), one is what one does in the world, a phenomenological reduction to one's own private experience is impossible; and because human action consists of a direct grasp of objects, it is not necessary to posit a special mental entity called a meaning to account for intentionality. For Heidegger, being thrown into the world among things in the act of realizing projects is a more fundamental kind of intentionality than that revealed in merely staring at or thinking about objects, and it is this more fundamental intentionality that makes possible the directness analyzed by Husserl.

Merleau-Ponty (1962) provides an existential interpretation of Husserl's ideas in his Phenomenology of Perception. Merleau-Ponty describes consciousness as embodied awareness of primordial experience. Consciousness is existence in and toward the world through the body. While Husserl's phenomenology is oriented to transcendental essences, Merleau-Ponty's phenomenology is existential, oriented to lived experience, the embodied human being in the concrete world. The purpose of phenomenological analysis for Merleau-Ponty is not the intuition of essences, but rather it is concentrated upon re-achieving a direct and primitive contact with the world. Instead of striving for certain knowledge Merleau-Ponty believed that phenomenological inquiry can never yield indubitable knowledge. For Merleau-Ponty, the most important lesson that the reduction teaches us is the impossibility of a complete reduction.

5.2.3 Hermeneutical phenomenology

Heidegger, Gadamer, and Ricoeur are the foremost representatives of the movement of hermeneutic phenomenology. Phenomenology becomes hermeneutical when its method is taken to be interpretive (rather than purely descriptive as in transcendental phenomenology). This orientation is evident in the work of Heidegger who argues that all description is always already interpretation. Every form of human awareness is interpretive. Especially in Heidegger's later work he increasingly introduces poetry

and art as expressive works for interpreting the nature of truth, language, thinking, dwelling, and being.

Heidegger's student, Hans-Georg Gadamer, continued the development of a hermeneutic phenomenology, especially in his famous work Truth and Method (1975). In it, he explores the role of language, the nature of questioning, the phenomenology of human conversation, and the significance of prejudice, historicity, and tradition in the project of human understanding.

Paul Ricoeur (1974) argues that meanings are not given directly to us, and that we must therefore make a hermeneutic detour through the symbolic apparatus of the culture. Ricoeur's hermeneutic phenomenology examines how human meanings are deposited and mediated through myth, religion, art, and language. He elaborates especially on the narrative function of language, on the various uses of language such as storytelling, and how narrativity and temporality interact and ultimately return to the question of the meaning of being, the self and self-identity.

5.2.4 Linguistical phenomenology

Heidegger, Merleau-Ponty, and Gadamer have been highly concerned with the role and significance of language in the context of phenomenological inquiry. Also the work of Foucault (1974) on the nature of language and discourse contributes to certain explorations of the relation between understanding, culture, historicity, identity, and human life.

Van Manen (2000) states that it is especially in the work of Derrida (1977) and his followers where we can speak of a radical linguistical phenomenology. During the 1950s Derrida read the works of Husserl and Heidegger extensively while studying with Levinas and Ricoeur.

Derrida (1977) takes issue with Husserl's idea that signification in language is primarily linked to consciousness and intentional experience. Like Heidegger and Merleau-Ponty, he too turns away from the idea of the transcendental ego. However, instead of turning to the question of being (as in Heidegger, 1962), or to the lifeworld (as in Schutz 1967, 1970), or to pre-reflective lived experience (as in Merleau-Ponty, 1962), or to language and tradition (as in Gadamer, 1975), Derrida aims to show that meaning is always primarily linguistical. For Derrida, meaning resides in language and the text rather than in the subject, in consciousness or even in lived experience. His famous claim that there is nothing outside of the text illustrates this well. For Derrida intersubjectivity is, therefore, intertextuality. According to Derrida, the meaning of a text has an autonomy of its own, and is dependent neither on a subject

(author or reader) nor on some external reference to which the text points. Through the method of deconstruction Derrida tries to demonstrate not the invariance of human phenomena, but the essential variance.

Van Manen (2000) states that the preoccupation of French philosophers with language is also reflected in the analytic theory of Jacques Lacan, the more semiotic work of Roland Barthes, in the writings of Julia Kristeva and Helene Cixous, and in the meditative writing of Michael Serres.

5.2.5 Ethical phenomenology

According to van Manen (2000) ethical phenomenology probably originates with Max Scheler, a contemporary of Husserl. It also finds its origin in Sartre's concern with ethical themes of freedom, responsibility, and choice. Interest in a phenomenological ethics is also noticeable in The Ethical Demand of Knud Lgstrup (1971). But ethical phenomenology is especially associated with the work of Emmanuel Levinas (1989).

Partly as a result of his Jewish experience of Nazi brutality, Levinas was set to radicalise the thinking of Husserl and Heidegger into an ethical phenomenology. Although he started out as a Husserlian phenomenologist, Levinas came to the realization that Husserl's transcendental ego remains idealistic and that Heidegger's ontological phenomenology revolves around being or presence - or in other words, with the self.

For Levinas (1989), the Husserlian focus on the essence of things and Heidegger's preoccupation with the modalities of being in the world, are manifestations of the primacy of the self or "mineness" in traditional philosophical phenomenology. For a truly profound understanding of the human reality, one must not ask for the meaning of being, self, or presence but for the meaning of what is otherwise than being, or the infinite. Levinas finds the phenomenological power of this question in the encounter with the face of the other that makes an appeal to us. In the vulnerability of the face of the other, says Levinas, we experience an appeal: we are being called, addressed (the vocative). And this response to the vulnerability of the other is experienced as a responsibility. This is an ethical experience, an ethical phenomenology.

Levinas has many followers. Especially worth mentioning are the later works of Jacques Derrida (e.g. The Politics of Friendship, 1997) and especially Alphonso Lingis the translator of many of Levinas' texts into English. The ethical engagement of the phenomenological studies of Lingis is evident in the titles of his books, such as: The Community of Those Who have Nothing in Common (1994a) and Abuses (1994b).

5.2.6 Phenomenology of practice

According to van Manen (2000), professional practitioners tend to be less interested in the philosophy of phenomenological method than its practice and application. Therefore, when exploring the nature of phenomenological research, it is helpful to make an immediate distinction between phenomenological research performed by professional philosophers and phenomenological research conducted by professional practitioners. The interest of the professional philosopher tends to lie with philosophical topics, themes, and issues emanating from the study of historical developments of philosophical systems and from the study of issues arising from the works of leading phenomenologists. For example, a philosopher may investigate the possibility of the phenomenological constitution of the transcendental ego, or the relation between transcendental phenomenology in Husserl and ontological phenomenology in Heidegger.

In contrast, professional practitioners tend to work within the applied domains of the human sciences such as education, clinical psychology, nursing, medicine, and specializations such as psychiatry or midwifery. A practitioner in the health sciences may study concerns such as the nurse/doctor-patient relation, how young children experience pain, or how the body is experienced in illness and in health.

As van Manen (2000) states, there are, of course, exceptions to this very general distinction between philosophical and practical phenomenology. There are philosophers who apply their inquiries to every day life concerns of people and others whose writings on technology, for example, have a direct bearing on the ways that practitioners may understand their daily work.

Van Manen (2000) refers to some historical precedents for this notion of applied or practical phenomenology. The Swiss physician Binswanger was one of the first to introduce the phenomenology of Husserl, Scheler, and Heidegger into the study and practice of psychiatry. Between the 1940s and 1960s in the Netherlands, Belgium and Germany there were phenomenologists who applied phenomenological methods to their practical professional concerns. Van Manen (2000) also makes note of the Utrecht School, which consisted of an assortment of phenomenologically-oriented psychologists (Buytendijk, Linschoten, van Lennep), educators and pedagogues (Langeveld, Beekman), paediatricians (Beets), criminologists and jurists (Pompe), psychiatrists (Rimke, van den Berg), and others, who formed a fairly close association of like-minded academics. Van Manen (2000) states that since the 1970s some of this work has inspired North American variations of a practice based

phenomenology - initially especially in psychology (e.g. Giorgi and Moustakas), in nursing (e.g. Benner) and in education (e.g. van Manen).

5.3 Principles of phenomenology

The following principles may be seen as common to the varying phenomenological approaches (Giorgi, 1994; Moustakas, 1994; Patton, 2002).

5.3.1 Fidelity to the phenomenon

According to Giorgi (1994), one of the reasons for seeking alternative methodologies, especially qualitative ones, is that many researchers were getting the sense that their research questions were not being answered as richly as they could be. It seemed that other probes of phenomena yielding different types of data could be more fruitful. Phenomenologists refer to this aspect as fidelity to the phenomenon (Giorgi, 1994).

According to Giorgi (1994), the first criterion for good research is to capture, as clearly as possible, the way in which the phenomenon appears in everyday life. This does not mean that every detail has to be recorded; rather it implies that the essential dimensions of the phenomena are permitted to manifest themselves in an observable way.

Other literature on qualitative research says the same thing in its own way. Faulkner (1982, p.72) writes: "While qualitative research designs and modes of analyses may be less elaborate than those in the mainline journals, the original data is of much higher quality and more closely tied to the complexities of reality under study". Hackman (1982, p.8) has lamented that the disciplines from which organizational research was borrowing its methods lacked the ability to generate "the kind of knowledge about their organizations that will be required to understand them in their full richness and complexity". Giorgi (1994) believes that to make fidelity to the phenomenon an explicit criterion, rather than an assumption, is clearly an advance.

5.3.2 Personal interest

In a phenomenological investigation the researcher has a personal interest in whatever he or she seeks to know; the researcher is intimately connected with the phenomenon (Moustakas, 1994, pp.58-59).

5.3.3 Subject matter

According to Patton (2002, p.106), what the various phenomenological approaches have in common is the need to know what people experience and how they interpret the world. Patton states that this is the subject matter, the focus, of

phenomenological inquiry: a focus on exploring how human beings make sense of experience and how they transform experience into consciousness, both individually and as shared meaning.

Van Manen (1990, pp. 9-10) believes that “anything that presents itself to consciousness is potentially of interest to phenomenology”. Moustakas (1994, p.49) concurs: “Any phenomenon represents a suitable starting point for phenomenological reflection. The very appearance of something makes it a phenomenon.” The phenomenon that is the focus of inquiry may be an emotion (for example, loneliness, jealousy, or anger), a relationship, a marriage, or a job, a program, an organization, or a culture (Patton, 2002).

From the perspective of phenomenology, whether the object is real or imagined, empirically measurable or subjectively felt makes no difference at all. Giorgi (1994) states that the phenomenological approach admits to a reality independent of consciousness, but claims that knowledge of such reality only comes through consciousness of it, so it's better to study the reality claims made by persons through their consciousness of it. The task here is to understand the reality claims (or nonreality claims) precisely as the research participants make them. In other words, it is the perceived reality that phenomenologists are interested in, and often “distortions” are more vital than veridical perceptions. Thus, according to Giorgi (1994), if workers think that their organisation is paternalistic, or that bureaucracies are always rigid, it would be important to document those perceptions. The researcher's phenomenological task, then, is not to specify in advance what reality is really like, but to describe the nature of reality as taken up and posited by the research participants. This frees the researcher to discover possible reality claims that may be outside of his or her a priori specifications.

According to van Manen (1990, p.10), from a phenomenological point of view, we are less interested in the factual status of particular instances: whether something happened, how often it tends to happen, or how the occurrence of an experience is related to the prevalence of other conditions or events. For example, phenomenology does not ask, “How do these children learn this particular material?” but it asks, “What is the nature or essence of the experience of learning (so that I can now better understand what this particular learning experience is like for these children)?”

5.3.4 Lived experience

Phenomenology requires methodologically, carefully, and thoroughly capturing and describing how people experience a phenomenon – how they perceive it, describe it,

feel about it, judge it, remember it, make sense of it, and talk about it with others (Patton, 2002). To gather such data, requires subjects who have directly experienced the phenomenon of interest; that is they have “lived experience” as opposed to second-hand experience.

According to Patton (2002), the only way for us to really know what another person experiences is to experience the phenomenon as directly as possible for ourselves. This leads to the importance of participant observation and in-depth interviewing.

5.3.5 Wholeness

According to Moustakas (1994), phenomenology is concerned with wholeness, with examining entities from many sides, angles, and perspectives until a unified vision of the essences of a phenomenon or experience is achieved.

5.3.6 Description

Phenomenology is committed to descriptions of experiences, not explanations or analyses. The operative word in phenomenological research is “describe” (Kruger, 1979, p.119). The researcher aims at describing as accurately as possible the phenomenon as it appears, rather than indulging in attempts to explain it within a pre-given framework. Descriptions retain, as close as possible, the original texture of things, their phenomenal qualities and material properties. Descriptions keep a phenomenon alive, illuminate its presence, accentuate its underlying meanings, enable the phenomenon to linger, retain its spirit, as near to its actual nature as possible. In description one seeks to present in vivid and accurate terms, in complete terms, what appears in consciousness and in direct seeing (Moustakas, 1994).

5.3.7 Essences of experience

Patton (2002) states that a dimension that differentiates a phenomenological approach is the assumption that there is an essence or essences to shared experience. These essences are the core meanings mutually understood through a phenomenon commonly experienced. The experiences of different people are bracketed, analysed, and compared to identify the essences of the phenomenon, for example, the essence of loneliness or the essence of being the parent of an ADHD child.

According to Patton (2002), the assumption of essence, like the ethnographer’s assumption that culture exists and is important, becomes the defining characteristic of a purely phenomenological study. Eichelberger (1989, p.6) states that phenomenologists are “rigorous in their analysis of the experience, so that basic

elements of the experience that are common to members of a specific society, or all human beings, can be identified”.

Patton (2002) believes that the assumption of essence is essential to understanding the philosophical basis of phenomenology, yet, he states, it is often misunderstood. According to him, some researchers are misled into thinking that they are using a phenomenological perspective when they, for example, study four teachers and describe their four unique views. Patton states that a phenomenologist assumes a commonality in those human experiences, and must use rigorously the method of bracketing to search for those commonalities. According to Patton, results obtained from a phenomenological study can then be related to and integrated with those of other phenomenologists studying the same experience, or phenomenon.

Patton (2002, p.107) concludes that conducting a study with a phenomenological focus (i.e. getting at the essence of the experience of some phenomenon) is different from using phenomenology to philosophically justify the methods of qualitative inquiry as legitimate in social science research. He states that both contributions are important. But a phenomenological study (as opposed to a phenomenological perspective) is one that focuses on descriptions of what people experience and how it is that they experience what they experience. According to Patton (2002) one can employ a general phenomenological perspective to elucidate the importance of using methods that capture people’s experience of the world, without conducting a phenomenological study that focuses on the essence of shared experience.

5.4 The role of values in phenomenological research

According to Giorgi (1994), value neutrality is related to the positivist paradigm whereby it was claimed that results are not contaminated by unwanted influences. From a phenomenological perspective, it would be nice to get results that would be exclusively dependent upon the selected variables, but it is admitted that unwanted and even unknown contextual factors are influencing the research process and outcome. Very often the undesirable and unknown factors are related to the subjectivity of the researcher.

According to Giorgi (1994) it is a simplistic understanding to assume that if subjectivity is present it is wrong or bad, and if it is wrong it has to be eliminated, and if it cannot be eliminated, then all results are contaminated. Phenomenologically, subjectivity cannot be eliminated, and it shouldn’t be, but not all presence of subjectivity is automatically negative. It is objectivism that makes that claim, and so it is assumed that rigour can only be achieved with the elimination of subjectivity.

For phenomenology, nothing can be accomplished without subjectivity, so its elimination is not the solution. Rather *how* the subject is present is what matters, and objectivity itself is an achievement of subjectivity. Thus, one could say that in all research one should value the truth, or “what is”, or the correct facts or meanings, and so on, but it is equally true that subjectivity is needed to achieve those values. Thus the real issue is how subjectivity should be present and which values should be fostered.

As Giorgi (1994) states, scientists are also human beings in the everyday world and they carry their prejudices, hopes and ambitions with them even when they begin to assume scientific roles or attitudes. Thus, in order to be sure that such wishes or ambitions are not projected onto scientific findings, phenomenologists recommend the use of reduction, which means an attitude in which such hopes and dreams may be temporarily disengaged so that the phenomena can manifest themselves “as they are” to the temporarily “disinterested” human subject who is the researcher. But this disinterestedness is value-laden: the researcher wants to know what is really happening with the phenomenon in the world, and in keeping with such an attitude he or she is deliberately not trying to influence the results of the research because as a theoretician the researcher would want to make claim that the phenomenon would present itself the same way if other researchers were to study it in other places. That, too, is a value. Thus, the reduction is a means of rendering oneself as noninfluential as possible during the process of research (neutral) in order to come up with valuable (value) findings – that is findings that are robust enough to endure even with other investigations in other places. Thus, according to Giorgi (1994), the relation between neutrality and values is not dichotomous, but phasic.

5.5 Is qualitative research merely exploratory, rather than substantive?

According to Giorgi (1994), it is often pointed out that phenomenology is interesting and even legitimate as exploratory research and that, after careful description has revealed what is important about the phenomenon, one could proceed even more certainly with traditional research. In other words, the suggestion is often made that qualitative research is merely preparatory. Of course, one could, based upon careful descriptions, define variables more precisely and proceed with traditional quantitative research. But, according to Giorgi, why should one? As Giorgi states, there is a logic to qualitative research that guides the entire process from conception and planning all the way to report write-up, just as there is for quantitative research. These are simply two styles of research, each with its own logic.

Faulkner (1982) attacked the problem of qualitative research as preparatory head-on. He complains about the fact that “the general journals in sociology are, in fact, not general at all, but are dominated by a narrow range of research designs, procedures for data collection, and modes of analysis and theorizing” (p. 73), and so there is an uneven picture given as to what counts as solid sociological research.

Faulkner (1982, p.74) then writes:

This practice perpetuates the canard that fieldwork or research based on qualitative methods is simply a preliminary or exploratory, intended to generate rather than confirm hypotheses. Interactionists may offer up their ideas, but not their findings to the real researchers who will pick them over for choice morsels they can “confirm” with multivariate analysis.

In such a perspective, the quantitative style will always be “real” or “hard” research, and qualitative will only be “soft”.

Only sound logic for qualitative research can overcome this prejudice. Osborne (1994) offers just such sound logic. According to him, phenomenological methods attempt to explore conscious experience directly through a specialized form of introspection, rather than inferentially through overt observation, as in cognitive science. Osborne states that exploration of the world or experience by phenomenology enables researchers to reclaim that part of human being that has been so long neglected due to the prevailing view that human science must be natural science. Osborne believes that there seems to be something to gain, and little to lose, by considering phenomenological research contributions, rather than rejecting them for scientific reasons. Osborne concludes that if psychology is to be existentially relevant it needs to address human experience in its fullness, rather than just that part of the experience that is compatible with prevailing methodological biases.

This chapter has outlined the various conceptualisations of phenomenology. The following chapter will go on to examine the research design employed in the current study.

CHAPTER SIX: RESEARCH DESIGN

6.1 Naturalistic Inquiry

In naturalistic inquiry, the researcher attempts to observe as carefully and accurately as possible, and to present the stories of those being studied in their own voices (Esterberg, 2002). Naturalistic inquiry designs cannot usually be completely specified in advance of fieldwork. Naturalistic inquiry is a discovery-oriented approach that attempts to minimize investigator manipulation of the study context, and places no prior constraints on what the outcomes of the research will be (Patton, 2002).

While the research design did specify an initial focus and initial guiding interview questions for the current study, the naturalistic and inductive nature of the inquiry made it both impossible and inappropriate to specify operational variables, state testable hypotheses, or finalize either instrumentation or sampling schemes. A naturalistic design unfolds or emerges as fieldwork unfolds (Patton, 2002).

6.2 The Phenomenological Method

According to Giorgi (1994) the phenomenological method essentially involves three interrelated steps, namely description, the reduction, and the search for essences.

6.2.1 Description

The phenomena to be studied have to be described precisely as they present themselves, neither adding to nor subtracting from what is given.

6.2.2 The reduction

Description of the phenomenon takes place within the attitude of the phenomenological reduction. This means that the researcher (a) brackets or disengages from all past theories or knowledge about the phenomenon, and (b) withholds existential assent of the phenomenon.

According to Giorgi (1994), many researchers have difficulty with the idea of the phenomenological reduction. Often researchers feel that it has to be practiced at its ideal limit (i.e., everything given to consciousness has to be reduced at once), or that once having entered the attitude, one is frozen in the neutrality state. The reduction means that one tries to bracket all past knowledge or theories about the phenomenon being researched that are relevant to the research question. This means that the researcher cannot base his/her insights on traditional or well-

established theories, whether philosophical or scientific, but must base them on immediate insight into the phenomena themselves (Stewart & Mickunas, 1990).

Within the reduction, one refrains from positing and looks at the research information with the attitude of relative openness: I wonder what the outcome will be here? Van Maanen (1982, p.16) states that the essential question in qualitative work is “What is going on here?” This is different from: “I will posit that X is going on and I shall try to prove it, or else hope that Y is actually taking place.”

6.2.3 Search for essences

The search for essences involves finding the core meaning of phenomena. The researcher attempts to describe the invariant characteristics of a phenomenon and their relationship to each other, and that becomes the structure of the phenomenon.

6.3 What was the primary purpose of the study?

The primary purpose of this study was what Patton (2002) defines as basic research. Researchers engaged in basic research want to understand how the world operates. They are interested in investigating a phenomenon to get at the nature of reality with regard to that phenomenon.

In the current study, the researcher’s purpose was to understand and explain the phenomenon of ADHD as experienced by parents of children who have been diagnosed with ADHD. My primary goal was, therefore, to add to knowledge, not to pass judgement on a setting or the people within it. It was not the purpose of this study to blame someone or something for a particular state of affairs, or to label a particular parent as “good” or “bad”. The worth of this study will be determined by the degree to which it generates theory, description or understanding.

6.4 What was the focus of the study?

The focus of the study was to obtain in-depth information on parents’ experience of ADHD. However, the fact that in qualitative studies the research information collection need not be constrained by predetermined analytical categories, also contributes to the potential breadth of the study (Patton, 2002). An inferential quantitative approach, on the other hand, would employ standardised questions that limit responses to predetermined categories. This has the advantage of making it possible to measure the reactions of many respondents to a limited set of questions, thus facilitating comparison and statistical aggregation of the data. However, an

inferential quantitative approach would result in less breadth and depth, and would be less helpful in developing new categories of understanding.

6.5 Sample

6.5.1 Small or large sample?

Qualitative inquiry typically focuses on relatively small samples, selected purposefully, to permit inquiry into and understanding of a phenomenon in depth (Patton, 2002). Inferential quantitative methods typically depend on larger samples selected randomly in order to generalize with confidence from the sample to the population it represents. The logic and power of probability sampling derive from its purpose: generalization (Patton, 2002). The logic and power of purposeful sampling derive from the emphasis on in-depth understanding. This leads to selecting information-rich cases for study in-depth. Information-rich cases are those from which one can learn a great deal about issues of central importance to the purpose of the research (Patton, 2002).

6.5.2 How many participants are enough?

Patton (2002) states that there are no rules for sample size in qualitative inquiry. According to him, sample size depends on what you want to know, the purpose of the inquiry, what is at stake, what will be useful, what will have credibility, and what can be done with available time and resources.

According to Seidman (1991, p.45) there are two categories for how many participants are “enough”. The first category is sufficiency. Are there sufficient numbers to reflect the range of participants and sites that make up the population, so that others outside the sample might have a chance to connect to the experiences of those in it?

The other criterion is saturation of information. A number of writers (Douglas, 1976; Glaser & Strauss, 1967; Lincoln & Guba, 1985) discuss a point in a study at which the interviewer no longer hears anything new. Bertaux (1981) states that the interviewer may recognise that he or she is not learning anything new and that the process of interviewing itself is becoming laborious rather than pleasurable. Douglas (1985) is even bold enough to attempt to assess when that began to happen in his studies. According to him, if he had to pick a number, it would be 25 participants.

Seidman (1991, p.45) is reluctant to put a number on “enough” and notes that “enough” is different for each study and each researcher. He says that the criteria of

sufficiency and saturation are useful, but practical exigencies of time, money, and other resources play a role, especially in doctoral research.

Patton (2002, p.246) concludes that “exercising care not to over-generalise from purposeful samples, while maximizing to the full the advantages of in-depth, purposeful sampling, will do much to alleviate concerns about small sample size”.

The current study made use of a sample of 16 subjects. Kruger (1979) highlights the importance of using more than one subject. According to him, it is inevitable that many, if not all, of the descriptions by the subjects of their experience will be incomplete or imperfect. Lack of skill in expression, forgetfulness, poor vocabulary, and the inability to express oneself clearly could all be contributing factors. These imperfect descriptions would certainly not invalidate the subject’s experience, but they may fail to reflect an essential part of the experience. This problem can be largely overcome by the use of more than one subject. By making use of a variety of subjects, the possibility of finding underlying constants or themes in the many forms of expression the experience takes is greatly increased.

6.5.3 Sampling strategy

Qualitative inquiry typically focuses on relatively small samples selected purposefully (Patton, 2002). The phenomenological researcher seeks out those who have experienced the phenomenon in question and can communicate their experiences (Osborne, 1994).

There are several different strategies for purposefully selecting information-rich cases. This study employed snowball or chain sampling. The units of analysis were individuals and the study looked at individual experience of the phenomenon, as well as variation across individuals.

The parameters for selection of participants were: parents (either male or female) of children (age 7-18) diagnosed with ADHD. One interview was, however, conducted with the mother of a 19-year-old. This mother requested to be interviewed as she felt she could share a lot with other parents from her many years of experience of parenting a child with ADHD.

This study was not concerned with the correct or incorrect diagnosis of these children. These children had already been diagnosed by the medical or educational systems. The researcher was interested in the parent’s experience of the child labelled as ADHD.

Moustakas (1994, p.107) suggests the following additional criteria as essential parameters for selection of participants: the research participant must have experienced the phenomenon, must be intensely interested in understanding its nature and meanings, must be willing to participate in a lengthy interview (and perhaps a follow-up interview), and must grant the investigator the right to tape-record, possibly videotape, the interview, and publish the research information in a thesis and other publications.

Participants for the research were initially accessed through the Attention Deficit Hyperactivity Disorder Association of Southern Africa (ADHASA). The association was not able to provide the contact numbers of parents belonging to ADHASA. The association, however, publishes a quarterly newsletter called PULSE and the Managing Director of ADHASA suggested placing a notice in the newsletter to call for participants. Eight mothers responded to the notice in PULSE and made telephonic contact with me. One of these mothers indicated that she and her husband would like to be interviewed together. From there, parents were asked: "Whom should I talk to?" Initial contact with the remaining seven participants was also made by telephone.

With all respondents, the initial telephonic conversation firstly consisted of (where applicable) an explanation of how the researcher gained access to the person's name and a brief introduction to the study, so that the potential participant could understand the nature of the study and how he or she would fit into it. The researcher also shared the information later presented in the written consent form, so that the participant would be familiar with all aspects of the form. Finally, it was determined whether the potential respondent was interested in participating in the study and a date was set for the interview. It must be noted that none of the potential participants declined to participate in the study once it was explained to them. The sample group showed a unanimous willingness to discuss and have their experiences recorded.

6.6 Interviewing

Patton (2002, p.340) says that we "interview people to find out from them those things that we cannot directly observe". According to him, the purpose of interviewing is "to allow us to enter into the other person's perspective".

Kruger (1979) discusses the importance of interviewing subjects in a place and under conditions that are comfortable for and familiar to them. Kruger (1979, p.125) states, "It is important that the researcher create a situation in which the subject can feel relaxed, unthreatened and where he has time to spend with the interviewer."

Consequently, arrangements for the interviews were made so as to accommodate the participants. The researcher emphasised that the subject should choose a time and place where he/she would feel relaxed and be able to devote his/her full attention to the interview. In most cases the researcher travelled to the participant's home. The length of the interviews was dependent on the amount of information the interviewee wished to share. Interviews ranged from 45 minutes to two hours.

This study made use of what Patton (2002, p.342) calls "the general interview guide approach". This approach involves outlining a set of issues that are to be explored with each respondent before interviewing begins.

According to Patton (2002) the advantages of the general interview guide are:

- It makes sure that the interviewer/evaluator has carefully decided how best to use the limited time available in an interview situation
- It serves as a basic checklist during the interview to ensure that all relevant topics are covered
- It increases the comprehensiveness of the research information and makes research information collection somewhat more systematic for each respondent.

The guide provided a framework within which the interviewer developed questions, sequenced those questions, and made decisions about which information to pursue in greater depth. The interview explored parents' perceptions regarding five aspects of raising children with ADHD, namely:

- Parents' perceptions regarding their interaction with health professionals and the child's use of medication
- Parents' perceptions regarding the effects of ADHD on family life
- Parents' perceptions about their ADHD child and the school experience
- Parents' concerns and hopes for their ADHD child
- Getting through the day and advice for other parents of ADHD children.

The researcher decided to include the first aspect because, by the nature of the disorder, parents will often have extensive interactions with health professionals. The use of medication for the disorder continues to be controversial, and parents' experiences around the medication need to be recorded.

Parents own perceptions regarding the effects of ADHD on family life remain largely unexplored. There has been some research on family interactions, but none where

parents discussed **their** perceptions of how raising a child with ADHD affected their whole family.

The school experience was included, as studies suggest that formal, compulsory education is the area of greatest impact on the child's ADHD (Barkley, Fischer et al., 1990; Biederman, 1997) and will create the greatest source of distress for many of them and their parents. As Barkley (1998) states, at any stage in the course of development of the ADHD child, the concerns of parents of ADHD children are likely to stem primarily from the impact of the child's deficits on their functioning in the school, in the family, and within the peer group, and not from the ADHD symptoms per se. The first three of these concerns (school) is also the primary reason to seek clinical services for their children.

The last two aspects, parents' concerns and hopes and parents' advice for other parents, are currently missing from the published literature. Participants' insights might prove very valuable for other parents of ADHD children.

Asking parents to relate their experience according to these five aspects helped participants to ground their experiences in a context, and thereby helped them to tell their stories (See Appendix C for the General Interview Guide).

The response format for questions was open-ended. The interview did not supply or predetermine the phrases and categories that needed to be used by respondents to express themselves, as is the case with fixed-response questionnaires. It's the difference between asking, "Tell me about your experience in the program" and, "How satisfied were you? Very, somewhat, little, or not at all" (Patton, 2002, p. 40). The purpose was to capture the individual experience of those being interviewed, rather than forcing them to fit their experiences into the researcher's categories. As Lofland (1971, p.7) puts it: "To capture participants in their own terms, one must learn their categories for rendering explicable and coherent the flux of raw reality. That, indeed, is the first principle of qualitative analysis".

Background/demographic questions were also asked, to help locate the respondents in relation to other people. Demographic questions included the age of the participant, educational level of participant, number of children, age of children, and marital status (See Appendix A for the Participant Information Form). Sample characteristics will be discussed at the beginning of chapter seven.

It is necessary to record as fully and fairly as possible each interviewee's perspective. As Patton (2002, p.21) states, "direct quotations are a basic source of raw data in qualitative inquiry, revealing respondents' depth of emotion, the ways they have organised their world, their thoughts about what is happening, their experiences and their basic perceptions". Consequently, all interviews were tape recorded so that the researcher had the verbatim responses of all respondents. The use of the tape recorder was explained to participants during the initial telephonic contact and at the beginning of the interview. Participants were told that the researcher did not want to either miss anything they say or inadvertently change their words while making notes. Respondents were informed that they could turn the tape recorder off at any time during the interview.

Besides increasing the accuracy of research information, using a tape recorder allows the interviewer to be more attentive to the interviewee. According to Patton (2002), if you are trying to write down every word, it is difficult to respond appropriately to interviewee cues. Verbatim note taking can also interfere with listening attentively. The interviewer can get so focused on note taking that the person speaking gets only secondary attention.

The tape-recorded interviews were transcribed word-for-word onto a computer disc. According to Kowal and O'Connell (2004, p.248) transcripts "are needed to make fleeting conversational behaviour available on paper for scientific analysis". In two cases, a second interview was conducted with participants, one telephonically and one face-to-face. The second interviews were conducted to clarify certain statements and to ensure the researcher understood their meaning correctly. These member checks were undertaken in an attempt to enhance the validity and reliability of the research information. The second interviews were both taped and then transcribed in the same manner as the first set of interviews.

6.7 Attaining informed consent

It is both ethically and methodologically desirable to secure participants' informed, written consent to be interviewed. Seidman (1991) says that in-depth interviews ask participants to reconstruct their life history as it relates to the subject of inquiry. In the process, a measure of intimacy can develop between interviewer and participant that lead the participant to share aspects of his/her lives that, if misused, could leave him/her extremely vulnerable.

Participants have the right to be protected against such vulnerability. Furthermore, interviewers can protect themselves against misunderstanding through the process of seeking informed consent, which requires them to be explicit about the range and purpose of their study in a way that makes them be clear about what they are doing.

The consent form for the current study:

- Informed participants as to what they were being asked to do, by whom, and for what purpose.
- Informed the participants about what rights they had in the process, particularly the right to review material and the right to withdraw from the process.
- Indicated that participants' names would not be used in the study. Respondents were assured that transcriptions would only contain initials for all proper names, so that even if a casual reader were somehow to see the transcripts, no proper names would be present. The interviewer also promised to use pseudonyms in the final report.
- Indicated that the results of the study would be included in a thesis and possibly in other future publications.

Each participant received a letter of consent to sign. The letter included permission to tape record the interviews (See Appendix B for the Letter of Consent).

6.8 Analysis of research information

6.8.1 Qualitative analysis: holistic and inductive

Researchers analysing qualitative research information strive to understand a phenomenon as a whole. According to Patton (2002), this holistic approach assumes that the whole is understood as a complex system that is greater than the sum of its parts. At the time of research information collection, each case under study, though treated as a unique entity with its own particular meaning and its own constellation of relationships emerging from and related to the context within which it occurs, is also thought of as a window into the whole (Patton, 2002).

Qualitative inquiry is particularly oriented towards exploration, discovery and inductive logic. Inductive analysis begins with specific observations and builds towards general patterns. Inductive analysis contrasts with the hypothetical-deductive approach of experimental designs that requires the specification of main variables and the statement of specific research hypotheses before data collection begins (Patton, 2002). A specification of research hypotheses based on an explicit

theoretical framework means that general constructs provide the framework for understanding specific observations or cases. The investigator must then decide in advance what variables are important and what relationships among those variables can be expected. The strategy of inductive designs is to allow the important analysis dimensions to emerge from patterns found in the cases under study, without presupposing in advance what the important dimensions will be. The qualitative analyst seeks to understand the multiple interrelationships among dimensions that emerge from the research information, without making prior assumptions or specifying hypotheses about the linear or correlative relationships among narrowly defined, operationalised variables.

6.8.2 Phenomenological analysis

Phenomenological analysis seeks “to grasp and elucidate the meaning, structure, and essence of the lived experience of a phenomenon for a person or group of people” (Patton, 2002, p.482).

According to Patton (2002), the first step in phenomenological analysis is called epoche. Epoche is a Greek word meaning “to refrain from judgement, to abstain from or stay away from the everyday, ordinary way of perceiving things” (Moustakas, 1994, p.33). In taking on the perspective of epoche, “the researcher looks inside to become aware of personal bias, to eliminate personal involvement with the subject material, that is, eliminate, or at least gain clarity about, preconceptions” (Patton, 2002, p.485). Epoche helps enable the researcher to investigate the phenomenon from a fresh and open viewpoint, without prejudgement or imposing meaning too soon. This suspension of judgement is critical in phenomenological investigation and requires the setting aside of the researcher’s personal viewpoint in order to see the experience for itself.

Following epoche, the second step is phenomenological reduction. In this analytical process, the researcher “brackets out” the world and presuppositions to identify the research information in pure form, uncontaminated by extraneous intrusions (Patton, 2002, p.485).

Bracketing is Husserl’s term. In bracketing, the researcher holds the phenomenon up for serious inspection. It is taken out of the world where it occurs and it is taken apart and dissected. The phenomenon’s elements and essential structures are uncovered, defined, and analyzed (Denzin, 1989). It is treated as a text or document; that is, as an instance of the phenomenon that is being studied. It is not interpreted in terms of the standard meanings given to it by the existing literature. Those preconceptions,

which were isolated in the deconstruction phase, are suspended and put aside during bracketing. In bracketing, the subject matter is confronted, as much as possible, on its own terms.

In this study the research information was “taken apart and dissected” according to the method laid out by Kruger (1979).

6.8.3 Research information Analysis: Kruger’s method

As Patton (2002) states, finding a way to creatively synthesize and present findings is one of the challenges of qualitative analysis. When there are several cases to be compared, an inductive approach begins by constructing individual cases, without pigeon holing or categorizing those cases. That is, the first task is to do a careful job independently writing up the separate cases. Once that is done, cross-case analysis can begin in search of patterns and themes that cut across individual experiences. The initial focus is on full understanding of individual cases before those unique cases are combined or aggregated thematically.

In line with this inductive methodology, Kruger (1979) identifies six sub-phases to explicate the gathered research information. These sub-phases are not seen as operating independently and may overlap with each other. The sub-phases are as follows:

6.8.3.1 An intuitive holistic grasp of the research information

In her initial reading of the protocols, the researcher should bracket her own preconceptions and judgement and, to the extent that she is able to do so, she remains faithful to the research information. After achieving a holistic sense of the research information, the protocols are read again – repeatedly if necessary – so as to assist the researcher in retaining a sense of the wholeness of the research information, despite its dissection in the subsequent phases.

6.8.3.2 Spontaneous emergence of Natural Meaning Units (NMUs)

The task of this phase is to articulate the central themes of each protocol. In this phase the research information is broken down into naturally occurring units – each conveying a particular meaning – which emerge spontaneously from the research information.

This unit, termed a Natural Meaning Unit (NMU) may be defined as a statement made by the subject, which is self-definable and self-delimiting in the expression of a single, recognized aspect of the subject’s experience.

The intention conveyed by each NMU is then expressed in a reduced form as concisely and accurately as possible. Wherever possible, the subject's own terminology and phraseology should be adhered to. However, the researcher may articulate the central themes (reductions of the NMUs) in words other than those used by the subjects so as to clearly express the intended meaning.

6.8.3.3 Constituent profile description

Having listed all the reductions of the NMUs, the researcher then eliminates those units which are repeated or which convey an identical intention of meaning, as well as irrelevant units that are not concerned with the experience being investigated. The remaining statements are considered tentatively to be non-repetitive and relevant descriptive statements concerning the experience, and are termed the First Order Profile. This First Order Profile is then converted to a Constituent Profile Description, in brief, a condensed summary of the original research information containing the essence of what the participant expressed. (See Appendix D to R for the constituent profiles of the respondents).

6.8.3.4 Second order profile

The second order profile results from a repeat of phases one through to three, but performed on the Constituent Profile Description. The elements emerging from this procedure are listed and numbered. This final elimination procedure performed on the Constituent Profile description aims at removing any redundant constituents and, as stated, is termed the Second Order Profile.

The four phases outlined above were repeated for all respondents.

6.8.3.5 Hierarchical Categorization

Having repeated the above four phases for all respondents, the researcher gathers those descriptive statements with similar, though not identical, meanings into clusters termed categories. Any given category may contain elements from only one subject or from possibly all the subjects. These categories, or key themes, are then arranged in a hierarchical fashion to facilitate the next phase.

6.8.3.6 Extended description

Taking the first few clusters of categories, the researcher writes an extended description of what these categories tell her about the overall question being investigated. She then adds to this description the next category in the hierarchy and so either extends or modifies it in light of the new information in the additional category.

This procedure is repeated until further addition of categories is rendered superfluous since the essence of the research information is already contained in the extended description.

Following this, the researcher systematically and carefully checks the remaining categories, ensuring that they are compatible with the extended description. Those thematic elements (contained in the categories) that are not compatible are described and, where possible, the researcher shows that these elements are only apparently incompatible.

The extended description presents as condensed an understanding as possible of the essential or invariant meanings of the phenomenon. This final description of the phenomenon, now divorced from the individual experience, illuminates the commonalities of human experience.

6.9 Objectivity versus Subjectivity

Qualitative research is often criticised for not being “objective”. Patton (2002, p.50) suggests that the terms subjectivity and objectivity be replaced by the phrase “empathic neutrality”. He believes this phrase suggests that there is a middle ground between becoming too involved, which can cloud judgement, and remaining too distant, which can reduce understanding.

According to Patton (2002), any credible research strategy requires that the investigator adopt a stance of neutrality with regard to the phenomenon under study. This simply means that the investigator does not set out to prove a particular perspective or manipulate the research information to arrive at predisposed truths. “The neutral investigator enters the research arena with no axe to grind, no theory to prove (to test, but not to prove), and no predetermined results to support” (Patton, 2002, p.51). Rather, the investigator’s commitment is to understand the world as it unfolds, to be true to complexities and multiple perspectives as they emerge, and to be balanced in reporting both confirmatory and disconfirming evidence with regard to conclusions offered.

Patton (2002) admits that neutrality is not an easily obtainable stance. He states that all credible research techniques should include strategies for helping the investigator become aware of and deal with selective perception, personal biases, and theoretical predispositions.

According to Patton (2002), neutrality does not have to mean detachment. Qualitative inquiry depends on, uses, and enhances the researcher's direct experiences in the world and insights about those experiences. This includes learning through empathy.

Empathy develops from personal contact with the people interviewed and observed during fieldwork. Empathy involves being able to take and understand the stance, position, feelings, experiences and worldview of others.

Patton (2002, p.53) states that at first the phrase "empathic neutrality" may appear to be an oxymoron. Empathy, however, describes a stance towards the people one encounters – it communicates understanding, interest and caring. Neutrality suggests a stance towards their thoughts, emotions and behaviours – it means being non-judgemental. Neutrality can actually facilitate rapport and help build a relationship that supports empathy by disciplining the researcher to be open to the other person and non-judgemental in that openness.

6.10 Validity

6.10.1 Positivist versus Post-positivist criteria for validity

The traditional criteria for 'validity' find their roots in a positivist tradition. "Within the positivist terminology, validity resided amongst, and was the result and culmination of other empirical conceptions: universal laws, evidence, objectivity, truth, actuality, deduction, reason, fact and mathematical data to name just a few" (Winter, 2000, pp.6-7). It is within this tradition and terminology that quantitative research is traditionally defined.

Qualitative research, arising out of the post-positivist rejection of a single, static or objective truth, has concerned itself with the meanings and personal experience of individuals, groups and sub-cultures. 'Reality' in qualitative research is concerned with the negotiation or 'truths' through a series of objective accounts. Whereas quantitative researchers attempt to disassociate themselves as much as possible from the research process, qualitative researchers have come to embrace their involvement and role within the research. For quantitative researchers this involvement would greatly reduce the validity of a test, yet for qualitative researchers denying one's role within research also threatens the validity of the research.

Winter (2000, p.7) believes that many of the allegations of invalidity from both sides can be attributed to "a failure to recognise the different purpose to which quantitative and qualitative methodology is suited". Winter states that the only similarity between the two research methods is that, at some, point, questions will be asked and

research information will be collected. Quantitative research limits itself to what can be measured or quantified and qualitative research attempts to 'pick up the pieces' of the unquantifiable, personal, in depth, descriptive and social aspects of the world. Unlike quantitative research, there are no standardised or accepted tests within qualitative research and often the nature of the investigation is determined and adapted by the research itself. There may not be any hypothesis or even findings as such. Instead the 'validity' of the research resides within the representation of the actors, the purposes of the research, and the appropriateness of the processes involved.

6.10.2 Validity in inferential quantitative research

6.10.2.1 Internal validity

According to Winter (2000), internal validity relates to whether the findings or results of the research relate to and are caused by the phenomena under investigation and not other unaccounted for influences. In essence, this essentially comes down to the issue of correlation and causality. Within quantitative research, causality must be established for the test to be valid, or indeed, of any use at all.

Winter (2000) states that researchers get around this by attempting to isolate the factors under investigation away from any confounding variables. The pollution of the results by other unwanted factors does not entirely invalidate the test, especially since they cannot really be fully isolated and stripped away, but a study with notable, and yet unaccounted for, influences is said to have low internal validity. According to Winter (2000), what the quantitative researcher is attempting to do is ensure that his/her explanation for the results can be the only possible or feasible one. There are many factors that pose a threat to validity in this case, such as the maturation of the individual in a longitudinal study, previous experiences of the individuals, 'lost data,' the effects of the test itself, or regression to the mean as a result of outliers or positively or negatively skewed values.

6.10.2.2 External validity

External validity is the extent to which the results can be generalised and thus applied to other populations. A test can have very high internal validity and very low external validity at the same time. Threats to external validity are similar to those for internal validity, except that the test itself is more likely to pose a threat as an alternative explanation for similar results.

Winter (2000) questions the value of the generalisability of quantitative research. According to him, quantitative research attempts to fragment and delimit phenomena

into measurable or 'common' categories that can be applied to all the subjects or wider and similar situations. Hence, quantitative research, whilst able to claim validity for wider populations and not just merely samples, is restricted to measuring those elements that, by definition and distortion, are **common** to all.

Winter (2000) states that this raises the question of 'at what cost' are we exchanging accuracy for generalisability. Within the quantitative definition, an account may be judged 'valid', 'replicable' and 'stable' on the merits of its generalisability. Yet, according to Winter (2000), one could argue that generalisation in itself is neither valid nor accurate. It is likely that a 'generalisable' statement, whilst relating to all those to whom it is applied, may not actually describe the phenomena of any single case with accuracy, in the same way that a mean average score need not be the same value as any of the numbers of which it is an average.

6.10.3 Validity in qualitative research

Winter (2000, p.7) states that "some qualitative researchers have rejected the notion of validity, in any form, as entirely inappropriate to their work". Other qualitative researchers, although they argue that the term validity is not applicable to qualitative research, have at the same time realised the need for some kind of quality check or measure for their research. As a result many researchers have espoused their own theories of 'validity' and have often generated or adopted what they consider to be more appropriate terms, such as 'trustworthiness', 'worthy', 'relevant', 'plausible', 'confirmable', 'credible' or 'representative'.

According to Osborne (1994, p.180), findings "are valid to the extent that they resonate with the experiences of others who have experienced the phenomenon in question". Stiles (1993, p.607) states that "validity concerns whether an interpretation is internally consistent, useful, robust, generalisable, or fruitful".

A "valid" account in qualitative research generally refers to the presentation of an account that is sound and grounded in the research information. According to Osborn and Smith (1998) the aim is not to produce a single true account of the research information. The emphasis is on understanding by people, including the readers of the study, rather than on facts.

6.10.4 Validity in the current study

6.10.4.1 The literature study

A literature study was conducted in which both psychological and medical perspectives of ADHD were reviewed. Some critics may object to the fact that the

literature study was conducted prior to the collection of research information, a procedure generally avoided by phenomenologists lest the literature should threaten validity by biasing the researcher's perceptions. However, Shantall (1996) argues that a literature study need not lead to theoretical bias and may in fact enhance understanding and empathy, by opening the researcher's mind and revealing existing pre-conceptions.

Moustakas (1994, p.111) concurs that "review of the professional and research literature connected with the research topic and question is necessary when preparing to conduct a phenomenological study". According to him, the investigator "assesses the prior relevant studies; distinguishes their designs, methodologies and findings from the investigator's own study; and indicates what new knowledge he or she is seeking and expects to obtain".

6.10.4.2 Misinterpretation

A possible threat to validity in qualitative research is misinterpretation. This risk is increased by a reliance on a limited range of information resources. According to Stiles (1993), the solution is to ask many questions and expose oneself to multiple perspectives. Accordingly, several participants were interviewed in this study and their perspectives were probed in depth in order to negotiate meaning.

6.10.4.3 Testimonial validity

According to Stiles (1993) one check on an interpretation's accuracy is to ask the people whose experience it purports to represent. Stiles refers to this as testimonial validity.

In the current study, the researcher decided not to follow this route. Stiles (1993) concedes that even when participants are consulted, there are circumstances in which literal agreement may not be expected. For example, a participant may not understand him/herself (Stiles, 1993). Or the interpretation may draw on language and concepts unfamiliar to participants. Further, the original experience that produced the text (or tape) no longer exists, and the participant does not necessarily have better access to it than the investigator does.

Giorgi (1989) states that a phenomenological analysis yields an explanation that is beyond the awareness of the participants themselves. According to him, phenomenologically, there is no doubt that the meaning for the participant that must be captured, but it is equally certain that the meaning must be taken up and be re-expressed in the language of the researcher's discipline (sociology, psychology etc.). Giorgi (1989) states that going back to the subject for confirmation of the disciplinary

expression is not really legitimate in this instance, even though it is a frequently practiced strategy. The reason is that only other members (and perhaps not even all, if theoretical orientations vary widely) of the same disciplinary community are in a position to critique or verify the expression. Giorgi (1989) uses the example of a survey based upon many manifest variables where the use of factor analysis will reduce the many variables to a few “basic” or “common” factors, which are then labelled according to the variables so reduced. How many survey researchers go back to the research subjects and ask them to approve of the reduction? It is almost never done because it is assumed that the subjects will not follow the logic or mathematics of the reduction process. Giorgi (1989) states that the reduction process in qualitative research from the subject’s everyday meaning to disciplinary meaning ought to be equally complex, and so the subject should not be expected to be the final arbiter if he or she cannot follow the reduction process. According to Giorgi (1989), this is not a matter of superiority as a human being, but a matter of specialization as with dentists or pharmacists.

Participants in the current study were, therefore, not invited to read and comment upon the interview transcripts or the interpretations thereof.

6.10.4.4 Consensus among researchers

Consensus among researchers is also one of Stiles’ categories for validity. Stiles (1993) states that consensus among researchers involves trying out interpretations on other investigators. The researcher’s supervisors acted as critics and mentors. This offers readers the assurance that other investigators who were familiar with the raw research information found the proposed interpretation convincing.

6.10.4.5 Revealing of the researcher’s orientation

Revealing of the researcher’s orientation can also improve validity. Stiles (1993, p.614) states that “deep personal involvement and passionate commitment to a topic can bring enmeshment, with its associated risks of distortion, but they can also motivate more thorough investigation and a deeper understanding”.

Revealing an investigator’s personal involvement and commitments and the process of the investigation allows readers to incorporate the investigator’s part in the story into their understanding and to adjust their understanding to compensate for the investigator’s biases.

As a researcher, my mind was not a blank slate with regard to this research. In fact, my values, interests, and intimate familiarity with the research problem were the origin of my motivation for this study. My interest in the research topic was mostly

derived from a personal perspective, as my son was diagnosed with ADHD a number of years ago. As a parent of a child with ADHD, I frequently interact with educational personnel and I am continually attempting to make sense out of these interactions. As a parent, I know how daunting the interactions with neurologists, paediatricians and therapists can be. I can relate to the familial stress that occurs when parenting such children, and I have often wondered how other parents make sense of similar experiences.

Is it a good thing that I have experienced many of the feelings that my participants have? Feelings, if handled appropriately, can be an essential aid in doing qualitative research (Rosaldo, 1989). I believe my feelings were a potent indicator of participants' feelings and provided a source for speculation. Likewise, my feelings also helped me to formulate questions to elicit deeper responses from the participants. In other words, my emotional reactions were a source for research hunches and allowed me to formulate follow-up probes. When expressed appropriately, my feelings also provided a powerful way of developing rapport with the participants.

6.10.4.6 Coherence of the report

Validity is also established by the coherence of the report, which can best be judged by the reader. Coherence refers to the internal consistency and comprehensiveness of the account. The research should enhance understanding of the phenomenon under study. This study confirmed many aspects of the literature review, but also transcended it by offering insights gleaned from entering the life-world of the sufferers themselves.

6.11 Reliability

Winter (2000, p.3) suggests that the aggregated definition of reliability is that of "replicability". According to him, some qualitative researchers deny that replicability is either useful or possible in situations concerning highly complex and transient circumstances: namely those that involve the lives, thoughts and behaviours of actors.

According to Stiles (1993) reliability concerns the procedural trustworthiness of the research. The report should convey what another person who was observing would have seen. With this in mind, the context of the research is described, as well as the researcher's orientation.

During the interview itself, Stiles (1993) states that reliability is enhanced by keeping the focus on questions which the subjects can answer, that is on **what** they experienced rather than **why**. Reliability is also strengthened by reflecting the researcher's understanding back to participants and by repeated interviews. These procedures were followed during the current study.

In order to ensure that interpretations were grounded in the research information, the researcher immersed herself in the research information: reading and re-reading the transcripts, moving between extracts and the unabridged form. The researcher's supervisors also read the transcripts and continually checked the emerging analytic account, not to produce a definitive reading, but to ensure that the analysis presented is supported by the research information.

Verbatim evidence, as well as the constituent profile for each respondent, is also included in the thesis to allow the reader to assess the interpretation. (Osborn & Smith, 1998; Stiles, 1993).

6.12 What about the claim that qualitative methods are unscientific?

Borman, LeCompte and Goetz (1986, p.51) have argued that criticism of qualitative approaches arises out of an "erroneous equation of the term 'empirical' with quantification, rather than with any real defect in the qualitative paradigm itself." Berg (2001) states that although various technologies may be used by different researchers, everyone is doing science, provided that *science* is defined as a specific and systematic way of discovering and understanding how social realities arise, operate, and impact on individuals and organizations of individuals.

This chapter has detailed the research design employed in the current study. The following chapter will describe the results of the study in detail.

CHAPTER SEVEN: RESULTS

7.1 Participant description

The participants in this study were 16 parents of children who were diagnosed with Attention Deficit Hyperactivity Disorder. The parents were all voluntary participants who either responded to a notice (nine parents) in the ADHASA (Attention Deficit Hyperactivity Disorder Association of Southern Africa) newsletter, or who were identified through colleagues and friends as likely to be willing to participate in the study.

One of the participants in the study was male and 15 were female. The ages of the participants ranged from 33 to 63 years, with an average age of 42 years. Formal education levels varied among the participants. One participant had some high school plus a trade certificate/diploma, five participants had completed Matric (Grade 12), five participants had completed a post-Matric diploma (not degree), two participants had a degree incomplete, and the remaining three participants had more than one degree.

With regard to marital status, 12 of the participants were married, three participants were divorced, and the remaining participant was living in a stable relationship.

The majority (ten) of the participants had two children, three participants had only one child, two participants had three children, and the remaining participant had four children. Four of the participants had more than one child with ADHD: three of them had two children with the disorder, and in the case of the remaining participant all four children have ADHD. A summary of each participant is presented overleaf in Table 1.

Table 1: Summary of participant information

Participant	Age	Marital Status	Education Level	# Of children	# Of children with ADHD
Brenda	43	Married	Post matric - diploma	2	1
Belinda	46	Married	More than one degree	3	2
Angela	45	Living in stable relationship	Degree Incomplete	2	1
Linda	45	Married	Matric	3	1
Marie	44	Married	More than one degree	2	1
Mia	33	Married	Some high school plus trade cert/dip	2	2
Pat	40	Divorced	Post matric - diploma	1	1
Samantha	38	Married	Post matric - diploma	2	1
Zelda	40	Divorced	Degree Incomplete	2	1
Sandy	39	Married	Post matric - diploma	2	1
Beth	46	Divorced	Post matric - diploma	1	1
Gill and Dylan	Gill 41, Dylan 35	Married	Matric	2	1
Michelle	34	Married	Matric	4	4
Carrie	47	Married	Matric	2	2
Rose	61	Married	More than one degree	1	1

Ages of the 21 children with ADHD ranged from two years to 19 years. Of the 21 children who had ADHD, 12 were male and nine were female. Fifteen of the ADHD children were on medication and six were not; all fifteen are taking Ritalin. The number of children in the present study who are on medication (71%) is slightly below the estimate of Santrock (2002) that 85 to 90 percent of learners with ADHD are taking stimulant medication such as Ritalin to control their behaviour.

A summary of for the ADHD children is presented overleaf in Table 2.

Table 2: Summary of ADHD children information

Participant	# Children with ADHD	ADHD Child 1				ADHD Child 2				ADHD Child 3				ADHD Child 4			
		Age	Gender	Age diagnosed	On meds	Age	Gender	Age diagnosed	On meds	Age	Gender	Age diagnosed	On meds	Age	Gender	Age diagnosed	On meds
Ja	1	8	Male	7	Yes												
Ja	2	17	Male	6	Yes	10	Female	8	Yes								
a	1	18	Female	14	No												
	1	7	Female	4	No												
	1	18	Male	17	Yes												
	2	11	Female	7	Yes	9	Female	9	Yes								
	1	8	Male	5	Yes												
antha	1	15	Female	3	No												
	1	12	Male	7	Yes												
y	1	9	Male	6.5	Yes												
	1	13	Female	7	No												
and	1	8	Male	5	Yes												
ille	4	12	Male	4	Yes	9	Female	3	Yes	5	Male	5 months	No	2	Female	Not yet formally diagnosed	No
e	2	17	Male	5	Yes	14	Male	Birth	Yes								
	1	19	Male	6	Yes												

The 16 parents have been assigned pseudonyms in order to report parent perceptions, whilst guarding the participants' privacy. During the interviews, a number of participants mentioned medical doctors and specialists, occupational and speech therapists, psychiatrists, psychologists, and schools by name. As the pool of practitioners dealing with ADHD children is a very small one, the same names tended to come up time and again. Some of the comments made by parents were positive and could possibly even be considered helpful referrals for other parents. Other comments made were, however, very angry and resentful. Interestingly, the same practitioner could be liked and disliked, and have both negative and positive comments made about him/her. It seems that parents need to find a practitioner or school that suits their particular family, and each family's experience of a practitioner or school may be different. The researcher has decided not to mention practitioners or schools by name.

7.2 The interviews

The interview process began in February of 2004. See Appendix C for the general interview guide used for the interviews.

Due to researcher time constraints, the interviews were staggered over a period of six months. Transcriptions began immediately upon completion of the individual interviews, and all transcriptions were completed by November 2004. Each transcription yielded approximately 35 pages of double-spaced text.

7.3 Constituent profile descriptions

Once all the interviews were transcribed fully, the researcher immersed herself in the data, reading and re-reading the transcripts and listening to the tapes in order to gain a holistic view of the data.

Once a holistic grasp of the data had been gained, the transcript of each participant was broken down into natural meaning units. Thereafter, those meaning units that were repeated were eliminated in order to construct a first order profile. This in turn was converted into a constituent profile, which is "a condensed summary of the original data in the words of the researcher containing the essence of what the subject expressed" (Shantall, 1996, p. 273). The constituent profile for each subject is presented in Appendix D through to R.

7.4 Categories disclosing the characteristics of being the parent of an ADHD child

As stated in Chapter Six (Research Design), statements with similar, though not identical, meaning were gathered into categories describing the characteristics of being the parent of an ADHD child. To enhance interpretation, and to aid the reader, key phrases related to categories have been italicised.

7.4.1 Interaction with medical personnel and the use of medication

7.4.1.1. The diagnosis

The identification process

For many of the parents, the identification process already began in *nursery school*. This is in keeping with research findings that the symptoms of ADHD appear to arise relatively early in childhood, with the mean age of onset being between three and four years old (Barkley, Fischer, Edelbrock & Smallish, 1990; Barkley, Fischer, Newby, Breen, 1988). Barkley (1998) states that most cases may develop before age seven years. Of the 21 ADHD children, 17 were diagnosed by the age of seven years. Of the remaining four children, two were diagnosed by the age of nine, and only the remaining two did not obtain a diagnosis until high school.

Brenda, Belinda, Angela, Marie, Mia, Pat, Samantha, Sandy, Beth, Gill and Dylan, and Carrie all *sensed something was wrong* with their child long before they got to an official diagnosis. The difference in most cases was the age at which parents began to have the sense that something was wrong. Brenda admits that even from pre-primary she thought: "My God, what is wrong with my child?" Belinda started noticing that Evan was "a different child" when he started at his first nursery school, and Angela sensed Tina was "different from when she was a small child". Marie and Leon knew in Grade 2 already that "something should be done" for Johan. Mia feels she "knew there was a problem from birth" with Lynn. Pat knew when John was about three-and-a-half years that "something was up". When Claudia was a baby, Samantha could already see she was different to her brother. Sandy "sort of had a feeling" by the time Aidan was four, and Beth's "gut feel" when Eve was a toddler "was that all was not okay". Even before Doug was diagnosed, Gill and Dylan "suspected for quite a while that there was something not quite right". In nursery school, Carrie already knew something was wrong with Luke, but nobody could tell her what was wrong.

In some cases, it *took a crisis* for the parents to begin the identification process. When Conor was in Grade 0, Brenda was told that there was no way he was going to make it through to Grade 1. In Belinda's case, she was faced with having to remove Evan from his nursery school if his behaviour did not improve. Angela felt that she had to find help when Tina was in trouble at school, and at home she was hitchhiking and disappearing for hours. Kim came home with a school report that was so shocking that Mia thought it might actually be another child's report. For Gill, the last straw was coming home one day to find "the curtains had been pulled off the wall".

Some of the parents who did begin the process of medical or educational assessments still experienced a *period of uncertainty* before a firm diagnosis was eventually made. Belinda took Evan for his first assessment at the age of four years, but he was only diagnosed at the age of six. Linda went through a period of working with speech and occupational therapists, but no one knew "what was wrong" with Ruth. Marie and Leon had Johan assessed for the first time when he was in Grade 2, but he was only diagnosed as ADHD in Grade 11. Mia took Lynn for her first assessment at age four-and-a-half, but the diagnosis of ADHD was only made when Lynn was seven. Beth had Eve assessed for the first time before she even started nursery school, but she was only officially diagnosed at age seven. Carrie "did the rounds" with Luke before he was officially diagnosed.

Having a formal diagnosis does not mean that parents won't face *difficulties in persuading teachers and family* that there is something wrong with their child, or that something needs to be done for their child. Belinda ended up fighting a heartbreaking battle with the school and the psychiatrist to get Cathy onto Ritalin. Cathy finally went onto Ritalin two years after her diagnosis.

Belinda, Michelle, Mia and Carrie all have *more than one child with the disorder*. Having one child already diagnosed with ADHD did not, however, mean an easier diagnosis of the second child. Cathy was a "very unhappy child" and her "marks just dropped" before her diagnosis was made. Kim came home with a school report that was "absolutely frightening" before her diagnosis was made.

Beth, Carrie and Rose all feel they were *blamed in the identification process*. After Eve's assessment at the children's clinic, it was suggested that Beth herself needed therapy. Carrie's "rounds" with the educational psychologists also had her and her husband being blamed and therapy was suggested for them. Rose was called a

“useless mother” by a principal and a paediatrician, and “an over-possessive older mother who didn’t really know what she was doing” by the educational psychologist.

Hearing the diagnosis

Despite the fact that over two-thirds of the participants in this study suspected that there was something wrong with their children, hearing and dealing with the diagnosis was still *emotionally and intellectually difficult*. Brenda feels the diagnosis had a “very big impact” on her. She did not find it a relief that Conor was diagnosed so early, but instead disliked the fact that he was being labelled as having a problem so early in life. Angela had “a huge problem” with the diagnosis, because “it’s intangible” and she feels she doesn’t understand it. Pat felt the diagnosis “was a shock”, mostly because she didn’t know anything about the disorder. Samantha felt like it “was the end of my world” and cried for days. Michelle found the diagnosis “very overwhelming” because she realised how much work would be needed.

A number of the parents spoke of having a feeling or *sense of relief*. Belinda, Marie, Beth, and Gill and Dylan reported feeling relieved at knowing what is wrong. Mia and Carrie felt the relief of knowing you are right, and of having your suspicions confirmed. For Michelle and Rose there was relief in knowing that they were not causing the child’s behaviour.

There was also a feeling that *once you know what is wrong, you can do something* about it. Marie felt the hardest part of this “whole journey” was “not knowing” and “not being able to give it a name”. For Marie “once it had a name I could deal with it.” Gill too thought: “Thank you’. It has a name. Because when it has a name you can deal with it.”

A number of studies in the 1990s, particularly those by Biederman and colleagues strengthened the evidence of the *familial nature* of ADHD. Between 10% and 35% of the immediate family members of children with ADHD were found to have the disorder, with the risk to siblings of the ADHD children being approximately 32% (Biederman, Faraone & Lapey, 1992; Biederman, Keenan & Faraone, 1990; Pauls, 1991; Welner, Welner, Stewart, Palkes & Wish, 1977). Even more striking, research has shown that if a parent has ADHD, the risk to the offspring is 57% (Biederman, Faraone, Mick, Spencer, Wilens, Kiely, Guite, Ablon, Reed & Warburton, 1995). A number of parents in this study feel there is a hereditary component to their child’s ADHD. Carrie and Brenda believe they might also have ADHD, and recognise themselves in a lot of their children’s behaviours. Pat has ADHD and takes Ritalin when necessary. In Samantha and Michelle’s case, both they and their husbands

have the disorder. Dylan was diagnosed a year after his son, and they started taking Ritalin at the same time. Rose's husband, Mark, believes he is ADHD. Angela thinks "there is probably a hereditary component" and notes that she has a cousin who has a son with ADHD. Linda believes that her husband and his mother both have the disorder. Marie believes her father-in-law has ADHD. Zelda believes that Karl's father and paternal grandmother have the disorder. Sandy's nephew has ADHD.

Beth and Michelle both believe the ADHD might also be connected to the mother's *pregnancy*. This is in keeping with very early investigations into ADHD such as Shirley's (1939) view that birth trauma was a potential cause of ADHD. Beth believes that if there is a "lot of emotional, intense stuff that happened" during the pregnancy, the chances are good the child might have ADHD. Michelle believes that having caesareans "compounded" her children's problems, as well as the fact that both Gary and Helen were in distress at birth. Michelle believes that being "ripped out" of their "environment" really has compounded their ADHD.

Behaviour following the diagnosis

Marie, Pat, and Zelda's reaction to the diagnosis was to immediately start to *read and learn* more about the disorder, to help them make sense of it. All three had a need to gather as much information as possible. Others began to *seek resources* to help their children. Beth sent Eve to a counselling psychologist for therapy. Both Sandy and Michelle decided to go on a parenting course.

7.4.1.2. Health professionals

Some parents were frustrated by the *number of professionals* that they ended up seeing. Brenda got "tired of being pushed from person to person" and believes that Conor had so many assessments that he started to feel there was "something wrong with him". Mia feel that "every time I got to one place, they would say: 'No, you need to go and get these three things looked at.' Then I'd go get those three looked at. Then somebody else would send me for another...." Carrie too "did the rounds" with professionals. Samantha's experience of health professionals has been positive, precisely because they "never, ever went from one to the other to the other."

Parents also get, in Brenda's words, tired of "just *coughing up money*". Linda's feeling towards health professionals dealing with ADHD is that it is "a money making racket". Pat too believes "there's a lot of people taking people for a ride". Sandy feels she spent so much money on the psychiatrist without him being "helpful at all". Sandy ended up feeling "hurt" and "very disappointed".

Parents also complain of a *lack of caring* among health professionals. Brenda feels they are quite happy to take your money, “but won’t pick up the phone to see how Conor is doing”. Brenda also believes that health professionals do not have enough understanding of what it means to raise an ADHD child. Not one of the professionals that Brenda has seen has ever asked her how she is coping. Rose feels that professionals don’t know how to handle ADHD children and do not treat them “as little people”. By contrast, Sandy is happy with Aidan’s neurologist because she feels “he’s **genuinely** (Sandy’s emphasis) concerned about the kids”.

Parents feel that health professionals actually *don’t know what they are doing*. Angela blatantly states that they “are not able to help”. Marie went to “every professional that we could think of. And it didn’t help – at all” – no one knew what was wrong. Pat believes that health professionals in this country are “not up where they should be” and feels that “a lot of them” have not done the research she has. Michelle feels she knows more than health professionals because she is living with the disorder 24 hours a day, seven days a week.

Some parents take offence to the *blasé attitude* of health professionals. Mia disliked the fact that some health professionals were “very quick” to suggest that she could easily solve all her problems by putting her girls in a remedial school. Brenda was horrified that a neurologist was happy to prescribe Ritalin over the telephone without even seeing her child.

Mia feels that because parents “don’t know” you go into these situations and “you trust that doctor so much”. This *trust* then *gets abused*. Mia feels she “could have killed” the doctor who incorrectly diagnosed her daughter with petit mal. “I was so devastated that I had put her onto such strong medication and she didn’t even have it”. This has led Mia to advocate that parents “actually need two or three opinions”.

Some parents have had *positive experiences* with health professionals. Belinda feels they have been able to trust the professionals they saw and that they were very understanding. Pat has found a “wonderful” psychologist she deals with. Mia’s girls see a psychiatrist who she feels is “the right professional” for their family. Zelda’s experience has also been positive – both the paediatrician and the psychiatrist she saw have children with ADHD. As a result they have an understanding of the disorder. Beth found an “amazing” occupational therapist that achieved results. The counselling psychologist who Beth takes Eve to is also very good because she confirms a lot of Beth’s thoughts, and she offers practical advice to Beth and Eve.

The school psychologist also offers Eve “practical handles”. Gill and Dylan have had no bad experiences with health professionals.

What parents do want, is someone who is *thorough* and *continually assesses* the ADHD child. Brenda likes the neurologist who “went through every page” of Conor’s school books. Sandy is very happy with the neurologist that Aidan is seeing because he is “**exceptionally** thorough (Sandy’s emphasis)”. The paediatrician that Michelle takes her boys to monitors them “**extremely** thoroughly (Michelle’s emphasis)”. Rose’s general practitioner insisted on continuous follow-up with Eugene.

Parents also need for the professional to *be accessible* – not just “two mornings of the week for an hour” like in Brenda’s case. They also need health professionals to *answer calls and faxes* – unlike the psychiatrist in Rose’s case.

There is also a benefit to parents *presenting a united front*. Both Mia and Rose suggest that both parents go to appointments. Rose feels that parents should also be *outspoken about lack of service*, and should not let professionals intimidate them.

Finding the right health professional, or combination of health professionals, is a significant issue for parents. Parents need to continue to look for a health professional until they find one acceptable to them. Mia believes parents need to see the “right professional”, not just “a GP or an everyday Joe Soap”. The “right” professional also means that there must be a “fit” with your child – Samantha stopped seeing a speech therapist when she “never bonded” with her daughter.

7.4.1.3 Medication

Four themes related to medication will be discussed, namely: medication and dosage, the process of taking medication, other people’s beliefs about medication, and medication as only part of the toolkit.

Medication and dosage

Many parents had *mixed emotions* about using medication, and for many putting their child on Ritalin was a *difficult decision* to make. It can also *take some time* between the diagnosis and the parents actually deciding to use medication.

Brenda did not want to put Conor on Ritalin as her sister-in-law’s children were on Ritalin and were “doped out, very tired and depressed”. Brenda kept hoping she’d come across a professional who would say that Conor did not need Ritalin. It took a year from diagnosis before Brenda started Conor on Ritalin. Gill and Dylan “fought

against” putting Doug onto Ritalin for almost two years. They tried everything else first. Two of Michelle’s children are on Ritalin. For Michelle too, Ritalin was “really a last resort”.

Belinda, Rose and Pat all had similar biases against Ritalin. Belinda found it “was difficult to put Evan onto Ritalin” as the family has a “very natural approach to illness”. Pat never goes to a doctor, she sees a homeopath; and she did not even want to “know the R-word”. When the psychiatrist suggested Ritalin, Rose was against it as she had been brought up homoeopathically.

In Mia and Carrie’s case, their husbands had more “issues” with Ritalin. Mia’s husband, Dave, initially felt: “My child will never go on Ritalin.” Mia, however, had gotten to the point where she “needed to make a big change”. Carrie’s husband also had more issues than she did with Ritalin. Carrie feels they “tried everything” besides Ritalin. They did the “homeopathic route” and the “supplement route” and the “herbal stuff”, but “no luck”. Carrie and the paediatrician had to persuade him to try it with Luke, and he finally agreed “with a heavy heart”.

Marie was initially “very against Ritalin” because she had “heard it is a bad thing and that it stunts their growth and that you’re a bad mother if you give them Ritalin – it’s the worst thing you can do”. Sandy didn’t really want to put Aidan onto Ritalin, and Samantha too felt “it was a big decision” putting Claudia onto the medication. Zelda had to think about putting Karl on Ritalin – “it’s not just a case of give it to them”. Beth felt it was a “massive decision to make” when she put Eve on Ritalin. Beth did “a lot of research” about Ritalin and, in the end, “it was not an emotional decision – it was a purely practical decision”.

By contrast, there was “no issue” for Angela when it came to putting Tina onto Ritalin: “quite honestly when you are faced with a child like Tina you are quite happy to try it”. Belinda even had to engage in a “big fight” to put Cathy onto Ritalin:

“You don’t want to put your children on Ritalin, you really don’t, but when you see the results you can understand.”

Once the child had started Ritalin, parents could still have conflicting feelings. Brenda still feels guilty about putting Conor onto the medication and wonders whether she is doing the right thing. Zelda, however, feels that giving Karl the medication means that he “has the chance of a normal education and getting out of school and having a job

and studying further or whatever". Eugene is now 19-years-old, and looking back Rose believes they "would not have survived" without Ritalin.

Although a lot of the parents were reluctant to use medication, most parents reported a *significant change in the behaviour* of their child. Cantwell (1996) states that stimulant medications help seventy percent or so of the children who take these drugs. A number of the parents mentioned the positive effects of the medication on the school context. Numerous studies of stimulant medication with ADHD children demonstrate significant improvements in academic productivity and sometimes accuracy when the children are on medication (Barkley, 1997; Pelham, Bender, Caddell, Booth & Moorner, 1985; Rapport, DuPaul, Stoner & Jones, 1986).

Brenda believes that Conor "has turned around". Belinda feels that the day Evan went on Ritalin "he was a different child. He could focus and started learning." Angela believes "you could actually watch the effect" when Tina took Ritalin: "Within 20 minutes there was a difference." On the day Johan started taking Ritalin, he phoned Marie from college to say: "You won't believe the difference. I can actually hear what the teachers are saying. I can actually start concentrating." When Mia and Dave started Lynn on Ritalin the family saw a big "turnaround – literally within 72 hours we had a different child." With both girls, Mia feels it is like "their brain's suddenly been switched on". Pat feels the difference in John was "like night and day. Big, big difference." When Beth took Eve back for her first assessment of the medication, Eve reported that she was finding it beneficial. Gill says: "thank God for Ritalin." With Luke, Carrie found the effect "was literally instantaneous". With both boys, Carrie feels it makes a difference in "how they socialize" and "how they concentrate". For Rose, Ritalin "was magic".

Some of the *parents have experienced for themselves* the difference that Ritalin makes. Pat has ADHD and she knows Ritalin helps her focus: "I tell you it works like a charm". Dylan went onto Ritalin about a month apart from his son Doug. Dylan can "definitely feel a difference" since he has been on Ritalin. Dylan "feels more in control" when he takes Ritalin and he feels far more self-confident. When Luke started on Ritalin, Carrie "wanted to see what it did". And so she took it too. Carrie "can tell you how Ritalin works" because it worked for her: "It was unbelievable".

For some parents there is a realisation that Ritalin is *not a cure-all*. For Mia and Lynn it has not been a case of "she'll get the medication and everything will fall into place".

Lynn still struggles through every year. Sandy has also never seen “a huge difference” in Aidan.

It can take a *long time to get to the correct dosage* of medication, and it often involves time and constant monitoring. Dosages may also need to be adjusted from time to time. Brenda’s son Conor was on three different trial doses of Ritalin. Pat had limited success with John on the short-acting Ritalin before he was moved onto the long-acting Ritalin. Sandy watched Aidan being moved from short-acting Ritalin, to the long-acting version, and back to the short-acting again. Carrie first had Luke on the short-acting Ritalin. Later they tried the slow-release version, but that didn’t last as long for Luke. When the long-acting version came out, Luke went onto that. With Peter, Carrie found he could not tolerate Ritalin at all when he was first put on it. He was then put on Reactivan. Eventually the Reactivan was having no effect and they decided to try Ritalin again; this time “it worked fine”.

A number of the children experience *side effects* with Ritalin, the most common being the suppression of appetite. Conor had terrible headaches when he first started on the medication. He also gets very lethargic and depressed, and his appetite is suppressed. Brenda does not want to put him onto an antidepressant to “cover the effect” of Ritalin. Johan experienced an initial dizziness and shakiness, but that disappeared after two days. Marie finds it also suppresses Johan’s appetite in the mornings, but he eats well at night. Initially when Lynn and Kim started taking Ritalin they were tired and got a bit of a headache. Lynn will not eat during the day, but Mia finds she makes up for it on weekends and in school holidays. With John, Pat finds, on the one hand, that it subdues him and makes him tearful. On the other hand, he is very aggressive and non-compliant when it wears off. Pat does not feel the side effects are bad enough, however, for her to take John off Ritalin. In the beginning Karl would not eat if he took the medication. Zelda now makes sure he only takes Ritalin after he has eaten breakfast. Aidan has a lot of side effects: Sandy reports that he cries a lot, he is very aggressive in the afternoon, he’s emotional, he’s uptight, and he’s difficult to work with. Doug’s appetite is suppressed. He generally doesn’t eat lunch, but Gill finds that by supper he’s starving. The only side effect Gary and Helen have is a lot of abdominal discomfort. Helen does not eat during school hours, but Michelle feels that Gary has actually improved in that respect. Before Michelle would pack him lunch and it would come home untouched. Now he will eat his school lunch and even ask for food. Ritalin affected Eugene’s appetite, but Mike and Rose made sure he ate a good protein breakfast before taking it. They also found that

protein snacking him through the day, rather than sticking to three proper meals, works better for him.

Samantha found the *side effects* to be *too extreme* with Claudia. Claudia had stomach cramps, battled to sleep, and it suppressed her appetite. Claudia was eventually taking Ritalin, plus medicine for stomach cramps, plus medicine to make her sleep, as well as medicine to make her want to eat. Claudia lost more and more weight, and Samantha eventually opted to take her off Ritalin.

Some of the *children realise they are a “different” person* on the medication. Belinda feels that Evan knows “that he **is** different when he is on it and when he is off it”. Even his friends know he is different and say he is more sociable and outgoing when not taking Ritalin. Zelda believes that Karl knows what it feels like “to be Karl on Ritalin and Karl not on Ritalin”. He can “separate the two” and is “totally aware of what the medication does”. Beth reports that Eve felt “strange” on the medication and “not herself in a negative way”.

The process of taking medication

Explaining taking the medication to the child

Belinda and Rob tried to explain to both Evan and Cathy how Ritalin works. With Evan they used the metaphor of a motorcar. They explained that the child with ADHD is like a motorcar without brakes, and Ritalin helps “him put on the brakes”. Cathy has a friend with diabetes, and Belinda and Rob explained to her that she needs Ritalin in the same way that her friend needs insulin.

The educational psychologist, as well as Marie and Leon, explained to Johan about taking the medication. Both Mia and the psychiatrist explained to Lynn and Kim what Ritalin would do, and Mia asked the girls to let her know if they “don’t feel right”.

When John first went on Ritalin, Pat felt he was “too small to explain taking the medication to”. Recently Pat took him to the psychologist and asked her to explain: “She drew little pictures of messages and all that kind of thing”.

Sandy explained to Aidan that taking Ritalin would help him to sit still, and take in what the teacher says, and help him to concentrate.

The child’s willingness to take the medication

The issue of medication can be complicated if the child is not willing to co-operate in the process and take the medication. Belinda finds that Cathy is “quite happy on the medicine.” Mia feels that both Lynn and Kim are “fine with taking it”. Taking Ritalin is

also “not an issue” for Karl and he is quite happy to take it in front of friends. Taking Ritalin doesn’t really bother Doug either.

Johan “really wanted” to take Ritalin and if he forgets to take his tablet he will let Marie and Leon “go to great lengths just to get that tablet to him”.

There seems to be a realisation that the world is a friendlier place when you take the medication. John doesn’t have a problem taking Ritalin. Pat believes he has realised that “with it the world’s not so cruel and harsh and people don’t shout at him all the time”. Michelle feels that both Helen and Gary “are quite happy taking Ritalin. They know that they need Ritalin to cope and concentrate.” If on occasion Michelle has forgotten to give Gary his tablet, he has had teachers remark that he obviously hasn’t had his tablet because he is behaving badly. Michelle feels that Gary now “associates Ritalin with the good behaviour”.

Luke, on the other hand, does not enjoy taking the medication. Eve took Ritalin for about two years and then decided she no longer wanted to take it. Eve likes to feel like “the life and soul of the party” and she believes Ritalin takes that away. Conor is reluctant to take the meds “because he knows he doesn’t feel good on it”. By the time of our interview, he had “refused utterly” to take it.

The child’s responsibility to manage the process

When the child is young, the parent is responsible for managing the medication process. But what happens with an older child? In some cases, an adolescent might even want to come off the medication.

When Evan was younger, Belinda and Rob simply gave him Ritalin and “he just took it”. At the end of primary school, Evan tried to come off Ritalin, and he has tried to come off it each year in high school. Rob and Belinda have allowed him to do “a little trial” each time, in conjunction with the doctor. Each time, Evan himself has decided he needs Ritalin; he can’t focus without it.

About once a year, Luke will decide: “No, it’s time to stop this”. Each time he decides he needs to go back on it. He realises he can’t concentrate without it. Carrie believes “he has seen the benefits.”

Zelda has always tried to involve Karl in his treatment. She has tried letting Karl take responsibility for the medication, but had to change her mind when he took two Ritalin tablets, instead of one tablet, one morning.

Drug holidays

Some parents make use of drug holidays and others choose not to. Evan and Cathy, Lynn and Kim, John, Karl and Doug do not take the medication on weekends or during holidays. When Eve was taking Ritalin, she did not take it on weekends or during holidays either.

Gary and Helen take Ritalin seven days a week, and Luke and Peter have also never been given a break from the medication.

Eugene does not take Ritalin on weekends or during holidays. Rose feels it made weekends “noticeably harder going”, and school holidays were also “a nightmare”.

“Those days stretched out before me like an eternity. He would be wild, bored and very angry and by the time he returned to school I was glad; depressed because I was glad, but sad at all the lost opportunities.”

The difficulty of mornings

Mornings were mentioned as a difficult time for parents. It is likely that this is a result of the lag between the time the child is woken and the time the medication kicks in. It is difficult to remain patient while assisting the child to prepare for his/her day, and it is difficult to begin the day with such negative feelings. Mia finds that for Lynn especially, getting ready in the morning and “trying to get out of the house” is a problem. Marie finds that Johan’s sleep and waking cycles are disturbed and if she doesn’t wake him, he simply doesn’t wake up. Mornings are also always a difficult time in Pat’s household. It takes half-an-hour for John’s Ritalin to take effect and “nothing happens” in their household until it has taken effect. Trying to do anything before the medication has taken effect is “a complete and utter waste of time”. Pat admits that there are mornings where she has screamed and shouted at John “like a fishwife” and both of them are in tears by the time she drops him at school. For Zelda mornings are a battle and consist of an endless: “Karl have you brushed your teeth? Karl, have you eaten? Karl, have you packed?” Zelda feels that “you’ve got to go step by step. You just can’t do anything else. It’s like looking after a baby.” In Rose’s house, Mark would come back home for tea after dropping Eugene, because he and Rose were so “fraught” most mornings just from getting Eugene to school.

Other people’s beliefs about medication

Once parents make the decision to use medication, they often have to contend with the belief system of *extended family, friends and teachers*. This is a difficult aspect, as parents often still have misgivings themselves. They are now put in the position of

either educating those around them, or *defending their decision*. Parents are also constantly faced with *conflicting recommendations* from teachers and extended family and the popular media.

Brenda has had people say: “Do you realise what you are doing to your son?” Brenda response is that they obviously don’t know what they are talking about, and she tells herself that she is doing what she feels is right for her son at this time.

Belinda has had Cathy’s teacher ask her if Cathy can stop taking Ritalin because she is far more “outgoing and bubbly and happy” when she is not taking it. Belinda had to explain to the teacher that Ritalin it “not for social behaviour, it’s for the concentration”.

Mia finds “people are very quick to judge” her putting Lynn and Kim on Ritalin, and she feels “that there is a lot of ignorance out there”. Mia has had friends tell her that she has taken the easy way out. Mia, however, feels she has tried “all the other options, such as the homeopath and natural supplements”. If any of it had made a difference, Mia would “have stuck with it”.

People whom Michelle has met socially have asked: “How can you put your kids on Ritalin?” Michelle feels that people question her decision because of *ignorance* and the sensationalism in *the media*: “It’s just something they have heard. They don’t really have an informed opinion.” Michelle also gets “a lot of flack” for putting the children on Ritalin from the nutritional physiologist she takes the children to, and the nutritional group she is involved with. They disagree with her view that nutrition is not a replacement for Ritalin.

Carrie has had run-ins with the school about the medication. When Luke went to high school, his grade tutor said to her “that under no circumstances should a boy in puberty be on Ritalin.”

Medication as only part of the toolkit

For many of the parents, medication is only part of their treatment strategy. Many of them have tried, and are willing to *try, a variety of things*. Often the medication does not “fix” their child, but in reality it only helps the child. As stated in Chapter 4, some physicians have suggested that ADHD may be due to bodily reactions to normal food constituents (Wender, 2000). One possibility is that some children may be allergic to

certain foods and the allergy may produce behavioural problems. According to Lensch (2000) there have over the years been reports of the co-occurrence of allergies in individuals with ADHD, indicating that there may be a relationship between the two conditions. Roth and colleagues (Roth, Beyreiss, Schienzka & Beyer, 1991) compared a group of children with allergies and a control group of children without allergies and showed that a significantly higher number of subject with allergies exhibited characteristics of ADHD than control subjects. A number of the parents in the current study make use of *diet* as a treatment strategy. Particularly in the case of Marie and Rose, allergic reactions to foods are evident.

Other parents have implemented the food-additive-free or Feingold diet (Feingold, 1975). A number of parents also make use of *supplements*, and *educational accommodations*.

Marie and Rose both have their sons on a *wheat free diet*, as their sons are allergic to wheat. Marie believes she saw a dramatic change “within 24 hours” of Johan coming off wheat. Rose believes the diet, along with the evening primrose tablets she gave Eugene, made a “vast improvement”. Rose also found that good quality *coffee* works for Eugene. This is in keeping with the findings of Leon (2000), who concluded that combining caffeine and stimulants to produce moderate levels of arousal might produce better functioning than caffeine or stimulant drugs alone.

Carrie has the boys on a diet that *avoids all artificial flavourants and colourants*. Carrie believes that if her boys are on the diet, the medication works better. Michelle has the children on a diet that is free of colourants, preservatives, flavourants, dairy, gluten and wheat. Michelle also has the children on a number of supplements and essential oils. Samantha has Claudia on a very strict diet and believes it has given her a “100% changed child”. A private tutor also teaches Claudia.

Belinda, Sandy and Beth have decided *not to do “the full diet route”*. For Belinda it is more about a “healthy eating plan” and she doesn’t want to become “phobic”. Belinda is, however, strict about Evan and Cathy not having fizzy drinks, and tries to avoid foods with preservatives. Sweet are only allowed on Fridays. Belinda gives them multivitamins and supplements such as Omega 3 and Salmon Oil. Evan is also at a school for assisted learning. Sandy too does not want to be “over-neurotic as far as the diet is concerned”. She does give Aidan supplements and she tries not to buy foods with tartrazine, colourants and MSG. Beth does not want to go the full diet route because she does not want to put “an additional burden” on Eve. Beth feels these children already feel different enough. Beth does, however, know that Eve

needs to avoid chocolate because it has “a direct impact” on her, and she tries to avoid buying foods with “MSG and all that kind of thing”. Beth is about to start Eve on an herbal product, and Eve is at a school for assisted learning.

Linda does not believe medication will solve Ruth’s problems and has chosen to go a more *natural route*. Linda relies on the *homeopath and supplements* such as a multivitamin, salmon oil, primrose oil, flaxseed oil, and an amino acid called GABA. Ruth also goes for *biofeedback therapy and reflexology*. Linda feels prayer is also an important part of her arsenal to “heal” Ruth. Linda too attends a school for assisted learning.

Pat has put John onto Omega 3. Although she has seen a difference with John being on it, she does not see it as a replacement for Ritalin. John attends a remedial school. Brenda is about to try Conor on an herbal supplement. He also attends a school for assisted learning. Gill and Dylan put Doug straight into a special needs school.

Many parents have taken their children to *occupational therapy* (Brenda, Belinda for both children, Mia for both girls, Linda, Pat, Samantha, Zelda, Beth, and Carrie with Luke); *remedial therapy* (Mia for both girls, Zelda, and Carrie with Luke); and *speech therapy* (Brenda, Linda, Pat, Samantha, and Zelda).

Other alternatives made use of are *play therapy* (Belinda for Evan), *social skills training* (Belinda for Cathy), *vision therapy* (Mia for both girls) and a *mindologist* who works on healing energy disturbances (Linda).

7.4.2 ADHD and family life

7.4.2.1 Parenting issues

Research on the larger domain of family functioning has shown that parents of children with ADHD children commonly experience considerable stress in their parenting roles (Anastopoulos, Guevremont, Shelton, & DuPaul, 1992; Fischer, 1990). This was evident in the lives of all the participants.

Learning to be a parent

The general consensus among participants was that being a parent means *making it up as you go along*. Brenda feels that you can’t learn to be a parent: “there are no books on being a parent. We do the best thing we think we can at that time in life.”

Brenda feels that the available books present you with “the perfect child, the perfect life. And then we hit problems and nobody can tell you how to handle it”.

Linda has a grown up daughter from a previous marriage, so she feels she had some experience by the time she had Ruth. For Angela, however, it's been a case of learning to be a parent by trial and error.

Marie too believes that “you just learn to be a parent as you go along; there's no one to teach you – **unfortunately** (Marie's emphasis).” Marie feels her own mother is the model she has for being a mother and she is grateful that her mother “enjoyed being a mother”, and “mothered intensely”, and “gave a lot for her children”. It is, however, a difficult model to “measure up to”, especially with Johan “being so difficult”.

Mia feels the girls “didn't come with manuals” and for her being a parent means taking each day “as it comes” and dealing with it. Pat also feels that when it comes to being a parent, you “definitely learn as you go along”. Pat feels that *parents need to be educated* about being a parent, but admits that she doesn't know who would take on the task: “the government, the schools? You know it's a hell of a dilemma.” Ultimately, Pat feels that parenting “all comes back to **your** values and **your** morals and how you were brought up” (Pat's emphasis).

Samantha feels that being a parent is a “day-to-day handling of every situation as it comes”. Sandy believes nobody can teach you to be a parent and that you can only “*follow your natural instincts*”. Sandy believes you do the best you can and try not to make the mistakes your parents made, although you still “make mistakes every single day”.

Carrie believes that you learn to be a parent “by *trial and error*”. “Nobody teaches you how to do this.” More importantly, Carrie feels that “nobody teaches you what to do when you have got children that are not the same as everybody else”. In some ways, Carrie feels you are also determined “*not to do what your parents did*”. For Rose it was a conscious decision that she did not want to parent the way her parents did.

Some parents felt the need to *learn appropriate parenting behaviours* to assist them with raising the ADHD child. These are changes beyond those they would need to make for a child without ADHD. Belinda and Rob went for parental counselling for a year after Evan was diagnosed so that they could learn to put boundaries in place. Marie started studying again to try to “get answers” about Johan. Beth, Sandy, Michelle and Rose all attended some form of parent's course.

Modifying daily routine

Daily routine often has to be adapted in the family with an ADHD child. Children with ADHD typically *require more of the parent's time* to manage behaviour and help with homework than non-disabled siblings.

Brenda knows her older son is okay when she goes away, but she worries that she's not there to see that Conor eats and drinks, and to help him with his homework – “you know he needs that little bit more time”. Belinda found Evan “**very** (Belinda's emphasis) demanding” as a little child, although he is getting better now. Marie feels it was fortunate for Johan that she didn't work, because he “took up so much attention”. Mia has always had to put in “a lot of time” with the girls, especially with Lynn and homework.

Samantha will often sit with Claudia doing schoolwork till late at night. Sandy too spends a lot of time with Aidan doing homework. She can't leave him to work on his own because then he does nothing. It can take Sandy up to two hours to do two readers with Aidan. Michelle has to sit with the children every afternoon and do homework or it doesn't get done. “I have to sit and monitor **every, every** afternoon (Michelle's emphasis).”

Carrie spends a lot of time working with the boys and feels they are lucky that she does not work and has always been there to do homework with them. Carrie feels they would be “lost” otherwise.

Michelle finds *trying to break the daily routine is a problem*. If she and her husband take the children for an ice cream on the odd occasion, the reaction will be: “But you said we can't do this and now look we're doing it.”

Family activities, like outings and vacations, also *have to be carefully planned* and organised. Michelle finds family outings are a “nightmare” and they are kept to “few and far between”. Rose and Mark too found that the anxiety of a planned trip or outing seemed to “totally unsettle” Eugene.

Finances

Children with ADHD often *require more of the family's monetary resources* for medical specialists, medications, supplements, psychologists, and special schools.

A number of parents admitted to *feeling the pinch financially*. Sandy is already paying for a private school for Aidan, but she has now heard of a woman who does assisted learning from home. Sandy would love to send Aidan to her, because she knows he

“would just excel”, but she can’t afford the R4 500 a month it will cost to send Aidan to her. Recently Sandy’s husband has questioned the amount of money being spent on Aidan’s treatment, which upsets Sandy. She feels she has to do these things for Aidan: “If I leave this, I feel I’m failing Aidan”.

Gill and Dylan found that they *could not afford to go the full diet route* with Doug, even though there was some improvement when he was on the diet. Gill and Dylan currently have Doug in a remedial school. Although they feel it is “the best thing” they could have done, they are “feeling it financially”. Pat too has her son, John, in a remedial school and, although it is a good school, she feels that financially it “kills” her. The psychologist, however, said to Pat: “You know what, Pat, if you have to go out and get a waitressing job at night to get him into a decent school, you’ve got to do that in the beginning.”

Michelle finds that “financially it’s hellish with all the supplements and things”. Michelle does not work, so “the burden of that responsibility falls on Matthew’s shoulders”. Michelle sometimes has to *forgo the supplements* because of finances. “And it is hard because then they deteriorate, and then when we can afford to again it is this long road before they are back where they were.” Michelle was also taking all four children to a neuro-linguistic therapist, but eventually they stopped going because it “becomes extremely expensive”.

In Brenda’s case, she admits to *buying peace and quiet*. Conor will obsess about getting something to the point where “it’s easier to buy that tank on the shelf, so that I get five minutes of peace.” Brenda then feels guilty about buying Conor something and buys Brad something so he doesn’t feel left out.

Differences in parenting a child with ADHD as compared to a non-ADHD child

A number of the participants felt there is a “*big difference*” between parenting an ADHD child and a non-ADHD child. Parenting strategies that were successful for a non-ADHD older child often do not work for the child with ADHD. Two of the participants mentioned the tension of having to be “two” parents in that they have to have a different parenting style for the ADHD child and the non-ADHD child.

Belinda’s two older children are both ADHD. Belinda sees “differences now, because Frank is different”. Frank will actually finish something that he’s working on. Belinda realises now that neither Evan, nor Cathy, ever finished something before moving on to something else. However, Belinda never thought it odd when Cathy *didn’t finish things*, because Evan had been the same. According to Santrock (2002), ADHD

children who display the characteristic of inattention display an inability to finish tasks, and often get bored with tasks after only a few minutes.

For Brenda the difference in parenting an ADHD child and a non-ADHD child is that she is *more protective* over Conor than Brad, because he has ADHD.

For Angela there is a big difference between parenting her children: “one’s a pleasure; one’s an absolute nightmare.” Angela feels she has had to *be two parents*. Tina needed her to be really strict, but if she had been that harsh with Colin, he would have been “devastated” and it would have changed her “son’s perception” of her. And so she had to “be two parents”.

Linda’s two children are very different. Reese is very sweet and loving and forgiving. Linda calls him “angel-like”. Ruth on the other hand can be “very nasty” and always *wants to be the centre of attention*. Luckily for Linda, Reese is content for Ruth to take the lead.

Marie feels it is “like Mars and Venus parenting these two – it’s like these children *come from different planets*”. Marie admits that the parenting style does vary from one child to the other and “at times it’s been very hard to hold that tension”. Marie sometimes feels she doesn’t know what to do. She doesn’t want to take sides, but sometimes she just knows that her “daughter is right and he (Johan) is wrong.” Marie admits it’s been emotionally hard and sometimes she just wants “to be left alone” and not to have “to take all that responsibility for them”.

Zelda too finds her two children very different to parent. Her daughter is very *academic* and comes home with distinctions and prizes and “does everything perfectly”. Karl, on the other hand really battles along. It is hard sometimes when her daughter comes home with a good report, because she feels she can’t “really be too happy”.

Samantha, however, does not “think there’s much of a difference at all” between parenting Claudia and parenting Ben. When Claudia was younger there was a difference, and Claudia would *battle to follow instructions*. Samantha believes there is not much difference now, because Claudia is on her diet. She does admit though that “Ben can carry on with stuff on his own and she (Claudia) might just need some directing”.

Parent’s feelings

Major themes with regard to parent’s feelings include (a) feelings of helplessness, (b) feelings of being blamed (c) feelings of guilt (d) feelings of resentment (e) feelings of

fatigue (f) feelings of embarrassment (e) feelings of isolation/loneliness (f) feelings of grief and disillusionment and (g) feelings of empathy.

Helplessness

Parents try a variety of techniques and strategies with their ADHD child and feel helpless when they don't work. These parents seem to be *constantly searching for an answer* for their child.

Belinda and Rob felt helpless because they did not know how to deal with Evan: "We had no idea how to limit this gorgeous child and *how to cope* with him". By the time Evan was diagnosed, Belinda "didn't know what to do anymore for him" and all three of them "felt totally out of control".

Angela feels helpless and has now "washed her hands" of Tina. Angela reached a point where she felt she could "*only do so much*". Angela has now thrown her hands up and said, "I am not responsible anymore".

Marie and Leon felt that they did "more than was expected of any parent" and "still *nothing helped*": "It was very hard for us, because we did the best we could. We thought we were very good parents." Marie felt particularly helpless when she asked the headmaster to keep Johan back at school and he said no, without any explanation. Marie had looked to him as someone who could give her an answer, but now she was "left in the middle of nowhere". Marie felt it threw her "totally off balance for such a long time".

Sandy too feels helpless because she does so much work with Aidan, but there is "*never any improvement*". Michelle felt helpless when Kenneth started screaming at 5 months. Michelle didn't know what was wrong and she *couldn't get anything right* with him. By the time Kenneth was 8 months old Michelle felt she "couldn't take it anymore". Michelle felt she had her "hands full". Michelle's feeling of helplessness is compounded because she has ADHD too. Michelle feels she can hardly cope with herself and "now I have got these four little people that really need me".

Blame

A number of the parents received comments that varied from *subtle suggestions* of blame, to *very direct comments* that they were to blame for their child's behaviour. In some cases there was complete *denial* by those who blamed them for their child's behaviour that ADHD was a neurological disorder, and a belief that the parents were somehow *promoting the behaviour*. These messages *came from a variety of people*:

spouses, siblings, extended family members, community members, medical professionals, and school staff. In some cases, participants even *blamed themselves*. How do parents cope when they are blamed? In most cases parents need to recognise that the child's behaviour stemmed from a biological cause, and was *not the result of bad parenting*. They need to recognise that their parenting skills could influence their child positively or negatively, but there are some behaviours they are unable to control.

Angela was *accused of being "dysfunctional"* by Tina's school guidance counsellor. Angela's older child, Colin, had had a very successful school career at the same school and is now in university. It angered Angela, who said to the counsellor: "I have another child who went through your school, and I was never accused of being dysfunctional with him, and he didn't have a problem. Now that there's a problem I'm dysfunctional. If there's anybody who is dysfunctional it's Tina, not me."

However, Angela blamed herself too and used to feel a *tremendous sense of guilt*. Angela felt she was going out of her mind and believed she must have "obviously done something wrong".

"But after a number of years – I was going to drive myself insane – I actually then sat and looked at it and thought: 'But Colin is brought up exactly the same way.' And you cannot get two more opposite children in the same household. And, if it hadn't been for him, I think I would definitely be blaming myself. And I got to the point where I said to myself: 'I am actually not to blame.'"

Mia experienced *implied blame from her husband*. Dave's attitude was: "There's nothing wrong with my child; you (Mia) are looking for a problem." Dave implied Mia was to blame by saying that she needed to "spend more time" with Lynn. Mia felt she couldn't spend any more time with Lynn than she already was.

Pat used to blame herself until the psychologist said to her: "You can't do any more. Just relax; there's nothing more you can do. Stop blaming yourself." Pat now realises that *assigning blame is not useful*. Knowing who or what is to blame will not change the situation:

"I don't care if it's when he fell out of his bed on the tile floor, or if there was something in the birthing. It's not going to help; it's not going to go away; it's not going to make anything better. Just deal with it and make the best of it."

Gill too used to blame herself. She would say to herself: “I’ve got to be the worst parent in the world. How come everybody else can do it and I can’t?” It’s only now that Gill realises it was “*really stupid*” to think that way, because there was actually something wrong with Dylan.

Beth felt blamed by the children’s Clinic. They even sent her for therapy. Beth also feels she was too intense a parent initially, and she would “beat herself up when she wasn’t perfect”. Beth believes she has now “*grown out of that*”.

Michelle feels other people would imply she was to blame for her children’s behaviour. Helen would have such bad tantrums that people would ask Michelle what she was doing to her child. Michelle “*developed such a complex* about it”. The same thing happened when Kenneth used to scream and they lived in flats. Michelle regularly had people come up to her and ask her what she was doing to her child.

Carrie had her husband tell her she was “a *terrible mother*” because she had managed to get it right with their first child, so why not this one. The educational psychologists also “blamed it on the parents” and suggested therapy for Carrie and her husband. Carrie feels that it’s hard when “you look at the other parents and their perfect kids”. It makes her ask: “*What am I doing wrong?*” Besides blaming herself, Carrie also feels other people are quick to blame the parents, making comments like: “They just need discipline”.

Rose was called a “useless mother” by a principal and a paediatrician, and an “over-possessive older mother” by the educational psychologist. This *fed* Rose’s *own fears*. She is an older mother and she questioned what it was that she might have done wrong. Rose’s family also thought she and Mark were to blame for Eugene’s behaviour because they were simply not strict enough.

Belinda has come to accept that she is not to blame and “just because the children have got a problem; it’s not **my** (Belinda’s emphasis) problem.

“But it **was** the kind of thing that you felt was something to do with your parenting, initially. Now I just know that it **might** have been the parenting (and I wouldn’t admit that many years ago) because we **didn’t** set limits, but it didn’t **cause** it.” (Belinda’s emphasis)

Guilt

Zelda is a perfectionist and feels that makes it hard to be Karl's mother. Zelda worries that she will *transmit a feeling of "you're not good enough"* to Karl: "without meaning to, but it will still be transmitted".

"Sometimes in your mind you have a picture of somebody who doesn't succeed, or who doesn't do well or something, and sometimes you see that in your son. (Sighs) And I feel so guilty."

Even though Sandy tries to cover all the bases with Aidan, she still feels guilty about *things she has not done*. The psychiatrist suggested that Aidan go for socialising, but Sandy feels they couldn't afford it. Sandy feels "guilty about it. Maybe it would have helped."

Before Doug went on Ritalin, Gill found it difficult to deal with "a child who is out of control". She would reach the point where she had enough, and would *lash out* at Doug. That would cause Gill to "spend the next three hours wallowing in guilt": "Terrible, it's the worst feeling in the world."

Resentment

Sandy used to feel "tremendous resentment" toward Aidan, because as a parent she felt she was failing: "I felt, *no matter what I did, it was never right*. I could never make this child happy. And I just did what I **needed** (Sandy's emphasis) to do. And I felt that I couldn't get close to him." It took going on the parent's course, and learning to understand Aidan more, for that feeling of resentment to change.

Fatigue

Coping with the ADHD child's disorder and the frustrations that accompany it is exhausting. Many of the parents feel the *need for a change or a rest*.

Marie feels Johan was fortunate that she could stay at home with him, because he needed the extra attention. It was, however, sometimes "very bad" for her "because there was *no me time*". Marie was "so busy rearing these children" and trying to divide attention between her daughter and a son who "took up so much attention", that she "was lost within that". At times she felt, "I just don't want these children; please take them away. I just don't want them."

Mia "had gotten to the point" where she "was very low" by the time Lynn was diagnosed. Mia "was very tearful all the time because trying to get Lynn to cope was

such a hard battle; it was such an *uphill battle*". By the end of Lynn's Grade 1 year, Mia told Dave she was "*exhausted*". Once both girls were diagnosed Mia found the demands of homework, OT, remedial therapy, and vision therapy to be "exhausting".

Samantha admits to coping by pushing herself. As a result she now feels "*burned out*". Michelle feels "drained most of the time" because she is trying to cope with her own ADHD, Matthew's ADHD and then the kids' ADHD.

Rose feels that there have been times when she has "quite understood stories about human combustion." There have been times when Rose has felt that she would "spontaneously combust from *sheer stress*".

Embarrassment

Parents can be embarrassed by the child's behaviour across a *variety of settings* – for example shopping, church, and school. It can progress to a point in parenting, where they are no longer concerned about it.

Besides the children embarrassing her at the shops, Michelle has had the ultimate embarrassment of having the *child protection unit* come knocking on her door, because Helen screamed so much. "Do you know how humiliating that was"? Michelle also gets embarrassed when the children constantly contradict her or *correct her in front of company*: "They don't have the slightest notion of what I'm talking about, but they will chip in and they will contradict: 'No mommy, it was like that. No mommy, it was like this.'"

Gill feels there *isn't* "*any embarrassment*" to having the disorder. Her attitude is: "So what. It's not something you asked for, but you've got it, so you deal with it." Her husband Dylan has the disorder too, and admits that in the beginning he was "kind of embarrassed" about his diagnosis. He has come to realise that he is not the only adult with the disorder, and he now has an attitude of "I don't care".

Isolation/loneliness

Parents can feel isolated from others outside of the immediate family, because they are *different from other families* and their child's disorder *interferes with ordinary social activities*.

Belinda feels that Evan's having ADHD has "left them more isolated". Belinda also experienced feelings of loneliness as she battled against the school and the

psychiatrist to get Cathy onto Ritalin. Belinda even started to avoid other parents: “my self-esteem took a great knock. It was like I was incompetent and, ja. And I felt very much, um. (Starts to cry) uh ... very alone.”

Because people always felt “uncomfortable” around Tina, Angela was left isolated because she battled to find a babysitter for her, or to leave her with anyone. According to Barkley (1998), difficulties in obtaining babysitters for their ADHD children, especially the more severely ADHD and oppositional among them, is reported by mothers in clinical interviews. He states that this may result in a greater restriction of both socialisation with other adults, and the ability to carry out the typical and necessary errands within the community needed to care for a household.

Michelle and Matthew *don't have friends*: “we are totally isolated”. Michelle finds it difficult to take the children out to other people’s homes because “as soon as we get into a different environment, they (the children) are ten times worse”.

Rose and Mark found that Eugene’s retching up of food seriously affected their social activities: “we were very reluctant to eat out or with other people for fear he would retch up his food. For us this was the beginning of our isolation.”

Rose believes that the actual nature of Eugene’s disorder isolates them. Rose feels that parents of an obviously handicapped child receive sympathy and maybe even offers of help, but parents of an ADHD child are merely seen as the cause of the problem. Far from receiving offers of assistance, parents of an ADHD child “are somewhat *ostracised* and that is a difficult thing to bear”. Rose believes that parents of ADHD children often have to “turn their backs on critical society and try and sail their ship in lone waters.” Rose and Mark feel that is the route they went.

Grief and disillusionment

Some of the parents report a grief reaction, sometimes at diagnosis but even years afterwards. These parents *want their child to be like other children*. They grieve over the loss of their “ideal child”. They grieve for the person their child could have been. These parents have to confront a very different child to their dream child: one who requires a significant amount of time, energy, financial support, and emotional stamina. They can end up feeling very overwhelmed by it all.

Belinda and Rob have had to learn to accept Evan “the way he is”. Belinda admits that at first there was “a *feeling of disillusionment* because he’s not going to be what you imagined he would.”

Once Johan was diagnosed, Marie felt that “the expectations she had for him when he was younger” all “had to die”. Marie feels there was a “*tremendous grieving process*” that she “had to work through”. It felt to her “like losing a loved one” and she knew “that those expectations that I had will never be”. Marie believes that her grief led to depression and she eventually had to go on medication for the depression.

Mia feels that the “mould” she had for her children was broken:

“And I think when you go for assessments there is nothing worse than hearing your child – you have an expectation for your child, you want your child to be somebody and you always think that they’re going to be up in the class and they’re always going to fit in – and they don’t. And all of a sudden somebody *breaks that mould* that you had for them.”

Mia believes “you actually have to take time out and you almost have to *mourn the child* that you thought you were going to have, and then you have to appreciate the child that you’ve got”.

Sandy finds it “*heartbreaking*” that Aidan doesn’t cope as well at school as she would like him to. She knows Aidan has potential.

“And, from my heart, I want to see him strive and I want to see him grow and I want to see him cope better. And that’s, that’s where I’m desperate. And that’s where it gets to me. That’s where I get very sad.”

The sadness for Carrie lies in knowing that her boys *realise they are different* to other children. The boys enjoyed the ADHASA camp for ADHD children because they “were all the same”. They admitted to Michelle that on things like school tours they felt different: “So they know they are different. Instinctively they know. And that is the sad part for me as a parent.”

Rose would experience her strongest moments of grief related to *school holidays*, when Eugene would be off Ritalin:

“Those days stretched out before me like an eternity. He would be wild, bored and very angry and by the time he returned to school I was glad, depressed because I was glad, but sad at all the lost opportunities. It was tragic that we could have had such a wonderful relationship and done so many lovely things together, but could not because of his temperament. They say parents who have a child with a problem *mourn for the child they never had*. I cried every time he returned to school wishing it had been different, but it never was.”

Rose feels that with any child, many of the *hopes and aspirations* of the parent will be *placed on the backburner*, “but with the ADHD child this can mean, not indefinitely but forever, and that can be hard to bear.”

Interestingly, while some of the parents feel grief related to the diagnosis, Dylan grieves over lost time because he was never diagnosed: “what might I have been like, or how would I have fared at school, if they had known about it at that age.”

Empathy

Dylan finds it easier to deal with Doug than Gill does, because he *himself has ADHD*. “Myself I’ve got more understanding; I know what he’s going through. So I’m a lot more patient with him because of it.... I can relate to it, where Gill can’t.”

Carrie sees the similarities between herself and the boys. For example, she hates shopping as much as they do. How can she shout at the boys when she understands and knows “exactly how they feel”? Carrie believes the boys are lucky that she is “*aware of how they feel* – all of it”.

For Michelle though, “it hasn’t really made it better” that she is also ADHD, “because I also have to cope with myself and then cope with them”.

“Looking at them and understanding what they are going through, I suppose I should have more compassion. But I have to go through the same thing all the time myself. It just *complicates it more*.”

Although Mia does not have ADHD, she can *empathise with the girls battling at school* as neither she nor her husband, Dave, finished school: “we were both the same ... we also both battled at school”. As a result they feel they “want more” for their children.

“And when you see they battle and when you see where the problems are, you don’t want that for them. So, I think in a way it kind of encourages you to try harder and try and help as much as you can.”

Parents’ frustrations

Research shows that ADHD affects the interactions of children with their parents and, hence, the manner in which parents may respond to these children. Children with ADHD are more talkative, negative and defiant; less compliant and cooperative; sustain their compliance for shorter time periods; are less likely to remain in task; are more demanding of assistance from others; and are less able to play and work independently of their mothers (Barkley, 1985; Danforth, Barkley & Stokes, 1991; Gomez & Sanson, 1994; Mash & Johnston, 1982).

The major frustration for parents in this study is *discipline*. This is in keeping with Wender (2000) who states that the main problem of the ADHD child at home involves discipline. All parents must discipline their children, and parents of children with ADHD are not unique in this respect. What is different is the *frequency and the intensity* of the negative behaviour that is exhibited by children with ADHD. Parents spend a significant amount of *time and energy* on attempting to manage the behaviour of their ADHD child.

Parents in this study were particularly frustrated by the child’s *inability to follow parental directions*. At times it seems that the child is unable to complete the task, rather than being deliberately noncompliant. Sometimes they don’t seem to hear the direction, or seem to have difficulty in interpreting what is said. Parents have to be careful how they word directions or communicate. It can be very tiring to constantly monitor what you say. On the other hand, there are times when it seems the child chooses to be non-compliant. Parents are not always sure when their child is being “ADHD” or “naughty”. The inability to follow directions or complete tasks caused parents to eventually initiate attempts at *behaviour management strategies* to help them deal with the behaviour. Some of the behaviour management strategies implemented by parents in this study will be discussed further under the theme of getting through the day and advice for other parents.

Linda finds that Ruth has always thrown “a lot of *tantrums*”. According to Barkley (1998), although temper tantrums may be common instances even for normal preschoolers, their frequency and intensity are often exacerbated in ADHD children.

Linda feels she has got to “be very hard” with Ruth and she ends up shouting “a lot”. Linda admits that Ruth has “gotten so many hidings – terrible hidings”.

Marie and Leon found that as Johan grew up, he challenged the teachers more, and he challenged Marie and Leon at home more.

“But we’ve always felt that he’s *challenging a discipline*, an order, searching for his borders – up to where will we tolerate him. Will we still love him if he does this? And it was, it was very hard at times.”

Mia found it very frustrating when Lynn did not follow directions. Mia would reach the point some days “when you just want to kill”. Lynn would say: “I didn’t hear you.” Mia knew she had heard, but believes Lynn didn’t know “how else to interpret the fact that she’s forgotten on the way”. Mia finds that on a daily basis “inevitably” she will “*scream and shout a lot*”.

It frustrates Pat that John seems to have a problem relating to the *consequences and implications of his actions*. John just doesn’t get: “If I don’t do this, that will happen.” Pat can stand there and “scream and shout like a wild banshee” and John does not seem to care. Giving John a hiding makes no difference. Pat finds she has to *be “innovative and creative all the time”* when it comes to discipline”. She has to keep on until she finds “the button that pushes and has an impact”. She also finds that you always have to *have a Plan B*. The problem is also complicated by the fact that every day is completely different: “**no** (Pat’s emphasis) day is the same”. Pat believes the *child’s inconsistency* makes it difficult for the parent to be consistent. “It’s very hard work.”

Samantha is also frustrated by Claudia’s inconsistency. Some days she wants to do things and “other days she just doesn’t give 100%”. When Claudia was younger following instructions was a big problem. It would be a case of: “‘Claudia look at me I’m talking to you.’ I would have to remind her all the time: ‘No Claudia, don’t touch it. I’m talking to you now listen to me and do what I’m saying and get these things done.’” Samantha has found that a *hiding never works* with Claudia. Sending Claudia to bed early is the worst punishment you can give her, because then she has to lie there for hours.”

Zelda finds it very frustrating that Karl “*can’t retain more than one instruction*” and then she has to “repeat it”.

Michelle finds the children are *defiant* and “that is a very hard thing to deal with”. She also finds that the children *pick up behaviours from each other* – especially if it’s a

behaviour that can get them something. “So for me to differentiate between what they’ve picked up and who they are is very difficult.” Michelle has found that a hiding never works with her children. Michelle hates the fact that “everything that they have, everything that they enjoy” has to be used as “a motivation to get them to do things”. Michelle finds it “awful” that “there *constantly has to be a threat hanging over them*” otherwise she will get “absolutely no co-operation”. Michelle feels that her *own inconsistency* is her biggest problem – the children know if they push her “buttons for long enough” she will probably “cave in”.

Angela believes that Tina “makes *conscious decisions* to do what she knows she shouldn’t”. The only thing Tina hasn’t “done” yet is being arrested, and Angela does not believe that is far off.

Rose speaks of Eugene’s not following directions because of *not “understanding” what was said*. They found if they said, “Eugene would you like to set the table,” the answer from him would be a simple: “No.” At first Rose and Mark could not understand this. They came to realise that “whereas it is a subtle instruction to the initiated (there is no question mark after table), to the uninitiated ADHD child it is a choice (there **is** a question mark) and his choice was always: ‘No I would not like to set the table.’” For another child it would be understood as an instruction from a parent to a child who had no choice. Similarly they found that if they said, “Would you close the door” in all probability Eugene would not close the door. For action Rose and Mark had to *demand*: “Close the door please.” Mark and Rose found Eugene to be “quite impervious” to discipline. Smacking never helped.

The ADHD child’s *inability to think in a flexible manner* can also be a huge frustration for parents. These children can become hyper-focussed or obsessed, and this is difficult to deal with on a daily basis. Brenda finds Conor to be “very obsessive” – “to the point of where I can scream. I can bang my head against a wall because I can’t take it.” Conor doesn’t just want something. He “has to have it”; “he **“needs** (Brenda’s emphasis) it”. Zelda also gets frustrated by Karl’s “fixating” on something and not then not wanting to “let go”. When Karl was three or four-years-old he fixated on a motorbike and “he’s still fixated on getting a motorbike”. When Johan was little he wanted to kick a rugby ball, and “he did it for days on end”. Marie admits that Johan is “over-focussed at times, on certain things”.

High-risk behaviours were also a major source of frustration for the parents. High-risk behaviours that the children of these parents exhibited included stealing, using drugs, and disruptive behaviour in school. As adolescents, the consequences for impulsive

behaviour are more severe and could end in arrest, something that Angela fears might happen to Tina.

Belinda's son, Evan, displayed *disruptive behaviour in school*. Belinda and Rob were called into his nursery school and told that Evan would have to be removed if he didn't change his behaviour. Evan was writing on the walls and swearing, and the teacher felt he was influencing other children. Barkley (1998) states that placement of ADHD children in day care is likely to be stressful as day-care personnel complain about the child's disruptive behaviour, aggression towards others in many cases, and difficulties in being managed. According to Reebye (1997) it is not uncommon to find the more active and aggressive among ADHD children to actually be kicked out of preschool.

By the end of primary school, Tina had started to *steal* from Angela, drink, and experiment with *drugs*. To date she has been in drug-rehabilitation on two occasions, and she had an abortion at age 16 after getting pregnant by a boy in her class. Tina has also disappeared from home for extended periods.

Marie and Leon were called in because Johan was *disrupting classes*. It was reported that "Johan was making it very difficult for the rest of the class". Johan has also experimented with drugs.

Zelda was called into the school last year because Karl had *sworn* at a teacher. Zelda feels that Karl gets into trouble because he *acts without thinking* first. According to Santrock (2002), children who display the characteristic of impulsivity have difficulty curbing their reactions and don't do a good job of thinking before they act.

Beth visited Eve's nursery school one morning and watched Eve create "such havoc" – running on tables and screaming. In Eve's Grade 2 year, things reached a stage where the teacher told Beth that Eve had to go on Ritalin, or she would *have to leave*.

Michelle reports the *destructive behaviour* of her children – Michelle can't leave any of her things around. The children have even ruined the inside of her car.

Luke has tried *drugs* and to this day, Carrie has a drug test in her cupboard. Carrie also worries about her boys and *alcohol* as she feels they "don't know when to stop".

Change as a parent and a person

Some of the parents in this study feel that having an ADHD child has changed them as a parent and as a person. Belinda believes that the experience of parenting an ADHD child has helped her to become “*more assertive*”. It has helped her “to be assertive to teachers and to stand there and not think I’m inadequate.” Belinda feels she and Rob “have learnt so much through this”. Although Belinda had come across ADHD in her studies, she feels “the *studying doesn’t prepare you for it*. You then just know the symptoms. It’s actually a total different ball game.” Belinda feels “it’s **definitely** (Belinda’s emphasis) been good for us. And Rob also says he’s like grown so much through the children.”

Marie believes that Johan’s having ADHD has “really empowered” her and recently she has come to appreciate herself and all the abilities she has been “blessed with in dealing with this difficult child”. She is now at a stage where she gives herself “recognition for that”, which she didn’t do in the past. Marie feels she has “really *achieved much*”.

Mia feels that through parenting her ADHD children she has “*learnt a lot*”. She believes she has become “*far more outgoing*” and her “*own self esteem is better* than it used to be”, because she has *had to “grow up* and deal with other people and doctors” and she has had to fight for her children. Mia feels that if she hadn’t been through this process she could never imagine herself going to a teacher and asking: “What is going on?” Now she realises that if she’s “not going to do it, no one else is going to do it”. Mia believes she has been “*pushed to cope with things* that maybe ordinarily I would have just stuck my head in the sand and hoped that they would have gone away. So, it does *make you stronger*, it makes you tougher.”

Carrie feels these days that she can actually pat herself on the back “a little bit”. Carrie feels she has learned to *trust her gut instinct* now more than what she used to. She feels she is at a point now where she can actually *help other people*, especially those with children younger than hers.

For Rose, however, the *change has not been a positive* one. Rose believes that having a child has made her more nervous and reduced her confidence. But having a child with problems has made her *doubt herself* further. Rose believes she is not the person she was and scarcely believes she was once adventurous and successful.

7.4.2.2 Spousal issues

Increased marital conflict, separations, and divorce, as well as maternal depression is also prominent in parents of ADHD children (Befera & Barkley, 1984; Barkley, Fischer et al., 1990; Cunningham et al., 1988; Lahey, Piacentini, McBurnett, Stone, Hartdagen & Hynd, 1988; Taylor et al., 1991).

Some of the parents in this study have experienced the *conflict in the interaction* between spouses that having such a child brings. The situation can be complicated even further when the *spouse has similar symptoms* to the child. Some of the parents also spoke of the frustration of their *spouse not contributing* enough, or not appreciating everything they do for the child. Often one parent is well versed in the nuances of the condition, while the other has only a vague idea of how the child's disability affects their educational performance and their behaviour. The "well versed" parent often makes the majority of childcare decisions. It is interesting to note that most of the participants in this study were women. Does this perhaps imply that it is often the mother that deals with the condition? By contrast, other parents in this study found their spouse to be a wonderful *form of support*.

A year ago, Gill and Dylan were *ready to get divorced* and Gill had already seen a lawyer. Gill was not only dealing with the stress of an ADHD child, but an *ADHD adult* (Dylan), and the effects on her daughter. Gill felt that, at some level, she could still "deal with" Doug, but trying to control an adult was not so easy. Gill believes that Ritalin has been "a saviour" for their marriage. There has been a big improvement in Gill and Dylan's relationship and the only time they fight now "are the days that he forgets to take his Ritalin".

Linda believes that Ruth has inherited her "over-active brain" and her inability to keep still from her father. Linda's husband "hasn't read one of these books on ADHD". Linda believes the reason is that "he doesn't want to read about himself". Linda feels that she deals with Ruth's ADHD alone: "*My husband hasn't helped me with this*".

In Carrie's case, she is the one who has *symptoms similar to the kids* and it has "*caused friction*" in her marriage, because of her inability to "switch off". Carrie believes the boys need a lot of input, and feels that her "*husband does not give any input*". She doesn't believe it is because he doesn't have the patience. In fact, she feels he has "10 times more patience" than her. Carrie feels he "actually ducks out of it". Carrie believes that her husband "*doesn't like to acknowledge that it's part of the*

family". She also feels that he subscribes to the stereotype that "the mother must do the kids and he brings in the money". Carrie feels it has caused problems within the relationship because she *resents it*. "And to this day he still doesn't get involved." When it comes to discipline issues, Carrie's husband also tends to be *inconsistent* and he "keeps giving them another gap".

Samantha feels she *bears the brunt* of dealing with Claudia. Samantha feels she is "really burned out" now from "always having to cope with it". She is starting to feel like she "can't carry on". Although her husband has been there to support them, "it's never the case of his actually, you know, being there in the afternoons to have done the homework". The night before our interview, Samantha "lost it" while doing homework with Claudia, and she believes it "was time" that her husband saw she "was losing it".

Two of the three divorced participants feel that *being a single parent might actually be easier*. This is in contrast to the view of Barkley (1998) who states that being a single parent may be more stressful, as there is no one to share the burden of raising such a child. Pat believes that it is actually easier for her to cope because she is on her own. Now that Pat and her boyfriend, Alex, have been seeing each other for two years, he wants to move in together. Pat's reaction is: "No ways! I can't **take** another child around here, you know. You come home from work, you want dinner – you demand this, you demand that." Pat has suggested that Alex start by moving into the flat on her property.

Beth feels that having an ADHD child "must be very difficult on a marriage" and "in many ways" she is really glad that she "was a single parent". "Because in so many marriages, the **guys** are babies themselves, now they must handle a difficult child."

Some parents find their partner to be a *good support system*. For Brenda, Mike "has been a good support". Mike "was very much *calming*" when they got the diagnosis and, at a time when Brenda felt like her "earth was falling apart", Mike's reaction was: "If they found a problem they can fix it." Belinda believes firmly that ADHD is "a *family thing* as well". She believes that the husband must be involved and she and Rob try to "tackle things together". Angela's "support system in all of this" is her partner Pam. Angela believes you "have to have a very *strong relationship* to live through this". Marie and Leon "parent intensely". Leon "is very involved, and his family is very important to him and it's well-being." For Leon it was also "a great, great relief" when Johan was diagnosed.

Dave initially *did not want to admit there was something wrong* with Lynn and did not even want to consider putting Lynn on Ritalin. The turning point for him was when Lynn's teacher said: "But it's not about you. It's about your child." Mia believes that when the teacher "said those words", Dave realised it "*wasn't about him*"; it was about his child falling apart." From that point on, Dave has been Mia's "support system in all of this." Dave has gone through the entire process with Mia and she believes that is why "the understanding is there; he has worked through it". Mia feels Dave "has been fantastic". Mia is also "lucky" in that she gets *recognition* from Dave for her efforts because they work from home together:

"So, in the afternoons he sees how much work we do; he sees how much homework. Whereas with other husbands they're maybe not there during the day and they don't see what goes into a day – the fighting, and the tears, and the arguing: 'If you don't do this you're not going to get through.'"

Sandy feels she has a "wonderful husband" and he is her support system. When Sandy was doing her course, it "was always great excitement to talk to him in the evenings about what I had learned". Sandy passed on a lot of her knowledge to Allan. She does, however, feel that "it's very *hard*" for Allan *to fully understand* Aidan's ADHD "because he is at work and I'm doing **all** (Sandy's emphasis) the work – I'm taking Aidan to here and there and everywhere".

Rose believes that "without a shadow of a doubt raising an ADHD child places a marriage under the most extreme of pressures - there can be no stronger *test of a relationship* than something like this". Rose feels it *requires "great maturity* from both partners", as well as *teamwork*. Rose found it hard that "just because one has an ADHD child the world does not stop spinning". Although having a child with ADHD is stressful enough in itself, there is always the *usual stress and family problems* that have to be handled at the same time. Rose believes parents must face the fact that ADHD places enormous strain on a marriage and the parental relationship, and must *discuss this and how to deal with it*.

7.4.2.3 Sibling issues

The interaction conflicts in families with ADHD children are not limited only to parent-child interactions. Increased conflicts have been observed between ADHD children and their siblings relative to normal child-sibling dyads (Mash & Johnston, 1983; Taylor, Sandberg, Thorley & Giles, 1991).

Three of the parents in this study only have one child. In the families where there is more than one child, a number of problems are evident. Three of the parents (Brenda, Samantha and Sandy) actually try to *pre-empt problems* by talking about and explaining the condition to the non-ADHD sibling.

The ADHD child often *annoys siblings* and sibling conflict occurs. Marie finds that Johan is always *picking a fight* with his sister. "If she wants to watch this programme, he wants to watch another programme and he always wins." Marie admits that she doesn't "know how to address it". At times, Johan's sister appears to just not "like him much"; even though Marie believes "she really loves him". The siblings "*don't interact that much*". Marie admits that she "would have liked them to be a brother and sister that go out together", but that is not the case. They also have their own friends. Marie believes her daughter "doesn't really want to get too involved, because if they do engage in some activity there's always a fight".

Claudia and her brother "don't really get along" and Samantha reports that they "*fight like cat and dog*". Samantha reasons that that "is normal for siblings; that's fine". Samantha believes that Claudia's *brother "does understand* about her having ADHD", as Samantha has spoken to him about it.

Aidan and his sister "*fight like cat and dog*". Sandy does not believe that the almost six-year age gap is the issue. It depresses Sandy that the two fight so much. Sandy has tried to *explain "extensively" to her daughter* why Aidan behaves the way he does. At one time, Sandy's daughter accused Sandy of treating Aidan differently to her.

Zelda finds there is a lot of *sibling rivalry* between Karl and his sister. Zelda works all day and when she is at home she feels there is a constant struggle between the two to *get her attention*. Because of the ADHD, Zelda does spend more time with Karl and she thinks her daughter "resents that". So, although Zelda does tend to spend most of her time with Karl, she makes a conscious decision to try to spend time alone with her daughter, so she doesn't feel neglected.

In some cases the sibling actually *wants nothing to do with the ADHD child*. In Angela's household, Colin basically ignores Tina, unless she approaches him. "There's as little contact as Colin can help". Angela tries her hardest to protect Colin from her, "because I think he's been through so much with her".

Both of Carrie's boys have ADHD. When they "were younger they got on quite well", and Carrie even used to pride herself on "how well they got on". Now "they don't like to be together" and they "*don't like to do things together*". The boys "*only tolerate*

each other" and "they don't connect". Carrie believes it is an "age thing": "It's like Luke just got that little bit too old for Peter and his peers".

In Michelle's home, where there is *more than one child with ADHD*, negative sibling interactions are *frequent and intense*. Things also *escalate very quickly*. Michelle feels that her children "don't get on very well", "especially the oldest two". "They will be playing beautifully one minute and the next minute there will be an explosion. And screaming. They stand and scream at each other. They lay into each other." Michelle feels "you cannot try and reason with them when they are in that state. You just have to kind of separate them". For Michelle the "*sibling rivalry is hellish*".

In Gill and Dylan's case the effect of Doug's ADHD on his sister was severe. Terri is a "very sensitive little child". Terri came to Gill one day in tears and said: "Mommy, I just actually can't deal with it anymore." Terri said to Gill: "Something has to be done about that boy." Gill admits it was the first time that "it actually hit home what it was doing to **her** (Gill's emphasis)". Because Terri is the older of the two children, Gill would expect her to be "the more responsible of the two". So Doug would do all sorts of things, and Terri would get moaned at: "Why didn't you stop him; why didn't you do this; why didn't you?" Gill realises now that Terri is not the parent and it's *not her job to control her brother*. Gill realises now that the situation "was affecting Terri badly": "I think even more than it was affecting me and Dylan".

For some of the parents, there are *no problems* with regard to siblings. Brenda finds that Conor and Brad have "a good interaction". Conor does ask Brad for help a lot though, and Brenda feels this is "a bit demanding for a teenager". Because of the big age difference, Brad does not always want Conor around him. If Brad has a friend visiting, Brenda will try and get one of Conor's friends over to give Brad "some space". Brenda does find Brad to be helpful with Conor and sees him as part of her support system. Brenda has *explained* to Brad about Conor's ADHD. She has also asked Brad to be *careful what he says* to Conor, because he does have a low self-image and "no confidence".

Belinda believes her children "get on". There is "no hate", even though they bug the hell out of each other". Evan is *very protective* over his younger brother, Frank.

Linda feels that Reese is the "most wonderful companion" for Ruth, because he's *prepared to let her "take the lead"*. Ruth, however can be "very nasty" to Reese and is jealous of Reese.

Mia believes that although her girls are very "different personalities", they generally get on "very, very well", although they have their "tiffs and fights".

Research points to the likelihood of the siblings of an ADHD child having ADHD too. Biederman and colleagues found the risk to biological siblings of the ADHD children to be approximately 32% (Biederman, Faraone & Lapey, 1992; Biederman, Keenan & Faraone, 1990; Pauls, 1991; Welner, Welner, Stewart, Palkes & Wish, 1977). In the current study, Mia, Michelle and Carrie all have more than one ADHD child. Belinda also has two ADHD children, but they are not biological siblings.

7.4.2.4 Extended family member issues

Research shows *decreased extended family contact* in families with an ADHD child (Cunningham et al., 1988). Parents may often *feel blamed* for their children's behaviour by extended family members. *Conflicting understandings* of ADHD and its treatment may further isolate parents from their families, who might otherwise be a source of support (Alexander-Roberts, 1995).

Respondents in this study reported both *negative and positive* experiences with extended family members. Some parents felt their extended family is *supportive*. Other parents feel they have to *educate* extended family. Some extended family *cause more stress* to the family by their behaviour or comments. Some extended family prefers to *pretend the disorder doesn't exist*.

Brenda's father-in-law *refuses to believe* there is anything wrong with Conor. He is firmly in the "don't give him the medicine camp", as he is anti taking medicine in general.

Rob's mom and dad *couldn't believe* it when Evan was diagnosed with ADHD. Belinda believes it's because "they don't have a psychological understanding". Belinda thinks Rob's parents probably thought Belinda and Rob just "didn't parent him properly". Belinda's parents were *very supportive*, "but also perhaps distant because they *didn't know how to handle* this".

Angela believes that the extended family "all think she's (Tina) mad".

Marie has had a "*support system*" in her family of origin. She has *included her parents* in everything and they have been "a *shoulder to cry on*" and a "*soundboard*" for her. Marie's in-laws are "fine with Johan having the condition and not eating wheat and all that". Her in-laws are actually "*very glad*" that Johan's condition has

been “addressed” because at times Johan didn’t want to go to them, because they were always complaining “about his bad behaviour and all that”.

Mia’s family initially told her that she was “*looking for a problem*” and that there was “nothing wrong” with Lynn. Mia eventually thought: “Well maybe I am looking for a problem and it’s not my child, it’s me.” Mia thinks though that by the time Lynn actually got diagnosed, the family “all realised there was something bigger”.

When John was about two-and-a-half, Pat’s father and brother started to *complain about* John’s behaviour. They blamed his behaviour on Pat not disciplining John. Eventually “relations completely broke down”, and to this day Pat doesn’t speak to her brother. Once John was diagnosed, Pat took her father for *therapy and counselling* so he could try and understand what was going on. She admits though that it hasn’t really changed his perception. Pat’s mom has been wonderful and she and Pat have “a very, very good understanding”. Pat’s boyfriend had the same initial reaction as her brother and father: “He’s a boy; you’re *making excuses* for him; you’re mothering him too much; you’re mollycoddling him; and he just needs discipline.”

Samantha believes the extended family “*always knew*” that Claudia had ADHD, because both she and her husband have the disorder. Samantha’s parents are very supportive of Claudia being treated through nutrition and will check with Samantha about what they feed Claudia. However, her husband’s parents “will make the spiciest food with everything in it ... and send her back home after three weeks holiday with an attitude and all sorts”.

Zelda’s family were “fine” when they heard the diagnosis. Zelda feels “it’s accepted; it’s *not a stigma* or anything.”

Dylan’s father feels that Doug’s ADHD diagnosis is “ a *load of nonsense*... he didn’t believe it at all”. According to him, Doug is “a boy; this is what boys do”. Dylan feels his family must now just accept that both he and Doug are on Ritalin “and deal with it”.

Michelle feels that her family has been *very accepting* of the children’s diagnoses: “I fortunately don’t have family who persecute me for the way my children act or react. My mother is very supporting.”

Carrie's mother *does not understand* the full extent of the disorder and makes naive comments like: "Don't worry; it will pass." Carrie's family do not like the boys being on the diet or the medication. Vernon's mother "just won't acknowledge that the children have a problem. Carrie has "long ceased to worry" about what her mother or mother-in-law think.

Rose's mother objected strongly to Rose and Mark wanting to take Eugene to the educational psychologist to be assessed, and even physically tried to stop them. She always claimed that he was *behaving the way all boys do* and that Mark and Rose "were making problems for him". In Rose's family in general, with the exception of her eldest brother, Eugene's ADHD is "a matter for *denial*". "It was generally felt that Mark and I were *not good parents* and that Eugene had no problems. We were making the problems; we were not strict enough; we had it all wrong."

7.4.2.5 The ADHD child and friends

Pelham and Bender (1982) once estimated that more than 50% of ADHD children have significant problems in social relationships with other children. Mothers (Campbell & Paulauskas, 1979), teachers (Barkley, DuPaul & McMurray, 1990), and peers (Johnston, Pelham & Murphy, 1985; Pope, Bierman & Mumma, 1989) find hyperactive children to be significantly more aggressive, disruptive, domineering, intrusive, noisy and socially rejected in their social relations than normal children, especially if they are male hyperactives, and particularly if they are aggressive (Hinshaw & Melnick, 1995; Milich, Landau, Kilby & Whitten, 1982; Pelham & Bender, 1982).

A number of the participants in this study reported on their child's *lack of close friends*. These children tend to be very *controlling* in their interaction with peers, and parents of non-ADHD kids sometimes *don't like their children playing with ADHD children*. This can be hurtful for the child, for example in Karl's case, and for the parent, for example Sandy reporting feeling hurt and isolated by this behaviour.

Belinda feels that Evan and Cathy have improved in their ability to make friends. In primary school, Evan was "*teased*" and "labelled by the children" and he "struggled socially". His Grade 1 year was "an absolute nightmare because none of the children liked him". Going to high school meant being able to "start on a different level" with "totally new people" and Evan now has friends. Cathy really *battled to make friends* before she went on Ritalin. Cathy was even sent for social skills training because she

“did not have any friends”. A study by Frankel and colleagues (1997) demonstrated the effectiveness of social skills training for ADHD children. Now that Cathy is on the medication she is “developing friends much better; she’s keeping them”.

In primary school, Tina would steal from Angela to “buy things for the other kids at school”. Angela believes Tina was trying to *buy friends*. Till today Angela believes that Tina still “buys” friends and does not have any real friends. Tina has got a couple of friends that “she rotates”:

“When one has really had enough of her, she moves onto the next one. And then a few months later she’ll go back to the first one. So, she has a huge *social problem*. It was evident as a child already; she’s always battled with it.”

Linda believes that Ruth makes friends, but not easily. Linda feels that “*long-term friendships are a problem*”. Because Ruth is “so *strong-willed* and so *controlling*” and has “a tendency to have her own way”, it may “break up the friendship”.

John is very sociable and tends to *befriend children younger* than him – likely because of the immaturity Pat sees in him. Pat does believe he has “more of a problem” making friends “now that he’s getting older”. John said to Pat recently that the older boys are horrible to him at school and nobody wants to play with him.

Zelda believes that Karl “*doesn’t make friends easily*”. Karl does, however, have a few loyal and good friends. Zelda feels that Karl tends to make friends with a quiet child. It surprises Zelda that Karl doesn’t make friends more easily, because he is “incredibly kind”. Zelda believes Karl battles to make friends because he “will go in there and say the wrong thing, and do the wrong thing”. Karl “won’t be invited to every single party or every single thing”. Brenda believes that ADHD children “*learn to be hurt from when they are little*”.

Aidan has always battled with friends, and Sandy feels it has been “very hard” for her. Even in nursery school, *other parents did not want their child to come over* to the house to play with Aidan. Last year, Aidan asked Sandy the question she had been dreading: “Mom, how come I never get invited to play at other people’s houses?” Sandy felt like Aidan’s question “broke her”. Sandy tried to explain to Aidan “that he can’t always be in control – he *needs to be less bossy*, he needs to give the other children a turn”. Both Sandy and Aidan cried. Aidan does currently have two friends. Interestingly enough, *both his friends have ADHD* and take Ritalin. This is perhaps in

keeping with research that shows that there is a tendency for ADHD children to accept other ADHD children as playmates more than do normal children (Hinshaw & Melnick, 1995).

Up until the last six months, Eve “battled very much” to make friends. “She *used to dominate* and she really was very bad actually.” Beth feels that at times, other children liked Eve to be in control “because she had the imagination and she used to make up these wonderful games, but the control she would take it too far”. Beth feels that Eve has “*matured a lot*” in the area of making friends.

Michelle feels that her children “are not very popular children to play with”. Gary is “*very bossy*” and “always wants to be in charge”. Gary has a “few choice friends that can tolerate that, but he is not hugely popular”. Helen, on the other hand, “makes friends easily”, but Michelle believes she “then *loses them easily* and then she is *devastated* – totally devastated”. Helen also tends to be a bit “overbearing” and if she can’t get her own way she has a *tantrum* or starts “crying and howling”. Michelle thinks that “just frightens other children”. Kenneth “doesn’t make friends at all”. He has such bad *separation anxiety* that Michelle “can’t leave him anywhere for any period of time”.

Carrie feels that Luke has always been quite sociable and makes friends quite easily. Luke’s two best friends are both gifted. Luke works ten times harder than either of them, and his marks are still way below theirs. So, to *fit in with his peers is difficult*. Peter does not make friends easily and “holds back”. Peter tends to *stick to one friend*.

Rose feels that making friends was not easy for Eugene and he was often the victim of *teasing and bullying*. He eventually made friends through being involved in *sport*.

Some of the parents report that their child has *no problems* making friends. Johan is a “very, very sociable child” and he has very good friends. Marie believes that Johan’s “social skills are wonderful” and “he can let a person feel so good and wanted”. For Mia, the “social side” of school is fine and both girls are very involved in activities at school. Samantha finds that Claudia has friends and was very much “in with the crowd”. Now that a private tutor is teaching Claudia, she misses her friends.

7.4.3 ADHD and the school experience

7.4.3.1 School placement

A significant concern for parents was the issue of *where to send their child* to school. Ten of the fifteen parents started their ADHD child's schooling in a *private school*. Parents also have to decide whether or not to place their child in an *assisted learning or remedial environment*. A number of the parents report *changes in school placement*. Six changes was the highest number of school placement changes that was reported by one participant (Beth).

Brenda had Conor at a mainstream private school for Grade 0; he is now in Grade 2 in a private assisted learning school. Belinda started Evan off in a private school. After his diagnosis he was moved to a primary school that caters for special needs. Currently he is in Grade 11 at a private assisted learning school. Cathy started, and is now in Grade 4, at a mainstream private school.

Angela started Tina in a government primary school. For her first two years of high school, Tina was in Cape Town. When she came back she was put into a government high school. After her abortion, in Grade 10, she was put into a private school. Linda put Ruth in a private assisted learning school from the beginning, as she realised she "could hardly have put her into a classroom where there were 25 children". Ruth is now in Grade 2. Linda was advised to keep Ruth in an assisted learning environment until the end of Grade 3. She was told that "once her foundation is set" she could move Ruth. Linda, however, does not think she will move Ruth, as she does not want to put her in a school with bigger *class sizes*.

Johan went into Grade 1 at a government school. In Grade 8 he went to a smaller school: "more a plaas (farm) school". About halfway through his Grade 11 year, Marie started home-schooling Johan. The following year Johan went to college to do a business matric. Mia put both girls into a private mainstream school for primary school. Neither of them has changed schools. John is in Grade 2 at a private remedial school. Samantha had Claudia in a private Christian school for Grade 1. She then went to another private school and repeated Grade 1. From Grade 4 Claudia has been taught by a private tutor. Karl had only ever been at one school – a mainstream private school. Aidan started, and is now in Grade 3, at a mainstream private school.

Beth first sent Eve to a small private school. For Grade 2, Eve went to a school where they catered for children with special needs. Beth had to remove Eve that same year, because she was being sexually harassed. Eve then went into a government school and was put into the aid class. The teacher told Beth that Eve had to go on Ritalin or leave. From the government school, Eve moved to another small private school. Eve then landed up at a cottage school with a teacher who is a qualified remedial teacher. The teacher emigrated and Eve then went to a home school. At the end of Eve's Grade 5 year, the teacher decided to close the school, and Eve moved to, and is still at, an assisted learning school.

In Grade 00, Doug was already "noticeably more *immature*" than the other children in his class. When the time came to go to primary school, Gill and Dylan did not send him to the primary school his older sister goes to, but put him straight into the private special needs school affiliated to the primary school. Michelle "really struggled" to find a school for Gary, as he is also vision-impaired. They eventually found a little pre-school that was government run. Gary did not cope there "at all", but had to stay there for a year until Michelle and Matthew managed to move to a city with a school for vision-impaired children. Helen attends the local government primary school.

Both of Carrie's boys went to a government primary school and are now in a government high school. Rose had Eugene in a government primary school and a mainstream private school for high school. Rose does not agree with *changing schools unnecessarily*: "We decided that if at all possible we would stick with the school of choice and rather help Eugene adjust to the school, it's teachers, it's pupils and the parents."

The actual *moving of schools can also be stressful* for the child and the entire family. When Brenda moved Conor from his mainstream private school to the private assisted learning school it was hard for both of them:

"And I think he thought there was something wrong with him – that he was stupid. And he wanted to know why he had left all his friends and gone to another school. You know it was really, it was **very** hard for me and it was hard for him."

If the school placement is not successful, life for parents is quite stressful. The idea did come through in a number of interviews, however, that *no school is a perfect placement* and the parent has to decide what the priorities are with regard to the

child's placement. Conor himself doesn't "have any complaints" about his school at present. Brenda is not as happy. She questions whether she has put her son in the right school, because he is surrounded by children who have "bigger problems" – "physical...emotional and mental". The neurologist has said that Conor is not ready to mainstream yet. So, even though she is not happy with the school, Brenda feels she has to "persevere" as there is no other school she can get him into.

Belinda is very sceptical about Evan's high school and she admits that every year they've "thought of taking him out". Belinda feels the school is "too slack" and Evan himself, at times, has felt that. They've now decided that "it's too late" in his school career to change schools again and have had to "just leave it". Belinda and Rob are also very reluctant to move Evan from the assisted learning environment "because in the other systems he might slip and no one would pick it up".

Aidan is in a mainstream private school. Sandy admits: "In my heart, I don't think his school is the right school for children who battle". Although it is a "good school" it is "highly academic" and they expect a lot from the children.

Rose believes that when dealing with the school, parents must realise that whatever school they choose "it will never be perfect". "Also parents must realise that they will have to *monitor the progress* of their child and the school the whole way."

Some parents have very definite ideas on putting the ADHD child into an assisted learning or remedial environment. At the stage when a decision had to be made on whether to keep Kim back, and Lynn was still battling at school, the principal told Mia that she "might need to look for remedial schooling, this may not be the place for them". Mia felt she was "*not prepared*" to put them in a remedial school unless she had "done everything". If she had exhausted all therapy options and she still found the girls were unhappy and not coping, she would "hang up her gloves" and "gladly look elsewhere". Mia believes that once "they start at a school like that, they will never mainstream again". Mia also believes that though the girls "battle", they "learn from it".

Zelda does not believe in putting ADHD children in a remedial school because "often they don't have any remedial problems or anything." She believes that putting an ADHD child among children with problems is going to "highlight all these problems and that's not good. You're going to tell them they're different in a bad way."

Carrie has never wanted to send her boys to a remedial school and does not believe it would do “anything for them”. It would only be an option “if they were really not coping within a normal school environment”. Carrie feels she has seen “too many children who do the remedial school route”.

“They struggle at school, and by the time they leave the normal school their confidence is down. They are way behind on their work and they go to a remedial school. And eventually they slot in, they fit in, and they love it – everybody is on a par with them; it’s cool. And then the school says no actually you have gone as far as you can go. You are ready for mainstream again. And once again, within a little while, they are back to square one.”

Reasons for moving a child involved academic issues, but also behavioural issues, including potential expulsion from school or daycare. Brenda moved Conor to assisted learning environment for academic reasons. She was told that Conor would “never make Grade 1, and he must go to a remedial school”. Marie and Leon took Johan out of his school to home school him because he was always in trouble at school, including with the headmaster.

7.4.3.2 Retention issues

The issue of retention was present in the lives of seven of the 16 participants, who had been faced with the uncertainty of whether to *promote or retain* their child. With some of the parents there was a realisation of their child’s *developmental immaturity* when compared to peers. Considering retention is then often more of a developmental issue, or social issue, than a cognitive one. Parents also expressed fears about the *effects of retention* on their child’s self-esteem.

In Marie’s case, she believes Johan went to school “a little early”, because his birthday is in November. Johan was assessed before he went to school and the “lady said he’s on the border-line”. As ADHD preschool children approach entry into formal schooling, research suggests they are already at risk for academic failure. Not only does their symptom picture predispose them to be less ready to learn in school, but they are also more likely to be behind in basic academic readiness skills (Mariani & Barkley, 1997; Shelton, Barkley, Crosswait, Moorehouse, Fletcher, Barrett, Jenkins & Metevia, 1998). Marie wanted to keep Johan back, but her husband insisted they let him go because “it’s always nice to finish young at school. That’s the perception he had then.” The issue of retention raised its head again in Johan’s Grade 2 year, when

he was battling. Marie made an appointment with the headmaster of the school. She asked for Johan to be kept back, because she and Leon “ascribed all this to him *being so young*”. The headmaster said no, and Marie was “devastated”.

Mia watched Lynn “*battling emotionally* terribly” in Grade 0, and Mia felt Lynn “should have actually stayed back a year”. When it was discovered how much Kim was actually battling at school, Mia felt she “had lost an entire year”. Mia was worried about Kim going to Grade 2. She felt the school “didn’t even know themselves what her abilities were”. Mia felt it was “not fair” for Kim to “*lose a year out of her life*”, but did not want to “put her up” and find she’s not coping: “So, there we sat.” The school eventually decided to put Kim up to Grade 2 and “see how she went”. If she really didn’t cope, they wouldn’t put her down a year. She would remain in Grade 2 for the rest of the year and be given work that she could cope with, and then she would have to repeat the year.

John is “*really battling*” and Pat doesn’t know if he’s going to make it through Grade 2. Pat feels “it’s not the end of the world” if he doesn’t and she would rather they “keep him back **now** than in Standard 4 (Grade 6), Standard 5 (Grade 7). Pat realises, however, that being kept back will “have an effect on him”, as John’s “confidence and his *self-esteem* is very, very delicate”.

When Aidan was in Grade 0, his teacher felt there was definitely a concentration problem. Sandy and Allan had Aidan tested. According to the assessment, Aidan was *not emotionally ready* for school. Sandy and Allan got permission to keep Aidan back for a year, and he repeated Grade 0 in the same school.

Eve completed her Grade 5 year at a home school. She then moved to a school that offers assisted learning. The school initially put Eve into Grade 5, believing it is better for the child’s *self-esteem* to be promoted than demoted. Eve was promoted to Grade 6 after a month or so, “so that was good for her too”. Beth feels it was also good for herself:

“I want to tell you, it was very good for me. Because, of course, you know, also being intense, I had this whole big thing that her whole life was going to be a mess now because she hasn’t had an education properly, and she is not up to where she should be.”

The objective of the school Doug attends is “to *get the kids up to scratch*” and then *mainstream* them into the affiliated primary school. When Doug is ready to mainstream, retention will be applicable. Doug is in Grade 2 now, and Gill and Dylan are hoping to mainstream him next year. If the school does decide to mainstream him next year, he will redo Grade 2 in the primary school. “So he will end up being that sort of one year behind but it **really** (Gill’s emphasis) doesn’t matter.”

7.4.3.3 Special education services

A number of the children attend schools where *special services* are provided to their child. Linda’s daughter, Ruth, and Brenda’s son, Conor, have speech and occupational therapy at school. Evan had play therapy and occupational therapy at the school in primary school. Karl had occupational and speech therapy *at school*.

With John, the therapists are also *available at the school*. Pat sees it as a *benefit* as she and her mom are no longer “schlepping” John “to this, that and the next thing”. Mia, however, expressed concerned about her child leaving the regular classroom to go to the remedial therapy room. She not only had concerns about what Lynn would miss by being *taken out of class* during certain subjects, but also worried about her child *feeling different* in front of classmates, and the effect it would have on Lynn’s self-esteem:

“If you have a child with low self-esteem, I’ve realised, the other kids all go: ‘Well, where’re you going? Why are you missing out?’ and she didn’t cope well with that. So I decided then that I would rather actually do it outside of school in our own time, you know.”

7.4.3.4 Change from primary to high school

The change from primary to high school can involve a change in teacher attitudes, parental involvement, increased difficulty of academic assignments, and social demands. It may also become harder to monitor the child’s progress and work as they move to higher levels. Carrie finds that with the high school, “there is no interaction between the teachers and parents. The *teachers are not interested*. They are there to do a job and they don’t want to get involved”.

7.4.3.5 Feelings when interacting with school personnel

Although parents appear to experience *predominantly negative emotions* when interacting with school personnel, some parents did report positive emotions such as a feeling of satisfaction, of trust and of respect.

Frustration

The primary emotion expressed by parents, related to their interactions with school personnel, is frustration. Parents find it frustrating and tiring to *continually advocate for their child's needs* to school staff. Often, on a yearly basis, they have to explain their child's disability to school personnel – doesn't anyone ever read the file? As Carrie says: "Apparently it goes up on the ed-lab, and if the teachers do their work they can actually see it." *Meetings* with school personnel regarding their child often take a significant amount of *emotional stamina*, and dealing with teachers about *homework assignments* can be just as frustrating.

Brenda has asked the teachers to watch what Conor eats and drinks at school, because of Ritalin suppressing his appetite. Brenda packs Conor a full lunch with cool drinks and often gets the whole lot back when she collects him. She is especially worried about him not getting in enough fluids. She has "written numerous letters" about this and gone in to see the teachers. To Brenda's frustration "they were *not understanding*". Brenda feels that the teachers have "*no empathy*". "There's not even sympathy, but there's just no empathy either." Brenda believes that the teachers, especially as it is an assisted learning school, "should have more input to these children and understand them more and be more supportive of the parents".

Marie wishes there had been "more understanding" from the school, and was particularly frustrated by the *lack of understanding* of the headmaster who refused to retain Johan. He "threw" her "totally off balance for such a long time". In a time when nobody had an answer, he was the person she "looked up to"; the person that she "thought could give you the answer". And yet he just said no: "And that was that. No explanation; nothing further."

Belinda is frustrated by the *lack of consistency* of Evan's high school. She feels that the school "gets their act together", but then "it fizzles".

Samantha got frustrated to the point where she felt she needed to move Claudia from her school. She didn't feel the school was actually *helping Claudia in class* and she thought: "No, this is rubbish." Samantha felt the school could help by not insisting that Claudia hand in her projects on a set day, and by being more lenient with spelling: "And things like that." A private tutor is now teaching Claudia, and there are only five pupils in her class. Samantha is still frustrated. She feels they haven't really "seen the results yet from her new school". Samantha was "thinking it would be nice to put

her back into a normal school environment". They have recently had Claudia assessed again, and the results of the assessment were not encouraging. Samantha also gets "frustrated with the teacher because she lets us know yesterday that there was a test today". Samantha gets "freaked out" because she knows that her son is an A-student because he starts learning well in advance.

Zelda is frustrated that the attitude at Karl's school seems to be: "You know this is *not the norm*, why should we?" She finds that strange because she believes there must be "a lot of ADHD kids" at Karl's school. Zelda doesn't feel that any of Karl's teachers do "anything to help him". She would like an attitude of: "Come after school for an extra lesson. Let's go over that if you don't understand." She doesn't believe it would "take that much effort either". The teachers could even have the homework written out for Karl and give it to him. Zelda believes the teachers don't understand why Karl can't do it himself and she feels they think he is lazy. Zelda knows it is *not laziness*: "Some things they can do and some things they can't and, until they can do them, just *help them*."

Even though Eve enjoys her current school, Beth is not as happy. She feels that that there "could be tighter *boundaries and consequences* at the school at this stage" and that the "kids run wild a bit there". It frustrates Beth that Eve is *not "being pushed* enough to produce her best and she's producing actually pretty sub-standard work, I think, for what she's capable of doing and what should be expected of her". Beth feels that Eve did work "two years ago when she was at that little cottage school that is far superior to anything that she produces now". Beth feels she can't "nag and perform and carry on and whatever if the teachers aren't requiring that from her (Eve)".

Michelle makes a real effort to *educate her children's teachers*, but she is frustrated when the teachers don't "really pay attention".

"Honestly, I sometimes feel like a real pest. Adults don't like being told what to do. A lot of them are *unteachable and unapproachable*."

Carrie would go in every year to discuss Luke's ADHD. She feels, however, that it was a *wasted effort*: "They will listen to you and that is the last they actually think about it". It takes a significant amount of *emotional stamina* for Carrie to attend meetings at school. Carrie and her husband go to parent's evenings and they "very

seldom get any positive feedback". They have been going to parent's evenings for eleven years now "and it hasn't helped a thing".

"The teachers all sit there and they make little notes: ADHD, on medication, battles with this, battles with that. And they all sit there and smile and say: 'Yes, we'll do this and that.' And the minute I turn my back... It's a waste of time to go and stand in those queues, to have 5 minutes with the teacher, to be told just how bad your child is. I as a parent have actually taken a tranquilliser before every parent's evening that I've ever been to. By the time I get to the teacher, my mouth is so dry that I can hardly talk."

Anger

Parents feel anger in their interactions with school personnel for a number of reasons. Parents feel anger over teachers trying to *blame them* for their child's behaviour. Parents feel anger over the type of *comments teachers or other school personnel make* about their children. Parents also feel angry over *specific events* that occur at school, or the *behaviour of specific teachers*.

In high school – once Tina was back living with Angela - she was seeing the school guidance counsellor virtually daily. Angela was phoned by the guidance counsellor and told that she (Angela) was "dysfunctional". Being *blamed* for Tina's behaviour angered Angela. Angela's son had been through the same school, had full colours, and did eight subjects. He is at university now – he qualifies this year. Angela said to the counsellor: "You know I have another child who went through your school, and I was never accused of being dysfunctional with him, and he didn't have a problem. Now that there's a problem I'm dysfunctional. If there's anybody who is dysfunctional it's Tina, not me."

Marie believes teachers "were *never understanding*" of Johan. The *comments that teachers would make* about Johan angered her. Teachers would call him a difficult child, a disruptive child, a child who can't do anything, a child who never does his homework, a child who never listens. No one "ever wanted to see the good in this child".

Brenda was angered by a specific *teacher's behaviour* toward Conor. Conor got a new teacher at the end of Grade 1 who would *shout* at him to the point where "he never wanted to go to school". Brenda addressed the teacher about it and the teacher responded that he doesn't concentrate. Brenda's response:

“That’s why he’s on Ritalin. That’s why he’s in a class of 12. That’s why he’s in a small class and I’m paying so much money for you to teach him.”

Kim’s Grade 1 teacher angered Mia. Lynn had had the same teacher in Grade 0, so the teacher “knew the family history” and how much Mia had “battled”. Mia kept checking in with the teacher and the teacher kept assuring her that everything was “fine”: “There was *never, ever mention of a problem*”. By the end of the second term of Grade 1, Kim came home with a “shocking, absolutely frightening” school report. Kim was “failing on every level, and the teacher had never said anything”. Mia feels the teacher knew nothing about Kim: “other than the fact that she knew the child was in class, I don’t think she knew anything about her. She just *forgot about her*.”

Carrie gave every teacher in the primary school a book on ADHD. It angered Carrie that when she was having problems with one of the teachers, she asked the teacher: “Have you even *bothered to read the book?*” The teacher had not and Carrie responded: “Then I don’t think we actually have anything to discuss”.

Zelda was angered by a *specific event* at school. She had a call from the principal last year because Karl swore at the after-care teacher. When Zelda got to the school, the principal, in front of her, “attacked” Karl: “Karl must do this and he can’t do that”. Only later Zelda asked Karl what happened and he told her another child actually hurt him and kicked him on his knee that was already sore. Karl had tried to tell the teacher, but she “*didn’t listen*” and “she *didn’t understand* or anything”. “And so there was this whole lot of steps and at the end he swore. And that happens all the time.”

Feeling discounted

School staff often *sees themselves as the experts* and *discount parents’ observations and skills*. Belinda experienced this when she wanted to put Cathy on Ritalin. The teachers at Cathy’s school “were very anti her going on anything”. Belinda was “open” to her going on Ritalin, because she has “known the success with Evan”. To Cathy’s frustration, the psychiatrist, in consultation with the teachers, decided that Ritalin “wasn’t the right way to deal with it”. Belinda’s *opinion meant nothing*.

Samantha felt her opinion was discounted at the private school Claudia attended. The teacher in Grade 2 insisted that Claudia be put on Ritalin or Samantha would have to take her out of her class. Samantha refused because of the side-effects that Claudia had experienced. The *principal believed that she knew better*. Samantha

was called in and the principal told her “that she had worked in special classes and that none of her children that were on Ritalin ever had the side effects that I was saying that my daughter had”.

Intimidated

Belinda initially felt intimidated when dealing with Evan’s school. It has “got much better, but it was, it was terribly hard. I mean when I got called in for Evan, I would feel, uh, I would *feel like they were going to attack me*”.

Concerned

At present, Sandy’s primary emotion when dealing with the school is concern. Sandy has always been told that Aidan has so much potential, but she *sees no results*. Sandy is concerned about Grade 4: “because they grow up next year and it’s a very different environment. And the teachers don’t have patience for children with ADHD, you know”. Aidan’s teacher has also voiced her concern about possible *emotional difficulties* that he’s experiencing.

Satisfied

Linda and Gill and Dylan experience a feeling of satisfaction in their interactions with the school. Linda feels that for the moment, Ruth “is in the *best school she could be in*”. Doug is in a special needs school and Gill and Dylan feel “the best thing” they could have done is put him where he is.

Trust

Evan was moved to a new school after his diagnosis. For Belinda, the major benefit of Evan’s new school was that the school staff “didn’t see him as a horrible child; they actually could see that he was a child who did not know how to help himself.” Belinda trusted the school: “I knew that he was in good hands.” And she went with their recommendations because she felt “they *knew what they were doing*”.

Respect

Pat has the “greatest respect in the world” for the principal at John’s school and believes “they’re *very good there*”.

7.4.3.6 Beliefs about school personnel

Teacher knowledge and behaviour

Participants believe that there is a lack of knowledge among teachers about ADHD. Although today there is a lot more information available about ADHD, parents believe many teachers still *lack basic information* about ADHD, how children in the classroom manifest it, and *how to appropriately teach these children*. This leads to a constant effort on the parent's part to *educate school personnel* about ADHD, and share their child's specific needs. This can result in frustration though when parents *provide materials* for teachers to read (e.g. Carrie) and *teachers do not follow through and read the literature*.

Brenda feels that teachers don't "have an understanding of ADHD". Marie does not think the "school system educates the teachers enough" on ADHD. She believes it is "getting there" now, but when Johan was in primary school, she doesn't "think the teachers knew anything and neither did the headmaster". Even the school psychologist did not know what was wrong with Johan.

Carrie cannot believe that not one of Peter's teachers has picked up at school that Peter can read everything perfectly, but he doesn't always understand what he's reading.

Zelda believes that Karl is "not understood a lot of the time by teachers and friends and other kids". She feels that school will be better for ADHD children if teachers are more understanding. Zelda believes ADHD children have a lot to offer and she wonders how many of them "leave matric and just can't carry on". Zelda feels that *more knowledge about ADHD needs to get into the schools* and that teachers need to be taught about ADHD at training college, and how to work with ADHD children.

"Teachers have to understand it, because if that doesn't happen it's sort of like they (the ADHD child) have extra lessons and therapy and that, but it's not an *integrated support system* and people that understand it and everything. And I don't know why it isn't done, because so many kids have it and teachers come across it a lot, and they don't understand and they don't cope with it."

It can be a problem if the child *does not manifest behaviour problems* in the classroom, and the teachers do not suspect that there is a disability present. Tina

wasn't a problem when she started school. She was never disruptive or restless in class. However, Tina "wasn't actually concentrating" and would spend her time in class "doing her own thing" – drawing, writing song lyrics or poetry. Angela believes Tina could get away with not concentrating because she is "*very intelligent*".

"So, on the one hand, I didn't have complaints from the school, but her problem remained untreated because she wasn't a problem in class. She was likely just *ignored by the teachers* because she wasn't a troublemaker."

Angela feels "that something should have been picked up by the teacher when she was in their class every day". Tina was only diagnosed as having ADHD at the age of 14. Barkley (1998) tells us that in a sizable minority of cases the child may have had their ADHD characteristics for some time, but they did not interfere with their academic or social functioning until later childhood. The latter seems to occur with very bright or gifted ADHD children whose superior intellect appears to allow them to pass through the early grades of school without difficulty, because they do not need to apply much effort to be successful.

Teachers also don't understand the *lack of organisation skills* that these children have, and do not realise it is something they need help with throughout their school career. Carrie feels that teachers *make no allowances* for ADHD children and "do not take into consideration the disorganisation and distractibility of these kids".

Teacher's *knowledge about medication is also very limited*. Some teachers discourage its use because of this. When Luke went to high school, his grade tutor said to Carrie that, "under no circumstances should a boy in puberty be on Ritalin".

Teachers can also be *careless with the medication* and parents don't always feel they can be trusted to administer medication. When Conor was put on Ritalin, Brenda made an appointment to see his teacher. The first reaction from the teacher was: "You know Ritalin is bad." Brenda also disliked the teacher's careless attitude about Ritalin tablets: "You can pop them in his bag." Brenda takes it very seriously that Ritalin is a scheduled drug and believes the teacher should be locking the tablets in a cupboard. Conor also ended up with tablets left over, which tells her "he wasn't given them." Michelle doesn't trust the teachers to give her children their medication: "they either forget or they give it too late".

Teachers who do have sufficient knowledge about ADHD are appreciated. Mia hails Lynn's Grade 2 teacher as "a fantastic lady". This teacher is "educated more in the remedial side". It was this teacher who asked if Lynn had ever been tested for ADHD, and the same teacher who persuaded Dave to consider Ritalin for Lynn. After the fight to get Cathy on Ritalin, her first trial of the drug took place at the end of her Grade 4 year. It didn't "work well" though with an anti-Ritalin teacher. In Grade 5 Cathy was placed with another teacher, who is a remedial teacher who "understood ADHD; understood why we need to go on Ritalin". Cathy went on Ritalin in her first term of Grade 5 and since then she's been on a B-average.

Teacher characteristics

A number of participants discussed their perceptions of the teacher characteristics that significantly impact their child's school success. Linda was advised by the educational psychologist to ensure that Ruth has a *teacher "that she can relate to"*. Linda believes that Ruth is "very happy" at school this year and that has a lot to do with the teacher. Linda feels that it is important for your child "to be guided and taught by *somebody that they are relaxed with*". Ruth's teacher this year has done a course in teaching children with learning difficulties. In Grade 2, Karl had "a lovely teacher". The teacher had "a nice relationship with Karl and understood his needs". She would deal with Karl by sending "him on errands and everything, so that he'd get a chance to walk around and not have to sit still so long".

The teacher should also be someone who can *see the ADHD child's potential*, instead of just the negative side of the disorder. This is the kind of teacher who will *bolster the child's self-esteem*. At the Christian private school Claudia attended, she and her Grade 1 teacher "didn't get along at all". Claudia actually ended up repeating Grade 1 at another school. In Grade 2 at the private school, Samantha was told Claudia had to be put on Ritalin or taken out of the class – "not because she was being disruptive or anything", but because the teacher could not "spend that extra attention with Claudia". Claudia's Grade 3 teacher, however, "was wonderful; I loved her". Samantha feels she made a difference to Claudia's life because she believed in Claudia and "could see potential in her".

Johan had an English teacher in Grade 9 who was "a wonderful teacher, and she saw the potential in him". Johan has "a very good ability to write poems and do literature". The teacher got him to enter a poetry competition for which he won

second place. But everyone else “just saw this bad one, this one with an attitude, this one who just wants to challenge the disciplinary system”.

When Eve was in her home school she had a teacher who “could see who Eve was, and she got a charge out of Eve’s mind and *challenged her*”. The teacher challenged Eve in “many areas, challenges that don’t normally come out in schools - like home truth, writing poetry and just the area of her imagination and artistic stuff and that kind of thing, so that was good”.

The ADHD child also needs a *teacher who cares*. It is almost more important that the teacher be accepting and nurturing, than someone who knows everything about ADHD. It is possible to teach someone about ADHD, but you can’t just change their personality and make them more generous and accepting. Zelda believes the relationship the ADHD child has with the teacher is “very important” and she thinks “that’s true for any kid”. Even her daughter who is a “straight A’s” student would only score B’s for a teacher she didn’t like. Zelda believes that if the teacher can “care about them and try and help them with everything, then of course the child is going to respond – it doesn’t matter whether they have ADHD or not”. Zelda believes a lot “depends on the individual, if they care or not. It doesn’t matter whether it’s a government school, or a school in Soweto somewhere, or a private school. If they care enough they would do more.”

It is also not enough for teachers to just have knowledge of ADHD; they need to be *open to actually trying techniques* that would help them deal with a child with ADHD. Teachers can know a lot and still be very impatient and intolerant. When Carrie was involved in the support group, schools would request courses to be run at their schools. “And the teachers would all sit there and make copious notes and buy all the books.” Carrie feels though that teachers are not prepared to implement what they learn. Carrie feels that teachers are not prepared to look “at alternative methods” of dealing with these children and consider the other 26 children in the class as more important than the three or four who have a problem.

The ADHD child also needs a *structured teacher*. In Grade 0 and Grade 1, Cathy did not appear to have any problems at school. She was, however, with “a very structured teacher” who “set limits” and “was very strict”. In Grade 2, Cathy had a teacher who was “very arty and free” and her “marks just dropped”. The Grade 3 teacher also had no concept of “putting in parameters” and, as Belinda says, “that

works, you know". In Grade 4, Cathy was fortunate to get a teacher who is "very strict, but very empathic. And she was open to more." When Eve was in the cottage school, Beth saw the effects of having an "unstructured" teacher. Eve had a teacher who was "very lovely"; however, there were "just no boundaries" and Eve just wasn't achieving her best.

The teacher also needs to realise that the child with ADHD, might not conform to their standard. He or she should *treat all children as individuals*. Seeing the child as an individual means less pressure on the child to conform to the norm, the child's uniqueness will be valued, and the teacher will take responsibility to make accommodations based on the child's unique needs. Cathy is fortunate enough this year to have a teacher who treats her as an individual. She also knows not to pressurise or "bombard" Cathy, because then she goes: "Can't do it".

7.4.3.7 Parent strategies when interacting with the school

Teach teachers about ADHD

Participants discussed the need to *advocate for their child* with school personnel. They believed it was crucial to continue to *teach teachers about ADHD*. Brenda gives the teachers pamphlets on Ritalin to read. Sandy gives Aidan's teachers guidelines as to what ADHD is. When Carrie's boys were in primary school, Carrie made sure "every teacher had a book" on ADHD and how to deal with these children at school.

Belinda too feels she has had to educate the teachers. For example, Belinda had to educate Cathy's Grade 4 teacher who had never had to deal with a child going on a trial of Ritalin – "it was totally new for her; she'd never had it before". Cathy recently went on a school tour, and did not take Ritalin while on tour. When they got back, the teacher asked if Cathy could come off Ritalin "because she was such a different child – she was like so outgoing and bubbly and happy and talking and laughing." Belinda had to explain to the teacher that Ritalin is 'hot for social behaviour, it's for the concentration."

For Michelle "dealing with the school is endless". Michelle feels it is a case of "constant education", because as far as the teachers "are concerned it (ADHD) is naughtiness".

“They can’t believe a child can be ruled by the moods and the highs and the lows. Some days they’re up, some days they’re down; some **minutes** they are up and some minutes they are down.”

Communicate with teachers

Many of the parents find that talking to the teachers is a crucial way to advocate for their child. Participants found a *variety of ways to talk to teachers* – they dropped by to chat, scheduled meetings, called on the phone, wrote notes. Basically parents stated it was crucial for parents to *be involved* with their child’s school.

When it comes to dealing with the school, Mia is “just **always** there” (Mia’s emphasis). Mia believes that what happened with Kim in Grade 1 has “pushed” her to have a *lot of contact* with the school and go in and see the teachers a lot.

“You know what, nobody else is going to do it for my child, and if I’m not on top of it and chasing, then it’s not going to happen.”

Next year Mia wants to “leave” Lynn and “see if the teacher has an opinion”. Mia feels “you also give your children a stigma sometimes – that the teachers now look for problems”. But for Kim, Mia will still spend next year going in and checking on her.

Pat feels that dealing with the school, for her, is “actually quite easy” because she *involves herself “in everything”*. Pat makes sure the school knows “**exactly** what’s going on”:

“If his fish dies, I send his teacher an SMS and I say: ‘Listen his fish died this morning. Or the cat got run over. Or he broke a chair.’ Or whatever, you know what I mean.”

Pat involves herself with absolutely everything at school. She fetches John as much as she can and watches his activities.

Sandy makes sure she has “*as much contact with the school as possible*”. At the beginning of each year, Sandy goes in to see *the teacher* on the first day to tell them about Aidan having ADHD. Sandy *writes notes* to Aidan’s teacher in his homework book, and the teacher writes back. Sandy *meets with the teacher* during the year when necessary.

Gill and Dylan find Doug's teachers to be fabulous because there is a *lot of contact* between teachers and parents, and Gill feels she can phone Doug's teacher at any time.

At the beginning of every year, Michelle *goes to their teachers and talks to them* "about what the children can and can't have, and what they need to do". Carrie too used to *set up an appointment* every year to discuss Luke's ADHD.

Monitor homework

Parents believed an important strategy was to *diligently monitor* their child's homework. Parents also try to find ways to *streamline homework* – such as doing homework at a set time, and trying to make sure the child copies down homework correctly. Parents also use things like monthly planners to *assist the child to organise and complete assignments*.

Belinda uses *monthly planners* for planning time for assignments: "*planning is very important*". Mia does homework with the girls every afternoon. With Lynn she will do up to an hour-and-a-half's worth of homework "and then we'd get up at half-past-four the next morning if she had a test the next day." Lynn still doesn't understand why she needs to start working for things like exams before the other children do. Mia is trying to show Lynn how to study and how to make notes. Even though Lynn "wants to learn", if left on her own "she'll look at that page and when I come back half-an-hour, twenty minutes, or an hour later, she's still on the same page. She just ends up daydreaming; her mind wanders". Mia admits to knowing "exactly what it feels like" because she did the same. Mia feels she still has to sit there with Lynn and asks questions and *help Lynn make notes*. Mia feels Lynn "absorbs so much" when she does that, but if *left "on her own she's unable to do it"*.

Michelle monitors the children's homework "**every, every** afternoon" (Michelle's emphasis). Rose would *read all Eugene's notes to him*, even when she didn't understand a word of them.

Sandy and Aidan do *homework at a set time* Monday to Thursday. After school, Sandy will make lunch for Aidan while he gets changed and puts his school clothes out for the next day. While Aidan eats his lunch, Sandy will go through his school bag "to see what rubbish he's put in his bag, what he's collected off the playground, and I go through his books". Sandy checks Aidan's homework diary and checks for any

notices. Once Aidan has eaten they start homework. Sandy *cannot leave Aidan to work on his own*: “I’ll come back and he is everywhere. He’s checking this out, and he’s playing with the cat, and he’s doodled on his pages.” Once Aidan has finished homework he has to pack his bag for the following day. Only then is he allowed to go play. Aidan also has *white boards up in his room* and each week he and Sandy write the words for the week on them – “the difficult words, the spelling words he got wrong in his spelling test that week.”

Pat willingly does *extra homework* from the therapists with John. Pat has even taken a lower paying job, which entails less after-hour work and being away from John. It means she can be *‘there* (Pat’s emphasis) for John”. Samantha actually stopped working before Claudia started school “to get her ready for school”, and “be there” for her. Samantha works with Claudia every day.

If the child is not experiencing success in the classroom then the parent often *assumes more of the teaching work*, or resorts to *finding a tutor* for the child. Mia finds that Maths is a big problem for Lynn and Kim. Now that Lynn is in Grade 5, Mia finds she can no longer help with Maths homework. She admits “we’ve had many days where I’ve helped them with their homework and they get the whole lot wrong”. Mia now has a maths teacher who comes once a week and helps Lynn with extra maths. Sandy is now going to have to send Aidan to extra maths lessons because he battles so much.

Carrie has always *worked intensively* with the boys. She bought all the textbooks that the teachers use and the extra workbooks that go with them, and she believes that is how the boys have got through school. Carol admits she *helps the boys out on projects*. She feels projects are “an absolute waste of time” and so she *‘will* (Carrie’s emphasis) help them”: “Because if they can score a better mark on a project, it buffers them for a test where they don’t do well”. Carrie makes both boys “start *learning for cycle tests a lot earlier* than the other kids. So they do more repeats of the actual work - for some of it to go in.” Luke now also has his *own study* at home.

Zelda, in particular, had experienced a *lack of co-operation from teachers* in setting up a system related to organisational needs and homework – maybe because they view the child’s inability to succeed in these areas as a lack of responsibility or laziness. Zelda tried to deal with the school over Karl not writing homework down properly. Zelda needs to know exactly what must be done for homework, so that she

can make sure that is what goes back to school. Zelda met with Karl's teachers and it was decided that every day, after every subject, he would have to write down the homework and the teacher would have to sign it. It didn't work "too nicely". Karl ended up being late for the next class and she feels the teachers just thought it was "extra stuff for them".

Present a united front

Belinda feels it was important for her to have Rob's support, and to have him with her so they could present a "united front". Belinda believes it makes a big difference if you **both** (Belinda's emphasis) go to see the teachers:

"Somehow they think women are, you know, you're over-emotional -which perhaps I have been. And with Rob being there *there's a balance*, you know. Maybe at times I **am** emotional and then with Rob being there, they can actually address him. And I know Rob knows what the whole story is, so he can deal with it, you know."

Fight

Eugene found writing to be "taxing". His Grade 6 teacher allowed him to print, but his Grade 7 teacher dug her heels in and said that the syllabus demanded cursive writing. Mike and Rose had to get permission from the head of department for him to carry on printing. In high school, Eugene could not finish exams, so Rose and Mike got permission from the school for Eugene to have extra time in exams. When the time came, they applied for Eugene to have more time in Matric. The school were not supportive of the application, but Rose fought on and Eugene got more time. Rose feels that parents "have to be prepared to *fight for their rights*" and must *not allow themselves to be intimidated*.

7.4.3.8 Sport and extra-curricular activities

Sport can be a *saviour for some* ADHD children, but a *source of stress for others*. Barkley (1998) states that ADHD children in middle childhood are likely to find themselves barely tolerated in group activities such as clubs, sports and scouts, and might even be outright ejected from them in some cases. For example, the child can annoy other players, the coach, and other people involved in the sport. Eugene was chosen for a soccer team in pre-school, "but it was useless because he couldn't understand how the game worked on the field". Rose reports that this made *other parents angry*. When Eugene tried judo, it was done in a big group, "which is never ideal for these kids". The instructor was Japanese and spoke strongly accented

English. Rose and Mark did not “know at that point that Eugene as an ADHD child would have trouble ‘hearing’, that is hearing as in understanding what was being said and then acting upon it.” With this strong accent in a large class, he was utterly *confused* and *could not follow*. The *teasing and bullying* started and that was the end of judo.

After that, Mark and Rose left Eugene to tell them when he wished to try some sport. Eugene’s father was a very good oarsman and in high school, Eugene took to rowing, joining the Rowing Club immediately. It paid off and “gave him *invaluable lessons, friends, and wonderful memories*”.

Karl is “very, very good” at archery and has already made provincial schools. Zelda believes it *aids his concentration*. The *discipline* is good for him as well, because he has got to wait until everybody has had a turn. Mia’s girls love sport. Peter plays a lot of sport. Carrie feels the sport “definitely *helps his self-esteem*”. Dylan feels that school was “difficult” for him and with the teachers he “was classified as lazy”. The saving grace for Dylan was to be able to play sport well: “I don’t know what I would have done without sport”. “I think that is what kept me going at school. I had a very *good self-image* at school because of my sport.”

Luke also tried sport at school. Carrie found it “very difficult” to watch her two boys compete in different teams at school, because Peter was always that much better, and it affected Luke’s self esteem. Carrie’s attitude is perhaps a good one: “Luke tried to play cricket. He tried. It just didn’t work for him. So, I have *never forced it*.” Parents of an ADHD child need to provide their child with *opportunities to succeed*. If sport is not such an opportunity, don’t force it.

7.4.4 Parents’ concerns and hopes for their ADHD child

7.4.4.1 Parents’ concerns

Some of the parents have *concerns* and even *fears* about their ADHD child’s *future*. Some parents have concerns about their child *staying out of trouble*. Two of the participants made specific reference to their fear of their child getting involved with *drugs*. Two of the parents were concerned about their child *driving*. This is a realistic fear as studies by Barkley and colleagues (Barkley, Guevremont, Anastopoulos, DuPaul & Shelton) and Weiss and Hechtman (1993) suggest that hyperactive adolescents have a higher incidence of automobile accidents than do normal adolescents.

Others parents worry about the child *coping without a parent* around to guide them. Three of the parents have concerns around their child *finding a life partner*.

Brenda worries about the future because there's so much *conflicting information about Ritalin*. If they keep Conor on Ritalin, she wonders how is he going to be when he's 15 or 16. She wonders what happens when they take him off Ritalin. She wonders whether he is "going to be using medication for the rest of his life".

"Those are worries that, as a mother, I think of **every day**. And I've got no answer to them. And nor can anybody else tell me. And it's always: 'Am I doing the right thing?'"

Belinda worries that Evan "actually hasn't got an *idea*" of "*what hard work is* about". She worries about "how he's going to *cope with university*, if he goes, or Technikon, and then there isn't this caring environment around him". Evan wants to study Mechanical Engineering "and he's quite set on it". Belinda and Rob "don't feel at this point in time that he's been programmed for that". They also worry that Evan is not going to be able to *create a structure* for himself on his own. Belinda realises that they will have to help him in the future and keep checking: "Are you organised?"

"Perhaps that's going to have to be, until he gets that, sees the importance of it and how he can't sort of survive without that."

Angela feels that "Tina doesn't seem to see a future for herself". Angela finds that "frightening". Angela feels that Tina "must be terrified". The one thing Tina did suggest was that she goes to England after matric, stays with a friend, and work for a couple of months. Angela feels that "it's a very good idea": "Just from the point of view of her then having to grow up." Tina's father, however, refuses to allow her to do that. Angela's main fear for Tina for the future is that she will be *on the streets*.

Linda sees Ruth as "very charming; she's a delightful child, very loving child". But Linda also sees her as "very controlling". One concern Linda has for the future is that Ruth "*might not find a husband like her brother* who's prepared to let her have her way and to do things her way".

"I mean are you kidding? I mean *who's going to put up with this?* Who is going to put up with this? Nobody."

Linda also *worries about whom Ruth is going to be friends with*. Linda doesn't want Ruth to be "a miserable, unhappy child": "I mean, you haven't brought a child into the world to be alone, or to have nobody to identify with". On a practical level, Linda is worried about Ruth *driving*, "because she's *easily distracted*".

Marie is "still worried about these ADHD children being addicted to *drugs* easily". She and Leon have had the experience of Johan experimenting with drugs. Marie "fears" that Johan will *marry "a woman that also has ADHD"* and of "them having difficulties in their relationship". She does realise, however, that he has to "live his life" and "he will sort it out as he goes along". She will, however, offer her "competencies" if there are "huge problems" so they "can tackle them together, **if** they want to (Marie's emphasis)".

Marie looks "forward to having grandchildren", but admits she "will be on the *look out for ADHD*" in her grandchildren.

"I think that it might make it difficult for my future daughter-in-law, but I will also try to explain **why** I am like that, and what we have been through, and not let her suffer the way that we did - try not to."

Mia worries about the amount of *pressure children are put under at school* and how "they are moving so quickly". Mia worries about the girls having *self-esteem problems*. Mia thinks that "everybody wants recognition; it doesn't matter what recognition you get as long as you feel like you fit in somewhere and you have recognition". Mia feels that a child with low self-esteem can "go off the deep end, because they don't know how else to cope". She does "worry about the future" and she worries that "that they're going to be one of those kids who gets *caught up in the wrong stuff*". She does, however, feel that she has "tried everything". Mia feels she must give them as much as she can "so that there are no loopholes".

Samantha worries about whether Claudia is "going to manage to *create structure for herself*". She also worries because, although Claudia knows that things like the diet work, she can't **wait** to get off it (Samantha's emphasis). Samantha believes that with Claudia she tends "to *want to hold on to her*".

"I would sort of like think that I would want to look after her for longer - like the reason for the shop like - so that she's got something to go into if she wants it."

Michele doesn't "know what is going to happen to them (the children)". Michelle "will give them all the encouragement" she can "without putting them under too much pressure". Michelle believes that "more often than not these children *fall off the rails*". "And it's dealing with that and getting them back on track again". Michelle is "very anguished about *how productive they will be as adults*" and whether "they will be able to *find their little niche*. For any adult it is hard, but for these children." Michelle hopes that "if at all possible" her children *do not "marry ADHD people"*. Michelle feels she will also need to *educate her children's spouses*.

The next big step for Luke is his learner's licence. Carrie worries about him *driving* "because it has been proven that these children have more accidents than others". *Drugs* remain a concern for the future. Luke has experimented with drugs already, "because he is very easily influenced", and Carrie does not "think it will be the end of his experimentation". To this day, Carrie has a drug test in her cupboard. Luke also "likes alcohol" and Carrie finds that "scary" because she knows "that *alcohol* is exactly the same as drugs". Carrie feels that her boys "*don't know when to stop*".

"If they have a drink, they feel all cool and calm and in control. Then they will go over the top. So that is a worry as a mother, watching them."

Zelda admits that she worries about the future. Zelda believes Karl will "always cope, no matter where he is, or what he's doing or whatever". But because of *society's standards* she feels it will take "a lot of hard work for him to succeed".

Gill and Dylan only "have the normal worries" for both their children as to whether they will *get a job*.

Beth doesn't have any real fears for Eve's future:

"I've spent the last I don't know how many years intensely fixated with a negative sort of projected outcome for her. But not now - now that I see who she is becoming. And it seems that *she's learning* and that she's actually buying into some of the stuff that I'm teaching her. And she's *becoming accountable*, and she *understands about consequences*, and she's *growing in good areas*, I feel. I think she will be okay if she carries on like this."

7.4.4.2 Parents' views of the future

Parents of an ADHD child often have to *adjust their dreams and expectations* for their child. They are confronted on a daily basis with the fact that their child is *different*, their family is different, and that they are different as parents. Parents often have to develop a '*new reality*' for their child's future. For many of them this means accepting that their child is "*not going to be an academic*". A number of the parents felt, however, that if the child's *interests were "channelled"* in the right direction they would be okay.

Brenda feels she is now "*only on the first lap*. I don't know how many more laps I'm going to go through". She hopes that by the age of 12 or 13, Conor will be back in a *mainstream school*, "and that he's coping fine". Brenda doesn't believe that Conor's ADHD will go away: "I don't think it's a thing that leaves you overnight. Once it's diagnosed and the medication is given, I think it is a *life-long thing*".

If Brenda looks at Conor's interests, she believes he will either be into marine life or in construction: "He's *not going to be an academic*". She *encourages his interests*: "You...you go with what he's good at". "So, you know ... that's my thoughts for later on in life. I'm going to channel what he's good on."

Angela would like Tina to *get her matric*: "It doesn't matter what matric it is". Angela wants Tina to be happy and to be able to *support herself*: "That is the sum total. Angela doesn't know "how that will happen" and she doesn't believe Tina will "be able to support herself even when she's 30." Tina has asked why she can't just stay with Angela "till she's 35 and just party. She can't see why she should have to actually earn a living". Tina actually verbalises that "she *doesn't want to grow up*; she doesn't want to be an adult; she doesn't want to take responsibility".

Angela *doesn't know where her parenting role ends* with Tina – "probably never".

"And that feels awful, absolutely awful, because life with her is very, very destructive.... I don't want to be abused for the rest of my life; and that is what is happening now. And it's destructive; it is really destructive. The simple, little things. It's almost as though anything that is right or decent she doesn't want. And your *life is destroyed along with her*, she tries to bring you down with her. I don't know whether that's conscious or it's just how it is. That's how I feel."

When Linda looks into Ruth's future, she believes Ruth "won't let anybody control her. She *wants what she wants*". Linda believes that Ruth is an *Indigo child*: "High-spirited, fun loving, fearless – this is the Indigo child. That's Ruth". Linda believes she has proof of Ruth being an Indigo child because a photo taken of Ruth's aura clearly shows it to be "blue and violet". Ruth just wants "to have fun all the time": "They want to go on Space Mountain – the ride at Disney World – **all** the time."

Johan is currently working with his father *in the family asphaltting business*. Marie feels "he's doing very, very well". At the moment it seems Johan will stay with Marie's husband in the business: "He's really enjoying it and he really wants to learn the ropes of the business". Johan asked to go into the business; Marie and Leon "didn't want to force him into the work." They also agreed that he start work on the lowest level at a basic salary. Marie and Leon believe: "Sometimes you have to be cruel to be kind."

Mia believes that her girls have to "*learn to become a structured person, you have to be a person that is diligent*". Mia does not feel they are there yet. Mia is trying to "give them the skills now" and *trying to teach them to plan time*. Mia *does not believe either of the girls will go to university*. This doesn't concern her – "as long as they are happy". Neither Mia nor Dave finished school and she feels they have "always been fine". She believes the girls must *find something that they are good at and passionate about* and they'll "take it from there". Mia does not want to "push them to be something that they can never ever be" and "give them expectations that they can never live up to".

Pat *does not believe that John is "varsity material"*. John is "very good on the computer". He loves cooking, he loves animals and he is very good with his hands. Pat feels he will *probably work with his hands* one day. Pat believes that if John's energy or *interest is "channelled* in the right thing he will *be okay*". Although Pat doesn't expect John to go to university, she feels "that is not the norm; that is *not what society dictates*. Society dictates you will go and be a doctor, or this, or that." Pat hopes that "society will one day realise that these kids are different; he's unique; he's special".

Samantha admits that she does "worry about her (Claudia's) future". Samantha would like her to *finish matric*, "and I'm sure if we carry on we will". Claudia has dreams of going to Paris and becoming an actress or a model. Although Samantha

doesn't know if Claudia has "got confidence to do things like that", Claudia did do modelling in the past and "she loved it". Claudia is also "*good with her hands* and she's arty". That is *one of the reasons that Samantha has started the arts and crafts shop*. Samantha is hoping that Claudia "can grow into it - that's if she wants to. I don't know if she wants to, but she can cope with the arty stuff."

Beth believes that intellectually Eve has the *ability to go to university*, and also feels that Eve "*needs a tertiary education*". Beth has panicked about it: "She's never going to have what she needs to be able to." One of the teachers at Eve's current school did a lot to reassure Beth.

"She said by the time Eve gets to that age she is *going to be fine*, and she will have to work on her own anyway, and that's really what she's best at, and just relax you know."

Beth believes this advice helped her to relax about Eve's education. Beth believes "it's a good idea to *get advice from practical people* who have been there before".

Both Gill and Dylan see Doug going into *some sort of trade*. Gill admits she wants Doug to be a horticulturist. She feels he seems to "lean in that direction" and she will "*encourage him*" as much as she possibly can. Doug has all his own gardening equipment; and whenever Dylan or the gardener is busy in the garden, Doug is there too. "So if this love of gardening holds then, ja, maybe it's an option for him." Gill concludes: "I reckon that Doug is *going to be fine*, you know." "I know in my heart he will achieve."

Luke's friends are all talking about going to university. Carrie is *not sure that Luke is going to be able to get the marks to get into university*, and if he does go, she is *not sure he will cope*. Carrie finds it "heart sore" to have to, on the one hand, "*show him what reality is*", but on the other hand, "*not to shatter their dreams*". "Luke works really well with his hands not with his brain". Carrie feels there is "nothing wrong with that, but he doesn't see it like that".

Rose believes that "the ADHD child can be raised successfully" because "there is a *great deal of potential* and there are possibilities".

"Our greatest wish is that with full maturity, Eugene learns to understand, control and love himself; that he learns to motivate and organise himself; that he finds something that will give him satisfaction and the minimum of stress

and anxiety, whilst earning a living; that he finds someone special who will understand, accept and love him; and, above all, that he will learn how to unselfishly and gently care for and truly love that person in return.”

7.4.5 Getting through the day and advice for other parents

Participants were asked what advice they would give to parents whose child had just been diagnosed with ADHD.

7.4.5.1 Find the right professional

From Brenda’s experience, if the ADHD is picked up, it’s normally picked up between five and six-years-old when they start pre-primary or primary school. She advises that as soon as somebody sees there’s a problem, you find yourself a good paediatric neurologist or psychiatrist. Her advice is that parents not “go through referral from school, to clinical psychologist, to EEG. *Start at the top; go to the person whose going to be able to help you most.*”

Belinda advises that parents avoid going “through your GP” and rather go to *somebody that specialises in ADHD*. Belinda suggests a *full testing* by a psychologist, as well as a medical screening for the medication by a medical professional that deals with ADHD. “You need to have the *right people* to help you and you need to cover all the areas, be they occupational therapy or play therapy or whatever. And if you are not happy with the professional you are dealing with “*change and find somebody that’s right*” – “it must be a *good gut feel*”.

Mia also advises that parents follow their “*gut feel*”. Parents must realise that “*not all doctors are right*”. If it doesn’t “feel good”, then “go somewhere else”. Mia also realises, however, that there is a point where you might have to admit that the professionals are right: “And if two people have told you the same thing then, you know what, maybe it’s *your expectation* that’s not where it should be”.

Beth also recommends “having the *right professionals*”. Carrie too feels you “need to see a doctor who *specializes in ADHD*, not just a GP. You need someone who really *knows what they are talking about.*”

7.4.5.2 Accept and act

Mia feels parents must *act on what they are told*. She knows of parents who decide to ignore what they are told and “they never go back; they never do anything about it”.

“And then a year down the line the problems have gotten bigger. Their *problems aren’t going to go away*; you have to address them.... And the only person that you’re cheating is your child. At the end of the day it’s *only the child that you’re cheating.*”

The first piece of advice that Samantha has is that parents *do not ignore the problem*. Samantha has a niece who she could see has ADHD. She spoke to the mother, and her reaction was: “No, there’s nothing wrong with my kid; don’t talk rubbish like that.” The child has now been assessed and she has ADHD. The parents “are devastated because they don’t believe it; they think it’s a whole lot of rubbish”. The parents now want to have her reassessed: “But they can have her assessed over and over again until they are blue in the face and they won’t be fixing it.”

Samantha has suggested the diet to the parents, but they persist in saying “there’s nothing wrong with our child”. “And they just won’t accept it.” Samantha admits that she too “didn’t want to accept” the diagnosis and it was hard to “deal with that initial shock of actually hearing it”. But she knew she had to *do something about it*.

For Zelda “the most important thing” is that you’ve got to “just *accept it*” and “then to *work from there*”.

Gill clearly recalls an incident when she was working for a homeopath. The homeopath wanted to visit local pre-schools and talk to the parents about ADHD. Gill remembers phoning one school and being informed: “Parents don’t want to hear that kind of thing.” Gill “was shocked; I was absolutely shocked”. It shocked Gill that parents “would rather bury their heads in the sand”. Gill feels “that’s a big problem”. Gill feels it was vital for her to be “very open to the fact that this might be Doug’s problem”, and she had to be “*willing to explore it*”. Gill feels she and Dylan could “have turned a blind eye and ignored it, but we chose not to”.

“And I do believe, because people look at their children and they expect their children to be little perfect beings. And I don’t know if, when they perceive that there is something wrong with the child, that they take it as a personal

failure. I don't. I look at my child and I think: 'Well, he *needs my help.*' That's the way I see it. I mean, if my child was a diabetic, you know. To me there's no difference. If there's something wrong, *don't bury your head in the sand*; do something about it."

Dylan is just as incredulous about parents "who wash their hands of it". Dylan has experienced such improvements since he started the medication and he wonders "what might I have been like, or how would I have fared at school, if they had known about it at that age". Dylan feels he has "only started learning a lot about growing up in the last six months, since I've been on Ritalin".

Michelle feels it is important that parents *accept the diagnosis*: "If parents find that they are in this situation they have to give themselves over to it. They *cannot fight it.*"

Carrie concludes: "And you have to accept the condition. It's not going to go away; you *have to deal with it.* And if you think it's difficult now (Carrie's emphasis), just leave it untreated."

7.4.5.3 Have a support system

Brenda believes parents should "find *some form of support*" because "there's nothing worse, because as mother you feel – you don't know what to do." "And, if support groups are available – if you feel you need a *support group* – go for them." Brenda feels she personally does not need a support group. She does find Mike and Brad to be a support though.

Brenda believes that a good support system also extends to the *'team' who works with your child.* Brenda believes "these children's lives could be made quite miserable; so you need a good remedial school, a good paediatric neurologist or psychiatrist, and your child needs support. People look at these children as being naughty or lazy – and they're not, they're very clever children."

Belinda also finds that having support helps. She doesn't attend a support group, but she has contact with *other mothers who have ADHD children.* Having a *friend* in the same situation is "a good support system for each other". She also talks to some of Evan's friends about ADHD – "like we talk about it, and can laugh about their antics". For Belinda, *humour* "is a saving grace and creates a feeling of connectedness".

Angela's "support system in all of this" is her *partner* Pam. Angela believes you "have to have a very *strong relationship* to live through this".

Sandy's *husband* is her support system. Sandy also had the opportunity on the parent course run by ADHASA to meet *other moms* with ADHD children:

"And we all had something to share. And we're all in the *same boat* – one way or the other. And it's just nice to know that there's somebody out there who's got problems just like you, if not worse problems."

Mia believes that "having a support system is vital and especially to have your *husband behind you*". Mia feels that Dave "has been fantastic" in all of this. "He is my support system in all of this".

Pat advises that parents have *someone to speak to* who understands the situation, be it in the form of a friend or a support group:

"And sometimes we don't even talk about the kids. It's just to speak to someone and when they say: 'You know what, he broke his toothbrush this morning.' And I'll say: 'Don't worry, he's done that three times already.' And you think: 'Well at least he's half normal.'"

At one stage Samantha did attend an ADHASA *support group*, "and we used to go to the evening meetings and that". Samantha, however, doesn't "have the time at the moment" to attend meetings. At present Samantha feels her support system is *just herself, which is dangerous*. "I just push myself and that's probably why I feel like I do - I feel burned out."

Beth was also a member of an ADHD *support group*, which she "found very helpful" in that she realised that she "was not the only person in the whole world with this challenge, or this child". Michelle has found ADHASA to be "very supportive" and although she doesn't have time now, she used to attend one of their support groups. Michelle also found you can also get *individual counselling* from them.

Carrie feels that the *support groups* have a role to play, "particularly for those parents who are just starting out on this road". Carrie was involved in a support group and being involved gave her "a sense of knowing that I was on the right track". Carrie does feel that you have to take what they say and "*adapt it to your own situation*".

Carrie too found that you could get *affordable counselling* through ADHASA.

“Parents don’t often have money for that. These are expensive children – the medication if they are on it, the diet, the extra therapies they need. Very often parents just do not have that money.”

ADHASA even has a *holiday camp* for ADHD children. Carrie feels that as a mother of ADHD kids, she “never gets a break”. She sent her boys on the camp, and they always enjoyed it.

Rose believes *support groups* can “play a very big part”.

“For parents trying to negotiate the hostile waters, to just have a place where one can go and talk to people who are living through the same problems, where one can shed tears of relief, pain, frustration, anger, recognition, is beyond belief.”

Rose also finds support in *her husband* Mark and feels he is “definitely my greatest source of support”.

7.4.5.4 Put structure and routine in place

A number of parents advise *putting structure and routine in place*. Parents feel they have more *success* when structure is present, and many parent realise that their child will *always need structure*.

Belinda feels structure is vital and if “you as parents aren’t used to structure then you’ve actually just, you’ve got to *force yourself to do it*”. For Belinda, structure extends to giving the children *boundaries*, so that behaviourally “they know there’s a *consequence* if they do this”.

“They *take responsibility for their behaviour*, because they can choose to behave like this and this happens, or they behave like that and that happens”.

For Belinda, on a practical level, structure includes things like *monthly planners* for planning time for assignments: “planning is very important”. Structure also includes *having a daily routine* – knowing that 6 o’clock in the evening is supertime and six o’clock in the morning is wake-up time.

Linda finds she has to *be “really organised - very organised”*. She believes that it is “a blessing for Ruth” that she is so organised and feels that she brings “structure and organisation to Ruth’s life”.

Mia has tried to *make the girls’ lives very structured*, “because otherwise there would be nothing. We would live in chaos”. Mia believes their home situation has improved because she has gotten much stricter.

“I now am a far more *disciplined person* as well. Because I find that if I am having an airy-fairy day, they are **definitely** going to have an airy-fairy day.”

At the moment, Pat has a “*set routine* and quite a *set structure*”. There is only ever a degree of variance in the structure. Pat feels it “works” for her: “You have to have that, otherwise I never get any time to myself. I’m not – if my jug’s not full there isn’t going to be anything left for him.” Having a routine extends to *John knowing when it is his time*: “I **always** do his reading with him; I may not do his spelling or whatever – he’s done that at aftercare. But he **knows**, from seven o’clock until eight o’clock – come hell or high water – that is **his** time (Pat’s emphasis).”

Samantha is “*very strict* with her (Claudia); I’ve got to be. She works in a structure. I’ve never let her run wild, I can’t. I just decided one day it’s not going to be like that.” Samantha believes that “structure definitely, definitely works” for her and they try “to be as structured as possible”. At the moment “it’s a continual call-back”, but Samantha is hoping that “one day the penny will drop. After about twelve years it hasn’t, but I’m prepared to wait.”

Zelda advises that parents must *be organised, especially when it comes to school*. For Zelda, organisation for school extends to colour coding books and finding ways to instil routine.

Sandy feels that routine is also very important for Aidan: “If you’ve got a higgledy piggledy life, it just doesn’t work with an ADHD child”. *Routine* also helps Sandy keep her “*sanity*”. Monday to Thursday afternoons in Sandy’s house always follow a similar pattern. After school, Sandy will make lunch for Aidan while he gets changed and puts his school clothes out for the next day. While Aidan eats his lunch, Sandy will go through his school bag “to see what rubbish he’s put in his bag, what he’s collected off the playground, and I go through his books”. Sandy checks Aidan’s homework diary and checks for any notices. Once Aidan has eaten they start homework. Once

Aidan has finished homework, he has to pack his bag for the following day. Only then is he allowed to go and play. At six o'clock Aidan bathes, and by eight he is in bed.

7.4.5.5 Discipline

Discipline is a *major source of frustration* for parents of an ADHD child.

Angela believes that parents who have got a child like this “*cannot be too hard*”.

“You **cannot** be too disciplined and you **can** give your kids a hiding. This thing that you can't is rubbish. You cannot be hard enough and you cannot be difficult enough. That's the only advice I can give. It's *too late when they are 18*; it's got to be from when they are two. But it's difficult.”

Angela believes that if she had known when Tina was born what she knows now, Tina “wouldn't have been allowed to look sideways without asking, and if she did she would have got a klap. And that is *not the socially acceptable way* to bring up a child.”

Mia has had to learn to *stick to her guns*. Lynn tends to forget things or lose things. “Nearly every single day for the first three years of school” Lynn lost something at school: “If it wasn't the shoes, it was the jersey, or it was an entire kitbag”. Mia found herself spending so much of her time “trying to find something that belonged to the child”. By the end of Grade 2, Mia had had enough. Lynn came home without her jersey and Mia told her that if she did not find it, she would have to replace it out of her pocket money. Lynn went to lost property the next day, found her jersey, and has never lost it since. But she “was in tears and she sulked the whole night”. Mia felt she just had to “stick” to “her guns”: “That's the hardest thing to do, I think”.

The ADHASA parent course that Sandy went on taught *behaviour modification* to improve discipline. Parents are encouraged to have *rules of the house* and a *reward system for children*. Sandy used to just give the children pocket money, but the course encourages parents to *make children earn pocket money*. Sandy now has a laminated poster in the kitchen with the rules of the house on it. There is another poster that outlines ways for the children to earn their pocket money, for example by feeding the animals, or tidying their bedroom, or getting their school stuff ready for the next day, or being downstairs in time for breakfast. Both children start on zero for

the month, and for every task they do they get points. But “if they fight, they argue, they swear – points get taken off”.

Before Sandy implemented the whole system, she sat the children down and told them she was going to do it and the reasons why she needed to do it. Sandy feels “it works okay”. Sandy still finds she has to say to Aidan: “Don’t you want to earn pocket money this month?” “Don’t you want to feed the cats before your sister does it – quickly so you can earn the money?” Sandy tries to encourage Aidan, but “it’s very frustrating” and “it’s an arduous task”. “Because I’ve got to constantly remind him – otherwise he’ll have nothing”.

Michelle has learnt through the neuro-linguistic therapist and through ADHASA’s parent course that the children need to be *taught that there are consequences* to their actions. “They have to know that if they do that, this is going to happen. And if that doesn’t happen, then this happens.” Michelle feels she has to “*drum it in*”. If the children want an hour of TV, “homework needs to be done, chores need to be done, and school things need to be ready for tomorrow and whatever”.

Something that has improved discipline in Michelle’s home was *removing the computer*. The children wouldn’t play outside and just wanted to sit in front of the computer. It was causing such contention between the children – “fighting about whose turn it was”. Michelle felt that “was just a stressor that I did not need added to this house”.

For Rose, discipline is the “most vexing question regarding ADHD children”: “They appear to be *quite impervious to discipline*.” Rose does not believe that negotiation or behaviour modification works with the ADHD child. Smacking Eugene also just made it worse. Rose feels that because ADHD is “a chemical, biological, allergy problem” the best route is trying to *restore that chemical, biological balance through medication and treating the allergies through diet*.

Rose and Mark discovered early that Eugene “*hated change*, so if something was planned there had to be an excellent reason for altering the plans”. Shopping was a nightmare as the crowds, the noise, and the smells drove him mad. Heavy traffic had the same effect. If the family planned lunch at a restaurant, “it was hell just to get him dressed and in the car”. “The anxiety of a planned trip or outing seemed to totally unsettle him”. For Rose and Mark, “discipline was improved when all the points

above were taken into account: trying to *keep calm*, *few people*, a lot of *planning* and *warning of what we were planning*, *no changes*, *staying out of noisy, air-conditioned places* etcetera”.

Rose and Mark found that in more *formal atmospheres* like the Country Club, Eugene behaved better. “If a place was quiet and structured and yet was interesting - the waiters, the gardens, lovely tables and settings, quiet people - the *fascination* of it all would keep him calm and quiet.” Rose believes that the key is that the *atmosphere was quiet*, “and maybe that calmed him and kept him quiet”. At home, Mark and Rose set up a bird feeder outside the kitchen window, and his interest in watching the birds often helped them to feed him, “especially in the mornings when he is at his worst”.

Mark and Rose also learned that if Eugene “did not *eat properly and at correct intervals*, the aggression was high”. Mornings were bad until they got food into him. It took some time for them to realise that Saturdays and Sundays were worse, because they took their time getting up and getting breakfast. They could not think of going out and postponing breakfast, “it was just not worth it”. If they did go out they took a snack in the car so they “were ready when he hit a downer”.

“Believe me, all this *took a long time for us to learn.*”

7.4.5.6 Learn and teach

Most of the participants expressed a *need to acquire knowledge* about their child’s disability. Throughout the interviews, I was struck by participants continued efforts to *know and understand ADHD* and its effects upon their child, so they could “do something”. A number of parents actively pursue knowledge, and feel more successful as parents because of it.

Three of the parents went for *counselling* in order to learn more about the disorder and how to deal with it. Rob and Belinda went for parental counselling for a year after Evan was diagnosed. The counselling helped them to learn to “put boundaries in place for Evan”: “It wasn’t something that came naturally to us”. Beth believes that parents of ADHD children need to go for “good counselling **themselves**” (Beth’s emphasis). Beth feels there are three reasons why parents need counselling: firstly so that “they don’t do the guilt thing... because that is hard to live with”; secondly, so that they “get intellectual handles on what’s going on”; and thirdly, “so that they get

practical handles, and that they have someone who can walk them through the processes, or the manifestation of the condition, through the different stages of development". Pat went for counselling for six sessions to learn more about ADHD and Ritalin.

Beth believes it is a good idea for parents to go on a *parenting course* of some sort. Most parent training courses strive to promote more positive, compliant, and generally pro-social behaviour while decreasing negative, defiant and disruptive behaviour in children. Typically, this is achieved by training parents in more positive, consistent, and predictable child management skills (Forehand & McMahon, 1981; Patterson, Dishion & Reid, 1992; Webster-Stratton & Spitzer, 1996). Beth actually went on a step-parenting course, which was very practical and helped her a lot. Beth feels parents should attend a course that is "practical and helps parents to also understand how the world works around them, and how to teach things like responsibility and accountability and choices, and how to teach your child how to make choices, and how to assess situations, and how to give alternatives. And how to discipline - what is healthy discipline or, you know, beneficial discipline. Because I didn't know any of that."

Belinda believes *educational talks* are very useful: "I've been to everything that I've seen that can help". Especially with Evan being an adolescent, new issues become pertinent – like drugs. It is important to get the facts so "you don't sort of get this panic".

Linda reads a lot *books* on the disorder. Marie too has read "lots of books" on ADHD and she believes parents must get "as much information as you can about the condition". Marie started *studying* again in 1999 to try to "get answers" about Johan. Marie did a course through Virginia, in the USA, on the two halves of the brain working together. She re-did the third year of her BA, completed her Psychology Honours, and is currently busy with her Masters degree in practical theology. Marie would like to work with mothers and "help them to live even more successfully with her child that has this condition". Marie has only recently joined ADHASA (Attention Deficit Hyperactivity Disorder Association of Southern Africa) and she goes to the support group meetings in Randfontein. In August, Marie will be giving a talk at a school. Marie finds it "very helpful" to talk to people about ADHD – "it's very empowering and it empowers Johan also".

Marie believes it has also been vital that Johan “gained *insight into his condition*”.

“It’s been just as important to Johan to have the knowledge as for us. It’s tremendously important for him – it’s life changing, completely life changing. It’s been important for me, but he has to live with the condition; so I think it’s slightly **more** important for him.”

When Marie reads something interesting, she shares it with Johan or gives him the article to read, and they discuss it. The *whole family* has read a book on ADHD and adolescents – “we all read it. That was a good experience; that opened our eyes a lot. “

Pat does not just educate herself, but tries to *educate those around her*. Pat has tried to get her boyfriend Alex to understand that John’s “brain works completely differently”. Alex will shout at John for not doing something, without taking into consideration that John interprets things differently. Pat has taken Alex for counselling to try and help him to understand.

Pat believes that parents must “educate themselves and not **ever** (Pat’s emphasis) think that someone knows more than them about their child”. Pat feels parents must know what they’re talking about, and must make people aware that they are *not scared to stick their necks out* and say: “No well, you know what, why do you say that?” Pat feels that educating herself about the disorder makes her “refocus” and puts her “back on track” and helps her to remember that she’s “*not the only one*”. Going to the talks “instils some sort of reality” and makes Pat feel: “You know what, you’re actually on the right track here.”

Sandy is always “*reading* articles and finding things out” about ADHD. Sandy did a *parent’s course* through ADHASA. Sandy feels the course “was the absolute turnaround” in her life. The course consists of eight sessions and each session focused on a particular aspect, such as medication, supplementation or education.

“That course was the most incredible thing I’ve ever done and it’s changed my whole outlook about my child.”

Dylan and Gill advise that parents must “*ask questions*” and “know as much as possible”. Gill and Dylan joined ADHASA and, although they have not felt the need to join one of their support groups, they enjoy reading their *newsletter*. Gill also uses

Doug's headmistress as a "sounding board" because "she's been around these kids for the last 30 years". Gill finds this "very helpful" and if the headmistress cannot answer her questions, she will refer Gill to someone who can. Gill also has "open lines of communication" with her general practitioner. Finally, Gill also uses Dylan as a "check point" as he often knows how Doug feels.

Michelle advises that parent find out about ADHD: "*Learn about it* as much as you can". Rose feels that if "there is one nugget of advice" she can offer parents of an ADHD child, then it would be "to *read* as much as you can about the subject, go to as many lectures as you are able, talk to as many people as you can, be they both professional and lay". The next step is to "set all that information to one side and *decide what suits your family the best*". Rose believes parents must "go with a very *informed gut feeling*". Rose also finds that *ADHASA's Pulse newsletter* "is packed with professional advice and information and news of lectures and seminars".

7.4.5.7 Attitudinal strategies

Parents employ a number of attitudinal strategies to help them get through the day. Among them are: trying to remain positive, accepting your child the way he/she is, being proactive, continuing to try, separating the child from the disorder, and taking one day at a time.

Remaining positive

This strategy involves *seeing the good*, the unique and the positive characteristics in your child and not being overly influenced by what others say about him/her.

Belinda doesn't view Evan's ADHD as all negative. She believes "there is definitely *something special* in him". Evan is "domesticated" and loves helping. Belinda believes he has a "*warm spirit*" – "I think, because of his struggles, he's got so much more compassion". Belinda sees the same qualities in Evan's ADHD friends: "And they do things that are, to me, like worthwhile, spiritual, not materialistically oriented." They are "very special" and they are "*incredibly loving*".

"They are not shy of being affectionate, even with their friends around. They're proud of their parents; they love their parents."

Evan also has a "sense of security about him". Belinda loves having him in the car with her, because he "makes her feel safe". Evan is also fantastic in an emergency. "He stays *cool and calm* and handles the situation." Belinda believes he "almost intuitively knows how to cope and how to handle stressful situations".

Marie too sees the good in Johan. Johan is a very sociable child with “*wonderful*” *social skills*. Johan perseveres. He is also very *curious* and inquisitive and has always asked questions that were “not like questions other children asked” – he “thought further”.

“And he wanted to **know**. He wasn’t satisfied with just superficial answers. Sometimes we went to the library and found books. And then he couldn’t really understand exactly what they said and I had to go into it, sometimes it was very difficult. But he caught onto those difficult ideas very quickly.”

Pat feels parents need to *look for their child’s “good points”*. “You have to dig **really** (Pat’s emphasis) deep sometimes. But, you know what, if you look hard enough you will find plenty of them. And when you find them, *capitalise on them* and make them bigger.”

Remaining positive also extends to telling yourself that all parents face problems, or that *there are others who are worse off*. Whenever Pat feels really “miserable” she reminds herself that there are always people with bigger problems. Brenda employs the same strategy. Although she admits that having a child with ADHD is “not easy”, she tells herself there’s always light at the end of the tunnel. “And I think I’m blessed. If I look at other children with more severe problems, I’m blessed. I really am.”

Mia feels her “way of coping” is to tell herself that “anybody who has a child”, is “going to come to a portion in that child’s life where you are going to have to deal with something; and everybody gets a turn”. Mia feels that if this is her “portion”: “I’m coping – I’m fine”. Mia believes “*every child’s going to battle with something* – if it’s not on a friendship basis, or an emotional basis, or an academic basis, there is going to be something.” Mia feels that at least she knows what her problems are, and she’s dealing with them. Mia believes there’s “*no point getting down in the dumps* and thinking: ‘Oh my God; what am I going to do?’”

Accept him the way he is

A number of parents had to decide to have an attitude of acceptance towards their child and had to learn to *appreciate their child as is*.

Rob and Belinda had to learn to accept Evan “the way he is”. This was particularly hard for Rob and it was “a *gradual process*”.

“At first there is a feeling of disillusionment because he’s not going to be what you imagined he would. And you see him as such a bright little boy. You’ve got to *accept the talents he has* and *see how special he is* (Belinda’s emphasis), rather than what you want him to be.”

Marie has found her studies to be “very healing”. It has “been a tremendous learning curve” for her as well. Marie believes there “are certain ideas that I had to unlearn because I used to put on the glasses of ADHD before looking at Johan, and those were not very good glasses to wear”. Marie feels her studies have opened up “much more possibilities for me to really *see him as I would like to see him* – this wonderful human being that God gave me - and to appreciate him”.

Mia believes “you actually have to take time out and you almost have to mourn the child that you thought you were going to have, and then you have to *appreciate the child that you’ve got*”. Mia believes you “really do” come to appreciate the child you have. Mia believes parents must know when to *accept their child’s limits*: “And it’s soul destroying when you see some kids that are battling and battling and the parents are just pushing and pushing. They have to be the best of what they can be – not what **you** want them to be. So you have to actually *re-look at everything*. And it is hard; it is soul destroying.”

Pat has now reached a stage where she feels there is “**nothing** else to rule out – **absolutely everything** has been tested (Pat’s emphasis)”. She feels she now needs to “*accept him for what he is and deal with it* (Pat’s emphasis)”. The fine-tuning of the medication has now come to the end of the road, and there isn’t anything else wrong with him. It is time to “just work with him the way he is”. Pat admits: “**I** (Pat) have to accept it”. Pat feels that at John’s school they “over-therapise them a bit – it’s like the quest for zero defect”. Pat has said to them: “Listen this is not a video machine; he’s a human being. This is as good as it gets; it isn’t going to get any better, so deal with it.” Pat feels parents need to recognise “when that point comes where, you know what, that is the way he is – just run with it and *do what you can do*”.

Being proactive

This strategy involves trying to *prevent problems* rather than treat them. This includes thinking ahead of time about how to deal with behaviour problems or specific situations.

Belinda advises that you must *be prepared to deal with behaviour problems* or specific situations like going to the shops and you know the child will have a tantrum: “you’ve got to actually anticipate problems ... anticipate the situations where things go wrong”.

Linda also believes she has the ability to *foresee difficulties*: “I see the problem happening, I’m looking already for the solution. That’s me. I’ve already **seen** the problem and I’m already thinking of where we’re going to find the solution now”.

Continuing to try

Parents of an ADHD child have to *persevere and keep trying*. For some this means always *trying something new* to try help their child. Pat, for example, budgets R100 a month “for experimental things for John – for extra supplements, or taking him to something that’s educational”.

Zelda admits that it is “very hard” being the parent of an ADHD child: “I think you’ve got to really just persevere as it all happens.” Zelda believes you’ve “got to *work ten times harder* than somebody else”.

Michelle believes that it is “a *long, long road*” that parents are going to walk and they need to “persevere”. She warns that “it’s hard”, but parents must put their shoulder to the wheel and “just *keep on pushing*”.

“It’s never, never ending. I feel like I climb 20 rungs up the ladder and I’m knocked back 19. Then I get up 19 and I’m knocked down again. So it’s up and down.”

Separating the child from the disorder

This attitude involves trying to see the *child as distinct from the disorder*. This includes consciously reminding yourself that the child is not always able to control his or her behaviour.

It is very important to Marie that Johan not “be defined by the condition”. She worries that Johan “defines himself by it” and that’s an issue she wants to address. Marie believes he “*doesn’t need to be defined by it* – he is a person living with ADHD, **he is not ADHD** (Marie’s emphasis).”

“Having Johan wearing the label of ADHD isn’t a problem for us. To me he is in the first place a person with a condition. It’s like someone having diabetes – you’re not defined by that. “

Ultimately Marie believes parents must “try to see what God has made - that **wonderful** human being. See **that**. Don’t see your child always through the lenses of ADHD. First see him as this wonderful human being – with a condition. (Marie’s emphasis)”

Michelle too feels parents must learn to “*separate the behaviour from the child*”. Always tell the child that you love the child, but don’t encourage the bad behaviour: “I really love you, unfortunately (never BUT) what you did was incorrect.” Michelle admits that in “the spur of the moment that doesn’t happen”: “What have you done you stupid child.” If Michelle does react that way, she asks the child to forgive her.

Taking one day at a time

This attitude involves the idea of taking things *step by step*. It also means that *each day should start afresh* – forget the events of yesterday and begin anew.

Marie’s first piece of advice is to “just take one day at a time”.

“If you’ve coped with today, pat yourself on the shoulder and go to bed and have a good night’s rest – tomorrow will look after itself. Don’t try to solve **all** the problems that there might be in your thoughts, or wherever – just take one day and *do the best that you can do today*.”

Pat feels “I just try my best and when I have a bad day, just go to bed early and hope that tomorrow the sun’s shining and it’s better.”

Michelle states: “And if I get through the day, I’m grateful. If **they** get through the day, I’m grateful.”

7.4.5.8 School

A number of parents had advice to give about school. Linda advises that the “most important thing is to *find a place where your child is comfortable*”. You have also got to put them into a “*structured environment* otherwise they’re lost and they don’t know who they are anymore”.

Brenda advises having *good interactions with the teachers* and seeing that they know about Ritalin and ADHD in children. Belinda advises *not chopping and changing schools unnecessarily* – “if it’s working, leave them there”.

Pat believes parents must *be involved with the school*: "You (Pat's emphasis) have to know what's going on because that child can't speak for himself." Pat advises that parents must "put them where they need to be".

"You can't expect a child like this to grow out of it, or not be as bad when he's ten, or that kind of thing. You have to *support them*. You decided to have that child; they didn't ask to be born. And, you know what, you have to take **everything** (Pat's emphasis) that comes with him."

Mia advises that parents *not expect their children to be academics*: "So long as they are coping within themselves and they are fitting into their classroom, it doesn't matter what they do or do not achieve. As long as they are achieving to the best of their own ability then it's fine."

Mia has told Lynn: "You know what, I would rather have your school report with the D+ and the C+ and we know how hard you worked, and I'm so proud. I'm so proud; I could actually burst I'm so proud of you. It doesn't matter what the symbol is, it's what you give." Mia believes you "have to just *boost them* and they have to *be proud of who they are*, where they are".

Marie and Leon found that at school Johan particularly battled with mathematics. Marie advises:

"If you see difficulty in maths, don't force him to take the subject at school. Life doesn't begin and end with maths. There is a life outside of maths. *Don't force the child to take maths*; there are other ways. It's just making it too difficult – for you and for the child."

7.4.5.9 Ritalin

Participants advise that parents *be open to the option* of using medication. Belinda advises that if the child is diagnosed as ADHD and Ritalin is suggested, then "put them on Ritalin". And "leave them on it" – don't "take them off, put them on, take them off, put them on". Even if their marks improve, you must not think you can take them off because they are doing better. Belinda believes you need to "*trust that first response of Ritalin*".

Dylan advises that parents must go into the situation "with an *open mind*". Gill and Dylan advise that parents "don't write off the possibility of Ritalin", even if they personally don't like the idea. When Dylan was diagnosed, his attitude was: "Let me

try this, let me see what. If it's going to work - fine. If it's not going to work that's also fine."

Carrie feels that as a parent you "need to *trust your own gut instinct*" and "you definitely need to be prepared to *try different alternatives*". She feels that parents must look "at how Ritalin works and look on how many **levels** (Carrie's emphasis) the medication works".

"That is what so many parents do **not** see; that it **doesn't** just work on the academic level - it works on the social level and the emotional level."

Carrie feels parents should "*give it (Ritalin) a try* – it doesn't have to be for life". Carrie insists that parents "owe it to their children to *try everything* (Carrie's emphasis). Carrie warns that parents should "*not believe everything they read or hear*" about Ritalin. She also cautions that it is important to realise "that Ritalin is a trial and error process".

"Go back; fill in the forms. There must be *proper monitoring*. You don't just let them give you a script and say see you in 6 months time. Especially when they start off, you have to figure it all out. It might not be the right medication. You have to go through this process of trial and error to find out where they fit in on the scale."

7.4.5.10 Try alternatives to Ritalin

Parents also should be open to adding other elements to their treatment toolkit. Marie feels parents should expose themselves to *dietary information*. She believes the available literature doesn't "make a big enough deal of dietary intervention". Dietary intervention has helped Johan "tremendously".

Samantha would "definitely" recommend the *diet*. Samantha actually walks around with the diet in her bag, and if she is with someone "who is battling with their kids", she will "haul it out and show them". Samantha warns, however, that the diet route is "*a life-long commitment*" and it is difficult to stay on it: "You have to just decide it's that or nothing."

If parents are totally against the medication route, then Gill and Dylan feel parents must *try the "natural stuff"*. They emphasise that parents must *DO something though* and not just "sit there and ignore" the problem. If there is any chance of something helping then parents must try it: "You owe your kids. You were the one that brought the kid there, so do it. It will make their life, and in turn your life, easier."

For Michelle “the *diet* definitely works”. Besides following the diet, Michelle recommends that parents *not microwave their food*. She recommends that parents *buy their food unprocessed*, as fresh as you possibly can, and *cook everything from scratch*. Michelle believes there are a lot of small changes you can make that are really effective.

Carrie also recommends that parents consider the *diet* as it works for some children. Carrie believes that if her boys do not follow the diet, she might as well not give them Ritalin – “that is the effect that it has”. Carrie has found that if her boys are *on the diet, the medication works better*.

7.4.5.11 It’s a process

Belinda cautions that parents shouldn’t expect “things to change immediately; it’s actually a *long process*”. For them the big change was when the two children went on Ritalin: “And we saw it in the marks and with Evan we just saw it – he was able to sit down and do some work”.

Michelle too feels that dealing with ADHD is “a process” and parents must know that there “is no ways they will be able to change everything in one go”. Once the child has been diagnosed, Michelle believes that parents should “*take the most problematic thing (usually their behaviour) and start there*”, because it can be so overwhelming when you get all this literature and you’re confronted with all these aspects.

7.4.5.12 Stick with what works

Belinda suggests sticking with what works. *Don’t “chop and change”* or the child will suffer.

7.4.5.13 Tackle things together

Belinda believes that ADHD is “a *family thing* as well”. She believes that the husband must be involved and the two of you need to tackle things together.

Mia believes that *both parents* must go the appointments with any professionals. The mother should not have to handle it alone: “it’s so hard when you have to go to an assessment and you come back and you have to tell them what happened”. Mia feels that health professionals “give you so much information” and “half of it you can’t even explain” to your spouse. Mia feels the father needs to be there “and they need to ask

the questions”. Dave has gone through the entire process with Mia and she believes that is “also why the understanding is there, he has worked through it”.

7.4.5.14 Let your strengths help you

Linda believes that when you parent an ADHD child, your “*strongest characteristics* come into play”. Linda feels her “logic and level headedness” see her through.

7.4.5.15 Find peace in yourself

Linda believes that parents need to find peace within before they can deal with an ADHD child. Linda believes she has this “*inner peace and inner calm*”. She feels she is “in tune” with herself, and in tune with whoever is around her. Her advice to people is to *be “happy in yourself”*: “Instead of wasting your money going to all of these different con artists, or so-called professionals – it depends on what the problem is, but it all boils down to you must be happy in yourself. You must have peace in yourself.”

7.4.5.16 Listen to your child

Marie advises to “listen to your children” and “*listen with your heart*, not your head”. Marie tries to “cut to the feeling behind the words”.

7.4.5.17 Be aware of what you say

Samantha warns that parents must *be careful about what they say* around their ADHD child. Until recently Samantha has always told people that she gave up work to get Claudia through school. When the children wanted “something extra” Samantha would tell them she doesn’t have the money. Claudia “put two and two together” and said to Samantha the other day: “Mommy, you know if you hadn’t given up work we would have been so rich and it’s all **my** fault. “ It shocked Samantha to realise that Claudia had “been living with that for years. Because she said to me: ‘Mom I knew for years and years that we’re not **that** rich because you stopped work you know.’”

7.4.5.18 Tell them you love them

Michelle’s final piece of advice is to “tell them you love them”:

“I love you no matter what you do. So don’t try and make me not love you, because it’s not going to work. I love you no matter what you do. Your behaviour is something else. You I love with all my heart.”

7.4.5.19 Don't discount them

Zelda's advice is that parents treat ADHD children "like *little people*". When Zelda's parents got divorced, she "wanted to know everything" and she feels she would have been "really upset" if she didn't know everything. Zelda *tells Karl everything* and *involves him* in his treatment. She believes the child will "tell you if they don't want to know".

With regard to the medication, Zelda believes that children have a *right to know* why they are taking Ritalin and when they take it, so that they also *have some control*.

7.4.5.20 Time with others

Pat tries to drum it into John that he is special, but she feels he needs to hear it from someone other than his mother or his grandmother. Pat feels that John is likely to think: "You know what, it doesn't matter what I do, they tell me that I'm great." Pat tries to create opportunities for John to spend time with different people – "he's with someone different; he's with someone who will see his special qualities; who will overlook for that period of time his lack of concentration or whatever." Pat has also "made" Alex "spend time with John": "I've kind of pushed him into it". Pat feels that by doing that Alex has seen "his (John's) good points; he's seen his sensitivity; he's seen how affectionate he is".

7.4.5.21.Allow your child to succeed

Samantha recognizes how important it is for Claudia to have *opportunities to succeed*. "If she just feels that she can do it maybe better than somebody else for once in her life, then she feels like she's done something wonderful."

7.4.5.22 Spend fun time

On "a more fun note", Beth and Eve "found a really good way of spending time together". They used to pack a picnic basket and then take the map book, randomly pick a piece of open ground, and go.

"It means the destination is always a surprise and we actually discovered quite a few nice places. She would walk, and climb, and get rid of all her energy. She would pick up leaves and plants and grass, and we would take them home and find out more about them. We would often take the dogs with us as well. As she got older, I would let her help plan for the day: she would plan and help make the picnic, plan what the dogs would need etcetera. It was a really wonderful time for us."

7.4.5.23 Let go

Zelda has also realised that she *can't always be responsible* for Karl: "If he doesn't sit and do his homework after I've told him to do his homework, I'm there to help him, but he's also got to own some responsibility". If Karl gets bad marks for a test because he didn't learn, it's not Zelda's fault.

7.4.5.24 Prayer

Religion helps to see Linda through. Linda advises that parents "guide" their ADHD child and "pray for them".

"Pray for them. Pray for your family. Pray for your marriage, because they're going to put you to the test. I mean, I just don't know how I've even survived this far."

Linda believes parents "have to *appeal to a higher power* to give you the wisdom and the strength to see this thing through".

"I would just pray. I mean I know a lot of people don't believe in things like that. You know a lot of people, anything that they don't see they don't believe in. But I assure you we're not here by pure coincidence; there is a reason for us to be here. And the reason is everything is a *learning experience*. We have to prove ourselves worthy for what comes after. Nobody's going to give you a bigger responsibility or another task to do if you cannot prove that you're responsible with the task that you've been given here."

7.4.5.25 Escape

Pat admits that there are days when the best thing she can do is just to get out of the house: "*I'm out of here*." There are also nights where she will "resort to *alcohol*".

"And I think, you know what, I don't care if I have to swap my glass of wine for eating. Let me just get him sorted out, eat, have your inhaler, bath, brush your teeth and then just get into bed by seven o'clock. And then after that I sit there and think that second glass is looking quite good."

7.5 Extended description

Parents often sense or feel there is something wrong with their child long before they get an official diagnosis. The process of identification can take a long time, and in some cases it takes a crisis for the parents to begin the identification process. During

the identification process, professionals often blame the parents, the family situation, or explore some other reasons for the child's behaviour.

The ADHD diagnosis can be emotionally and intellectually difficult to deal with, even if parents suspected there was something wrong. A number of parents do, however, experience a sense of relief on hearing the diagnosis. After hearing the diagnosis, parents often seek knowledge and the help of professional resources. A number of parents recognise that there may be a hereditary component to their child's ADHD.

Interacting with health professionals is not easy. Parents get frustrated by being shunted from professional to professional, and get tired of endlessly coughing up money. Parents feel many health professionals are not knowledgeable enough about ADHD. Parents want a health professional who will continually monitor their child, and who will be accessible to parents.

Parents have mixed emotions about using medication for ADHD, and putting your child on the medication it is a difficult decision to make. It can take some time after diagnosis for the parents to actually start the child on medication. Most parents do, however, see positive changes in their child's behaviour after putting them on medication, and they are mostly glad that they made the decision to use medication. Most children experience some form of side effect, and it can often take time though to get the dosage and the combination of medications correct for the child. For most parents, medication only forms part of their treatment toolkit for the child with ADHD.

The child must be willing to take the medication and to co-operate in the process. Explaining the taking of the medication to the child can be helpful. At some point the ADHD child must become responsible for monitoring the process. It is a consideration for parents whether the child should take medication during holidays and on weekends. Mornings can be difficult times with regard to medication and transitioning to the day's activities. It is often difficult to deal with extended family on the issue of medication, and the comments from extended family are often negative and biased. Parents may find themselves frustrated with the need to educate extended family, teachers and friends, and the need to defend their decision to use medications.

Most parents feel that you learn to be a parent through trial and error, and that no parenting book can really prepare you for parenting an ADHD child, or any other child for that matter. Family routines often have to be significantly altered to accommodate the child with ADHD. Parenting strategies that were successful for non-ADHD children often do not work for the child with ADHD. Parents tend to spend more time

and energy parenting their child with ADHD than their non-ADHD children. Children with ADHD also often require more of the family's monetary resources. Family activities have to be carefully planned and organised to accommodate the ADHD child.

Parents can feel helpless at times due to an inability to affect change in their child's behaviour. The ADHD child does not follow directions, and parents have to establish behavioural management strategies. Parents are frustrated by their child's inflexible approach to directions or perceptions of events. Parents also have to be extremely careful about how they word directions or during basic communications, as they are easily misinterpreted. Some ADHD children also exhibit high-risk behaviours such as experimenting with drugs.

Parents receive subtle and direct messages from various community members that they are to blame for their child's misbehaviour. Some parents may feel lonely and isolated in their struggle to deal with their child's disorder. Parents can feel overwhelmed and tired at times from dealing with their child's disability. Parents may also feel embarrassed by their child's behaviour across a number of settings and activities. Parents do express grief over the loss of their image of how life was supposed to be with their child.

Some of the parents who have ADHD symptoms themselves find it possible to empathise with the child. Some parents feel that parenting a child with ADHD has changed them as a parent and as a person.

Conflict is evident in the marital relationships of a number of parents of an ADHD child. Single parenting can even be viewed as an easier option for some. Often the ADHD parent's current or former spouse exhibits behaviour characteristics that are similar to their child with ADHD. One parent often makes the majority of childcare decisions, but some parents do find their partner to be a source of support.

In a family who has a child with ADHD, sibling interactions are often negative. In families with more than one child with ADHD, negative sibling interactions can be frequent and intense. For some parents of an ADHD child, the extended family is tolerant; with others the extended family do not fully understand ADHD. Some parents do not have much contact with or help from their extended families, and family members can cause more stress to the parents and their families with their comments or behaviour. There is often a need to educate extended family members about the disorder.

Children with ADHD often have difficulty interacting with peers or making friends. The parents of an ADHD child can also feel isolated socially.

Deciding where to send the ADHD child to school is a significant issue for parents. A number of parents report changes in school placement, for either behavioural or academic reasons. The decision to move their child and the actual move itself can be stressful for all members of the family. Retention can be a significant issue for many parents, and they are concerned about the effects of retention on their child's self-esteem. For some parents having therapy available at school is a benefit, but it may be a concern that the child leaves the regular classroom to go to therapy. Teacher attitudes, the amount of parental involvement, and the increased difficulty of academic and social demands can be of concern as the child progresses from primary to high school.

It is frustrating and tiring for parents to continually advocate for their child's needs with school personnel. When a child moves to a new level, parents have to work with an entirely new set of staff. It is difficult and frustrating to have to, yet again, teach the new staff about their child and to establish a new collaborative relationship. It takes a significant amount of emotional stamina for parents to attend meetings at school regarding their child.

Parents are concerned about teachers' knowledge regarding ADHD and their skills in working with children with ADHD. Some parents are told in subtle or even direct ways that they are to blame for their child's academic and behavioural problems by a variety of school personnel. Parents can be frustrated by the negative comments school personnel make about their children. Often parents feel discounted by the behaviour of, or comments made by, school personnel.

Parents feel that while teachers' knowledge about ADHD is increasing that most teachers still lack basic information about ADHD and how it is manifested in the classroom. Parents believe all teachers should be knowledgeable about ADHD. It is a constant effort for parents to inform school personnel about ADHD, to share their child's particular needs, and to agree upon strategies that would work for the child. Parents are extremely frustrated when they provide materials for teachers to read and later discover the teachers have not read the provided literature.

Often if a child does not display behaviour symptoms of ADHD in the classroom, teachers think there is nothing wrong with them. ADHD children need accommodations made for them related to organisational skills in the classroom. Parents perceive that teachers' knowledge about medications for children with ADHD

is limited. The personality and mind-set of the teacher appear to have the most influence on their ability to successfully teach a child with ADHD. It seems it is better to have a teacher that is innately accepting and nurturing than to have a teacher with a great deal of knowledge about ADHD, because people can always learn about ADHD, but you cannot teach a person to be generous and accepting. Parents feel strongly that teachers should see the potential their child has, and help the child develop their self-esteem.

Parents employ a number of strategies when interacting with the school. First off, parents believe it is important to continue to inform teachers about ADHD. Parents also use a variety of strategies to communicate with teachers, and feel that it is vital to be involved in their child's school activities. If a child's school situation is negative then parents themselves have to pick up more of the work of teaching. Parents believe it is important to diligently monitor their child's homework.

Sport and other extra mural activities have to be approached with caution by parents. The emphasis is on finding an activity where the child can succeed.

With regard to the future, parents fear high-risk behaviours such as getting involved with drugs. There are general fears about long-term goals such as being a responsible adult, partner or parent; enjoying their work; or being prepared for their chosen career. Parents generally accept that their child will not be an academic. Many parents do not see their child as varsity material and often envision their child working with his/her hands.

Parents offer the following advice for other parents whose child has just been diagnosed with ADHD:

- Find the right professionals
- Accept the diagnosis and act
- Have a good support system
- Put structure and routine in place
- When it comes to discipline, stick to your guns, consider implementing a reward system, and teach the child there are consequences for his/her behaviour
- Learn about ADHD and teach others
- Remain positive, accept your child the way he/she is, be proactive, see your child as separate to the disorder, and take one day at a time

- Find a school where your child is comfortable (a remedial school if needs be), don't change schools unnecessarily, be involved with the school, and don't have unrealistic academic expectations
- Be open to trying Ritalin
- Try other alternatives to Ritalin
- Remember it's a process – things won't change overnight
- Stick with what works
- Tackle things together if you have a life-partner
- Let your strengths help you
- Find peace in yourself
- Listen to your child
- Be careful of what you say in front of your ADHD child
- Tell them you love them
- Don't discount them
- Let them spend time with others so they can see the child's special qualities
- Allow your child opportunities to succeed
- Spend fun time together
- You can't always be responsible for them
- Pray
- Escape when you need to

The following and final chapter sets out the implications of and concluding reflections on this study.

CHAPTER EIGHT: IMPLICATIONS AND CLOSING

REFLECTIONS

The purpose of this study was to examine parent perceptions of raising a child with ADHD focusing on

- Parents' perceptions regarding their interaction with health professionals and the child's use of medication
- Parents' perceptions regarding the effects of ADHD on family life
- Parents' perceptions about their ADHD child and the school experience
- Parents' concerns and hopes for their ADHD child
- Getting through the day and advice for other parents of ADHD children

Very little information on parenting an ADHD child could be found in the literature that came directly from parents who had a child with ADHD. This study was unique in that the themes presented emerged from the parents' own words and the methodology allowed a rich and in-depth view of their feelings and beliefs. It would be an important extension of this work to continue the study, using the same methodology, and to interview more parents, especially fathers, to determine if the themes remained static, were enriched, or if they changed.

As stated in the introduction, it is necessary for parents and professionals to understand each other and speak the same language if they are to work together to provide the most effective treatment programme for the ADHD child. A number of implications for health and educational professionals arose from the current study's examination of parents' experiences, insights, and strategies for dealing with the ADHD child.

8.1 Implications for research and practice regarding medical issues

First off, health professionals need to be sensitive to the fact that putting an ADHD child on medication is a difficult decision for parents to take. Prescribing Ritalin is not like prescribing medication for influenza. Parents have to decide whether or not to give a scheduled drug to a child who is not visibly "ill". Health professionals need to be more supportive of parents in this time. Health professionals could assist parents by having literature available on the medication, advising that parents speak to other parents who have had to make this decision, and being available and willing to

answer any questions regarding the medication and the effects thereof that the parents might have. Health professionals also need to warn parents that the medication might need to be adjusted a number of times until the correct dosage for the specific child is achieved.

The grief reaction reported by some of the parents was very striking to the researcher, and the idea of parents going through a grieving process warrants further attention. Parents of an ADHD child may feel they have lost their ideal or dream child. Parents may find themselves trying to find reasons why their child emerged as a different person to their dreams. This aspect of ADHD was not present in the published literature. Literature exists about parents' grief related to having a handicapped or disabled child, but not an ADHD child. It would be important to, firstly, describe the grief process of parents who have a child with ADHD and then, secondly, to describe the similarities and difference between their grief process and the grief process experienced by parents with children who had different types of disabilities.

It must be asked: Do health professionals realise or understand the grief that parents of an ADHD child might experience? What implications does the experience of grief have for the way medical professionals deal with these parents? Do the behaviours and responses of health professionals retard or worsen the parents' grieving process? Do health professionals realise the level of non-acceptance there might be to the news they are about to impart when having to inform parents that their child has ADHD?

Answers to such questions might change health professionals' attitude and behaviours towards parents of an ADHD child. It definitely has the implication that health professionals who present the diagnosis to the parent must learn to be sensitive to the parents' reactions. How the parents are told can have an impact on how the family adjusts to the disability of one of its members. Presenting the diagnosis is not just the transmission of new information.

A possible grief reaction from the parents also has implications for educational professionals, who need to be more responsive to the needs of the parents and family who are in a grieving process. Implications are also that health and educational professionals need to be aware that parents might need counselling after the diagnosis, including some form of grief counselling.

It is often difficult for parents to find a suitable health professional or combination of health professionals. The ideal would be to have one medical person who treats their child as a total person, and who could view the various aspects of treatment from that perspective – rather than fragmented treatment, or trying this here, and trying that there. From the parents' perspective, that person needs to be thorough, be accessible, and provide continuity. Medical professionals also need to include the parents as equal members of the treatment team and value their input regarding the child.

8.2 ADHD and family life

Parents of an ADHD child often deal with constant bombardment of negative perceptions from the community in which they live. One research participant admitted that sometimes she wished that her son had a visible disability so they could actually have some sympathy from the community, instead of being looked at as bad parents. It is evident that a lot of work still needs to be done to educate the general public as to the disorder. According to Barkley (1998), parent support associations, such as ADHASA, offer the best hope that the general public can be provided with a more accurate depiction of ADHD and its treatment. As stated in Chapter Two, Barkley believes these associations can help the public understand that hyperactive disruptive child behaviours can arise out of a biologically based disability, rather than being entirely due to the simplistic, yet pervasive, societal view of bad parenting or diet as its cause.

Participants' attempts to cope with discipline problems include using behaviour modification. One of the multidimensional treatment recommendations for children with ADHD is the use of behaviour modification (Barkley, 1990). It would be important for parents of children with ADHD to receive supportive instruction in behaviour management strategies designed to enhance their child's attention to household tasks and rules. Such programmes are available, but parents need to be more aware of them. An example of such a programme is the eight-session parent course offered by ADHASA. Each session is three hours long and one of the sessions covers behaviour modification at home. Parents, however, need an entry point into such programmes. Health professionals could be an entry point, but health professionals then need to be open to suggesting solutions other than medication, or at least be open to suggesting that parents join an association such as ADHASA. Schools could also be an entry point into such programmes.

One area of support for the family that is missing from programmes such as ADHASA's parent course is a grief counselling component. Perhaps it is missing because the professionals who provide such programmes are unaware of its importance, or are not trained in techniques to address the grief issues of these parents. Grieving issues can, however, have a significant effect upon the lives of the parents. As stated above, additional data needs to be gathered regarding the issue of grief for parents of children with ADHD, and programmes that are developed to assist ADHD families should include components such as coping with grief.

8.3 ADHD and the school experience

From the mouths of the parents, teachers who have an ADHD child under their care should:

- Accept that ADHD exists
- Exhibit a nurturing personality
- Possess or acquire knowledge of ADHD
- Be open and flexible
- Listen to the parents' input
- See the child's potential
- Promote the child's self-esteem

Parents have a desire that their relationship with school personnel be positive and that it be less time consuming. Parents want teachers and other school personnel to treat them with respect and to include them as an equal member of the team. Parents want teachers to listen to them and believe them when they say their child has a problem. When there is a problem, parents want to collaborate with the teacher to solve it as quickly as possible and in a mutually agreeable manner.

Parents want to be updated on all issues regarding their child – problems, but also progress. Parents get tired of always hearing about the negative behaviour traits of their child – say something nice, anything! These parents are compelled to relinquish more time, energy, finances, and emotional energy, in order to persevere when raising the child with ADHD. Yet when they interact with members of the educational community, and their larger social community, the messages they receive are often that their children are “bad”, “lazy”, “disorganised” or that they are “bad parents”.

The work of collaboration needs to begin and there needs to be orientation to, and acceptance of, a collaborative parent-professional relationship in the schools.

Parents do worry about the teacher the child will have. The reality is that parents generally do not have a say in who will teach their child. Barkley (1994) contends that the most ideal teacher for a child with ADHD is not one who is only knowledgeable about ADHD, but who can transfer their knowledge and shape their instructional style based on the needs of such children. Participants in this study demonstrated an intuitive sense of what kind of teacher characteristics were needed for their child to succeed in the classroom. Schools need to listen to that.

Parents also recognise the disparity between the organisational skills required in the school system, and the actual organisational skills that are present in the child with ADHD. In most schools there is little or no direct instruction provided in study and organisational skills. Students are assumed to have developed these skills as they progress through school. It was clear to the participants in the current study that their child had not acquired adequate study and organisational skills, and that the child's academic performance was, therefore, compromised. It is crucial that students with ADHD receive direct instruction in study and organisational skills, and ongoing monitoring especially during their middle and high school years as work demands increase. It is also likely that this lack of planning and organisational skills will carry over into their ability to plan for their own future. It seems, therefore, that they will require greater assistance in planning for post-secondary school activities. Vocational counselling would need to be ongoing and intensive. Input from ADHD adults might be valuable to determine if there are certain careers that are better suited for adults with attentional difficulties than others. School guidance counsellors and school psychologists could incorporate that information into their counselling programmes with learners with ADHD to help them stay focussed on a career.

A final recommendation is for training for professionals who work with learners with ADHD. A consistent comment by the participants in the current study was that their child's teachers did not appear to have much background in working with learners who had ADHD. It may be that teachers are still inadequately prepared to effectively teach children with ADHD. It seems reasonable to recommend that more training on ADHD occur in teacher training programmes for both regular and special education teachers. This training should include both instruction, as well as supervised practice in effective teaching and behaviour management strategies.

8.4 Parents' advice

A number of research participants advised that parents of an ADHD child find a support system. As parents strive to find meaning in their experience it can be helpful to make connections with other parents of children with ADHD. They can identify with each other and find meaning in shared experiences. This can be in the form of a support group, a friend, or a mother at school. Research into the available support groups in South Africa could be valuable to see how they do, or better can serve the needs of parents with children who have ADHD.

Parents also exhibited a very real need to learn about ADHD. Professionals who deal with the disorder need to be aware of this and should be open to reviewing new and old information with parents, and be willing to answer questions. Schools could also take it upon themselves to address this need by holding information evenings for parents. If health and educational professionals are not prepared to answer to this need, they should at the very least refer parents to sources such as ADHASA who can provide information to parents.

8.5 Closing reflections on this study

The primary focus of this research was to provide a description of the experience of parenting a child with ADHD. Using the phenomenological approach, it was possible to access the "insiders" perspective of being such a parent. Phenomenology permits access to the lived experience of the phenomenon.

One of the possible limitations of this study is that some of the experiences reported by the research participants, and some of the behaviours they report that their children display, can also be evident in "normal" families. Further research could perhaps engage a control group of parents with non-ADHD children. This would help in identifying the **unique** experiences of parents with an ADHD child. It is possible that the parents of both ADHD children and non-ADHD children have similar experiences, and that the difference is not in the nature of the experiences or the behaviour, but rather in the intensity thereof.

Another possible limitation of this study is that the participants and the researcher shared a cultural context; therefore the results may not be applicable to persons from a different culture. However, the aim of the research was not to produce statistically generalisable results. A further limit is the fact that, with the exception of one participant, all participants were female. This might imply that mothers are the ones

who primarily deal with the disorder – this, however, needs to be substantiated. It is necessary, however, to examine whether the female experience differs from that of males.

Parents of an ADHD child/ren expend enormous energy and time on their child/ren, often without feeling they are making any progress. And yet they persevere. On the completion of this study, the researcher found herself left with a renewed respect for the resilience and strength of these ordinary, yet extraordinary, parents. Perhaps the major strength of this study lies simply in the advice of the parents who participated because they've been there, done that, got the T-shirt. As one parent says they are living with it twenty-four seven.

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APPENDIX A: PARTICIPANT INFORMATION FORM

PARTICIPANT INFORMATION FORM

1. NAME _____

2. SURNAME _____

3. ADDRESS _____

4. TELEPHONE _____ (W)

_____ (H)

5. BIRTH DATE _____

6. WHAT IS THE HIGHEST LEVEL OF EDUCATION YOU HAVE ACHIEVED? PLEASE CIRCLE THE APPLICABLE OPTION ON THE TABLE BELOW.

6.1 None	1
6.2 Some primary	2
6.3 Primary completed	3
6.4 Some high school	4
6.5 Some high school plus trade certificate / diploma	5
6.6 Matric (Grade 12)	6
6.7 Post-matric – diploma or certificate, not degree	7
6.8 Degree incomplete	8
6.9 Degree completed	9
6.10 More than one degree	10

7. WHICH OF THESE BEST DESCRIBED YOUR MARITAL STATUS? CIRCLE ONE OPTION IN THE TABLE BELOW.

7.1.	Married	-1
7.2.	Living with someone in a stable relationship	-2
7.3.	Single/never married	-3
7.4.	Divorced/separated	-4
7.5.	Widowed	-5

8. PLEASE COMPLETE THE TABLE BELOW FOR **ALL** CHILDREN IN YOUR HOUSEHOLD UP TO AND INCLUDING 18 YEARS OF AGE.

Name	Gender	Age

9. NAME OF ADHD CHILD _____

10. AGE WHEN ADHD CHILD WAS DIAGNOSED _____

11.1 IS HE/SHE ON MEDICATION? _____

11.2 IF SO, WHAT KIND? _____

APPENDIX B: WRITTEN CONSENT FORM

To participants in this study

I am a doctoral student at the University of South Africa (UNISA). The subject of my doctoral research is: *Raising a child with Attention Deficit Hyperactivity Disorder: A parents' perspective*. I am interviewing parents, mothers and fathers, who are raising children who have been diagnosed with Attention Deficit Hyperactivity Disorder. You are one of approximately thirty-five participants.

As part of this study, you are being asked to participate in an in-depth interview. The interview will focus on your everyday experience up to the present time of raising your ADHD child. It will also ask you to reflect on your experience and look ahead to the future. As the interview progresses, I may ask an occasional question for clarification or further understanding, but mainly my part will be to listen as you recreate your experience.

My goal is to analyse the material from all the interviews conducted in order to better understand your experience and that of other adults who are parenting ADHD children. The interview material will be used in my thesis, and I may also use some of the interview material for journal articles, presentations to interested groups, or a book based on my thesis.

Each interview will be audio-taped and later transcribed. In all written materials and oral presentations in which I might use materials from your interview, I will not use your name, names of people close to you, or the name of your work place or city. Transcripts will be typed with initials for names, and in final form the interview will use pseudonyms, as will the report.

You may at any time withdraw from the interview process. You may also withdraw your consent to have specific excerpts used, if you notify me at the end of the interview. If I did want to use any materials in any way not consistent with what is stated above, I would ask for your additional written consent.

I, _____ (NAME IN BLOCK LETTERS) have read the above statement and agree to participate as an interviewee under the conditions stated above.

Signature of participant

Date

APPENDIX C: GENERAL INTERVIEW GUIDE

Introduction

I am a researcher who is interested in the experiences of parents with ADHD children. As a parent of such a child, you are in a unique position to describe what that experience is like and how it affects you. And that is what this interview is about: your experience of ADHD and your thoughts about your experiences.

The answers from all the people I am interviewing, and I'm interviewing about 15 people, will be combined in a report. Nothing you say will ever be identified with you personally. As we go through the interview, if you have any questions about why I am asking something, please feel free to ask. Or if there is anything you don't want to answer just say so. The purpose of this interview is to get your insights into ADHD and how it affects people.

Do you have any questions before we begin?

Interview Questions

1. Describe your family to me.
2. Tell me your perceptions of how you learned to be a parent.
3. Tell me your feelings about the process that you went through that lead to your child's diagnosis.
4. Talk to me about how it felt when you found out that your child has ADHD and the impact it had upon you.
5. Discuss your perceptions of how your immediate family, as well as extended family and friends reacted to the diagnosis.
6. Tell me about your views relating to the medical personnel that you have dealt with regarding your child's ADHD.
7. (If applicable) Tell me about your feelings regarding the use of medication and how that process has been for you.
8. Describe your perceptions of your child's school experiences.
9. Discuss your beliefs regarding the school personnel that you have come into contact with.
10. (If applicable) Describe your views about your child's behaviour with his/her siblings.
11. Discuss your perceptions of what it is like to deal with your child's behaviour.
12. Explain your view of other people's perceptions of you as a parent.
13. Tell me about your view of yourself as a parent.

14. Reflect upon the differences between parenting an ADHD child and a non-ADHD child.
15. Tell me, from your experience of parenting an ADHD child, what you feel would be valuable advice to give to a parent whose child has just been diagnosed as being ADHD.
16. Reflect on your views of the future with regard to your ADHD child.

That covers the things I wanted to ask; is there anything you would like to add.

APPENDIX D: CONSTITUENT PROFILE – BRENDA’S STORY

Brenda and her husband, Mike, have been married since 1990. Their oldest son, Brad, is 17-years-old and is Mike’s son from a previous relationship. Mike and Brenda have “maintained him from the day he was born financially”. When Brad was 13-years-old, his biological mother decided “she couldn’t handle him” and that he must rather live with Brenda and Mike. Mike and Brenda have legally adopted Brad.

Conor is 8-years-old and is Brenda and Mike’s biological son. Conor was diagnosed with ADHD at age seven and takes Ritalin.

Brenda is a registered theatre sister and is currently consulting for theatre for a private company. Mike works in the family business, has a B.Com degree and is currently studying his teaching diploma part-time.

The road to Conor’s diagnosis

Brenda battled to fall pregnant and it is “only through a procedure” that she managed to conceive. She enjoyed her pregnancy and “couldn’t wait for this baby to come”. From day one Conor slept with her – “he was never in the nursery. He slept in my arms in the bed in the maternity ward.”

As a baby and toddler, Conor “was an active child – he would sleep all night, but he was awake all day. But a very happy child, very, always into something.”

When Brenda went back to nursing, Conor was in the crèche at the clinic where she worked. When she started consulting work, Conor went into pre-primary at a private school. Brenda now got her first indication that something was “wrong”. The pre-primary teacher informed Brenda: “There’s something wrong with this child; he **needs** to go onto Ritalin.” Brenda was “very disturbed” that they would suggest putting such a young child onto Ritalin: “This child hasn’t even started school. He was four, four going on five.” The teacher’s response was that Conor must go on Ritalin or he was “never going to make it in Grade 0”.

Brenda did not put Conor on Ritalin: “we just went forward.” Conor did, however, start occupational therapy at the school.

Conor then started Grade 0 at the same private school, and had “a very nice teacher”. There were about 35 children in the class. One day the teacher said to Brenda: “Do you not think your child should go on Ritalin?” The teacher suggested more occupational therapy, so Brenda started taking Conor to a private therapist in the mornings, before she started work. Brenda found it very frustrating that the therapist would not allow her to be in the room for therapy. Brenda wanted to see what the therapist was doing, but the therapist insisted that it would distract Conor. The occupational therapist also thought that Conor should go on Ritalin. Brenda’s thought: “You know, this is like too many people who think that my son must go onto Ritalin.” Brenda’s reaction was to stop seeing the therapist.

Brenda was called into the school at the end of the Grade 0 year. The headmistress told her: “There’s no way this child is going to make it though to Grade 1. He’ll never make Grade 1, and he must go to remedial school.” Brenda was left with three months of the year to find a new school for Grade 1. The headmistress referred Brenda to a special needs school, which “was a nightmare”. To Brenda, the children looked “unkempt”, “handicapped in one way or another”, or “drugged”. Her reaction was: “This is not a place for my son. This is not the place for him. He shouldn’t be here.”

The headmistress had also suggested that Conor go for an EEG to check for epilepsy, even though Brenda – with her medical training – had never seen “any signs of epilepsy whatsoever”. The school referred them to a clinical psychologist at a private clinic. Conor went through a two-hour assessment, for which Brenda had to pay R1 000 before she would be given the report. The report stated that Conor “definitely needs Ritalin” and “definitely needs a remedial school”. The clinical psychologist, however, could not prescribe the Ritalin. He advised Brenda to get the chemist to call him and he would prescribe 10mg three times a day. Brenda’s reaction: “No, I’m not doing this.” Brenda’s sister-in-law has her children on Ritalin, and Brenda sees them as “doped out, very tired, and depressed”. The report also referred Brenda to a neurologist for an EEG. Brenda was upset by inconsistencies in the report itself. The report mentioned two children: Conor and someone called Michael. The report clearly addressed two different children and scenarios. The psychologist stated, “he was very busy, but he would change it”.

By now Conor’s self-esteem was starting to be effected:

“And by now this child thinks that he’s stupid, there’s something wrong with him. We’ve had so many new assessments that now the child’s self-image is gone, his confidence and he feels that he’s.... He’s labelled. ‘Am I stupid, Mom?’ ‘No, you’re not stupid. I think some of the people we see are stupid.’”

Conor went for the EEG, which was “very traumatic” for him, even though Brenda “explained to him in a way that he could understand that there’s not going to be any pain, it doesn’t hurt, he must just lie there still.” The neurologist had a technician do the EEG, which took half-an-hour, and “this child was told not to move.... Which is totally impossible, because I don’t even think any adult can sit for half-an-hour without touching his nose, or moving his fingers or moving his toes.”

Once the EEG was done, Brenda was told that the neurologist was not available to discuss the results as he only deals with Bell’s palsy children, and not ADHD children. Brenda was “very upset”. She phoned and insisted on speaking to the neurologist. The neurologist asked how Conor was coping at school and Brenda told him that Conor was not coping. The neurologist’s response was: “if he’s battling we can give him 10mg of Ritalin three times a day”. Brenda was horrified: “I didn’t know how he could do that, because he hadn’t even seen my child.”

Brenda then went to see her GP, whom she has known since 1985. She saw him as “her ray of hope”. She said to him: “I hope you’re going to tell me he doesn’t need it, because of what I know of Ritalin.” After a physical assessment and after watching Conor for the 45 minutes they were there, his reaction was: “Brenda, I think he does need it.” Brenda, however, reasoned that because her GP knows the psychologist who did the report, he was backing him. She admits: “I was I was hoping I’d meet someone who’d say: ‘he doesn’t need Ritalin, Brenda. He just needs maybe a little bit more learning or discipline into **how** to learn.’”

Belinda decided to find a paediatric psychiatrist to assess Conor, but had no luck getting an appointment with one. By now she had taken Conor out of his school.

Conor started Grade 1 at an assisted learning school and “went to that school with no confidence, low self-esteem and image”.

“And I think he thought there was something wrong with him – that he was stupid. And he wanted to know why he had left all his friends and gone to

another school. You know it was really, it was **very** hard for me and it was hard for him.”

Conor had a very good Grade 1 teacher and the school undertook to assess him over his Grade 1 year. At the end of Grade 1, Brenda was called into a group meeting with the teacher and Conor’s therapists: “What I did like was they treated it holistically.” The whole group, even his teacher who was very much against medication, agreed that Conor must go onto medication. The school referred Brenda to a paediatric neurologist who confirmed the ADHD diagnosis and Ritalin trials began.

Brenda’s feelings about Conor’s diagnosis

It had “a very big impact” on Brenda “when they made the official diagnosis”. Brenda admits, however, that even from pre-primary school she had thought: “My God, what is wrong with my son?” She wondered even then: “how is this child going to cope?”

Brenda believes she might also be ADHD. Brenda “hated school” and her mother told her “she had her on some kind of tablet” when she was at school. Brenda admits: “I’m active... you’ll never see me sitting down for hours on end and watch a soapie, or something... If I look, it’s myself.”

Brenda did not find it a relief that Conor was diagnosed even before starting Grade 1: “it was diagnosed like so early and I thought: ‘He hasn’t even started school and they’ve already got him labelled that he has a problem learning, and he’s never going to get through school.’”

Brenda questions whether we are “pushing these children too far; are we expecting too much out of them?”

“Yes, but the other kids can do it.” **So**, maybe mine’s a little bit slower. I know doctors, specialist anaesthetists who are ADHD and hyperactive. There are marine biologists. You know there are really clever people. But **they’re** not frowned upon. They are looked up on and put on a pedestal. And I was treated like: “**Do you know** your child has a problem?” (Brenda’s emphasis)

Brenda’s husband was “very much calming” when they got the diagnosis. Mike’s reaction was: “You know, Brenda, if there’s a problem at least they’ve addressed the

problem – they can work on it. That's fine – we'll go with it. If he needs to go for an EEG, if he needs the help of the tablets, that's what we do to help him.”

Conor and Ritalin

Belinda admits to feeling guilty about the medication and she questions herself: “I **do** (Brenda's emphasis) have these fights within myself: am I doing the right thing? ... I'm always fighting with my conscience”.

If she doesn't give Conor the medication, Brenda wonders if she will be sorry in ten years time. If she does give it to him, will she have “a serial killer” on her hands in ten years – as the popular media would have her believe? The “contradicting information” frustrates Brenda: Somebody will go: “Ritalin is great. I've seen it; it helps these kids.” And you think, yeah, maybe I am doing the right thing for him. And then you hear: “No, it's really bad.”

Brenda has had the: “Do you realise what you are doing to your son?” Her response is: “Do you have a child with ADHD, because you obviously don't know what you're talking about.” She tell herself that she is doing what she feels is right for her son at this time.

Conor has been on three different trial doses of Ritalin. Brenda admits that she “doesn't like the effects of it.” Conor started on a 10mg dose only in the mornings. He started having headaches to the point where he would vomit. Brenda also noticed a reduced appetite, although because Conor is slightly overweight she wasn't worried about the weight.

The neurologist then cut the dose to 5mg in the mornings and 5mg at half-past eleven. Conor still had the same side-effects and also started to show “a bit of a mood swing, and an extreme tiredness – where this child was like he could hardly walk”. By now he “wasn't eating, simply picking”.

This meant getting hold of the doctor again, who is only available on two mornings of the week for an hour. If Brenda is busy at work, or in theatre, she has to wait for another week.

Conor is now on 7.5mg in the morning and 5mg at 11:30. The neurologist assessed Conor the week before my interview with Brenda. Brenda admits, “he has turned

around”; “there is an improvement”. The neurologist has suggested they continue with the medication as is. The neurologist says Conor needs more help because he is memorising to make up for what he is not learning. He will recite his whole reading book to Brenda, but cannot recognise individual words in the book. As Brenda says: “He’s trained his memory; he’s got an excellent memory. That’s the way he’s coping at school.”

Brenda has two concerns regarding the medication. The first is that Conor is reluctant to take the Ritalin “because he knows he doesn’t feel good on it.” He has, however, told her that he can work better at school when he is taking it. Before the Ritalin, Conor actually said to her: “Mommy, I’m battling at school.” As Brenda says: “For a seven-year-old to tell you that, you know that this kid is **battling**. “ (Brenda’s emphasis)

Brenda’s other concern regarding the medication is how depressed Conor is when she picks him up in the afternoons: “He slumps; he’s tired; he’s introverted”. She has even found him crying in his room in the afternoon. She has said to the neurologist that “his depression” is worrying her, but the neurologist never took it any further: “She doesn’t see him as I see him and I see as a mother; I know how my son is.”

Brenda is adamant that she will not put him on an anti-depressant “to cover the effect of the drug.”

“You know, when do you stop? How many drugs does he need to take? He is eight years old for goodness sake, you know.”

The day before my interview with Brenda, Conor refused to take his morning dose of Ritalin: “He refused utterly and this morning he refused to take it.” Brenda’s husband, Mike, has “seen him much better on it, but he’s also seen him depressed.” When Conor refused to take the Ritalin, Mike’s reaction was: “Don’t give it to him. Don’t give him that anymore – that’s it. Please, don’t give it.”

Brenda is now considering putting Conor onto an herbal supplement instead. She is going to tell the teachers not to give him the Ritalin.

Conor and school

Brenda believes Conor is not hyperactive: “He’s active, but he doesn’t bounce. It’s more of an attention deficit and concentration.” Brenda believes that he can concentrate on something he **wants** to do – “he can channel that”. The problem is

that he can only concentrate “on what he wants to do, not on like the boring things we have to do at school”.

Conor himself doesn’t “have any complaints” about school at present. Brenda is not as happy. She questions whether she has put her son in the right school, because he is surrounded by children who have “bigger problems” – “physical...emotional and mental”.

Brenda has also had problems with the teachers. Conor got a new teacher at the end of Grade 1 who would shout at him to the point where “he never wanted to go to school. She addressed the teacher about it and the teacher responded that he doesn’t concentrate. Brenda’s response:

“...That’s why he’s on the Ritalin. That’s why he’s in a class of 12. That’s why he’s in a small class and I’m paying so much money for you to teach him.”

Brenda feels the teachers don’t “have an understanding of ADHD”. When Conor was put on Ritalin, Brenda made an appointment to see his teacher. The first reaction from the teacher was: “You know Ritalin is bad.” Brenda also disliked the teacher’s attitude about the Ritalin tablets: “You can pop them in his bag.” Brenda takes it very seriously that Ritalin is a scheduled drug and believes the teacher should be locking the tablets in a cupboard. Conor also ended up with tablets left over which tells her “he wasn’t given them.” Brenda has even given the teachers pamphlets on Ritalin to read.

Brenda has also asked the teachers to watch what Conor eats and drinks at school, because of the Ritalin suppressing his appetite. Brenda packs Conor a full lunch with cool drinks and often gets the whole lot back when she collects him. She is especially worried about him not getting in enough fluids. She has “written numerous letters” about this and gone in to see the teachers. According to Brenda “they were not understanding”.

Brenda feels that the teachers have “no empathy”. “There’s not even sympathy, but there’s just no empathy either.” Brenda believes that the teachers, especially as it is an assisted learning school, “should have more input to these children and understand them more and be more supportive of the parents”.

The neurologist has said that Conor is not ready to mainstream yet. So even though she is not happy with the school, Brenda feels she has to “persevere” as there is no other school she can get him into.

Dealing with health professionals

Brenda has got “tired of being pushed from person to person”. She is also tired of “just coughing up money”.

“A thousand rand for a report that didn’t even correlate. The neurologist that has a technician to do the EEGs, but cannot see him. To try and find a paediatric psychiatrist was ...I phoned 15 numbers. To be offered, also by the neurologist, a prescription, a prescribed dose on a daily basis without even **seeing** my son frightens me.”

It annoys her that none of the practitioners that she pays so much money to have ever picked up the phone to ask how Conor is doing – “They’ve taken the money, but they’ve never continued, followed up. There’s no follow-up.” It also annoys her that nobody has asked how she is coping.

Brenda likes the fact that the neurologist assesses Conor to see how he is doing – physically and mentally: “She went through his whole schoolwork book. I was really impressed. She went through every page.”

Extended family

Brenda’s father-in-law refuses to believe there is anything wrong with Conor. He is firmly in the “don’t give him the medicine camp”. He is, however, anti taking medicine in general.

Being Conor’s parent

Brenda clearly loves being a parent: “I would never have it any other way – I don’t know how my life would have been if I didn’t have them and I don’t know what I did with all my time before them.”

Brenda feels you can’t learn to be a parent: “there are no books on being parent. We do the best thing we think we can at that time in life. And all these beautiful books that you buy during pregnancy, which give you the perfect child, the perfect life. The

baby hasn't read it. You're not ready for what you encounter at baby stage, toddler, pre-school. And then we hit problems and nobody can tell you how to handle it."

Brenda finds Conor to be "very obsessive" – "to the point of where I can scream. I can bang my head against a wall because I can't take it." Conor doesn't just want something, he "has to have it"; "he **needs** it" (Brenda's emphasis). Because of how obsessive Conor is, sometimes "it's easier to buy that tank on the shelf, so that I get five minutes of peace." Brenda then feels guilty because she has bought something for Conor and Brad might feel left out. She will then get Brad something. She doesn't want to put Brad in the position where he can say: "Ja, but he always gets and I don't".

Conor also has a problem with being separated from Brenda. He will go and play at a friend's house, but he doesn't want to spend the night: "He wants to be home with me." Even at night time Conor has got to have Brenda there and hates to sleep alone. Brenda has "done everything – the lights on, the dogs are there. 'Do you want a TV on? What would you like?'" Brenda admits though that she was "like that as a child; that was me. I never wanted to be separated from my mother."

Conor and Brad have a "good interaction". Conor asks Brad for help a lot, and Brenda feels that this "for a teenager is a bit demanding". She is aware that there is big age difference and that Brad does not always want Conor around him. Brenda tries to make sure Brad has time for himself. If Brad has a friend visiting, Brenda will try and get one of Conor's friends over so that he gives Brad some space.

Brenda does ask Brad to help out with Conor at times - like with computers and TV games. Brad "always helps him". Brad knows that Conor is ADHD and when Brenda does "remind him about it he relents a bit". Brenda has explained to Brad that Conor's obsessions and his getting upset in the afternoons are part of the disorder and "not Conor's true character". She has also explained to Brad that Conor has a low self-image and "no confidence" and, therefore, Brad must not call him things like "stupid".

Brenda admits that she is "more protective over Conor" than Brad because of the ADHD. When Brenda has to go away on business, she knows that Mike and Brad can look after themselves. However, she always has "doubts" about Conor. She

worries that she's not there "to see that he does eat, that he will drink. And help him with his homework – you know he needs that little bit more time".

Coping

Brenda feels she doesn't need a support group: "I'm one of those people; I can cope on my own. I've got the coping ability. I don't need to meet on a weekly basis and sit there crying with another ten mothers." Brenda does, however, find her immediate family to be a source of support: "Mike was my support. Because, when I felt like my earth was falling apart he'd say: "If they found a problem they can fix it." Yeah, Mike has been a good support. And also Brad. So, there's been that support."

Belinda also copes by telling herself that they are dealing with the problem "the best way we can".

Brenda does admit that having a child with ADHD is "not easy".

"It's not easy; but there's always light at the end of the tunnel. And I think I'm blessed. If I look at other children with more severe problems, I'm blessed. I really am."

Conor and the future

Brenda worries about the future because there's so much conflicting information about the Ritalin. If they keep him on the Ritalin, she wonders how is he going to be when he's 15 or 16? What happens when they take him off the Ritalin? She wonders whether he is "going to be using medication for the rest of his life".

"Those are worries that, as a mother, I think of **every day**. And I've got no answer to them. And nor can anybody else tell me. And it's always: 'Am I doing the right thing?'"

Brenda believes Conor has to learn coping skills, and this is what she wants the school to do. She wants them to teach him how to cope and not have the attitude of: "Well, there's the Ritalin. Now we'll continue learning. Now we're all sorted out."

Brenda feels she is now "only on the first lap. I don't know how many more laps I'm going to go through". She hopes that by the age of 12 or 13, Conor will be back in a mainstream school, "and that he's coping fine". Brenda doesn't believe the ADHD will go away: "I don't think it's a thing that leaves you overnight. Once it's diagnosed and the medication is given, I think it is a life-long thing".

If Brenda looks at Conor's interests, she believes he will either be into marine life or in construction: "He's not going to be an academic". She encourages his interests: "You...you go with what he's good at".

"So, you know ... that's my thoughts for later on in life. I'm going to channel what he's good on."

Brenda's advice for other parents

From Brenda's experience, if the ADHD is picked up, it's normally picked up between five and six-years-old when they start pre-primary or primary school. She advises that as soon as somebody sees there's a problem, you find yourself a good paediatric neurologist or psychiatrist. Her advice is that parents not "go through referral from school, to clinical psychologist, to EEG. Start at the top; go to the person whose going to be able to help you most."

Brenda believes parents should "find some form of support, because there's nothing worse because as mother you feel – you don't know what to do." "And, if support groups are available – if you feel you need a support group – go for them."

Brenda advises having good interactions with the teachers and seeing that they know about Ritalin and ADHD and hyperactivity in children. She believes "these children's lives could be made quite miserable; so you need a good remedial school, a good paediatric neurologist or psychiatrist, and your child needs support. People look at these children as being naughty or lazy – and they're not, they're very clever children."

APPENDIX E: CONSTITUENT PROFILE – BELINDA’S STORY

Belinda is married and she and her husband, Rob, have three children. Evan (17-years-old) and Cathy (10-years-old) were both adopted – they are not biological siblings. Belinda fell pregnant with their youngest son, Frank, through IVF. Frank is now four-years-old.

Both Evan and Cathy have ADHD. Evan was diagnosed at the age of six and Cathy at age eight. Both of them take Ritalin.

Belinda does not work outside of the home, but is currently busy with an Honours degree in Psychology through correspondence.

The road to Evan’s diagnosis

Belinda and Rob started noticing that Evan was a “different child” when he started at his first nursery school. Evan wasn’t a behavioural problem, but “he avoided everything to do with writing and to do with fine motor, and he just avoided things that he struggled with.”

When Evan was put into his second nursery school, things “totally changed”.

“We were called in after he was there for 2 to 3 months and told that if he didn’t change his behaviour we would have to take him out of the school. He was writing on the walls, he was swearing, and the feedback was that he was influencing the other children; that’s what they were saying. And they couldn’t deal with him; they couldn’t cope with him.”

Belinda believes that she and Rob contributed to the problem: “we didn’t know how to set boundaries and limits at home at that point. We had no idea how to limit this gorgeous child and how to cope with him.”

Evan had an assessment by a psychologist at age four. ADHD was not diagnosed at this point, although Belinda believes that “you could see there were signs of it.” Evan went into play therapy and the psychologist focussed on working with his emotions and anger

Evan's Grade one year was "an absolute nightmare because none of the children liked him."

"I would arrive to fetch him and he would be so angry with me and so cross with me, that I didn't know what to do."

Things were not much better at home: "He was becoming very insecure because we needed to like lay down the law for him, and we didn't know how to deal with him."

Evan then went for an assessment with another psychologist and was diagnosed with ADHD at the age of six.

Belinda's feelings about Evan's diagnosis

By the time Evan was diagnosed, Belinda "didn't know what to do anymore for him". Nothing in her upbringing had given her any idea of how to deal with him. All three of them "felt totally out of control." Belinda and Rob felt very relieved when they hear the diagnosis; they now "knew what was wrong".

Evan and Ritalin

Once diagnosed, Evan had an assessment by a paediatrician to be put onto Ritalin. Belinda admits it "was difficult to put Evan onto the Ritalin". Belinda and her family have a "very natural approach" to illness and they don't take medication unless it's serious – "we try and work it through".

"The day he went on Ritalin he was a different child. He could focus and he started learning". Belinda believes the Ritalin helped Evan learn to control his impulses and take the consequences of his behaviour.

Evan takes Ritalin during the week, but not on weekends or in holidays. The most important thing was remembering to give it to him because "the day he didn't take it, something went wrong at school." Belinda and Rob did "sit down and talk to Evan about the medication". They tried to explain to him how it works. They used the metaphor of a motorcar. The child with ADHD is like a motorcar without brakes and Ritalin "is going to help him put on the brakes."

Initially, because Evan was young, they gave the Ritalin to him and "he just took it". As Evan's get older there have been times when he has wanted to come off the

Ritalin. Evan tried to come off Ritalin at the end of primary school. His teacher reported back that he was sitting there and “it took him 45 minutes to actually pick his pen up and start to write – he just could not get going.” Each year in high school they’ve allowed him to do a little trial in conjunction with the doctor. And Evan himself just decides that he needs the Ritalin; he can’t focus without it. Belinda thinks he’s actually decided now that he’s going to stay on it till he’s got his matric, “because he **knows** that it works for him”.

Evan does know though “that he **is** different when he is on it and when he is off it”. Even his friends know he is different. His friends say he is more outgoing and sociable when he is off the Ritalin. But for Belinda taking Ritalin is not about Evan’s social life; it’s about his academic performance.

Part of the family’s natural approach is to try and eat healthily. Belinda did try the diet route with Evan, but found “it was a waste” because he does not enjoy a lot of the prescribed foods. She is, however, very strict about them not having fizzy drinks with sugar in them – sugar-free versions are allowed. She also tries not to buy foods with preservatives although “sometimes there are, and too bad”. The children are allowed sweets on Fridays and she tries to make sure they get fish in their diet. “But it’s more general now than ADHD specific. More a healthy eating plan.” Belinda doesn’t want to become “phobic”: “I’ve seen phobic moms and I just thought, no, I’m not going there.” She does give Evan and Cathy supplements and vitamins – such as Omega 3 and Salmon Oil.

Evan and school

Following his diagnosis, Evan was moved to a school that caters for children with special needs. Evan started play therapy and occupational therapy at the school. For Belinda it was a relief not to have to “rush him around” to these therapies outside of school hours.

For Belinda, the major benefit of Evan’s new school was that the school staff “didn’t see him as a horrible child; they actually could see that he was a child who did not know how to help himself.” Belinda trusted the school: “I knew that he was in good hands.” And she went with their recommendations because she felt “they knew what they were doing”.

Evan is now at an assisted learning school for high school. Evan “loves his school”. Belinda feels “he wasn’t that happy” at his primary school.

“He still struggled socially – he was teased and he was, I think he was labelled by the children. He had good teachers’ ... but he struggled socially.”

The new school “was brilliant because it was totally new people and he could start on a different level.”

Belinda is sceptical about the current school and admits that every year they’ve “thought of taking him out.” They have decided now that “it’s too late” in his school career to change schools again and have had “to just leave it.” Even Evan at times has felt “this isn’t right because it’s too slack.” She feels the school “gets their act together”, but then “it fizzles”.

Belinda believes Evan goes through a “pattern” – “he kind of slips and if you don’t catch him quick enough....” This is one of the reasons Belinda and Rob have not moved Evan from the assisted learning environment – “because in the other systems he might slip and no one would pick it up.” The psychologist at his current school agrees with them that another school might not “catch Evan if he slips”. She feels “it will be worse to actually move him out of another school and bring him back because then his self-esteem will have taken a knock”. Belinda and Rob understand the concern about self-esteem: ‘that we understood and we said: ‘No, let’s just keep him here’.’ Belinda feels Evan’s self-esteem “has been really good” since he’s been at his current school, mostly because he is no longer struggling with friends.

Belinda does believe the current school has taught Evan responsibility: “Because that’s definitely happened and it’s happened at his current school that he’s become responsible”. Evan himself now picks up when he’s slipping academically and says to Belinda: “please will you nag me again”.

When it comes to subjects, Evan is good at maths. He has extra maths lessons as well, because Belinda and Ron believe “that maths is very important”. He is also good at languages – “he’s been very verbal since he was a small child.” He enjoys reading too, as long as it’s a book he has chosen himself. Belinda likes Evan to do an hour or schoolwork on weekdays in his school holidays “just so that the keeps his concentration going and his mind into it”. Evan still battles with handwriting and

Belinda and Rob have had him at an occupational therapist in the last two years to improve it.

For Belinda, dealing with Evan's school has "got much better, but it was, it was terribly hard. I mean when I got called in for Evan, I would feel, uh, I would feel like they were going to attack me". It was important for her to have Rob's support, and to have him with her so they could present a "united front". Belinda believes it makes a big difference if you **both** (Belinda's emphasis) go to see the teachers:

"Somehow they think women are, you know, you're over-emotional -which perhaps I have been. And with Rob being there there's a balance, you know. Maybe at times I **am** emotional and then with Rob being there they can actually address him. And I know Rob knows what the whole story is, so he can deal with it, you know."

Evan and the future

Belinda worries that Evan "actually hasn't got an idea" of "what hard work is about". She worries about "how he's going to cope with university, if he goes, or Technikon, and then there isn't this caring environment around him". Evan wants to study Mechanical Engineering "and he's quite set on it". Belinda and Rob "don't feel at this point in time that he's been programmed for that".

They also worry that Evan is not going to be able to create a structure for himself on his own. Belinda realises that they will have to help him in the future and keep checking: "Are you organised?"

"Perhaps that's going to have to be, until he gets that, sees the importance of it and how he can't sort of survive without that."

The road to Cathy's diagnosis

Cathy started her formal schooling in a mainstream private school. In Grade 0 and Grade 1, Cathy did not appear to have any problems. She was, however, with "a very structured teacher" who "set limits" and "was very strict".

In Grade 2, Cathy had a teacher who was "very arty and free" and her "marks just dropped". Cathy "is a bit of a perfectionist" and she could no longer get the A's she wanted. She started fighting and was having temper tantrums. Belinda believes that Cathy was also trying to deal with the adoption at the time. Cathy was just "a very

unhappy child and did not have any friends.” Belinda states that socially Cathy “was totally inept”.

Belinda and Rob thought that Cathy's problems might be related to a sugar problem, because her behaviour would be worse at certain times of the day, when she was tired. Cathy also had a bladder problem at one point.

Cathy then had an assessment. ADHD was not diagnosed, but it was suggested that Cathy become involved in drama and chess. The family tried that, but “nothing really changed”. A psychiatrist then assessed Cathy and she was diagnosed as ADHD.

Cathy and Ritalin

The teachers at Cathy's school “were very anti her going on anything.” Belinda was “open” to her going on Ritalin, because she has “known the success with Evan.” To Cathy's frustration, the psychiatrist, in consultation with the teachers, decided that Ritalin “wasn't the right way to deal with it.”

“It was very annoying. It felt very, I felt very, like, my self-esteem took a great knock. It was like I was incompetent and, ja.... And I felt very much, um.... (starts to cry) uh ... very alone.”

Belinda found she even started avoiding other parents. With Evan she had already pulled herself away from people, but “somehow I managed to survive that better than with Cathy; when this all came out it was a real struggle.”

In Grade 4, Cathy started social skills training and occupational therapy and “that helped enormously”. She had a new teacher who was “very strict, but very empathic. And she was open to more, although also anti-Ritalin.” At that point there was a “great improvement” in Cathy's socialising, “but her marks, she still struggled with her marks.”

And then, both the occupational therapist and the therapist in the social skills group stated they felt that Cathy was an ADHD candidate. Cathy then went onto Ritalin” “Well, in terms of how she reacted when she was on Ritalin, that was such a relief, that we'd found it.”

Cathy's first trial on Ritalin took place at the end of her Grade 4 year. Things were a "little bit unsettled" though, being the end of the year and it didn't "work well" with an anti-Ritalin teacher. In Grade 5 Cathy was placed with another teacher, who is a remedial teacher who "understood ADHD; understood why we need to go on Ritalin". Cathy went on Ritalin in her first term of Grade 5 and since then she's been on a B-average. They have also been able to "work with the temper tantrums" and she's "now developing friends much better; she's keeping them."

Cathy is "quite happy on the medicine". She has a friend with diabetes and, when putting Cathy onto the Ritalin, Belinda and Rob compared it to her friend's need for insulin.

For Belinda the process of getting Cathy onto Ritalin was a "big fight".

"You don't want to put your children on Ritalin, you really don't, but when you see the results you can understand."

Cathy and school

Cathy is at a mainstream academic school and there is a lot more academic pressure. There are 20 to 23 children in a class.

Cathy enjoys her school. Belinda believes the school understands her daughter and know not to "bombard" her, because then she goes: "Can't do it". Belinda believes Cathy is treated as an individual, although she feels a lot depends on the teacher. Some teachers, such as Cathy's Grade 3 teacher "didn't understand what was going on." The Grade 3 teacher had no concept of "putting in parameters" and, as Belinda says, "that works, you know".

Belinda feels she has had to educate the teachers. For example, the Grade 4 teacher had never had to deal with a child going on a trial of Ritalin – "it was totally new for her; she'd never had it before".

For Belinda, school is a better place now that Cathy is on Ritalin:

"I've actually got to a point now this year, I know, I can just sense in her that's she's, she's capable; she's grown so much, that I don't have to worry so much."

Normally Belinda would insist on knowing which teacher Cathy is going to. This year, even though Cathy has a teacher who only just started teaching, Belinda is quite at ease:

“I know the school won’t employ someone who is not good. And they also know Cathy - they wouldn’t put her with a teacher that’s lenient, she needs somebody with parameters, which is what her teacher is. And she’s just carrying on you know.”

Cathy recently went on a school tour and did not take Ritalin while on tour. When they got back, the teacher asked if Cathy could come off the Ritalin “because she was such a different child – she was like so outgoing and bubbly and happy and talking and laughing.” As with Evan, Belinda had to explain that “it’s **not** for social behaviour, it’s for the concentration.”

Dealing with health professionals

The psychologists that Belinda has dealt with “have been wonderful” and “have really understood ADHD”. She has “been able to trust them”. Belinda feels that the more help they get, the more she has “been able to trust”. There is a psychologist at Evan’s school and Belinda likes the fact that there is “that option for him at the school when he needs it”.

Belinda did have a bad experience with a General Practitioner, when Evan was four years old. Evan had to have his thyroid tested and was nervous and over-active. The GP’s reaction, in front of Evan, was: “Oh, all adopted children are difficult.” As Belinda says: “He had no idea and he was horrid, really horrid.” Naturally the family never went back to him. Belinda also found one of Evan’s occupational therapists to not be “as understanding”.

Family and friends

Belinda believes that Evan’s having ADHD has left them “more isolated”.

“We went away with friends of ours, very close family friends, the one holiday. And they, I know that they actually just couldn’t wait to get away from us because of what was happening, the dynamics in the family were just so, I suppose, difficult.”

Rob's mom and dad couldn't believe it when Evan was diagnosed with ADHD, because "they're not, like they don't have a psychological understanding. Perhaps they did think it was just that we didn't parent him properly."

Belinda's parents were very supportive, "but also perhaps distant because they didn't know how to handle this."

Belinda and Rob set about educating their parents "especially like Rob's parents. They, they didn't understand it."

Being their parent

Belinda believes the children "get on". There is "no hate", even though they bug "the hell out of each other". Evan is very protective over his younger brother, Frank. Belinda and Rob recently went on a ten-day overseas trip. The boys stayed with Rob's parents and Evan "was the security for Frank". Belinda believes Evan "knows how to meet Frank's needs and understands".

Belinda does see differences between her ADHD children and her non-ADHD child. Frank will work on something "till its finished and then go on to something else". Cathy didn't finish things. For example, with colouring she didn't actually finish a picture. And Belinda "never thought it odd because Evan had done the same". She admits to seeing "differences now, because Frank is different."

There are also differences between Belinda's two ADHD children. Cathy is more organised than Evan and she likes to be prepared. Belinda believes it is possibly because Cathy has a milder form of ADHD.

As a little child, Evan was "**very** demanding". Now he "does his own thing." Evan has a workshop and he works on motorbikes, go-karts, friends' bicycles and even the neighbour's lawnmowers. Belinda and Rob instigated that – "that he find something that he enjoys and gets into, channel his energy into it".

Belinda doesn't view Evan's ADHD as all negative. She believes "there is definitely something special in him". Evan is "domesticated" and loves helping. Belinda believes he has a "warm spirit" – "I think, because of his struggles, he's got so much more compassion".

Belinda sees the same qualities in Evan's ADHD friends: "And they do things that are, to me, like worthwhile, spiritual, not materialistically oriented." They are "very special" and they are "incredibly loving".

"They are not shy of being affectionate, even with their friends around. They're proud of their parents; they love their parents."

Evan also has a "sense of security about him". Belinda loves having him in the car with her, because he "makes her feel safe". Evan is also fantastic in an emergency. "He stays cool and clam and handles the situation." Belinda believes he "almost intuitively knows how to cope and how to handle stressful situations."

Belinda stresses that she **has** changed as a parent. Initially she had "no experience in how to put in limits." Belinda believes the experience of parenting an ADHD child helped her to become "more assertive". It has helped her "to be assertive to teachers and to stand there and not think that I'm inadequate."

Belinda has also accepted that she is not to blame and "just because the children have got a problem; it's not **my** (Belinda's emphasis) problem.

"But it **was** the kind of thing that you felt was something to do with your parenting, initially. Now I just know that it **might** have been the parenting (and I wouldn't admit that many years ago) because we **didn't** set limits, but it didn't **cause** it." (Belinda's emphasis)

Belinda believes she and Rob have "learnt so much through this; wow we've learnt – incredibly". Although Belinda has come across ADHD in her studying she feels "the studying doesn't prepare you for it. You then just know the symptoms. It's actually a total different ball game."

"It's probably been, I think it's **definitely** been good for us. And Rob also says he's like grown so much through the children."

Belinda's advice for other parents

Belinda advises that parents avoid going "through your GP" and rather go to somebody that specialises in ADHD. Belinda suggests a full testing by a psychologist, as well as a medical screening for the medication by a medical professional that deals with ADHD. You need to have the right people to help you and you need to cover all the areas, be they occupational therapy or play therapy or

whatever. And if you are not happy with the professional you are dealing with “change and find somebody that’s right” – “it must be a good gut feel”. Belinda does not, however, believe in chopping and changing schools – “if it’s working, leave them there”.

If they are diagnosed as ADHD and Ritalin is suggested, then “put them on Ritalin”. And “leave them on it” – don’t “take them off, put them on, take them off, put them”. Even if their marks improve, you must not think you can take them off because they are doing better. Belinda believes you need to “trust that first response of Ritalin”.

Belinda suggests sticking with what works. Don’t “chop and change” or the child will suffer.

Belinda believes that ADHD is “a family thing as well”. She believes that the husband must be involved and the two of you need to tackle things together.

Belinda also cautions that parents shouldn’t expect “things to change immediately; it’s actually a long process”. For them the big change was when the two children went on Ritalin: “And we saw it in the marks and with Evan we just saw it – he was able to sit down and do some work”.

Belinda feels structure is vital and if “you as parents aren’t used to structure then you’ve actually just, you’ve got to force yourself to do it”. Structure extends to giving the children boundaries, so that behaviourally “they know there’s a consequence if they do this”.

“They take responsibility for their behaviour, because they can choose to behave like this and this happens, or they behave like that and that happens”.

Belinda advises that you must be prepared to deal with behaviour problems or specific situations like going to the shops and you know the child will have a tantrum: “you’ve got to actually anticipate problems ... anticipate the situations where things go wrong”.

Rob and Belinda also went for parental counselling for a year after Evan was diagnosed. The counselling helped them to learn to “put boundaries in place for Evan”: “it wasn’t something that came naturally to us”.

On a practical level, structure includes things like monthly planners for planning time for assignments: “planning is very important”. Structure also includes having a daily routine – knowing that 6 o’clock is supertime and six o’clock in the morning is wake-up time. Belinda also no longer nags. If Evan is not ready to leave for school, she goes without him.

Belinda finds that having support helps. She doesn’t attend a support group, but she has contact with other mothers who have ADHD children. Having a friend in the same situation is “a good support system for each other”. She also talks to some of Evan’s friends about ADHD – “like we talk about it, and can laugh about their antics”. For Belinda, humour “is a saving grace and creates a feeling of connectedness”.

Belinda believes educational talks are very useful: “I’ve been to everything that I’ve seen that can help”. Especially with Evan being an adolescent, new issues become pertinent – like drugs. It is important to get the facts so “you don’t sort of get this panic”.

Ultimately, Rob and Belinda had to learn to accept Evan “the way he is”. This was particularly hard for Rob and it was “a gradual process”.

“At first there is a feeling of disillusionment because he’s not going to be what you imagined he would. And you see him as such a bright little boy. You’ve got to accept the talents he has and see how special he **is** (Belinda’s emphasis), rather than what you want him to be.”

APPENDIX F: CONSTITUENT PROFILE – ANGELA’S STORY

Angela has two children, Colin (20-years-old) and a daughter, Tina, who is 18-years-old. Angela is living in a stable relationship with Pam. Tina was diagnosed with ADHD at the age of 14; she is currently not taking any medication.

The road to Tina’s diagnosis

Angela feels Tina “was always different – from when she was a small child”. There was, however, never anything definite that she could put her finger on and say: “Well, this is a problem.” Tina was “very obviously different” to her older brother though: “they are worlds apart”. Angela told herself “that it’s because they are different”.

As soon as she could walk, Tina started to demonstrate repetitive movement: jumping up and down on the same spot for extended periods, or running back and forth on exactly the same path. Tina was always busy and she would “jump off everything”. Tina would also talk “incessantly and she loved to be the centre of attention”. Angela feels other people were “uncomfortable” around Tina and Angela battled to find a babysitter for her, or to leave her with anyone.

“Funnily enough”, Tina wasn’t a problem when she started school. She was never disruptive or restless in class. However, Tina “wasn’t actually concentrating” and would spend her time in class “doing her own thing” – drawing, writing song lyrics or poetry. Angela believes Tina could get away with not concentrating because she is “very intelligent”.

“So, on the one hand, I didn’t have complaints from the school, but her problem remained untreated because she wasn’t a problem in class. She was likely just ignored by the teachers because she wasn’t a troublemaker.”

Towards the end of primary school Tina started to misbehave. She also started to steal from Angela and lie a lot. Tina would steal money from Angela and “use it to buy things for the other kids at school”. Angela believes that Tina “was trying to buy friends”. Tina also started “a reign of terror on her brother and she would really make his life hell at school”. That she had to give up on when her brother left the school to go to high school. By the end of primary school Tina had started drinking and experimenting with sex.

At the end of primary school, Tina decided that she wanted to go and live with her father in Cape Town. Angela “didn’t think it was a good idea” as her behaviour “was really becoming impossible”. Angela didn’t, however, feel she could keep Tina away from her father. Angela told Tina she could go to Cape Town, “but she had to go for at least two years”. Tina would not be allowed to “just go and come back” as it would have “implications for things like school”.

At that stage, Angela feels, Tina was already “refusing to accept responsibility for anything in her life”. Angela believes that Tina didn’t want to have to say: “I want to go and live with my dad,” because that would imply a choice and she would have to take responsibility for that choice. Tina “ground her fist into her eye socket until she had a black eye” and told people that Angela had hit her “so she **had** to go and stay with her father (Angela’s emphasis)”.

Tina went to Cape Town. She wasn’t happy, and she was “behaving really badly”. Tina was supposed come home to Angela for Christmas at the end of her standard six (Grade 8) year. Tina’s father phoned and said he didn’t want to let her come home. “She was behaving so badly at that stage and he felt he needed some sort of leverage over her. He wanted to stop her going to me as a punishment for her behaviour”. Angela felt that wouldn’t solve anything and Tina came home for Christmas. While Tina was with Angela she tore up her return ticket as a way of not having to go back.

“I put my foot down though and she went back.”

When Tina came back at the end of standard seven (Grade 9), she was “worse than ever”. She was always angry with Angela, and Angela “was always to blame for everything”. Tina would hitchhike and disappear from home, and Angela would “spend hours on the streets looking for her”. Tina wasn’t doing any work at school and “now she was getting into trouble because she wasn’t completing anything or handing anything in”.

Angela took Tina to her GP: “I said to him he had to help me”. “I said to him there’s something wrong with this child”. The GP diagnosed Tina as ADHD and prescribed Ritalin.

Tina and medication

There was “no issue” for Angela when it came to putting Tina on the Ritalin – “not at all”.

“Ritalin was something I had heard about and I know there’s a huge amount of negativity, but quite honestly when you are faced with a child like Tina you are quite happy to try it.”

Angela believes “you could actually watch the effect” when Tina took the Ritalin. Within “20 minutes there was a difference” after Tina took her first Ritalin tablet. “She could concentrate and her schoolwork started to improve”.

Angela’s medical aid, however, would not accept a prescription from a GP and so Angela took Tina to a psychiatrist. The psychiatrist diagnosed a “basal lobe dysfunction”. The psychiatrist explained to Angela that the basal lobe controls emotions, and that Tina’s emotional maturity lagged behind her intellectual and age maturity. The psychiatrist said that Tina “would outgrow this when she was 18”. Tina persuaded the psychiatrist her to put her onto anti-depressants, and at the same time Tina came off the Ritalin. The psychiatrist was very anti Ritalin. According to her the slow release Ritalin is supposed to be addictive, and Tina has an addictive personality. Tina was put onto Lamictin as a mood stabiliser.

Angela feels “it’s been downhill since then”. The following year, when Tina was 16, she fell pregnant by a boy in her class. Angela insisted that Tina have an abortion: “There was no way she was ready to be a mother. And I just wasn’t prepared to put the family through that”.

Angela felt she couldn’t send Tina “back to the same school after that” and put her in a private school. Tina was admitted to Riverfield that year for drug addiction. A new psychiatrist saw her and diagnosed her as compulsive obsessive with a borderline personality disorder. She was put onto Arapax and taken off Lamictin.

At the age of 17, Tina was back in Riverfield for drug rehabilitation. Tina was then taken off Arapax, and put back onto Lamictin and Efexor. Throughout this time she “always leaving home and going to live with friends”. There was also “a succession of different boys that she was seeing”. The year ended with Tina running away for a week with a boy and Angela “didn’t have a clue where she was”. At that stage Angela decided to stop paying for Tina’s medications: “the two tablets combined were costing me R1350 a month. I decided that if this child is going to run away while I’m

paying this, then I don't know what I'm paying it for." Angela spoke to Tina about it when she came back home and Tina's response was "she doesn't need it anymore – she's come off it". So, Tina is now on no medication.

Tina is now 18 and she's "been working not too badly, up until two months ago or a month ago". Angela believes that Tina also suffers from sort of seasonal disorder: "with Tina it seems that as soon as spring starts to come, she goes mad". Tina is in the middle of prelims now, and when prelims started, "she started to go out, and go and a stay at a friend's - not come home; I don't where she is half of the time". Tina has been coming home "sort of a day or two before an exam, and then I would drop her at school and she would go and write her exam". Tina did not write her Maths prelim; she informed Angela that she was missing a book and had probably left it in Cape Town. On the day of my interview with Angela, Tina had decided not to "bother to write" another exam. Angela has decided not to confront her about it: "I'm leaving it, because the consequences are – I'm writing exams now, Colin's writing exams – the consequences are just too great for everybody else. And I think she's disrupted our lives enough."

Angela suspects that Tina is taking drugs again. Tina is usually fanatical about personal hygiene and spends "a fortune" on hair care and make-up. "And for the last month she's bought **nothing** and that money is going somewhere."

Angela has discussed the Ritalin with Tina. Tina has said to Angela that she needs Ritalin to concentrate, "because she does definitely have a bad concentration problem". Angela feels that the "Ritalin has had the best effect that I've seen from any of the drugs. Definitely." Angela believes it "definitely did help". Angela "would like to see Tina back on the Ritalin if it would mean her behaviour would fall in line".

Angela's feelings about Tina's diagnosis

Angela admits that she has "a **huge** (Angela's emphasis) problem" with Tina's ADHD diagnosis and her subsequent diagnoses, because "it's intangible and I don't understand it. I really and truly don't understand it." Angela had asked the doctors to explain: "while they're explaining I might grasp a bit, but the minute I walk out I don't understand it at all. I really have a problem with that."

Angela thinks there is "probably a hereditary component to the ADHD". Angela's cousin has a son with ADHD and he has been on Ritalin since he was in Grade one.

Tina and school

Angela feels that Tina doesn't have any of the learning disabilities "that often go with the ADHD".

Angela feels the primary school Tina was at was not "any help at all". Angela believes that "something should have been picked up by a teacher when she was in their class every day".

In high school – once Tina was back living with Angela - she was seeing the school guidance counsellor virtually daily. Angela was phoned by the guidance counsellor and told that she (Angela) was "dysfunctional". Angela "really was not happy" about this. Angela's son had been through the same school, had full colours, and did eight subjects. He is at university now – he qualifies this year. Angela said to the counsellor: "You know I have another child who went through your school, and I was never accused of being dysfunctional with him, and he didn't have a problem. Now that there's a problem **I'm** dysfunctional. If there's anybody who is dysfunctional it's Tina, not me."

The only problem Tina's teachers had in high school was not disruptive behaviour, but her not handing in work, not doing her homework, and not doing her work in class. There was "virtually nothing on paper for them". The teachers would get hold of Angela and tell her that Tina was not doing her homework. Angela felt that she could "only do so much", and then she had "to back off because the consequences for the rest of the household are huge".

Tina is in Matric (Grade 12) this years and Angela doesn't know if she will pass. Angela believes Tina has got to matric because of "sheer intelligence". Tina particularly battles with Maths, because she missed a year of it. With the learning subjects she can get by on "reading a bit here and there".

"She's managed to get where she is. But look everything's standard grade and she's scraping – but she's still there. But I don't know what to do."

Angela feels that Tina "doesn't want to write matric, in case she fails" – "she cannot have a failure, because then it might be her fault. So she's got to find another way out that she doesn't write that's not her fault."

Dealing with health professionals

Angela feels that the health profession “are not able to help”: “I honestly don’t think they know what to do; that’s my honest opinion”. Angela feels that her GP “was the best one”. He has unfortunately immigrated – “so I don’t even have him to fall back on”.

Angela feels that the psychiatrists Angela has seen “take the side of the patient against the world”. Angela doesn’t believe that that helps.

Extended family

Angela believes that the extended family “all think she’s (Tina) mad”. Angela’s partner, Pam, is a schoolteacher and she “definitely does agree with the ADHD diagnosis”: “She thinks there may be other problems with it, but she does agree with that diagnosis”.

Being Tina’s parent

Angela believes that you learn to be a parent by trial and error: “Purely by trial and error”.

Tina is generally not “hyperactive”. For Angela, Tina’s ADHD is “more about not being able to deal with life, and organise it, and deal with the consequences. No concept of consequences. That, to me, is what ADHD is.”

Tina has been “difficult with food from birth”, and her diet is “terrible”. Angela admits that she doesn’t know how Tina “lives”. Tina decided to become a vegetarian when she was about nine-years-old. The catch is that Tina doesn’t eat vegetables: “So you have a vegetarian who doesn’t eat vegetables”. Tina then went through a phase of living on toasted cheese: “She would eat that morning, noon and night”. She would also eat eggs occasionally. At the moment her craving is tomatoes. For the rest, she lives on “milkshake and ice cream and rubbish”. She drinks a lot of milk – “probably a litre a day” – and she “craves sugar”: “So that’s what she eats – rubbish”. Angela suspects that Tina “probably suffers from malnutrition with the way she eats”.

Tina “definitely” has a concentration problem – “except if it’s something she shouldn’t be doing: then she can concentrate fine”. Tina constantly seeks attention– “it’s like a three year old”. Tina’s attention seeking has even extended to cutting herself.

“I don’t think she’s a self-mutilator – but she read about it. So she decided she’d do this and she only did it **in front** of people. So it wasn’t like you think

– someone sitting in a dark corner in despair. But with her friends, she would take out a blade – attention again. And it gets a reaction – not a good one, but it's still attention.”

Angela believes Tina is “**highly** (Angela’s emphasis) intelligent”. Angela feels that is “half the problem”. “I think if she wasn’t as intelligent, I wouldn’t perhaps have so many problems with her”. The only thing Tina hasn’t “done” is been arrested and “I don’t know that it’s that far off”. Angela has told Tina that if she does something like steal Angela’s car – “which believe me is very possible” – Angela will have her arrested. Angela has to hide her car keys all the time. Tina also doesn’t have access to the telephone landline because she runs up R2000 a month – “she couldn’t care”. Angela has instead bought her a cell phone and put a limit on it – “it shuts off after the limit”.

Angela has to lock the alcohol cupboard, her bedroom, and her son Colin’s bedroom: “Anything that can lock I have to lock”. Tina has broken into the fridge to get alcohol and Angela thinks: “she has a huge alcohol problem”. Angela’s mother was an alcoholic and Angela has always warned her children of the dangers of alcohol: “this is what alcohol does; this is how bad it is”. When Angela speaks to Tina about her drinking, Tina says: “It’s in your family. **Your** family; it’s not my fault – it’s your family.” Angela feels this is Tina again shifting responsibility.

Angela feels that Tina “makes conscious decisions to do what she knows she shouldn’t. It’s not peer pressure – she’s the type of child that you warn **your** kids about. Really. It’s not peer pressure”.

“It’s just horrible. I live in a house with locked doors and it’s not normal – it’s not. But it’s not – and I keep having to stress this to everyone – it’s not the family that’s not normal; there’s one element that is not normal and that is Tina. And if I don’t lock everything it’s far worse. So I rather live like this.”

It worries Angela that Tina doesn’t seem to care about anything: “But then I think there are things that she **must** care about – that she hides. But I don’t what they are or how you would get to them.” Angela worries about Tina because she thinks Tina is “a very unhappy person”.

On a daily basis, Angela feels it’s “like living in a soap opera”.

“If I think of the things that I have done with her and had to go through – it’s almost not true. Because as far as I can see you’d look at somebody like me

and think it must be in my imagination, but it's not. I in fact play it down. I do anything but exaggerate. I can't add salt and pepper – my mind can't go that far.”

Tina and her brother

When it comes to parenting her children, Angela feels “one's a pleasure; one's an absolute nightmare.” Angela cannot spontaneously say things and joke around, because Tina “takes everything very literally”.

“So I've got to think – before I say something I've got to think about it. So that whole spontaneous relationship is not there.”

Angela feels that Tina will be “sweet” and “a little bit helpful” when “she thinks she can use me to her advantage”. If Tina feels that Angela's “usefulness at that point is low”, then she's very aggressive to Angela – “exceptionally aggressive”.

“So dealing with her is very difficult – I've got to think before I say anything.”

Colin basically ignores Tina, unless she approaches him. “There's as little contact as Colin can help”. Angela tries to be “the one though that she (Tina) has to deal with” - “just to keep her away from them”. Angela tries her hardest “to protect Colin from her, because I think he's been through so much with her.” Angela feels it gets easier, because Colin is now twenty and he will eventually live his own life. Angela feels that because Pam is not Tina's mother, “it's easier for Tina to attack her than it is to attack me”. “So it's better if I deal with it.”

Coping

Angela used to feel a tremendous sense of guilt. At first, Angela felt she “sort of was going out of my mind”. Angela believed she must have “obviously done something wrong.”

“But after a number of years – I was going to drive myself insane – I actually then sat and looked at it and thought: ‘But Colin is brought up exactly the same way.’ And you cannot get two more opposite children in the same household. And, if it hadn't been for him, I think I would definitely be blaming myself. And I got to the point where I said to myself: ‘I am actually not to blame.’”

Angela now tries not to react – “I used to react; you know we used to have these stand up screaming fights. Now I just say: ‘It’s your future.’ But it’s easy to do that now that she’s older; when they are younger, you cannot do it.”

Angela feels that, so far, the thing that has helped Tina the most was when she threw her hands up and said: “I am not responsible anymore.” Tina is 18 now and Angela feels “she has to start acting like an adult at some stage”. Angela believes it gave Tina “a big fright for a long time”.

Angela’s “support system in all of this” is her partner Pam. Angela believes you “have to have a very strong relationship to live through this”. Angela feels they used to have friends and family that would spend time with Tina, but “she now isolates herself”. Angela believes that Tina doesn’t “want to be a part of a normal every day life”. “So, people only see her if they come to the house and she happens to be at home.”

Tina has friends, but Angela believes “she buys them and they’re not the friends that she would like you to think they are”. Tina has “got a couple of friends that she rotates”.

“When one has really had enough of her, she moves onto the next one. And then a few months later she’ll go back to the first one. So, she has a huge social problem. It was evident as a child already; she’s always battled with it.”

Tina and the future

Angela feels that “Tina doesn’t seem to see a future for herself”. Angela finds that “frightening”. Angela feels that Tina “must be terrified”. The one thing Tina did suggest was that she goes to England after matric, stays with a friend, and work for a couple of months. Angela feels that “it’s a very good idea”: “Just from the point of view of her then having to grow up.” Tina’s father, however, refuses to allow her to do that.

Angela’s fear for Tina for the future is that she will be on the streets. Angela would like Tina to get her matric; “it doesn’t matter what matric it is”. Angela wants Tina to be happy and to be able to support herself: “That is the sum total. Angela doesn’t “how that will happen” and she doesn’t believe Tina will “be able to support herself even when she’s 30.” Tina has asked why she can’t just stay with Angela “till she’s 35 and just party. She can’t see why she should have to actually earn a living.” Tina actually verbalises that “she doesn’t want to grow up; she doesn’t want to be an

adult; she doesn't want to take responsibility". Angela feels it is "because she's terrified".

Angela doesn't know where her parenting role ends with Tina – "probably never".

"And that feels awful, absolutely awful, because life with her is very, very destructive.... I don't want to be abused for the rest of my life; and that is what is happening now. And it's destructive; it is really destructive. The simple, little things. It's almost as though anything that is right or decent she doesn't want. And your life is destroyed along with her; she tries to bring you down with her. I don't know whether that's conscious or it's just how it is. That's how I feel."

Angela's advice for other parents

Angela believes that parents who have got a child like this "**cannot** be too hard".

"You **cannot** be too disciplined and you **can** give your kids a hiding. This thing that you can't is rubbish. You cannot be hard enough and you cannot be difficult enough. That's the only advice I can give. It's too late when they are 18; it's got to be from when they are two. But it's difficult."

Angela believes that if she had known when Tina was born what she knows now, Tina "wouldn't have been allowed to look sideways without asking, and if she did she would have got a klap. And that is not the socially acceptable way to bring up a child."

Angela believes the situation is complicated though when you have more than one child. She can be really hard with Tina, but if she shouts at Colin "he's devastated". It means having to be "two different parents".

"Like there's no ways I could treat Colin the way I should have disciplined Tina. I think I would have ruined him; I think he would be different."

Angela feels that if she treated Colin as harshly as feels she should have treated Tina it would have changed her "son's perception" of her: "I couldn't have done that to him." Instead, Angela has "tried to be the same with both of them. And one worked and one didn't."

However, Angela feels it would “not have been easier to have her as an only child”. Angela feels she needed Colin to keep her “feet on the ground and keep perspective”.

APPENDIX G: CONSTITUENT PROFILE – LINDA’S STORY

Linda and her husband, Ray, have two children: Ruth, who is seven-years-old and Reese, who is five-years-old. This is Linda’s second marriage; she was married “very young” the first time. Linda has a 28-year-old daughter from her previous marriage. Linda is a stay-at-home mother.

Ruth was diagnosed as ADHD at the age of four and does not take any medication.

The road to Ruth’s diagnosis

The “first thing that was a problem” with Ruth was that “she didn’t speak”. Linda felt she understood everything that was said because when she did books with Ruth, Ruth could “point to what was what”, but she wouldn’t speak. Linda thought it might be Ruth’s palate, because when they took Ruth for speech therapy “the women said it’s the way her tongue is sitting in her mouth”. Linda felt Ruth might be like her father who “spoke late as well”, whereas in her family they “spoke early”.

Ruth was three-and-a-half “before she was talking properly”. Linda “had other problems with her”. Ruth was a “difficult child” and they battled “to get her to do certain things”. Then they had a problem toilet training her. Linda feels it was “almost as if her mind was somewhere else”. Ruth would “pee in her bed” and “pooh in her pants”: “Gosh, she got so many hidings for that.”

Linda felt it “was just like a continual fight with this child to get her to **do** anything”. Ruth was “defiant all the time. You know always fighting with us, always being difficult. Being oppositional.”

From the age of two Ruth went to a Montessori school. By now Reese had arrived. Ruth got a cold one winter and the Montessori teacher noticed that she wasn’t doing things correctly – “like drawing lines straight and whatever”. Linda took Ruth to the GP and he did tests on her. Her ears were found to be very blocked and she eventually had to go to an ENT to have grommets inserted. Linda admits: “I don’t know for how long she couldn’t hear, for how long her ears were blocked.”

After that Ruth went to occupational therapy because she was believed to be sensory defensive and had poor muscle tone. She was also always putting things in her

mouth. No one knew “what was wrong” with Ruth – “they thought that she was autistic. Can you believe it? They couldn’t understand what was wrong with this kid.”

Linda and Ray decided to take Ruth to a child psychologist who specialised in sensory defensive children. Ruth could “do things that astounded the psychologist”. Ruth was “able to put puzzles together within seconds” including a complicated wooden puzzle the psychologist had:

“And she (the psychologist) sat there, sort of like astounded. She said, ‘Well, I don’t even know how to do this thing.’”

The child psychologist was the one who first called Ruth ADHD. Ruth was four-years-old then.

Ruth did Grade 0 at the Montessori school as well, and “she just wouldn’t keep still”. Linda says of Ruth’s teacher: “The woman had to hold onto this kid for her to do her worksheets”.

With Grade 1 on the horizon, Linda realised she “could hardly have put her into a classroom where there were 25 children”. Ruth was put into an assisted learning school with a maximum of 12 children in a class. Ruth’s Grade 1 teacher insisted that she go for further assessment because of her handwriting. And so “it was off to the paediatric neurologist” who diagnosed Ruth as having Oppositional Defiant Disorder as well.

Linda feels that Ruth’s diagnosis “was like a process”. Ruth has “just been one continual powerhouse from the very beginning”. Linda feels Ruth has always “been a very strong-willed girl and she’s got an incredible will power and stubborn and whatever”. Linda perceives Ruth as always having “a mind of her own”.

Linda’s reaction to Ruth’s diagnosis

The neurologist felt that Linda should take Ruth to a child psychiatrist because it is wrong “to have a mind of your own at the age of six”. The neurologist believed Ruth needed to be treated with medication. Linda felt this was absurd: “And I laughed. You know I was actually insulted. Then I said to her: ‘But I’ve always had a mind of my own. Always.’ So I said, ‘Well, she gets it from me. And I’m not ADHD. And I’m not ODD. I’m just myself.’”

Linda believes that you “have to look at the parents to see where the problem comes from”. Linda believes Ruth has inherited her “over-active brain” and inability to keep still from her father.

“But strangely enough, her father is a major success. So, who are we to say what is normal and what is not normal. I can promise you that there are millions of people who fall into this category of ADHD who are very successful. So, I mean, who are we to say what is not normal and what is normal. What, because you have a mind of your own, you’re not normal?”

Treating Ruth

Linda does not believe that medication will solve Ruth’s problems:

“I just feel that my child has got a very strong character, you know. I don’t feel that that’s a reason to chastise her or to hold her back. She’s got an overactive mind. I mean no amount of medication is going to change that. My husband’s never been on medication, you know. I don’t see why I should put her on medication.”

Linda chose to go a more natural route. Linda’s oldest child suffered from allergies as a teenager and Linda had, therefore, already come to know about treatments such as the homeopath and the Centre for the BEST (Bio Energetic Stress Test) Screening. The BEST Screening “tells you the state of your organs and how balanced they are”. The screening can “tell you what bacteria and what viruses you’ve come into contact with”. The screening pinpointed that Ruth had a problem with Candida Albicans. Candida is a fungus that grows wild in the body and can “cause all kinds of problems”. It causes, amongst other problems, irritability, thrush and depression. Ruth has it in her liver and in her descending colon. Linda started giving Ruth Interflora “because that’s the healthy bacteria”.

Linda also took Ruth for allergy testing. Ruth has since outgrown her allergies. Linda started to give Ruth supplements of salmon oil, primrose oil, and flaxseed oil every day and she is still on these. Another thing that she was told to give Ruth is Gingko. Ruth has recently started taking an amino acid called GABA after Linda read about it in book called “Healing ADD”. GABA is “supposed to calm neuronal activity and to inhibit nerve cells from overfiring or firing erratically”. Ruth also takes a multivitamin. Ruth takes all of this in the morning and Linda believes “she’s fine”.

Linda’s feelings about Ritalin

Linda admits that her opinion on Ritalin has changed since reading *Healing ADD*. The author “uses SPECT studies to see what areas of the brain work well, which work too hard or do not work hard enough”. Linda now “can see that Ritalin is suitable for some of these children”. Initially though she “was dead against Ritalin because without seeing the brain as it is and how it functions, it is a criminal thing to put a child onto Ritalin without checking to see whether it’s suitable.”

Linda took Ruth for biofeedback therapy. The therapist sent Ruth’s brainwave readings to New York to ask an expert what he thought. The expert’s opinion was that Ruth must not be put on Ritalin or they will “send her into a bipolar state of mind and once she’s there, you cannot get her back.” As a result, the only way Linda has treated Ruth “is through natural means and homeopathic remedies”. Linda also takes her for reflexology “to balance her energy levels”. “I’ve never put her on any kind of medication, you know”.

Dealing with health professionals

Linda has little respect for health professionals: “I think it’s a money making racket, that’s what I think. And I think they’re misguided”. Linda admits she “was very apprehensive and insulted” that she had to take Ruth to a neurologist.

Linda and Ruth have both had their auras photographed by a mindologist. The mindologist believes you must “heal the energy disturbance, then everything knits together”. The mindologist scoffs at the “neurologist, psychologist, all of these therapies” and believes: “None of you people can do what I do.” The mindologist works through hypnosis and feels that that is the way to heal. This is in keeping with Linda’s belief that “the only way to heal is spiritually”.

“No, I **really** believe it. And it is possible hey; it is possible. I’ve actually seen it; we know that we can do it. I’ve done it with Ruth. If you put your mind to it, you can do it. If you appeal to a higher level you can do it.”

Linda feels there is “no conclusive test” here (in South Africa) to be diagnosed for ADHD; there’s nothing: “The Americans have got technology and equipment where they can see better through SPECT than we’ve got”. Linda believes it is “criminal” to put children onto medication “without knowing whether it agrees with them, whether they’re allergic, what kind of reaction it’s going to have”, just because “the **teacher** says so”. She also believes it is “a waste of money” and that the professionals who “push” Ritalin have “shares in the company and that’s why they want to promote it”.

She concedes that: “as the man who wrote *Healing ADD* says some children benefit from Ritalin. But **not** my child.”

Ruth and school

Linda was advised by the psychologist to put Ruth in “a classroom with a small group of children” and to make sure that she finds “a teacher for her that she can relate to”.

Ruth is “very happy” at school. She doesn’t really have any learning problems, although she does battle with her handwriting and “maybe she could do better with her sums”.

At this point, Linda does not “find the school too bad to deal with”, but admits it is “probably because of the teacher she has this year”. Linda believes the teacher the child has is very important: “Obviously your child has to be guided and taught by somebody that they are relaxed with”. Ruth’s teacher this year has done a course in teaching children with learning difficulties.

Linda feels that for the moment Ruth “is in the best school she could be in”. The psychologist suggested keeping Ruth in the assisted learning environment until Grade 3. After Grade 3 – “once her foundation is set” – Linda could move her. Linda does not think she will move Ruth, because she does not want her in a school with bigger class sizes. More importantly, Ruth is “very happy there”: “You know, she has no complaints and she likes the children. And she’s got a good self-esteem.” Linda believes the “most important thing is to find a place where your child is comfortable”. You have also got to put them into a “structured environment otherwise they’re lost and they don’t know who they are anymore”.

Being Ruth’s parent

Because Linda has a grown-up child from her previous marriage, she feels she “had some experience” being a parent by the time she had Ruth. Linda was married as a teenager the first time and she found it “a huge challenge and a learning curve”. Linda is “very close” to her oldest child.

Linda feels that Ruth’s brother, Reese, is the “most wonderful companion for **her** (Linda’s emphasis)”. Linda has been told that Reese is “one of the crystal children” – “he’s loving and forgiving”. Linda feels Reese is a “delightful child”. He is a “sweet’

and “angel-like child”. He might be “a big teaser”, but he’s willing to allow Ruth “to take the lead”.

Ruth can be “very nasty” to Reese and has “done things to him”. Linda believes Ruth is “jealous” of Reese and initially “resented him being around” because “she’s always wanted to be the centre of attention”.

Linda feels that on a daily basis she has got “to be very hard” with Ruth and has “to shout a lot”. Ruth doesn’t like shouting and noise, but Linda reaches a stage where “enough is enough”. Ruth “throws a lot of tantrums”. Linda “won’t let her get away with anything” and Ruth has “gotten so many hidings –terrible hidings”.

Linda believes both children are “very spoilt though” and “manipulate” her and Ray into “doing things for them”. “If I had to wait for **them** to do things, I’d be waiting forever”. Linda feels that the children are “**difficult**, because they don’t **want** to listen” (Linda’s emphasis).

Linda believes that Ruth makes friends, but not easily. Linda feels that “long-term friendships are a problem”. Because Ruth is “so strong-willed and so controlling” and has “a tendency to have her own way”, it may “break up the friendship”.

Linda finds she has to be “really organised - very organised”. She believes that it is “a blessing for Ruth” that she is so organised and feels that she brings “structure and organisation to Ruth’s life”. Linda believes that “if something were to happen” to her, the “whole thing would fall apart”. Linda feels her husband “doesn’t give attention” to what he thinks are ‘trivial’ things”. As a result Linda has to “pick up all the lose ends”.

Linda’s husband “hasn’t read one of these books on ADHD”. Linda believes the reason might be that “he doesn’t want to read about himself”.

“My husband doesn’t want to read about himself – are you kidding! They don’t want to be told. My husband’s mother is the same. I told his mother. I said that this thing Ruth’s got, she gets it from them. I said to them there’s no hyperactive people in my family.”

Linda feels that she deals with Ruth’s ADHD on her own: “My husband hasn’t helped me with this”.

Coping

Linda believes that when you parent an ADHD child, your “strongest characteristics come into play”. Linda feels her “logic and level headedness” see her through.

Religion also helps to see Linda through. Linda feels that people who “don’t give two hoots about religion until they become chronically ill” are “not very well brought up”. Linda firmly believes that we are “not here by mistake” and that we “are here for a purpose”.

Linda believes that “how we think is so important”. She believes that we need to be positive. If “your mind is negative”, you can “cause of a lot of the bad luck that happens” to you: “Everything that you do comes back to you; everything you think; everything you do”.

Linda believes that Ruth is lucky to have the parents she does. Linda feels Ruth is “very lucky that her father’s got money”. Linda feels there is also a reason that she is Ruth’s mother: “I know what I’m here for. I am the healer”. When Linda had her aura photographed, she was found to have “a green aura” – this means she is “the healer” and she seeks “peace and harmony”. A BEST screening also revealed that Linda’s system is “perfectly balanced”. She believes “that balance” in her system “links in with the centeredness and the healing”.

Linda also believes she has the ability to foresee difficulties: “I see the problem happening, I’m looking already for the solution. That’s me. I’ve already **seen** the problem and I’m already thinking of where we’re going to find the solution now”.

Ruth and the future

Linda sees Ruth as “very charming; she’s a delightful child, very loving child”. But Linda also sees her as “very controlling”. One concern Linda has for the future is that Ruth “might not find a husband like her brother who’s prepared to let her have her way and to do things her way”.

“I mean are you kidding? I mean who’s going to put up with this? Who is going to put up with this? Nobody”.

Linda also worries about whom Ruth is going to be friends with. Linda doesn't want Ruth to be "a miserable, unhappy child": "I mean, you haven't brought a child into the world to be alone, or to have nobody to identify with".

On a practical level, Linda is worried about Ruth driving, "because she's easily distracted".

Ultimately Linda believes Ruth "won't let anybody control her. She wants what she wants." Linda believes that Ruth is an Indigo child: "high-spirited, fun loving, fearless – this is the Indigo child. That's Ruth". Linda believes she has proof of Ruth being an Indigo child because the photo taken of her aura clearly shows it to be "blue and violet". Ruth just wants "to have fun all the time": "They want to go on Space Mountain – the ride at Disney World – **all** the time."

Linda's advice for other parents

Linda believes that parents need to find peace within before they can deal with an ADHD child. Linda believes she has this "inner peace and inner calm". She feels she is "in tune" with herself, and in tune with whoever is around her. Her advice to people is to be "happy in yourself": "instead of wasting your money going to all of these different con artists, or so-called professionals – it depends on what the problem is, but it all boils down to you must be happy in yourself. You must have peace in yourself."

Linda believes parents need "to be very, very strong" to be able to take ADHD children on and "to make a success of it". "You have to be your own person. Don't allow them to take you."

"These children are going to encounter mammoth problems. They're going to bring them to you on your doorstep. They are going to make you want to pull all your hair out. You're going to have to do their homework with them or for them and put their names on the bottom and pretend that they did it, because they couldn't care less. I mean who are we trying to fool here?"

Linda advises that parents "guide" their ADHD child and "pray for them".

"Pray for them. Pray for your family. Pray for your marriage, because they're going to put you to the test. I mean, I just don't know how I've even survived this far."

Linda believes parents "have to appeal to a higher power to give you the wisdom and the strength to see this thing through".

“I would just pray. I mean I know a lot of people don’t believe in things like that. You know a lot of people, anything that they don’t see they don’t believe in. But I assure you we’re not here by pure coincidence; there is a reason for us to be here. And the reason is everything is a learning experience. We have to prove ourselves worthy for what comes after. Nobody’s going to give you a bigger responsibility or another task to do if you cannot prove that you’re responsible with the task that you’ve been given here.”

APPENDIX H: CONSTITUENT PROFILE – MARIE’S STORY

Marie and her husband, Leon, have been married for 23 years. They have two children, a daughter, Liesl, who is 21-years-old and a son, Johan, who is 18-years-old. Johan was only diagnosed with ADHD at the age of 17 and is on Ritalin. Marie is currently busy with an MA in Practical Theology.

The road to Johan’s diagnosis

Both Marie’s children were “allergic babies”, and after breastfeeding they were put on soya milk. Marie and Leon “were worried that there was something wrong” because Johan was “so quiet” as a baby: “actually he slept 23 out of the 24 hours”. Even in utero, Johan was very quiet and at times Marie “was very worried that this child didn’t move”.

Then at about two years of age, Johan had terrible temper tantrums. Marie and her husband would call him “die klein kwaai babatjie” because he had “this terrible anger”. Marie reasoned that he takes after his grandfather “who also has a temperament like that”.

Johan “enjoyed his meals” and by primary school “he was a little chubby”. He was also “very lethargic” and just wanted to sit on the couch and watch TV.

Marie believes Johan went to school “a little early” because his birthday is in November. Johan was assessed before he went to school and the “lady said he’s on the border-line”. Marie wanted to keep him back, but her husband insisted they let him go because “it’s always nice to finish young at school. That’s the perception he had then.”

Johan went into Grade 1 at a government school. The teacher “never complained” about him. Marie is not sure “if she didn’t see it, or if she didn’t want to see it, the teacher, because she was a friend of mine.” If Marie asked, the teacher just said: “No, he’s fine.”

Then, in Grade 2, the teacher called Marie in and said Johan is “suffering.” Marie and Leon had Johan assessed by the school psychologist and he told them “that Johan has an IQ that is only in the upper six per cent of the population”. He recommended

an eye test, which revealed nothing wrong. Johan also did a reading test and a math test. His reading ability “at that age was very good, but his math ability was poor”.

Marie and Leon were “very worried”.

“Now, this man says that Johan has a very high IQ and when we look at the results that he gets from school, it’s not compatible. It worried us and we didn’t how to live with that tension.”

After a few months Marie made an appointment with the headmaster of the school. She asked for Johan to be kept back, because she and Leon “ascribed all this to him being so young”. The headmaster said no. Marie was “devastated”.

“The only resource that I thought I could use to help this child, this man rejected. And I was at a loss for words. And I was in a place that was very uncomfortable for the whole family. Because we **knew**, we knew deep down something should be done for this young man, but we didn’t know what it was and it didn’t have a name. (Marie’s emphasis)”

The search continued. Marie and Leon took Johan for an EEG, which showed nothing wrong with his brain waves. They had him assessed again, in standard 3, by an educational psychologist. She also “confirmed this high IQ and she said we must teach him the spelling rules”. Marie did that, and he “caught onto it so fast”. Johan spells very well, and even better in English than in Afrikaans. He also “reads so well”. The math, however, remained a problem: “always the math”.

Johan then became “very mischievous” and actually “became the class clown – **especially** in the math’s class”. Consequently, it “was always the maths teachers complaining” to Marie. In Standard 6 (Grade 8) Johan went to a smaller school, “more a ‘plaas (farm)’ school”. “But **still**, the math teacher complained (Marie’s emphasis)”.

When Johan was in Standard 9 (Grade 11), his marks deteriorated. Marie believes that he had passed up to that stage because “being so intelligent he caught on to certain things”. But in Standard 9, Marie and Leon saw that Johan wasn’t coping. They were asked to see the biology teacher at parent’s evening. She said that Johan was “really a problem” in class and that he and his friends would “chat the whole way through the lesson”. The teacher felt that Johan was “creating this whole atmosphere of them not wanting to participate or do what they have to do”, and believed that he was “making it very difficult for the rest of the class”.

Marie and Leon did not know what to say. They “knew there was something different with the child”, but they didn’t know “**what**” (Marie’s emphasis). Marie and Leon felt that they did “more than what was expected of any parent” and “still nothing helped”.

“It was so very hard for us, because we did the best we could. We thought we were very good parents.”

Marie and Leon then heard of a woman who is with the National Institute for Enhancement of Learning Potential, and works with learning disabled children. They took Johan to her for tests. She said that Johan was very depressed. Marie admits that even before being told that, she could see Johan was depressed and getting more so. The women did not diagnose Johan as ADHD, which Marie feels “actually confused me more”. She did, however, say that there was a very big difference between Johan’s verbal and non-verbal IQ, and that whenever there is such a big discrepancy it indicates a learning disability. Marie was thrilled: “A learning disability! It was wonderful – having a name for it! Wow!”

The woman at the institute works with dietary interventions, and she suggested taking Johan off wheat and milk immediately – especially because he suffers with sinus as well. Marie and Leon decided to do it and “see what happens”.

It was just before Mother’s Day three years ago that Johan went to the institute, and that Mother’s day the family had their “last wheat meal”. They discussed it with Johan. Marie and Leon “felt so bad” about it, but Johan “knew that something had to be done and he was fine with living without”.

The following afternoon Johan “was a different child”. Johan’s room is usually “such a mess” that you actually don’t “want to walk past it with the door closed”. That afternoon, Johan came home and tidied up his room and packed away everything. Marie couldn’t believe he had the energy to do that: “So, it changed dramatically - within 24 hours”.

One of the things Marie can “really appreciate” about Johan is that “he’s very honest and he talks about his feelings”. If he feels a certain way, he lets Marie know, and she always knows where she stands with him. Johan “immediately said how much better he feels”. So, since that day, they have followed the diet. From Marie and Leon’s side “it’s very difficult”, because “it feels like the whole world revolves around food”. “Wherever you go, whatever you buy, whatever recipe you see, there’s always wheat in it.” The whole household eats wheat-free. They will sometimes cheat and

have something when Johan is not with them. Johan is “so weaned off bread that he doesn’t notice it anymore”.

The woman at the institute also suggested home schooling Johan, because he was having trouble at school, including with the headmaster, and he wanted to leave school. Marie did that for the rest of the year herself. Marie feels that at that time the lectures were very “sub-standard” and nothing “really made sense” to her and Johan. But Johan wanted to do it and “he sat there and studied”.

“He saw that we also wanted him to be better, and he wanted to be better. He wanted so much to be better because he’s always seen himself as not good enough.”

Johan got very lonely being at home though, because he was “this very social being” who “enjoyed being with his friends”. Now that he wasn’t at school, his friends “didn’t contact him that much. Out of sight, out of mind.”

Johan’s friends then completed standard nine, and he didn’t. He didn’t want to go back to school again and Marie and Leon suggested a college. They enrolled him in college and he did a business matric. He finished the same time as his friends did, although he failed two subjects and must still do a re-examination. He’ll be doing that at the end this year.

It was in his matric year that Johan was finally diagnosed as ADHD. Although the dietary intervention had made a big difference, Johan “was still having concentration problems and he was very depressed”. Johan had even asked Mari to do something about the depression. Marie took Johan to see an educational psychologist. The psychologist felt Johan was “severely depressed” and after a few sessions, she referred them to a psychiatrist.

The educational psychologist finally “called it ADHD”. Marie “still called it a learning disability”, but the psychologist asked: “Why do you call it a learning disability? He’s got full-blown ADHD.”

Marie’s feelings about Johan’s diagnosis

Mari felt put out because she “had just started reading up about learning disabilities”, but “it was so nice to be able to give this a name.”

“It took such a huge load off my shoulders. Once it had a name I could deal with it. And for my husband it was just as huge a relief to know what we’re dealing with. Because we parent intensely, and he is very involved, and his family is very important to him and it’s well-being. So for him it’s also been a great, great relief. “

The hardest part of this “whole journey” for Marie was the “not knowing”, the “not being able to give it a name”. After it had been given a name, she studied the subject, so much so that she is doing her Master’s degree in that direction. Marie feels she has “become very knowledgeable”. Marie believes that sometimes she will “look **too** much for the symptoms” (Marie’s emphasis). But her “wish” is “for children to be diagnosed as young as possible, and to empower the parents from a very young age to live with this condition, and to live with it well”.

It is very important to Marie that Johan not “be defined by the condition”. She worries that Johan “defines himself by it” and that’s an issue she wants to address. Marie believes he “doesn’t need to be defined by it – he is a person living with ADHD, **he** is not ADHD (Marie’s emphasis).”

“Having Johan wearing the label of ADHD isn’t a problem for us. To me he is in the first place a person with a condition. It’s like someone having diabetes – you’re not defined by that. “

Johan and Ritalin

The woman that Johan saw at the institute was “very, very much against Ritalin”. Marie believes this is because “the children who reacted badly to Ritalin are often the ones who go to see her”. The dietary intervention likely “really works well for them”. But Johan “still couldn’t concentrate”.

The educational psychologist that Johan saw in Matric said that the “best treatment for ADHD is Ritalin”. Marie was initially “very against Ritalin” because she had “heard it is a bad thing and that it stunts their growth and that you’re a bad mother if you give them Ritalin – it’s the worst thing you can do”.

The educational psychologist reassured her that “things have changed” and explained that her husband was on Ritalin. The psychiatrist that Marie was referred to also has a son who takes Ritalin. The psychiatrist put Johan on something for the depression, and then suggested that they “try the Ritalin”. The educational

psychologist and they psychiatrist explained to Johan about taking the Ritalin, and Johan “wanted to try it – he really wanted to”.

Johan was in college and he had his cell phone with him on the day he started the medication. He phoned home and said: “You won’t believe the difference, I can actually hear what the teachers are saying. I can actually start concentrating.” He experienced an initial dizziness and shakiness, but that disappeared after about two days.

At home Marie found “you could speak to Johan and he registered what you were saying. You could actually ask him to do something and it got done.” Previously they would not give him that many chores in the house “because it became such a thing to get it done – rather leave it and do it yourself”. After he started on the Ritalin, “he was actually looking for opportunities to help us”.

Another “huge improvement” was that Johan “could also study more”. Marie believes, however, that “his history with studies hasn’t really enabled him to really get into it.” But the other day, he got his learner’s licence: “on the first try, he went out and got it”.

So, Johan has been on Ritalin since last year and Marie is not sure how long he will stay on it. The Ritalin does suppress Johan’s appetite, “but with him always being a bit chubby that wasn’t a problem”. His appetite only decreases after he’s taken the dose, so he doesn’t really feel like eating in the mornings. In the afternoon and evenings he’s very hungry though, so he still gets all the nutrients in.

Marie keeps a few Ritalin in her car and Leon does the same, and she has a few in her purse: “Because if he hasn’t taken it, he will let you go to great lengths just to get that tablet to him.”

Health and educational professionals

Marie does not think the “school system educates the teachers enough” on ADHD. She believes it is “getting there” now, but when Johan was in primary school, she doesn’t “think the teachers knew anything and neither did the headmaster”. The school psychologist also did not know what was wrong with Johan.

“No one could give a name to that and it’s not that we have not been to professionals. We’ve been to every professional that we could think of. And it didn’t help - at all. “

Marie believes teachers “were never understanding” of Johan. Teachers would call him a difficult child, a disruptive child, a child who can’t do anything, a child who never does his homework, a child who never listens. No one “ever wanted to see the good in this child”. The exception was an English teacher Johan had in Standard 7. She was “a wonderful teacher, and she saw the potential in him”. Johan has “a very good ability to write poems and do literature”. The teacher got him to enter a poetry competition for which he won second place. But everyone else “just saw this bad one, this one with an attitude, this one who just wants to challenge the disciplinary system”.

Marie wishes there had been “more understanding back then”, especially from the headmaster because he “threw” her “totally off balance for such a long time”. In a time when nobody had an answer, he was the person she “looked up to”; the person that she “thought could give you the answer”. And yet he just said no: “And that was that. No explanation; nothing further.” Marie felt she walked out there and “was left in the middle of nowhere.”

“And it was a very, very difficult place for us to be in at that time – which we didn’t realise then because, being in such difficult, I don’t know, you don’t really think about what you’re going through – you just cope as it comes.”

Extended family

Marie has made an effort to educate her immediate family. Marie’s sister is a teacher at a school for cerebral palsy children and she previously called ADHD “Minimal Brain Dysfunction”. Marie’s sister felt Johan had minimal brain dysfunction. Marie’s sister works with learning-disabled children and does remedial work. Marie feels she has educated sister and her sister has, in turn, educated her.

Marie had had a “support system” in her “family or origin”. Marie has educated her mother and father and given them “reading material”. She included her parents in everything and they have been a “shoulder to cry on” and a “soundboard” for her. Marie’s mother believes that both Marie’s brothers have ADHD. Marie believes her sister has also got the condition, but admits she might be “looking too much”.

Marie believes her father-in-law is also ADHD, but she can't get him to "acknowledge that he's got the condition". Her in-laws are, however, "fine with Johan having the condition and not eating wheat and all that." Her in-laws are "very glad" that they "addressed" Johan's condition, "because at times Johan didn't want to go there because they were always complaining about his bad behaviour and all that".

Being Johan's parent

Marie believes that you "just learn to be a parent as you go along; there's no one to teach you – **unfortunately**" (Marie's emphasis). Marie feels the model she has for being a mother is her own mother: "you just hear your own mother's voice when you work with your children". Marie believes she is fortunate to have a role model who "mothered intensely", "who enjoyed being a mother" and who "gave a lot" for her four children. Mari admits, however, that it's a difficult model to "measure up to", "especially with Johan and him being so difficult".

Mari remembers one night, when she was pregnant with Johan, she prayed to God for a very intelligent child –a leader. Mari admits that after "the bubble burst" and they "knew everything", it felt to her that "the expectations she had for him when he was younger" all "had to die". Marie felt there was a "tremendous grieving process" that she "had to work through". It felt to her "like losing a loved one" and she knew "that those expectations that I had will never be". She believes that her grief led to depression and last year she got medication for depression.

Marie now believes she actually did get the intelligent leader she asked for. She "got all that – but it was in the form of ADHD." In the end "it's been most rewarding".

Johan is a "very, very sociable child" and he has very good friends. Marie believes his "social skills are wonderful" and that "he can let a person feel so good and wanted". Johan also appears "so interested in what the person has to say". Some of his other skills are less well developed. "Although he knows where left and right is, he can't follow direction". His sleep and waking cycles are also disturbed –"if you don't wake him, he won't wake up". Marie believes he would "easily sleep for 24 hours" and he still has "that lethargy".

Marie believes Johan perseveres. When he was little he wanted to kick a rugby ball, and "he did it for days on end". Marie admits that Johan is "over-focussed at times, on certain things". Even as a young child, Johan was "very inquisitive" and "very

curious about funny things, like chemistry for example”. Marie had chemistry 1 at university and Johan thought she should “know everything”. He was always asking questions, which Marie couldn’t always answer. Marie believes Johan asked questions that were “not like questions other children asked” and that he “thought further”.

“And he wanted to **know**. He wasn’t satisfied with just superficial answers. Sometimes we went to the library and found books. And then he couldn’t really understand exactly what they said and I had to go into it, sometimes it was very difficult. But he caught onto those difficult ideas very quickly.”

Marie believes it was fortunate for Johan that she didn’t work, and was at home with him. She admits, however, that it was sometimes “very bad” for her, “because there was no me time”. Marie “felt burdened” and “didn’t know why”. Marie was “so busy rearing these children” and trying to divide attention between her daughter and a son who “took up so much attention”, that she “was lost within that”. At times she felt, “I just don’t want these children; please take them away. I just don’t want them.” Marie especially felt this way later in high school, when Johan was really challenging the system. As he grew up, he challenged the teachers more and he challenged Marie and Leon at home more.

“But we’ve always felt that he’s challenging a discipline, an order, searching for his borders – up to where will we tolerate him. Will we still love him if he does this? And it was, it was very hard at times.”

Johan is always picking a fight with his sister. “If she wants to watch this programme, he wants to watch another programme and he always wins”. Marie admits that she doesn’t “know how to address it”.

At times, Johan’s sister appears to just not “like him much”, even though “she really loves him”. The siblings “don’t interact that much”. Marie admits that she “would have liked them to be a brother and sister that go out together”, but that is not the case. They also have their own friends. Marie believes her daughter “doesn’t really want to get too involved because if they do engage in some activity there’s always a fight”. It seems to Marie that Johan looks for a fight; it’s almost “stimulation seeking”.

Marie feels it is “like Mars and Venus parenting these two – it’s like these children come from different planets.” She admits that the parenting style does vary from the one to the other and “at times it’s been very hard to hold that tension”. It is hard

because she doesn't always know what to do. She doesn't want "to take sides" but sometimes she just knows that her "daughter is right and he is wrong." It's been "emotionally hard" for Marie. At times she doesn't "want these children", she just wants "to be left alone" and not have to "take all that responsibility for them".

Johan spent the first four months of this year doing an environmental education course in Hermanus through the National Sea and Sand Institute. He went with a very good friend of his.

"It was such a good experience for them, because it's not very academic, it's nature, it's diving in the sea, walking in the mountains. It just nature and them, adventure, that thrill-seeking that these children want so very much, just every day."

Johan returned in April and is currently working with his father in his asphaltting business. Marie feels "he's doing very, very well".

Marie believes Johan is grateful for what she and Leon have done. He "thanks us so much that we have walked this way with him".

"He's so grateful because it was such a change when we started making these changes to how it was previously. And he could see that we really wanted to help him and that we were on his side. We were together with him against ADHD. And I really think we've come a long way."

Coping

Marie has read "lots of books" on ADHD. She started studying again in 1999 to try to "get answers" about Johan. Marie did a course through Virginia, in the USA, on the two halves of the brain working together. She re-did the third year of her BA, completed her Psychology Honours, and is currently busy with her Masters degree in practical theology. Marie describes practical theology as a narrative way of working with people: "People bring their story to you and you search with them for a new, better story to live with." Marie would like to work with mothers and "help them to live even more successfully with her child that has this condition".

Marie has found her studies to be "very healing". It has "been a tremendous learning curve" for her as well. Marie believes there "are certain ideas that I had to unlearn because I used to put on the glasses of ADHD before looking at Johan and those were not very good glasses to wear". Marie feels the narrative approach has opened

up “much more possibilities for me to really see him as I would **like** to see him – this wonderful human being that God gave me - and to appreciate him”.

Marie has only recently joined ADHASA (Attention Deficit Hyperactivity Disorder Association of Southern Africa) and she goes to the support group meetings in Randfontein. In August, Marie will be giving a talk at a school. Marie finds it “very helpful” to talk to people about ADHD – “it’s very empowering and it empowers Johan also”. Johan is “not shy of his condition” and he tells people he has ADHD and is taking Ritalin and that he’s so much improved now. Recently Johan was working at a pet shop and he told the owner he is ADHD and that he takes Ritalin. Johan warned the owner that “at times” he does “forget” and asked the owner to “just remind me and be patient with me”. Johan had a wonderful time working there; it “really worked so well”. Marie sees Johan as “very mature – he’s actually an old soul in a young body”.

Marie goes to classes for her Master’s degree and the group must see clients. Johan agreed to be a client and besides enjoying it “tremendously”, Marie believes he “he got such new insights into his problem”. At the session, Johan told the class that you “have to first go through difficulty to get better”. That is Johan’s “motto in life” – “he knows that sometimes you must suffer in order to heal”.

Marie did, however, realise after the session that Johan had built up a negative image of himself. The session had been videotaped and, at home the next day, Johan watched the tape and then asked to watch the home videos of when he was little. He watched them and said to Marie that he had thought he was always this “depressed”, “loner” child. Now he could see he “was actually a very bright, sociable, happy child.” Marie believes that it has “changed his attitude – when he saw how he was, and it was different to the picture that he had of himself in his mind.” Marie feels Johan is now “living out” this happy image.

Marie believes that Johan’s having ADHD has “really empowered” her and recently she has come to appreciate herself and all the abilities she has been “blessed with in dealing with this difficult child”. She is now at a stage where she give herself “recognition for that”, which she didn’t do in the past.

“And, yes, I actually look up to myself, if you can see it in that sense (laughs). And I feel that I have really achieved much and it is this achievement and this knowledge that I would like to share with other people, which has empowered

me tremendously – and my whole family – because it’s empowered us tremendously.”

Johan and the future

Marie is “still worried about these ADHD children being addicted to drugs easily”. She and Leon have had the experience of Johan experimenting with drugs. “

Marie “fears” that Johan will marry “a woman that also has ADHD” and of “them having difficulties in their relationship”. She does realise, however, that he has to “live his life” and “he will sort it out as he goes along”. She will, however, offer her “competencies” if there are “huge problems” so they “can tackle them together, **if** they want to (Marie’s emphasis)”. Marie would “really like to have a good relationship” with her future daughter-in-law and will accept her in “whatever condition she comes”. She just wants “Johan to be happy and them to face the problems which they might encounter. And I’ll be there just to rescue full-speed”.

Marie looks “forward to having grandchildren”, but admits she “will be on the look out for ADHD” in her grandchildren.

“I think that it might make it difficult for my future daughter-in-law, but I will also try to explain **why** I am like that and what we have been through and not let her suffer the way that we did - try not to.”

At the moment it seems Johan will stay with Marie’s husband in the business: “He’s really enjoying it and he really wants to learn the ropes of the business”. Johan asked to go into the business; Marie and Leon “didn’t want to force him into the work.” They also agreed that he start work on the lowest level at a basic salary. Marie and Leon believe: “Sometimes you have to be cruel to be kind.”

Marie’s advice for other parents

Marie’s first piece of advice is to “just take one day at a time”.

“If you’ve coped with today, pat yourself on the shoulder and go to bed and have a good night’s rest – tomorrow will look after itself. Don’t try to solve **all** the problems that there might be in your thoughts, or wherever – just take one day and do the best that you can do **today**.”

Marie also believes parents must get “as much information as you can about the condition”. She feels parents should also expose themselves to dietary information.

Marie believes the available literature doesn't "make a big enough deal of dietary intervention". Dietary intervention has helped Johan "tremendously".

Marie believes it has been vital that John "gained insight into his condition".

"It's been just as important to Johan to have the knowledge as for us. It's tremendously important for him – it's life changing, completely life-changing. It's been important for me, but he has to live with the condition; so I think it's slightly **more** important for him."

When Marie reads something interesting, she shares it with Johan or gives him the article to read, and they discuss it. The whole family has read a book on ADHD and adolescents – "we all read it. That was a good experience; that opened our eyes a lot. "

With regard to his learning problems, Johan particularly battles with math. Marie and Leon found that knowing his times tables and using a calculator, has helped him. Marie advises though:

"If you see difficulty in maths, don't force him to take the subject at school. Life doesn't begin and end with maths. There is a life outside of maths. Don't force the child to take maths; there are other ways. It's just making it too difficult – for you and for the child."

In conclusion, Marie advises to "listen to your children" and "listen with your heart, not your head". Marie tries to "cut to the feeling behind the words". Ultimately Marie believes parents must "try to see what God has made - that **wonderful** human being. See **that**. Don't see your child always through the lenses of ADHD. First see him as this wonderful human being – with a condition. (Marie's emphasis)"

APPENDIX I: CONSTITUENT PROFILE – MIA’S STORY

Mia is married and she and her husband, Dave, have two daughters: Lynn (11-years-old) and Kim (9-years-old). Both Lynn and Kim have ADHD. Lynn was diagnosed at the age of seven and Kim at the age of nine. Both of them take Ritalin. Dave has his own business and both he and Mia work in the business from home.

The road to Lynn’s diagnosis

Mia “started to notice little things” with Lynn “from little”. When Lynn was about three-years old, Mia would be getting ready to go out and would tell Lynn to go to her room and get her shoes. Lynn would come back and say: “I didn’t hear you.” Mia knew she had heard, but believes Lynn didn’t “know how else to interpret the fact that she’s forgotten on the way to go get the shoes”. Mia would send Lynn to get her shoes again and she’d come back with a doll. Mia admits: “there were days when you just want to kill.” Mia didn’t know if Lynn couldn’t understand or if she was on her “own mission”.

Lynn also battled to learn her colours:

“I’d say to her: ‘A red bucket.’ And she’d say: ‘A red bucket.’ And then I’d pick up a spade and say: ‘What colour’s the spade?’ And she goes: ‘Pink.’ And I’d say: ‘No. This colour and this colour are the same – it’s also red. What colour is the spade?’ ‘It’s red.’ ‘What colour is the bucket?’ ‘Green.’”

Mia started to wonder if Lynn was colour blind, because “that went on and on and on”. But there was never any consistency: “one day we were perfect and half-an-hour later it was gone”.

Once Lynn started nursery school, the teacher started to say: “she’s not quite this or we’re not quite getting that”. Lynn was “never a behaviour problem” though. Mia took Lynn for her initial testing when she was about four-and-a-half. Mia was told Lynn needed occupational therapy (OT), and she had a remedial problem, from the point of view that she didn’t have enough vocabulary. Mia and Dave sent Lynn to remedial for about six months. She also did OT for a year – “working on spatial perception and that type of thing”. After a year the occupational therapist told Mia that Lynn had “caught up now” but “might need to go back” in time.

Lynn went into a private school for Grade 0, where the classes are relatively small. Mia watched her “battling emotionally terribly” and felt she “should have actually stayed back a year”. Lynn seemed to manage okay with the schoolwork. In Grade 1, however, “the wheels came off”. Learning to read “was a constant struggle”, handwriting was “a huge problem” and “basic maths was also a problem”. Mia feels Lynn’s self-esteem also “started to go” then. Lynn’s teacher suggested having an EEG done. Dave had petit mal as a child and his father was a grand-mal epileptic, so “there was that history there”. Mia and Dave had Lynn tested, but nothing was found.

Mia was now “starting to get frustrated”, because she wanted to help Lynn who “was in tears all the time”. Dave, however, had an attitude of: “There’s nothing wrong with my child; you’re looking for a problem.” Mia was putting in a lot of time with Lynn:

“All the kids were doing one book or two books; we were doing four books. If they were doing one little bit of maths, we were doing three times the maths. And we were drawing pictures, and I was any which way we could find to try and get her to learn.”

Dave suggested that Mia needed to “spend more time” with Lynn, but Mia said to him: “I can’t spend any more time with her. “ Dave then suggested that Mia go back to OT and remedial. Mia had her reassessed and there were remedial problems, but no occupational problems. So Mia went “back into remedial again”. Mia felt that Lynn’s “self-esteem was getting worse and worse and worse”.

In Grade 2 had a teacher “who is a fantastic lady” and “educated more in the remedial side”. Mia went to see her on the first day: “at this point I couldn’t even believe she had got to Grade 2, and her self-esteem was so, so low that I didn’t know how to cope with it myself.”

The teacher asked if Lynn had been tested for ADHD. Mia admitted that she believed this to be the problem, but was faced with “a husband who believes there is nothing wrong with his child.” At the first parents’ meeting early in the first term, the teacher got all the books together to show Mia and Dave. The teacher first showed them Lynn’s work, and then showed them an “average child’s work”. Lynn wasn’t finishing tasks, and the average child was. Lynn’s handwriting was shocking, and the average child’s, although it wasn’t the best in the class, was still far more legible. Dave’s response was that Lynn needs more remedial, but the teacher insisted: “You’re not listening. I think she needs to go now to someone who’s going to look at her

medically and look at Ritalin.” Dave told her: “My child will never go on Ritalin.” So she said to him: “But it’s not about you. It’s about your child.”

“And when she said those words, he actually stopped. It just wasn’t about him anymore, it was about his child falling apart.”

Mia was “so grateful” to go and see someone. They saw a psychiatrist who told them Lynn was “just screaming out.” Lynn went onto the Ritalin and three days later called Mia in so she could see the difference.

“And you could see the handwriting change, she was finishing her tasks; she was a happier child. And it was just, from there, it’s always been a struggle, but the self-esteem improved so much so quickly.”

Mia’s feelings about Lynn’s diagnosis

Mia was “so relieved” when Lynn was diagnosed and it “wasn’t a shock”. Mia “knew there was a problem from birth”, even though other people, including her family, told her she was “looking for a problem” and there’s “nothing wrong” with her child. Mia eventually thought: “Well maybe I am looking for a problem and it’s not my child, it’s me.”

The family’s reaction to the diagnosis

By the time Lynn was diagnosed Mia “had gotten to the point” where she “was very low”. Mia admits she “was very tearful all the time because trying to get Lynn to cope was such a hard battle; it was such an uphill battle”. By the end of Grade 1, Mia told Dave she was “exhausted.”

” I had pushed her the whole way and pulled her from the front, and this poor little girl had worked so hard without getting there.”

Going to remedial and doing extra homework had “helped, but it wasn’t fixing what was going on”. Mia thinks that by the time Lynn actually got diagnosed the family “all realised that there was something bigger”.

The road to Kim’s diagnosis

Kim’s diagnosis was “a whole different process”. Mia sees her daughters as “very different” personalities. Lynn is a “far more gentle child”; “she seems to take things far more personally and self-esteem is far more of a problem”.

Mia sees Kim as “far more outgoing and nothing seems to get Kim down”. Kim “takes everything in her stride, whereas Lynn doesn’t”. At nursery school Kim just “never seemed to battle with anything”. She learnt all her colours and nursery rhymes without problems and every milestone we had was fine.

Because of Lynn, Mia kept going to the nursery school teacher and saying: “If you see anything, I’d rather have a test now.” Mia was “very aware with Kim”. The school reassured Mia that “everything’s fine...no problems here. “

Kim “flew through Grade 0”. In Grade 1 Kim had the same teacher that Lynn had in Grade 0. Mia felt the teacher “knew the family history” and how much Mia had “battled”. Mia still kept checking in with the teacher and the teacher continued to assure her that everything was “fine”: “There was never, ever mention of a problem.”

Kim would come home in the afternoon and doing her reading: “it was just quick.” Math was also “never a problem”. This was a relief to Mia:

“So, whatever homework we were doing with her (Kim) I was whizzing through, but Lynn still battled. So, I was still sitting spending so much time with Lynn trying to get her through each thing. So it was: ‘ This one’s finished. Fine you go and play.’ And then sit there with the next one.”

Mia now realises Kim was just reciting her reading book, which her “very good memory” allowed her to do.

Kim was still fine in the first term of Grade 1, but at the end of the second term she came home with a school report that was “shocking, absolutely frightening”. Mia was so shocked that she checked the envelope to see whether she had been given “the wrong child’s” report. Kim was “failing on every level, and the teacher had never said anything”.

Mia went to see the teacher at the beginning of the third term. The teacher reported that Kim seemed “to be battling with one or two things. It’s nothing major.” When Mia asked the teacher to be more specific, the teacher was “not so sure”. Mia insisted on going through “every one” of Kim’s books and found “nothing’s finished, nothing’s completed, nothing’s stuck in”.

Mia was horrified as she is at school “all the time” and the teacher “never said anything to me”. The teacher also reported that Kim kept complaining that her “tummy is sore” and asked to go home. Again, Mia had not been told this. Kim was “happy enough” to go to school, but Mia realised that “once she gets here and the work gets going there’s now a problem”. Mia feels the teacher knew nothing about Kim: “other than the fact that she knew the child was in class, I don’t think she knew anything about her. She just forgot about her.”

Mia saw the principal and the teacher ended up getting fired – although not just because of the situation with Kim. Mia felt she didn’t “pay for an education like this.” Ultimately, Mia felt she “had lost an entire year”. Mia was worried about Kim going to Grade 2. She felt the school “didn’t even know themselves what her abilities were”. Mia felt it was “not fair” for Kim to “lose a year out of her life”, but did not want to “put her up” and find she’s not coping: “So, there we sat.”

Mia admits that the school were “very good” and the principal started teaching Kim “on a one-to-one basis”. Mia started having Kim assessed, and after the first assessment, they said that they felt there was an eye problem. Mia took Kim to see a doctor who is an optometrist as well as an educational vision therapist. Mia feels he is “the most phenomenal doctor”. Mia wishes that people could get sent to him “in the first place”, especially after the “run-around” they had with Lynn. The vision therapist looks at how the eye takes in information, how they process it, and then how they’re able to put it out again. Vision therapy is like physical therapy for the eyes and the brain. The vision therapist explained to Mia that the eyes are direct physical extensions of the brain. We see with our brains and minds, not just our eyes.

Mia got to sit and **watch** (Mia’s emphasis) the eye test although she was not allowed say anything. When the therapist did the first eye test on Kim, Mia “actually burst into tears”. The vision therapist shone a red light on the wall. Kim had to wear “fancy glasses”, and shine her own light on top of the red light. Kim’s “was about 30cm out and she thought the two lights were on top of each other”. The therapist found that Kim could not cross the mid-line, and she was ambidextrous – “which I had only just started to realise at home because she would swap hands when she was writing”. Kim was also short-sighted, and she didn’t have any 3-D vision. Mia felt “there was so much that it was mind-boggling”.

Mia liked, however, that you could “physically for yourself see where the problem is”. With a lot of “other assessments they go for, you know you drop the kid there for the day, you come back, they give you a list of where they think the problems are”. The vision therapist asked Mia to come back in a week for a full report-back, but in the mean time suggested checking Kim for epilepsy which, with the family history, Mia agreed to.

Kim had the EEG done and the neurologist said she definitely had petit mal. Mia thought: “Well, that’s fine; now we’ve found the problem.” Kim was put on medication, but had an allergic reaction to it. Kim now had to be put onto an antidote, weaned off, and put onto the next medication. She then got hyperactive, so she had to be weaned again and put onto something else. With each new medication an EEG was done. The doctor also checked Kim for brain tumours and cancer. Mia was also advised to take Kim for a hearing test, which revealed no hearing problems.

“We did all that. It just felt like every time I got to one place, they would say: “No, you need to go get these three things looked at.” Then I’d go get those three looked at. Then somebody else would send me for another... and that part, where you don’t know always what’s wrong”.

The vision therapist’s report recommended that Kim go for occupational therapy and remedial work, which she did. The school decided to put Kim up to Grade 2 and “see how she went”. If she really didn’t cope, they wouldn’t put her down a year. She would remain in Grade 2 for the rest of the year and be given work that she could cope with, and then she would have to repeat the year.

In the interim, Lynn “still was battling along so much”. Mia decided to take Lynn to the vision therapist as well. Lynn’s results were almost identical. Both the girls were given “tinted glasses”, which they wear for reading and writing or any work that they do”. Both girls also ended up going for remedial, OT and eye therapy work. The remedial they can do at school, but Mia found with Lynn doing it at school that she was being taken out of class during certain subjects. Mia felt this was not good for Lynn’s self-esteem:

“If you have a child with low self-esteem, I’ve realised, the other kids all go: ‘Well, where’re you going? Why are you missing out?’ and she didn’t cope well with that. So I decided then that I would rather actually do it outside of school in our own time, you know.”

The eye therapy involved “exercises to fix the problems”. The vision therapist actually teaches the parent how to teach the child. Mia thought this was “fantastic”: “rarely do you go somewhere and they actually show you how to help the child”. Mia believes the blue tinted glasses have made a difference and Lynn’s initially sceptical teacher agrees. Lynn’s reading and the speed of her reading have improved because she can decipher individual letters. The glasses also help her 3-D vision. At Lynn’s school they have white boards and they write on them in black pen. Because it’s white, with black on top, for somebody who has a 3-D vision problem, the words don’t stand out properly. The vision therapy also corrected Kim’s inability to write on a line “in no time at all”.

Mia admits that she has not sustained doing the eye therapy exercises. “It built up and built up until it was almost like an hour each a day”, and the girls have to practice individually. Homework, OT and remedial also had to be slotted into the day: “we just couldn’t keep pace with it all. It’s exhausting.”

In the end, it turned out Kim does not have petit mal. Kim was due for another EEG before starting Grade 3 this year. Because Mia “just didn’t like her doctor”, Kim went to another neurologist at the end of last year. This doctor found no evidence of petit mal and Mia had it confirmed by a third doctor: “Nothing. So we’d gone through all that for nothing.”

So, “after all that, my child had to get weaned off of all the medication again and we started from scratch again this year”. Halfway through this year, Kim’s teacher called Mia in as Kim was battling. Kim has now been put on Ritalin, and “it’s made a huge difference”.

The medication

By the time Lynn saw the psychiatrist, Dave was “quite happy to put her on the Ritalin”. The family saw a big “turnaround – literally within 72 hours we had a different child”. For the first time, Lynn could come home and say: “Mommy, I finished first in my class today”. Lynn’s handwriting also improved “and just little things that obviously meant so much to her”. Mia believes Lynn’s teachers also make a “big difference” because they “boost her all the time and praised her”. It still took a long time for Lynn’s self-esteem to recover: once she started to get on her feet it still took...it really was tough. It just took one child to have a comment or something to say and then she’d fall apart again, you know”.

Mia knows that Ritalin is not a cure-all for Lynn:

“But every year’s been, I mean we just get through; we just struggle through. It’s not kind of a thing where you think: ‘Oh well now she’ll get the medication and everything will fall into place and I’ll have a genius on my hands.’ It doesn’t work that way.”

Kim has only been on the Ritalin for a while. Mia believes both girls are “fine with taking it”. Both the psychiatrist and Mia explained what Ritalin would do and Mia asked the girls to let her know if they “don’t feel right”. When the girls are taking Ritalin it seems to Mia that “their brain’s suddenly been switched on. I mean, all of a sudden they’re finishing their work and they’re on the ball.” Initially when they start taking it they are tired and they get a bit of a headache. Lynn will not eat during the day: “while the Ritalin is still in her body she won’t eat.” Mia just makes sure that Lynn has a decent breakfast and that she eats at night. Lynn will, however, “make up for it” on weekends and during the holidays when she is off the Ritalin.

“So I’ve got a child who maybe will be skinny for her whole life. If that’s the biggest side effect I’ve got no complaints.”

Mia finds “people are very quick to judge” her putting the girls on Ritalin and that “there is a lot of ignorance out there”. Mia has had friends tell her that there’s “nothing wrong” with her child and that she “has taken the easy way out”. People ask her why she has not tried other options. This really annoys Mia because she has tried all the other options, such as the homeopath and natural supplements. If any of the natural stuff “had made a difference”, Mia would “have stuck with it.” As Mia says: “I didn’t wake up one morning and say: ‘Well I think today I’m going to go and put my child on Ritalin’.” Mia feels that she got to the point where she “needed to make a big change”.

Dealing with school

At the stage when a decision had to be made on whether to keep Kim back, and Lynn was still battling at school, the principal told Mia that she “might need to look for remedial schooling, this may not be the place for them”. Mia felt she was “not prepared” to put them in a remedial school unless she had “done everything”. If she had exhausted all therapy options and she still found the girls were unhappy and not coping, she would “hang up her gloves” and “gladly look elsewhere”. Mia believes that once “they start at a school like that, they will never mainstream again”. Mia also

did not want to move the girls, as they both “love” their school. Mia’s only other option would be to “maybe home school them”, but Mia admits she “might kill somebody”. Mia also believes that though the girls “battle”, they “learn from it”.

To Mia’s relief, by the end of that year Lynn’s marks for Grade 4 were the best ever. Lynn’s teacher saw an improvement “every month” and felt “her self-esteem is so high.” Mia finally felt there was “light at the end of the tunnel”. Mia also admires how her girls have “never complained once, they never moaned”, even though they were doing remedial twice a week, OT twice a week, and eye therapy.

“There wasn’t one day we didn’t get home between half-past-five and six. And then Lynn still sat and did an hour-and-a-half’s worth of homework and then we’d get up at half-past-four the next morning if she had a test the next day.”

Mia said to the girls: “If you get this right, you won’t have to battle anymore.” She believes that, for **them** (Mia’s emphasis), that was the biggest motivation.

The “social side” of school is fine. Both the girls are “creative children” and they love art and music. They also love sport. When it comes to academics the girls “keep their head above water” and “they’re not the bottom end of their classes”. Maths and English are problems for both girls. With the leaning subjects, “funnily enough”, Lynn does very well, especially history “because there’s an understanding to it; it’s a story”. “Maths has no understanding to it and it makes no sense to them”. At Grade 5 level Mia finds she can no longer help with Maths homework. She admits “we’ve had many days where I’ve helped them with their homework and they get the whole lot wrong”. Mia now has a maths teacher who comes once a week and helps Lynn with extra maths.

When it comes to dealing with the school, Mia is “just **always** there” (Mia’s emphasis). Mia believes that what happened with Kim in Grade 1 has “pushed” her to have a lot of contact with the school and go in and see the teachers a lot. “You know what, nobody else is going to do it for my child, and if I’m not on top of it and chasing, then it’s not going to happen.”

Next year Mia wants to “leave” Lynn and “see if the teacher has an opinion”. Mia feels “you also give your children a stigma sometimes – that the teachers now look for problems”. But for Kim, Mia will still spend next year going in and checking on her.

Mia has also realised that her girls “don’t have to be academics”. “They don’t have to be top of the class. So long as they are coping within themselves and they are fitting into their classroom, it doesn’t matter what they do or do not achieve. As long as they are achieving to the best of their own ability then it’s fine.”

Mia has told Lynn: “You know what, I would rather have your school report with the D+ and the C+ and we know how hard you worked, and I’m so proud. I’m so proud; I could actually burst I’m so proud of you. It doesn’t matter what the symbol is, it’s what you give.” Mia believes you “have to just boost them and they have to be proud of who they are, where they are”.

Dealing with health professionals

Mia has found “one or two” health professionals to be very quick to suggest that she just “stick them in a remedial school and they’ll get everything there.” This makes Mia “angry” because she feels the girls are not “stupid”: “You’ve just got to give them the tools and once they’ve got the tools they do accomplish so much.”

Mia feels she “could have killed” the neurologist who diagnosed Kim with petit mal – “I was so devastated that I had put her onto such strong medication and she didn’t even have it”. Mia feels that because you as a parent “don’t know” you go “into those situations” and “you trust that doctor so much”. Mia has now learned that you “actually need two or three opinions and then **you** need to make a decision for yourself. You cannot go to just one person. It’s frightening actually”.

Mia feels parents need to see the right professional, such as the psychiatrist the girls see. You can’t just go to “a GP or an everyday Joe Soap” when you are putting your child on Ritalin. She believes that parents who go the “Joe Soap” route are “the first ones to tell you that there’s something wrong with that medication”. Mia feels that people who don’t have the medication adjusted or monitored give “the medication a bad name”. Parents who don’t use the full spectrum of services available for these children also frustrate Mia. Mia believes “you need the other things to fix it” – like the remedial and the OT.

Coping

On a day-to-day basis, Mia feels her daughters are “such good girls”. Neither of the girls is really a behaviour problem: “they are easy-going; they are not difficult children; so I can’t really complain”.

Mia’s biggest problem is Lynn’s not being “a very well disciplined person”. Getting ready in the mornings and “trying to get out the house” is a problem. Lynn also tends to forget things at home or school. Mia believes the situation has improved because she has gotten much stricter.

“I now am a far more disciplined person as well. Because I find that if I am having an airy-fairy day, they are **definitely** going to have an airy-fairy day.”

Mia finds it helps if she is up, dressed, ready, and downstairs before the girls. And then she will “push them” with “constant” instructions: “Okay it’s now half-past-six, by quarter-to-seven you are in the kitchen.” “You’ve got ten more minutes.” “In five minutes you must be in the kitchen.” Mia finds that if she can “run it like that, it runs smoothly”.

Mia has tried to make their lives very structured, “because otherwise there would be nothing. We would live in chaos”.

Lynn also tends to forget things or lose things. “Nearly every single day for the first three years of school” Lynn lost something at school: “If it wasn’t the shoes, it was the jersey, or it was an entire kitbag”. Mia found herself spending so much of her time “trying to find something that belonged to the child”. By the end of Grade 2, Mia had had enough. Lynn came home without her jersey and Mia told her that if she did not find it, she would have to replace it out of her pocket money. Lynn went to lost property the next day, found her jersey; and has never lost it since. But she “was in tears and she sulked the whole night”. Mia felt she just had to “stick” to “her guns”: “That’s the hardest thing to do, I think”.

Mia feels that Dave “has been fantastic” in all of this. “He is my support system in all of this”.

Mia feels her “way of coping” is to tell herself that “anybody who has a child”, is “going to come to a portion in that child’s life where you are going to have to deal with something; and everybody gets a turn”. Mia feels that if this is her “portion”: “I’m coping – I’m fine”. Mia believes “every child’s going to battle with something – if it’s

not on a friendship basis, or an emotional basis, or an academic basis, there is going to be something.” Mia feels that at least she knows what her problems are and she’s dealing with them. Mia believes there’s “no point getting down in the dumps and thinking: ‘Oh my God; what am I going to do?’”

Mia believes things have gotten easier. The worst part for her was when she didn’t “know what’s going on – that side, the unknown, is very hard”.

“But as the years have gone by, I don’t know if you just get so used to it, and you get used to your own family and how you cope with things, it has gotten easier I must say.”

Being their parent

When it comes to being a parent, Mia just takes every day “as it comes”: “you just deal with it and get on with it. They didn’t come with manuals”. Mia believes that on a daily basis “inevitably” she will “scream and shout a lot”.

Mia’s feels her daughters are very “different personalities” and Mia feels this means they “also push you in different ways”. Kim is a “much stronger child, so she tends to cope better”. Kim seemed to cope with the whole diagnosis process: “she was doing fine... it never worried her”. As a result, “as a mother or a parent” Mia didn’t get as emotional with Kim, because she coped so much better. Mia admits that with Lynn “I kind of tend to fall apart far easier for her”.

The girls have their “tiffs and their fights” but in general get on “very, very well” although “they’re very different”. Kim loves her dolls and is very imaginative. She’ll sit “for hours on her own and play”. Lynn likes to play sport and “she’s always bouncing a ball or screeching around”.

Academically the girls are “on the same par”, although Mia thinks that “as time goes by, Kim will catch onto things much quicker”. Kim gets “through things quicker and it takes far less effort”, so, “to a degree, she can be lazy as well”. With Lynn, “everything comes with a struggle and she’s far more diligent, she works very hard, and she really wants to achieve”.

Mia realises that she and Dave “were both the same” as their daughters: “we also both battled at school; neither of us finished school.” As a result they feel they “want more” for their children.

“And when you see they battle and when you see where the problems are, you don’t want that for them. So, I think in a way it kind of encourages you to try harder and try and help as much as you can.”

Mia thinks because she herself has attention deficit, that sometimes she is “overly protective” of her children and “very quick to do things”. Dave says there “isn’t anything my children haven’t been tested for or done”. Mia admits:

“I **am** extreme; I’m very extreme and I know that. But I don’t want them to battle like the way that I know that I battled at school. I think when we were at school I didn’t get any help. You were kind of like always just stuck at the back of the class: ‘Oh she’s the slow one.’ And I don’t want them to feel like they’ve been labelled.”

Mia believes parenting her ADHD children has meant she has “learnt a lot”. She believes she has become “far more outgoing” and her “own self-esteem is better than it used to be”, because she had “to grow up and deal with adults and other people and doctors” and she had “to fight” for her children. Mia feels that if she hadn’t been through this process she would never imagine herself going to a teacher and asking: “What is going on?” Now she realises that if she’s “not going to do it, no one else is going to do it”. If she wants the girls “to get through”, then she will “have to do it”. Mia believes she has been “pushed to cope with things that maybe ordinarily I would have just stuck my head in the sand and hoped that they would have gone away. So, it does make you stronger; it makes you tougher.”

The future

Mia believes that her girls have to “learn to become a structured person, you have to be a person that is diligent.” Mia does not feel they are there yet. Mia is trying to “give them the skills now” and trying to teach them to plan time. Lynn still doesn’t understand why she needs to start working for things like exams before the other children do. Mia is trying to show Lynn how to study and how to make notes. Even though Lynn “wants to learn”, if left on her own “she’ll look at that page and when I come back half-an-hour, twenty minutes, or an hour later, she’s still on the same page. She just ends up daydreaming; her mind wanders”. Mia admits to knowing “exactly what it feels like” because she did the same. Mia feels she still has to sit there with Lynn and asks questions and help Lynn make notes. Mia feels Lynn “absorbs so much” when she does that, but if left “on her own she’s unable to do it”.

Mia does worry about the amount of pressure children are put under at school and how “they are moving so quickly”.

Mia worries about the girls having self-esteem problems. Mia thinks that “everybody wants recognition; it doesn’t matter what recognition you get as long as you feel like you fit in somewhere and you have recognition”. Mia feels that a child with low self-esteem can “go off the deep end, because they don’t know how else to cope”. She does “worry about the future” and she worries that “that they’re going to be one of those kids who gets caught up in the wrong stuff”. She does, however, feel that she has “tried everything”. Mia feels she must give them as much as she can “so that there are no loopholes”.

Mia does not believe either of the girls will go to university. This doesn’t concern her – “as long as they are happy”. Neither Mia nor Dave finished school and she feels they have “always been fine”. She believes the girls must find something that they are good at and passionate about and they’ll “take it from there”. Mia does not want to “push them to be something that they can never ever be” and “give them expectations that they can never live up to”.

Mia’s advice for other parents

Mia believes that “having a support system is vital and especially to have your husband behind you”. Mia believes that both parents must go the appointments with any professionals. The mother should not have to handle it alone: “it’s so hard when you have to go to an assessment and you come back and you have to tell them what happened”. Mia feels that health professionals “give you so much information” and “half of it you can’t even explain” to your spouse. Mia feels the father needs to be there “and they need to ask the questions”. Dave has gone through the entire process with Mia and she believes that is “also why the understanding is there, he has worked through it”.

Mia is also “lucky” in that she gets recognition for her input. Mia and Dave work from home together.

“So, in the afternoons he sees how much work we do; he sees how much homework. Whereas with other husbands they’re maybe not there during the day and they don’t see what goes into a day – the fighting, and the tears, and the arguing: ‘If you don’t do this you’re not going to get through.’”

Mia feels that the “mould” she had for her children was broken:

“And I think when you go for assessments there is nothing worse than hearing your child – you have an expectation for your child, you want your child to be somebody and you always think that they’re going to be up in the class and they’re always going to fit in – and they don’t. And all of a sudden somebody breaks that mould that you had for them.”

Mia believes “you actually have to take time out and you almost have to mourn the child that you thought you were going to have, and then you have to appreciate the child that you’ve got”. Mia believes you “really do” come to appreciate the child you have.

Mia advises that parents remember when they go for assessments that “the reason you have gone there is so that they can show you where the faults are”. Parents need to try and “take in” what they are told, “but maybe not let it destroy you, I don’t know”. Mia also feels parents must act on what they are told. She knows of parents who decide to ignore what they are told and “they never go back; they never do anything about it”.

“And then a year down the line the problems have gotten bigger. Their problems aren’t going to go away; you have to address them.... And the only person that you’re cheating is your child. At the end of the day it’s only the child that you’re cheating.”

Mia also advises that parents follow their “gut feel”. Parents must realise that “not all doctors are right”. If it doesn’t “feel good”, then “go somewhere else”. Mia also realises, however, that there is a point where you might have to admit that the professionals are right: “And if two people have told you the same thing then, you know what, maybe it’s your expectation that’s not where it should be”.

Mia believes parents must know when to accept their child’s limits: “And it’s soul destroying when you see some kids that are battling and battling and the parents are just pushing and pushing. They have to be the best of what they can be – not what **you** want them to be. So you have to actually re-look at everything. And it is hard; it is soul destroying.”

APPENDIX J: CONSTITUENT PROFILE – PAT’S STORY

Pat is divorced and has one child, John, who is eight-years-old. Pat got divorced “very, very soon after John was born”. Pat and her ex-husband had been living in Cape Town for ten years. The family advocate suggested that Pat move to Johannesburg after the divorce, because her family is here. Pat’s ex-husband has moved to the UK. Pat has been dating her boyfriend, Alex, for two years.

When Pat first moved up to Johannesburg with John, they lived with her mom and her husband. The house has a flat downstairs and when that became available, Pat and John moved down there. Pat’s mom has since moved out, and Pat and John have moved into the main house.

John was diagnosed with ADHD at the age of five, and is currently taking Ritalin.

The road to John’s diagnosis

Pat had a “completely normal pregnancy”. As a baby John never slept well and he would never settle. He also had colic until he was six months old. As soon as Pat moved up to Johannesburg, he got asthma. “You know there were little things. I couldn’t quite put my finger on it.”

John was “very immature”. He only walked when he was 17-months-old and he spoke when he was “I think three, three-and-a-half”. Pat reasoned that John was just “a boy” and doing “things in his own time”. Pat believes that her “he’ll get there” attitude is a product of how she was brought up as they “were allowed to do what we wanted to do”.

John started crèche at the age of two-and-a-half and adjusted **very** well (Pat’s emphasis). The teacher’s little girl was also in the class. So, when the teacher told Pat that John “can’t do this and John can’t do that”, Pat thought: “well this poor child is being shown up against this little girl”.

“And obviously girls draw ... they do all the right things, and boys throw crayons through the window and stuff like that. So I didn’t take too much notice of it. “

A friend of Pat's has a little boy who was also "very young for his age group". This little boy was going to occupational therapy (OT) and the friend suggested that Pat take John to the OT to be assessed. John then spent the next year at occupational therapy. "In all that time, and I only heard when he **left** there, he never ever said one word to the therapist – he never spoke to her." John was about three-and-a-half then. "So, already then, I **knew** something was up."

OT "didn't help" and the therapist suggested that Pat take John to speech therapy. So he was in speech therapy and Pat and her mom "were schlepping him around every afternoon – this one, this one – taking turns – still never helped".

When John was about four-and-a-half years old, his paediatrician said to Pat: "You know, I think this child's ADHD."

"And all I knew from Discovery and from reading magazines and that was that ADHD was linked to Ritalin and it was a scheduled drug and whatever. And I said: 'Listen, I will have nothing of it.'"

Pat herself never goes to the doctor; she goes to the homeopath. Pat feels she is "as fit as a fiddle". Pat felt that if John was ADHD they needed to "deal with it another way, because I don't want to know the R-word." She said to the paediatrician: "Don't even mention it in my company."

The paediatrician "left" Jo "for about a year". When Pat took John to see the paediatrician for his asthma, he said to her: "Pat, he's got a year to go before he goes to school.... Please, just take him for an assessment." Pat took John to a psychologist. The psychologist started assessing John and she phoned Pat on her cell phone and said: "Pat, I can't do anything with this child, you've got to put him on medication. He is hectic." At this point Pat relented, went back to John's paediatrician and had him prescribe Ritalin.

Pat's feelings about John's diagnosis

Pat feels that John's diagnosis "was a shock", even though she "knew something was wrong." Pat believes that her feeling of shock was related to the fact that she "didn't know anything about it".

Pat admits, however, that there is "some sort of payment in knowing what it is".

“At least you know, okay, we’re on to something here and there are other people who know a little bit of how to deal with it.”

Pat’s reaction to the diagnosis was to try and learn as much as possible about ADHD. Pat “read up about it”; saw the psychologist for information sessions; and goes to a “lot of the talks and lectures and whatever”. Pat has even been to lots of talks that are not relevant to John. Pat feels that if she goes to a therapist and is told: “You know what, we think he’s dyslexic,” at least she has some knowledge on the topic:

“That’s the problem with the ADHD as well, it’s not the ADHD – it’s the peripheral things. It’s the self-esteem; it’s the over eating – it’s all these other little things that form that complete picture.”

John and Ritalin

Pat admits that she “didn’t like it” when John was put onto the Ritalin. Pat then attended a briefing and six educational sessions with the psychologist who diagnosed John. Pat felt “a bit better” after that. Today Pat feels she is at the stage where she would “stand up on a table at the Spur and say: ‘Listen, the people who aren’t putting their kids on Ritalin need to be shot.’ You know what I mean? Because once I had seen the **difference** in him – it was like night and day. Big, big difference.”

When John first went onto the Ritalin, Pat feels he was “too small to explain taking the medication to”. About six months before I interviewed Pat, John had been to London to visit his father. His father said to him: “Oh, you don’t need glasses, you don’t need asthma medicine, Ritalin’s for sissies.” When John got back, Pat took him to the psychologist and said to her “we need to try explaining to him”. The psychologist explained to John why he takes the Ritalin: “She drew little pictures of messages and all that kind of thing”. Pat feels that John “definitely does understand now” and he doesn’t have a problem taking the Ritalin. Pat thinks he realises that when he takes the Ritalin “the world’s not so cruel and harsh and people don’t shout at him all the time”.

Pat feels that John is starting to realise that “he doesn’t always listen or he doesn’t interpret things the way we do”. Pat tries to explain to him “that he’s special, that he’s unique, that we **all** learn in different ways. That’s why we’re at different schools (Pat’s emphasis).”

John was initially on 10mg of Ritalin, but when he started school it was very difficult to see when it “was active, and when it started wearing off”. The teacher then had to start giving him a 10 mg tablet as well, and “there were these little white pills in boxes everywhere and it was just a nightmare”. John is currently on 30mg of the long-acting Ritalin, and they “top him up” in the mornings at school with a 10mg. He does not take the Ritalin on weekends or in the holidays. Pat admits that she “would **love it** if he only took **10**mg of Ritalin and substituted with Omega and Barley Green and everything else I could shove down his throat”, but he seems to be alright on the current medication”.

John has had side effects from the Ritalin. On the one hand, the Ritalin subdues John and makes him “very tearful” On the other hand, he is **very** aggressive (Pat’s emphasis) when it “wears down” and “non-compliant – and just a **nightmare**, just not pleasant to be around”. Pat has been told that the Ritalin doesn’t “**store** in their bodies”, but when he breaks up for school holidays it takes “three or four days” before Pat “can see it’s worn off and he starts sleeping better”. The Ritalin has never had an effect on John’s appetite. Pat doesn’t feel the side effects are bad enough for her to take John off the Ritalin and say: “Right, go on your own.” “Because, you know what, he will still be in Grade one in seven years time. You know what I mean. He just will never, ever cope.”

Pat has recently also put John onto Omega 3. She believes that she has “seen the effect on his reading” and he is sleeping better. Pat doesn’t see the Omega as a replacement for the Ritalin though: “Look, I’d love to say that I think he will not need the Ritalin one day. But I don’t think so – he’s just one of those kids – he’s hectic and, you know what, he’s going to need it for the rest of his life.”

Pat actually knows what taking Ritalin feels like, because she also has ADHD.

“No one wants to sit in a meeting with me. I drive my boyfriend, Alex, mad because I don’t sit still. I can’t sit still.”

If Pat is going to a meeting, or a course or a lecture, she will take a Ritalin. She knows it helps her focus: “I tell you it works like a charm. So, I know what he’s going through.” Initially the Ritalin used to give Pat headaches, but then “your body gets used to it”. Pat reports that “it’s a terrible feeling” when it wears off; “it’s a horrible feeling – makes you feel sick and everything”.

John and school

John is in Grade 2 at a remedial school – he’s been there since Grade 1. Pat admits that financially it “kills” her, but feels “they’re very good there”. Pat has the “greatest respect in the world” for the principal, and the therapists who work at the school are very co-operative. It also helps that the therapists are available at the school, so Pat and her mom are no longer “schlepping” John “to this, that and the next thing”. The psychologist said to Pat: “You know what, Pat, if you have to go out and get a waitressing job at night to get him into a decent school, you’ve got to do that in the beginning.”

John “**flew**” (Pat’s emphasis) through grade one: “His self-confidence; his self-esteem – he was just **flying** (Pat’s emphasis).” John was reading, spelling, “everything – I couldn’t believe it – he was like a different child.” John “loved his Grade one teacher” and Pat used to speak to her at least twice a week.

At the end of Grade one, John’s father wanted him to go to London for three weeks. John’s paternal grandparents took him over. When John came back, Pat feels “he just regressed – went **right** (Pat’s emphasis) back to where he was”. Since John has been back his father has had “**absolutely** (Pat’s emphasis) no contact with him”. Two months after John started Grade 2, Pat was called into the school and told: “He’s regressed – he can’t remember anything, his concentration is completely out the window.” The school told Pat “it’s probably emotional”. John is now going to therapy at school, and they’re “doing the whole divorce thing with him and he’s starting to ask questions now”. Pat feels she is left with trying to get John “to believe that his dad does love him; he just has a strange way of showing it”.

John is “really battling” and Pat doesn’t know if he’s going to make it through Grade two. Pat feels “it’s not the end of the world” if he doesn’t and she would rather they “keep him back **now** than in Standard 4 (Grade 6), Standard 5 (Grade 7). Being kept back will, however, “have an effect on him” as John’s “confidence and his self-esteem is very, very delicate”.

On a daily basis at school, John battles with reading, even though he has always loved being read to. Pat tells him her just need “to practice and practice and practice”. The school have tried to find the best way for John to learn, and they seem to have “narrowed down that he’s an auditory learner, but then because of his concentration it doesn’t complement the way that he learns”. Being an auditory

learner has given John the ability to learn birdcalls, and John knows all the birds. Pat tries to build on things like that, and other people also “pick it up”: “now people at the school will say to him: ‘Gee wiz, how did you know that that was a lesser spotted whatever?’” This builds John’s self-esteem, but Pat feels “it’s not enough to counteract and rule out all the other bad things” he hears.

Pat feels that dealing with the school, for her, is “actually quite easy” because she involves herself “in everything”. Pat makes sure the school knows **‘exactly** what’s going on”:

“If his fish dies, I send his teacher an SMS and I say: ‘Listen his fish died this morning. Or the cat got run over. Or he broke a chair.’ Or whatever, you know what I mean.”

Pat involves herself with absolutely everything at school. She fetches John as much as she can and watches his activities. Pat also willingly does extra homework from the therapists with John. Pat has even taken a lower paying job, which entails less after-hour work and being away from John. It means she can be “**there** (Pat’s emphasis) for John”.

Dealing with health professionals

John’s paediatrician is not a guru on ADHD. Pat admits that she is the kind of person who, if there’s something she wants to know, will “go on the Internet”, “speak to people” and “make frigging sure I know **everything** that’s going on and **more**” (Pat’s emphasis). Pat feels that people “do not understand” her need to know more and their reaction is often: “Oh, there you go with your ADHD again.”

Pat started taking John to “**everyone**” (Pat’s emphasis). Pat’s feeling is that the medical fraternity in this country are not “up where they should be”, whether they are paediatricians or educational psychologists or neurologists. Pat feels there “are a lot of them – and I can name all of them – that have not done the research that I’ve done”. Pat believes she has reached a stage “where she can walk in there and after a session I can tell you whether that woman’s going to help me or not”.

Pat feels “that there’s a lot pf people taking people for a ride”. Pat mentions the experience of paying a doctor R782 “before you walk in the bloody **door**” and then the doctor asks: “Oh well, what script would you like me to write out?” Pat has had to

“restrain” herself from saying: “Excuse me, I’ve just paid you nearly R800 to gain some information and knowledge from you. And here you’re expecting **me** to tell you what to write on the script.”

The one professional that Pat finds “wonderful” is the psychologist – “she just can’t prescribe the drugs. I go to her for everything else.”

Extended family

When John was about two-and-a-half, Pat’s father and brother started to complain about John. “Oh you know, he’s broken the hose pipe and he’s fallen in the pool. And he’s done this and that.” Their attitude was “Oh well, you don’t discipline your child; he’s flipping wild.” Eventually “relations completely broke down”, and to this day Pat doesn’t speak to her brother because of his inability to realise that “it’s not just discipline”. Once John was diagnosed, Pat actually took her father for therapy and counselling so he could try and understand what was going on. She admits though: “he’s over 60; he’s not really going to change – it’s like a children should be seen and not heard scenario, you know”.

Pat’s mom has always been “like another parent”. When John started formal school - Grade 1- she would go to parent’s meetings with Pat: “She would be there for John”. Pat’s mom would relieve her when John was driving her mad, and vice versa.

“My mom and I have got a very, very good understanding and I think that’s important. If you don’t have it in the form of a husband, or a fiancé, or whatever - you’ve got to have somebody.... You need that outlet, you know.”

Alex’s initial reaction to John being ADHD was the same as her brother and father: “He’s a boy; you’re making excuses for him; you’re mothering him too much; you’re mollycoddling him; and he just needs discipline”.

Being John’s parent

When it comes to being a parent, Pat feels you “definitely learn as you go along” and she thinks that maybe the “second time round would be easier”. Pat doesn’t feel that John is going to turn out “perfect” or that “he’s not going to come out of it unscathed”. She admits to thinking that he might even end up “emotionally damaged for the rest of his life”. Pat feels that parents need to be educated about being a parent, but doesn’t know who would take on that task: “the government, the schools? You know, it’s a hell of a dilemma.”

Pat feels that parenting “all comes back to **your** values and **your** morals and how you were brought up. (Pat’s emphasis)” It horrifies Pat that children are left at John’s school until six o’clock at night.

“And maybe the parents need a break, maybe they don’t care, maybe they don’t know how to handle it – I don’t know. But, you know, I just **feel** for those children. “

Pat concedes that she is “not an angel either”, and admits there are days that she might love John, but she doesn’t really like him. “I always tell John: ‘I still love you, but the things that you do make me **really mad.**’”

It frustrates Pat that John seems to have a problem in relating to the consequences and the implications of his actions, and to logic. “**If** I don’t do this, **that** will happen!” Pat feels he has an attitude of: “Well, I don’t care. You can stand there and scream and shout like a wild banshee”. Pat knows from experience that giving John a hiding makes no difference. Pat has also tried taking things away from John. For example, she has tried telling John that he can’t ride his bicycle for a week, but then his reaction is: “Well actually I don’t care because I’ll just go do something else.” When it comes to discipline, Pat finds she has “to be innovative and creative all the time” and she has “to keep on until you find the button that pushes and has an impact”. She also finds that you always have to have a Plan B: “Okay if he does this, or if he doesn’t do that, I’m going to take cubs away from him. But then if he says well that’s not a problem, then I’ll say you’re not getting a Happy Meal from McDonald’s after that either.”

On a daily basis, John still battles with a lot of things. For instance, at the age of eight, he still can’t tie his shoelaces. Pat believes she must just “relax” and he’ll get there, but she feels other people find it “very difficult” to understand though.

Mornings are always a difficult time in Pat’s household. Pat gives John his Ritalin “as **soon** (Pat’s emphasis) as he wakes up with his breakfast. It takes half-an-hour for the Ritalin to take effect, and before it takes effect “nothing happens” in their household: “**me** (Pat’s emphasis) trying to do it without the medication is a complete and utter waste of time”. Pat admits that there are mornings where she has “screamed and shouted at him like a fishwife” and both of them are in tears when she drops him at school. “Thankfully he does not hold grudges and he doesn’t sulk.”

Sometimes on weekends, John will “be a treasure”. Other times, he’s just “not in the right place”. And every day is completely different; “**no** (Pat’s emphasis) day is the same. No consistency. And that’s why it’s so difficult for parents to be consistent, because they are so flipping inconsistent. It’s very hard work.”

Pat feels that ADHD children are “very special in their own little ways” and “very, very affectionate”. John is kind, and giving, and thoughtful. He is also “very, very helpful”. John is very sociable and tends to befriend girls and children younger than him. Pat believes he has “more of a problem” making friends “now that he’s getting older”. He has said to Pat recently that the older boys are horrible to him at school and nobody wants to play with him.

Coping

Pat believes that it is actually easier for her to cope because she is on her own. Now that Pat and her boyfriend, Alex, have been seeing each other for two years, he wants to move in together. Pat’s reaction is: “No ways! I can’t **take** another child around here, you know. You come home from work, you want dinner – you demand this, you demand that.” Pat has suggested that Alex start by moving into the flat on her property.

Pat has had to get Alex to understand that John’s “brain works completely differently”. Alex will shout at John for not doing something, without taking into consideration that John interprets things differently. Pat has taken Alex for counselling to try and help him to understand.

Pat has also “made” Alex “spend time with John”: “I’ve kind of pushed him into it”. Pat feels that by doing that Alex has seen “his (John’s) good points; he’s seen his sensitivity; he’s seen how affectionate he is”.

At the moment, Pat has a “set routine and quite a set structure”. There is only ever a degree of variance in the structure. Pat feels it “works” for her: “You have to have that, otherwise I never get any time to myself. I’m not – if my jug’s not full there isn’t going to be anything left for him.” Having a routine extends to John knowing when it is his time: “I **always** do his reading with him; I may not do his spelling or whatever – he’s done that at aftercare. But he **knows**, from seven o’clock until eight o’clock – come hell or high water – that is **his** time (Pat’s emphasis).”

Pat tries to always be consistent. Pat admits that a lot of the times “it’s very hard” because “the relationship is so strained – you’re always shouting at them, you’re always screaming at them.” “And eventually, by six o’clock you think, you know, all that I’ve done is shout at this poor child. So, for me, consistency is the biggest hurdle.”

Pat admits that there are days when she just has to get out of the house: “I’m out of here.” There are also nights where she will “resort to alcohol”.

“And I think, you know what, I don’t care if I have to swap my glass of wine for eating. Let me just get him sorted out, eat, have your inhaler, bath, brush your teeth and then just get into bed by seven o’clock. And then after that I sit there and think that second glass is looking quite good.”

Pat has now reached a stage where she feels there is there is “**nothing** else to rule out – **absolutely everything** has been tested (Pat’s emphasis)”. She feels she now needs to “accept him for what he is and **deal** with it (Pat’s emphasis)”. The fine-tuning of the medication has now come to the end of the road, and there isn’t anything else wrong with him. It is time to “just work with him the way he is”. Pat admits: “I (Pat) have to accept it”.

Whenever Pat feels really “miserable” she reminds herself that there are always people who are worse off.

John and the future

Pat does not believe that John is “varsity material”. Pat has always told John that he must be whatever he wants to be. John is “very good on the computer”. He loves cooking, he loves animals and he is very good with his hands. Pat feels he will probably work with his hands one day. Pat believes that if John’s energy or interest is “channelled in the right thing he will be okay”.

Pat doesn’t expect John to go to varsity. But she feels “that is not the norm; that is not what society dictates. Society dictates you will go and be a doctor, or this, or that.” Pat hopes that “society will one day realise that these kids are different; he’s unique; he’s special”. Pat tries to drum it into John that he special, but she feels he needs to hear it from someone other than his mother or his grandmother. Pat feels

that John is likely to think: “you know what, it doesn’t matter what I do they tell me that I’m great.”

Pat tries to create opportunities for John to spend time with different people – “he’s with someone different; he’s with someone who will see his special qualities; who will overlook for that period of time his lack of concentration or whatever.” It worries Pat that John thinks: “You know what, it doesn’t matter how hard I try – why should I even bother, why should I even expend the energy? No one’s going to notice; everyone’s always shouting at me.”

Pat also tries to let John see that she is not perfect; she makes mistakes.

“Often if he asks me a question that I know the answer to, I’ll purposely say: ‘I don’t know, let’s go on the internet and have a look or let’s go look in a book. You know, mommy doesn’t know everything. I try and help you.’”

Pat’s advice for other parents

Pat believes that parents must “educate themselves and not **ever** (Pat’s emphasis) think that someone knows more than them about their child”. Pat feels parents must know what they’re talking about, and must make people aware that they are not scared to stick their necks out and say: “No well, you know what, why do you say that?”

Pat feels that educating herself about the disorder makes her “refocus” and puts her “back on track” and helps her to remember that she’s “not the only one”. Going to the talks “instils some sort of reality” and makes Pat feel: “You know what, you’re actually on the right track here.” On a practical level, Pat also budgets R100 a month for experimental things for John – for extra supplements, or taking him to something that’s educational.

Pat believes parents must be involved with the school: ” **You** (Pat’s emphasis) have to know what’s going on because that child can’t speak for himself.” Pat advises that parents must “put them where they need to be”. You can’t expect a child like this to grow out of it, or not be as bad when he’s ten, or that kind of thing. You have to support them. You decided to have that child; they didn’t ask to be born. And, you know what, you have to take **everything** (Pat’s emphasis) that comes with him.

Pat feels parents need to look for the child's "good points". "You have to dig **really** (Pat's emphasis) deep sometimes. But, you know what, if you look hard enough you will find plenty of them. And when you find them, capitalise on them and make them bigger."

Pat advises that parents have someone to speak to who understands the situation, be it in the form of a friend or a support group:

"And sometimes we don't even talk about the kids. It's just to speak to someone and when they say: 'You know what, he broke his toothbrush this morning.' And I'll say: 'Don't worry, he's done that three times already.' And you think: 'Well at least he's half normal.'"

Pat feels it would help if "more people had a deeper understanding". Pat also feels that parents mustn't "go over the top about it". Pat feels that at John's school they "over-therapise them a bit – it's like the quest for zero defect". Pat has said to them: "Listen this is not a video machine; he's a human being. This is as good as it gets; it isn't going to get any better, so deal with it." Pat feels parents need to recognise "when that point comes where, you know what, that is the way he is – just run with it and do what you can do". The psychologist says to Pat: "You can't do anymore. Just relax; there is nothing more you can do. Stop blaming yourself." Someone actually said to Pat the other day: "Why do you think this happened?". Pat replied: "I actually don't care why, because it has no bearing or consequence on my life."

"I don't care if it's when he fell out of his bed on the tile floor, or if there was something in the birthing. It's not going to help; it's not going to go away; it's not going to make anything better. Just deal with it and make the best of it."

At the end of the day, Pat feels "I just try my best and when I have a bad day, just go to bed early and hope that tomorrow the sun's shining and it's better."

APPENDIX K: CONSTITUENT PROFILE – SAMANTHA’S STORY

Samantha is married and has two children: Ben (15-years-old) and Claudia (12-years-old). Samantha runs her own business, an arts and craft shop, which she opened four months ago.

Claudia was diagnosed with ADHD at the age of three and is currently not taking any medication.

The road to Claudia’s diagnosis

When Claudia was a baby, Samantha could see that she was different to her brother. By his first birthday Samantha’s son could already sit down with a Tupperware ball and put the shapes in. Her son sat and “worked on this thing and those little hammer things and that”. When they took the same toys out after Claudia’s first birthday, “she didn’t have a clue”. Claudia showed no interest in the toys at all: “It was just something in her toy box that was in her way.” Samantha feels: “it was always in my mind: ‘Now how am I going to get this child to do this if she doesn’t want to?’”

Samantha remained concerned about Claudia and when she went to nursery school, Samantha kept checking in with the teachers. Claudia still didn’t know how to put a puzzle together. Samantha was getting told: “No there is nothing wrong with her, she’ll get there. No, she’s just not interested in it.” Samantha felt this was “absolute rubbish”. Samantha went to her doctor and “explained everything” and he suggested taking it further. The doctor referred Samantha to an occupational therapist, and she diagnosed Claudia as ADHD.

Samantha’s feelings about Claudia’s diagnosis

Samantha felt “it was like it was the end of my world” when she was told Claudia has ADHD. Although the doctor had warned her it may be the case, and although Samantha had been “really trying to get to grips with it”, it was still a shock: “it was devastating for me; I cried for days. I burst into tears and I cried.”

Extended family and the diagnosis

Samantha believes the extended family “always knew”, because both Samantha and her husband are ADHD and both took Ritalin when they were younger. Samantha believes her husband’s mother is also ADHD “although she won’t admit” it.

Because both Samantha and her husband both have ADHD they did suspect Claudia might have it too: “It wasn’t a case of we didn’t know. That’s why when we were leading up to it and everything, that is why I knew at the back of my mind you know. But it was still a shock.”

Claudia and Ritalin

When Claudia turned five she was put on Ritalin. The family doctor told Samantha he could put Claudia onto Ritalin for them, but suggested that they get her further assessed. Claudia went for a number of assessments including an EEG. The assessment process was difficult as Claudia “didn’t want to do any of it – like, you know, why must she do it?” This hasn’t changed and Samantha still finds it “is very difficult to schedule a test for today; if she doesn’t feel like doing it, then you will get a terrible result.”

It was recommended that Claudia be put onto Ritalin “to help her”. Samantha admits it “was a big decision putting her onto the Ritalin”. Samantha herself was on Ritalin until she went to high school, at which point she was taken off. Her mother, however, still gave it to her when she wrote exams. Samantha remembers having “terrible, terrible mood swings”: “I was never mediocre - I was always very happy or I was very, very sad.”

Initially, Claudia was on half a tablet, but Samantha found “there was no difference in her at all”. The dosage was adjusted to one tablet. Claudia was picking up a number of side effects, such as stomach cramps, not being able to sleep and suppressed appetite. They were now in a situation where Claudia was taking medicine for stomach cramps; medicine to make her sleep; and medicine to make her want to eat. Claudia was losing more and more weight and Samantha feels “it just wasn’t working for us”. Claudia was also experiencing the same mood swings that Samantha experienced when taking the Ritalin: “And it was always like so dramatic. Everything is heartbreaking or everything is so funny.”

Samantha feels the Ritalin turned Claudia into “a zombie”: “we used to give it to her at quarter to seven and by quarter past seven it had kicked in and she would sit in

the car, riding to school, and she wouldn't say a word and her moods were totally different."

Samantha eventually felt she couldn't do this any longer. Claudia came off the Ritalin, even though Samantha "had a lot of people that was against me taking her off it", including her parents and in-laws. Samantha decided to "rather do the diet thing" and with the diet she believes she has "a 100% changed child".

Claudia and the diet

Claudia is on a diet provided by ADHASA (Attention Deficit Hyperactivity Disorder Association of Southern Africa). Samantha's medical aid referred her to ADHASA and she became a member. Samantha admits that she had the diet for two years before she fully implemented it. In those first two years she would just "refer" to it: "And it would be like, okay we just won't have this, we'll have this, but it wasn't a strict like you and I sticking to this and that."

Claudia has been on the diet properly since she was about six-years-old and Claudia is the only one in the family to follow the diet. Samantha admits that during the holidays, it is difficult to implement the diet strictly, and she has "compromised a bit". If Claudia does not stick to the diet, however, Samantha finds that by the end of the holidays Claudia is "driving" her "mad".

Samantha feels that having Claudia on the diet "does put a damper on everything", but it works for her. Samantha does believe that Claudia "is not as bad as other kids".

"I've seen kids that aren't even diagnosed as ADHD and I think they're far worse. Ja I really do; and I can't understand why their parents can't see that there is something wrong with them."

On a daily basis, Claudia will have something like rice crispies or corn flakes, or oats for breakfast. Samantha does not "keep her away from tea or coffee" and lets her have that. School lunch consists of water crackers, rice cakes or bran muffins. "And then she lives on her apples."

Parties were initially a problem. At one stage Samantha "just made it known that Claudia wasn't invited to parties", but she has since realised "you can actually work

around it". Some of Samantha's friends are understanding and will make up a "special package" for Claudia if goes to one of their houses for a party.

Samantha's parents are supportive when it comes to the diet and will check with Samantha about what they feed Claudia. However, her husband's parents "will make the spiciest food with everything in it. Ja, and then they will send her back home after three weeks holiday with an attitude and all sorts."

Claudia and school

Claudia's first kindergarten's just "denied" her ADHD "totally". Samantha and her husband then moved Claudia to "a lovely Christian nursery school" for the year before Grade 0. The school was more understanding and would do things like warn Samantha in advance if there was a party, so she could send something for Claudia that she was allowed. They would also phone if they had forgotten to give Claudia medication and "ask if it was all right if they gave it to her late": "So I was very happy".

Claudia then went to Grade 1 in the same school. Samantha thought she was "doing good for her" by insisting on a certain teacher for the year. In the end, Claudia and the teacher "didn't get along at all". Claudia actually ended up repeating Grade 1 at another school - a private school where there were smaller classes of 12 to 15 children.

In Grade 2 the teacher told Samantha that if she didn't put Claudia on Ritalin, she would have to "take her out of her class - not because she was being disruptive or anything, but because she can't spend that extra attention with Claudia". Samantha refused because of the side effects Claudia had experienced. The principal was called in and said to Samantha "that she had worked in special classes and that none of her children that were on Ritalin ever had the side effects that I was saying that my daughter had." Samantha and the school settled on Claudia being kept on the diet very strictly.

Claudia's Grade 3 teacher "was wonderful; I loved her". This teacher "prayed for the kids" and Samantha feels she "made a difference to my child's life" because she believed in Claudia and "could see potential in her".

At the end of Grade 3, Samantha decided to move Claudia again “because the classes were getting a bit bigger and I saw she was battling again”. Samantha didn’t feel the school was actually helping Claudia in class and she thought: “No, this is rubbish.” Samantha felt the school could help by not insisting that Claudia hand in her projects on a set day, and by being more lenient with spelling: “And things like that.”

Claudia is now taught by a private tutor who is an ex school inspector. There are five pupils in Claudia’s class. The tutor offers primary school before eleven o’ clock, and then after eleven, until two o’clock, it’s high school. Two of the five children in Claudia’s class are 16-year-old “high school kids that battle”. They do some subjects on high school level, and then the other subjects on primary school level. The other two children in Claudia’s class are boys, “so she doesn’t have friends at school and that’s what she misses; she misses the friends.” Claudia misses the fact that when she was at the other school “she was in with the crowd”. She does see her friends still; she will go and visit them. Her brother is at her old school, so she also gets to see her friends at school functions.

Claudia’s books look “like a pigsty” and studying is difficult for her. Because she battles to read, it takes her two and a half hours to study two pages. But when Samantha sits down to go through the work with her, “she hasn’t a clue”. Samantha will often sit with Claudia doing schoolwork till late at night. Claudia also battles if Samantha asks her the question a certain way, and the teacher then asks the question in another way: “that will throw her totally and she will get like 30%”. Samantha knows that Claudia knows the work, “but she just can’t answer the question”.

Samantha has had Claudia assessed again since she started with the private tutor and she feels they haven’t really “seen the results yet from her new school.” Samantha was “thinking it would be nice to put her back into a normal school environment”. The results of the assessment were not encouraging:

“You know, it feels like within the four years that she hasn’t been tested, it feels like we’ve got nowhere, because her results were like a year older. Her spelling and that just...well, you know, in four years she has grown a year in spelling and reading.”

Math is Claudia's "stronger point", because "she can actually handle math, whereas the other subjects she's battling". The assessment showed Claudia's reading, comprehension and spelling to be at a seven-year-old level, and math at ten-and-a-half years or nearly eleven years. "And I mean she's twelve, so that of course **is** her strong point and that's why she likes it". Samantha and Claudia have made a habit of working on her times tables every day and Samantha believes that is probably the reason her math is her strong point

So, for now, Claudia stays where she is. Samantha sometimes gets "frustrated with the teacher because she let's us know yesterday that there was a test today." Samantha does, however, believe that the teacher has "got her reasons for that" and "she knows what she's talking about". It does make her "get freaked out" though because she knows that son is an A student because he starts learning well in advance.

Samantha's son does really well at school, which makes it "a difficult scenario". He will come with a really good result "and then she (Claudia) will be there and I can see she is disappointed, and then I don't make a fuss of him". Samantha admits that she does try to "play his achievements down a bit". At the end of term Samantha gives them "a bit of money for their reports" and to make up she then gives her son "more on the side". What saddens Samantha is that, "in all her life, I must say that she has worked probably even harder than him, although he works. And yet she just copes."

Samantha actually stopped working before Claudia started school "to get her ready for school", and "be there" for her. Samantha feels she personally hates school now "with such a passion, because I mean it feels like I've put my whole life into these couple of years and I don't get any results". Samantha feels she is "really burned out" now, "always having to cope with it". She is starting to feel like she "can't carry on". Although her husband has always been there to support them, "it is never the case of his actually, you know, being there in the afternoons to have done the homework". The night before our interview Samantha lost it while doing homework with Claudia and believes it "was time" that her husband saw she "was losing it".

Samantha believes she **had** so much patience (Samantha's emphasis). If the occupational therapist wanted to see Claudia three or four times a week, Samantha would go three or four times a week, and still do Claudia's homework with her. Samantha feels she just doesn't "have that any more".

Claudia is about to start a reading programme to help her with her comprehension and understanding, and maybe reading a bit faster. She has also recently started group speech therapy. Samantha is hoping it will “build confidence as well as talking”.

Dealing with health professionals

Samantha’s “experience of the medical profession has been quite positive”. The family ‘never, ever went from one to the other to the other. I mean we stayed with those that we saw.’ The only reason Claudia has had two speech therapists is because the first speech therapist stopped practicing.

Samantha believes the occupational therapist and the first speech therapist “were wonderful”: “They took us under their wings and they looked after us”. Even though the occupational therapist hasn’t been treating Claudia for five years now, Samantha still feels she can “phone her and she will talk to me as if she had seen Claudia yesterday”.

Claudia’s second speech therapist was not quite in the same league. Samantha feels she “never bonded with Claudia, and Claudia never felt like she had a relationship with her”. Once the medical aid stopped paying for speech therapy, Claudia stopped seeing her.

Being Claudia’s parent

For Samantha, being Claudia’s parent is “a day-to-day handling every situation as it comes”. A lot depends on Claudia’s mood: some days she wants to do things and “other days she just doesn’t give 100%”.

Claudia and her brother “don’t really get along”. “In the playground they would stand up for each other, and amongst friends they would stand up for each other”, but “at home they will fight like cat and dog”. Samantha reasons that that “is normal for siblings; that’s fine”.

Samantha believes that Claudia’s brother “does understand about her having ADHD”. Samantha has spoken to Ben about the ADHD.

Samantha does not “think there’s much of a difference at all” between parenting Claudia and parenting Ben. When Claudia was younger there was a difference:

“Then I would have to say to her: ‘Claudia look at me I’m talking to you.’ I would have to remind her all the time: ‘No Claudia, don’t touch it. I’m talking to you now listen to me and do what I’m saying and get these things done.’”

Now there is not much difference. Samantha believes it is because Claudia is on her diet. She does admit though that “Ben can carry on with stuff on his own and she (Claudia) might just need some directing”.

Samantha doesn’t “particularly think that she (Claudia) is a badly behaved child”.

“I sometimes maybe over-exaggerate a bit, but she is not as bad as like I’ve seen other kids that are **on** medication and they are still.... Then I think gee she’s not even half this when she’s **not** on medication or she’s **not** on the diet. (Samantha’s emphasis)”.

Samantha believes Claudia has been brought up “very strictly, because I saw like other kids; and I saw that and I just thought there was like no ways I’m going to be stretched that extra mile.” Samantha feels Claudia’s “home foundation has been very stable”. Samantha admits that in their household, you “do it my (Samantha’s) way and I don’t want to hear any complaints, I don’t want to hear any arguments otherwise, you know, bed early - it’s the worst punishment you can give her because then she’s got to lie there for hours.” Samantha believes “a hiding never works; well it’s never worked with her anyway.”

Bedtime is “a bit of a problem” in the household; Claudia is “actually taking something for sleeping now”. If Claudia doesn’t take it, or she takes it too late, she tends to lie around and not sleep.

Coping

Samantha is “very strict with her (Claudia); I’ve got to be. She works in a structure. I’ve never let her run wild, I can’t. I just decided one day it’s not going to be like that.” In their household not running wild extends to keeping quiet in the car: “I’ve never ever had my kids jumping around on the back seat making a lot of noise”. Samantha “also can’t handle it when kids just lie around on the sofa and make a noise. I’m just funny in that way, so they were never allowed to do that.”

At one stage Samantha did attend an ADHASA support group, “and we used to go to the evening meetings and that”. Samantha, however, doesn’t “have the time at the moment” to attend meetings.

At the moment Samantha feels her support system is just herself:

“I cope by pushing myself. I hate to be a failure; I hate anything that’s a failure. I’m very structured; I don’t leave things lying around – things must be put away right now, I don’t like it lying there. Even at home I don’t leave anything for tomorrow. If it can be done today then why must it be left for tomorrow? I do everything today. And I think it’s the same with coping with anything - it has to be done today. I just push myself and that’s probably why I feel like I do - I feel burned out. That worries me, because like last night I lost it. And then there are other days that I can just take it, and take it, and take it, and take it. Then I will be alright for a couple of months; and then one day I just lose it again.”

Claudia and the future

Samantha admits that she does “worry about her (Claudia’s) future”. Samantha would like her to finish matric, “and I’m sure if we carry on we will”. Claudia has dreams of going to Paris and becoming an actor or a model. Although Samantha doesn’t know if Claudia has “got confidence to do things like that”, Claudia did do modelling in the past and “she loved it”.

“I mean here was my daughter actually enjoying something and because she was interested in it she could do it. So, it was like probably the only thing that she’s ever done that she felt good about and felt: ‘Wow, I can actually do it.’”

Claudia is also “good with her hands and she’s arty”. That is one of the reasons that Samantha has started the arts and crafts shop. Samantha is hoping that Claudia “can grow into it - that’s if she wants to. I don’t know if she wants to, but she can cope with the arty stuff.”

Samantha worries about whether Claudia is “going to manage to create structure for herself.” She also worries because, although Claudia knows that things like the diet work, she can’t **wait** to get off it (Samantha’s emphasis). Samantha believes that with Claudia she tends “to want to hold on to her”.

“I would sort of like think that I would want to look after her for longer - like the reason for the shop like – so that she’s got something to go into if she wants it.”

Samantha’s advice for other parents

The first piece of advice that Samantha has is that parents not ignore the problem. Samantha has a niece who she could see is ADHD. She spoke to the mother, and her reaction was: “No, there’s nothing wrong with my kid; don’t talk rubbish like that.” The child has now been assessed and she is ADHD. The parents “are devastated because they don’t believe it; they thinks it’s a whole lot of rubbish”. The parents now want to have her reassessed: “But they can have her assessed over and over again until they are blue in the face and they won’t be fixing it.”

Samantha has suggested the diet to the parents, but they persist in saying “there’s nothing wrong with our child”. “And they just won’t accept it.” Samantha admits that she too “didn’t want to accept” the diagnosis and it was hard to “deal with that initial shock of actually hearing it”. But she knew she had to do something about it. “Where they, on the other hand, are not going to do anything about it; they’ve already decided – they’re going to just leave her, she must be a child.”

Once parents have accepted the diagnosis, Samantha’s advice is: “Hang in there and just don’t burn yourself out. “

Samantha warns that parents must be careful about what they say around their ADHD child. Until recently Samantha has always told people that she gave up work to get Claudia through school. When the children wanted “something extra” Samantha would tell them she doesn’t have the money. Claudia “put two and two together” and said to Samantha the other day: “Mommy, you know if you hadn’t given up work we would have been so rich and it’s all **my** fault. “ It shocked Samantha to realise that Claudia had “been living with that for years. Because she said to me: ‘Mom I knew for years and years that we’re not **that** rich because you stopped work you know.’”

Samantha would “definitely” recommend the diet. Samantha actually walks around with the diet in her bag, and if she is with someone “who is battling with their kids”, she will “haul it out and show them. And explain the whole thing to them. And so, yes I’m willing to, I’m always trying to give advice to other folks.” Samantha warns,

however, that the diet route is “a life-long commitment” and it is difficult to stay on it: “You have to just decide it’s that or nothing.”

Samantha believes that “structure definitely, definitely works” for her and they try “to be as structured as possible”. At the moment “it’s a continual callback”, but Samantha is hoping that “one day the penny will drop. After about twelve years it hasn’t, but I’m prepared to wait.”

Samantha admits that “it’s definitely an emotional ride that the parents go through; you have your ups and you have your downs”. Samantha recognizes how important it is for Claudia to have opportunities to succeed. “If she just feels that she can do it maybe better than somebody else for once in her life, then she feels like she’s done something wonderful.”

“Just that one time that she actually, you know, does something better than somebody else just boosts her. And it boosts me as well because I then feel: ‘Ag shame she’s happy about what she’s achieved.’”

APPENDIX L: CONSTITUENT PROFILE – ZELDA’S STORY

Zelda is divorced and lives with her two children: 18 year-old Sue, and her son, Karl, who is 12-years-old. Zelda left her ex-husband when Karl was a week old. She went back to Karl’s father, but left again when Karl was 10 months old. Zelda has a sister and brother, and her parents are also divorced.

Karl was diagnosed with ADHD at the age of seven and is on Ritalin. Karl does not have a lot of contact with his father. According to Zelda, Karl’s father has ADHD, and she thinks that Karl’s paternal grandmother might have ADHD. Zelda believes there is “a lot of ADHD in their (Karl’s father’s) family”. One of Karl’s cousins on his father’s side has Conduct Disorder as well as ADHD. Zelda believes there is no ADHD in her family “at all”.

The road to Karl’s diagnosis

Zelda never noticed anything different about Karl when he was a baby. She felt Karl was “bright” and she remembers teaching him “to suck through a straw when he was really tiny – he was a few weeks old.” Karl was also “a really happy baby” and he was walking at 10 months.

Zelda got her first indication that something was “wrong” when she herself went to see a psychologist when Karl was two-years-old. Zelda’s “sister and everybody” had suggested she “see someone after what happened”. Zelda remembers Karl having something in his hand – “a toy or something” – and he was repeatedly knocking on the table with it – “the whole time”. Zelda “knew things like that must have happened before”, but she admits: “you just sort of adapt to it, just get used to it”. The psychologist, who didn’t know Karl, commented: “Can you take him away, because I can’t work. This noise all the time – it doesn’t stop.”

In nursery school Karl bit other kids. The teachers put mustard in his mouth, which Zelda felt was “the worst thing you could ever do” to her child. She thinks they also had to take him out of his class sometimes, and put him with another class.

Before Grade 0, Zelda had Karl tested by an educational psychologist, “just to see if he was ready for school”. The psychologist picked up in his spatial tests that he “had problems; he couldn’t copy a picture where dots were joined.”

Karl then started school and he started occupational therapy, speech therapy, and remedial therapy. He was at a school where the speech therapist and the occupational therapist came to the school. Karl's Grade 0 teacher told Zelda that he had a concentration problem, and asked if Zelda could "give him some herbal thing".

In Grade 2, Zelda felt Karl had "a lovely teacher". She would deal with Karl by sending "him on errands and everything, so that he'd get a chance to walk around and not have to sit still so long". The teacher had "a nice relationship with Karl".

At that point Zelda took Karl to his paediatrician who "finally diagnosed him". Zelda then took Karl to a psychiatrist: "because it's psychiatric medication, I thought a psychiatrist should look after him". The psychiatrist doesn't have to monitor Karl that closely, but they do go back to him for repeat prescriptions.

Zelda's feelings about Karl's diagnosis

Zelda felt she initially didn't know much about ADHD. Her reaction to the diagnosis was to "try and find out about it a little more – how it works". She feels a need to try and understand ADHD: "it would be nice to be able to understand it. You know, you think your kid is so smart."

Zelda does wonder about the ADHD child being labelled as having something "wrong" with them.

"We look at it as though, okay, there's something wrong with his brain – that his neurotransmitters aren't getting through or something. But is there something wrong? Maybe there isn't. I don't know. Different from ours, but not necessarily wrong."

Karl and Ritalin

Karl is on Ritalin, but not at weekends and not during holidays. In the beginning he wouldn't eat if he took the medication. Zelda found that "quite difficult, because you'd fetch this little child at 5 o'clock and he's only drunk a juice." It made her "feel terrible".

Zelda now makes sure Karl only takes the Ritalin after he has eaten breakfast: "if he takes the Ritalin before he eats breakfast he won't eat during the day".

Zelda believes you have got to “think about putting them on Ritalin”. It’s not just a case of “give it to them”. For Zelda, giving Karl the medication means: “he has the chance of a normal education and getting out of school and having a job and studying further or whatever”. Not giving the Ritalin to him means “he can’t manage at school”.

Zelda thinks she has made the only decision she could make putting Karl on Ritalin. The only other alternative would be if she “could teach him on a one-to-one basis always without medication and he didn’t have to go to school, then that would have been the best.” But having to work full-time means this is not a viable option.

Zelda has always involved Karl in his treatment. From the beginning she has asked him, “How does it feel to have Ritalin?” Zelda believes Karl knows what it feels like “to be Karl on the Ritalin and Karl not on the Ritalin”. He can “separate the two” and is “totally aware of what the medication does”.

Zelda tried letting Karl take responsibility for taking the medication, until he took two Ritalin one morning. Zelda believes taking the medication is “not an issue for him” – “He doesn’t say I want to not take it, or I want to take it.” It is also not an issue for Karl to take the Ritalin in front of friends.

Zelda believes these children do mature and “little things get better”. On the other hand she realises parents might actually just “get used to them”.

Zelda has never “gone the diet route at all” or tried to control Karl’s diet. She thinks it is better not to either. Zelda feels there is too much conflicting information about nutrition: “I mean one day you hear that **this** gives you cancer, **that** gives you cancer, don’t do **this**, don’t do **that**. So little is really known there.”

Zelda’s sister-in-law always tells Karl that he drinks too many fizzy drinks. Other people have also sometimes made “a comment about their diet, or this or that.” Zelda once took Karl to a homeopath and “came home with all these little bottles.” But then she thought, “What’s worse: the bottles that I know nothing about or the Ritalin.” Zelda feels Karl “must take the Ritalin because there’s nothing else”.

Karl and friends

Zelda believes that Karl “doesn’t make friends easily”. Karl does, however, have a few loyal and good friends. Zelda thinks that Karl tends to go for a quiet child as a friend. Zelda sees Karl as being “incredibly kind.” It surprises her that someone as kind as Karl doesn’t make friends easily. She believes Karl battles to make friends because he “will go in there and say the wrong thing, and do the wrong thing”. Karl “won’t be invited to every single party or every single thing”. Brenda believes ADHD children “learn to be hurt from when they are little”.

Karl and school

Karl is in a mainstream private school. Zelda does not believe in putting ADHD children in a remedial school because “often they don’t have any remedial problems or anything.” She believes that putting an ADHD child among children with problems is going to “highlight all these problems and that’s not good. You’re going to tell them they’re different in a bad way.”

Zelda believes that Karl is “not understood a lot of the time by teachers and friends and other kids”. She feels that school will be better for ADHD children if teachers are more understanding. Zelda believes ADHD children have a lot to offer and she wonders how many of them “leave matric and just can’t carry on”. Zelda finds the attitude at Karl’s school to be: “You know this is not the norm, why should we?” She finds that strange because she believes there must be “a lot of ADHD kids” at Karl’s school.

Zelda feels that more knowledge about ADHD needs to get into the schools and that teachers need to be taught about ADHD at training college, and how to work with ADHD children.

“Teachers have to understand it, because if that doesn’t happen it’s sort of like they (the ADHD child) have extra lessons and therapy and that, but it’s not an integrated support system and people that understand it and everything. And I don’t know why it isn’t done, because so many kids have it and teachers come across it a lot, and they don’t understand and they don’t cope with it.”

Zelda had a call from the principal last year because Karl swore at the after-care teacher. When Zelda got to the school, the principal, in front of her, “attacked” Karl: “Karl must do this and he can’t do that”. Only later Zelda asked Karl what happened

and he told her another child actually hurt him and kicked him on his knee that was already sore. Karl had tried to tell the teacher, but she “didn’t listen” and “she didn’t understand or anything”. “And so there was this whole lot of steps and at the end he swore. And that happens all the time.”

Zelda finds it “sad” when Karl gets into the trouble. She believes the problem is that Karl will act without thinking first:

“It’s like, another kid if he wants to do something wrong he’ll think about it; he’ll make sure that he does it without anybody noticing. An ADHD kid will do it without thinking and think about it afterwards, and he’ll get into trouble.”

With regard to subjects, Karl “excels at maths”. Since he was tiny he could “add figures in his head”. He, however, battles with English and he doesn’t like to read. Zelda finds that “funny”, because when Karl was little the only thing that he sat still for was when she read him a book.

It frustrates Zelda that Karl can sit for “hours and hours and hours” and focus on something like TV, but schoolwork is very hard to focus on. She also gets frustrated by his “fixating” on something and not then not wanting to “let go”. When Karl was three or four-years-old he fixated on a motorbike and “he’s still fixated on getting a motorbike”.

Karl is “very, very good” at archery and has already made provincial schools. Zelda believes it aids his concentration. The discipline is good for him as well, because he has got to wait until everybody has had a turn.

Zelda feels school is “very hard” for her. She can’t be there and she “can only do so much”. She has tried to deal with the school over issues like Karl not writing homework down properly. Zelda wanted a plan to get what has to be done across from teacher to pupil so that she can get it, and so that she can make sure it goes back to school. Zelda met with his teachers and it was decided that every day, after every subject, he would have to write down the homework and the teacher would have to sign it. It didn’t work “too nicely”. Karl ended up being late for the next class and she feels the teachers just thought it was “extra stuff for them”.

Zelda doesn’t feel that any of Karl’s teachers do “anything to help him”. She would like an attitude of: “Come after school for an extra lesson. Let’s go over that if you

don't understand." She doesn't believe it would "take that much effort either". The teachers could even have the homework written out for Karl and give it to him. Zelda believes the teachers don't understand why Karl can't do it himself and she feels they think he is lazy. Zelda knows it is not laziness: "Some things they can do and some things they can't and, until they can do them, just help them. "

Zelda believes the relationship the ADHD child has with the teacher is "very important" and she thinks "that's true for any kid." Even her daughter who is a "straight A's" student would only score B's for a teacher she didn't like. Zelda believes that if the teacher can "care about them and try and help them with everything, then of course the child is going to respond – it doesn't matter whether they have ADHD or not." Zelda believes a lot "depends on the individual, if they care or not. It doesn't matter whether it's a government school, or a school in Soweto somewhere, or a private school. If they care enough they would do more."

Dealing with health professionals

Zelda feels that medical practitioners generally advise you to give the child Ritalin: "I've haven't met any doctor who would go against them taking Ritalin." Zelda has only seen Karl's paediatrician and the psychiatrist regarding the ADHD. Karl's paediatrician and the psychiatrist each have a son with the disorder. The paediatrician's son took Ritalin through his school years and university and "that's how he managed to get his degree." Zelda believes that is why the paediatrician "feels quite strongly about Ritalin". The psychiatrist's son is also on Ritalin. Zelda feels she hasn't "really had a bad experience with the medical community – just teachers".

Extended family and friends

Zelda's family "were fine" when they heard the diagnosis. Zelda feels "it's accepted; it's not a stigma or anything." Even Karl's seeing a psychiatrist is accepted: "every second person goes to a psychiatrist these days".

Zelda friends know about Karl's ADHD and she believes that "because there are so many kids that have it" all her friends know of somebody in their own family that has it too. That is why she finds it "so surprising that teachers and schools are not geared up for anything like this".

Being Karl's parent

Zelda believes she learnt to be a parent from her children: “They’re pretty quick to tell you when you are doing something right or wrong.”

Zelda finds her two children very different to parent. Her daughter comes home with distinctions and prizes and does “everything perfectly”. It makes Zelda feel: “Ah, it’s so wonderful.” On the other hand, Zelda admits her daughter is very selfish.

Zelda also tends to be a perfectionist and that makes it hard sometimes to be Karl’s mother. Zelda worries that she will “transmit that feeling that you’re not good enough, without meaning to, but it will still be transmitted”.

“Sometimes in your mind you have a picture of somebody who doesn’t succeed, or who doesn’t do well or something, and sometimes you see that in your son. (Sighs) And I feel so guilty.”

It is “hard” for Zelda that sometimes when her daughter comes home with a good report, she feels she can’t “really be too happy”.

Zelda works all day and she feels there’s a constant struggle between the two children to get her attention. Because of the ADHD, Zelda does spend more time with Karl and she thinks her daughter “resents that”. So although Zelda does tend to give Karl most of her time, she makes a conscious decision to try to spend some time alone with her daughter, so that she doesn’t feel neglected.

Zelda feels ADHD children “have no organisational skills”. Mornings are a battle in their household: “Karl, have you brushed your teeth? Karl, have you eaten? Karl, have you packed?” Zelda finds it frustrating that Karl “can’t retain more than one instruction” and she then has to “repeat it:

“You’ve got to go step by step. You just can’t do anything else. It’s like looking after a baby.”

Karl is also very accident-prone and he hurts himself all the time. Zelda finds that “terrible”. She wonders if the doctor is going to start thinking that she batters her child.

Coping

Zelda admits that it is “very hard” being the parent of an ADHD child: “I think you’ve got to really just persevere as it all happens.” Zelda believes you’ve “got to work ten times harder than somebody else.” Ultimately she has just got to do the best she can.

Zelda has also realised that she can't always be responsible for Karl: "if he doesn't sit and do his homework after I've told him to do his homework, I'm there to help him but he's also got to own some responsibility". If Karl gets bad marks for a test because he didn't learn, it's not Zelda's fault.

Karl and the future

Zelda admits that she worries about the future. Zelda believes Karl will "always cope, no matter where he is, or what he's doing or whatever". But because of society's standards she feels it will take "a lot of hard work for him to succeed". She does not worry about him on his own, without her, one day though.

Zelda's advice for other parents

Zelda believes there isn't a lot of advice available to parents. Zelda's advice is that parents treat ADHD children "like little people". When Zelda's parents got divorced, she "wanted to know everything" and she feels she would have been "really upset" if she didn't know everything. Zelda tells Karl everything and involves him in his treatment. She believes the child will "tell you if they don't want to know".

With regard to the medication, Zelda believes that children have a right to know why they are taking Ritalin and when they take it, so that they also have some control.

Zelda advises that parents must be organised, especially when it comes to school. Organisation for school extends to colour coding books and finding ways to instil routine.

For Zelda "the most important thing" is that you've got to "just accept it" and "then to work from there".

APPENDIX M: CONSTITUENT PROFILE – SANDY’S STORY

Sandy has been married for almost 20 years. She and her husband, Allan, have a daughter Heather, who is 15-years-old and in grade nine now. Their son, Aidan, is nine-and-a-half-years-old and is in Grade 3. He should have been in Grade 4, but “because of his emotional problems” he wasn’t quite ready to go to school at the age of six-and-a-half. Sandy and Allan decided to keep him back.

Aidan was diagnosed with ADHD at the age of six-and-a-half. He is currently taking Ritalin and Convulex.

The road to Aidan’s diagnosis

Aidan was “the most unbelievable baby” and he slept through the night at six weeks. He was “a good baby” and never demanding: “He was great.” The first indication for Sandy that something was wrong was that Aidan “never rolled over when a baby should roll over – he rolled over later”. Sandy had to do “a lot of encouraging”. He also sat and walked “a little bit later”. Aidan was generally never an active baby.

When Aidan was about three-years-old, Sandy sent him to a playgroup - initially for two or three mornings a week, and then every morning. The women who ran the playgroup kept telling Sandy what an intelligent child she had. Aidan was also remarkably verbal – to the point where “people always used to comment on how verbal he was”. The playgroup teacher felt Aidan had “a lot of potential”.

At the end of that year, Sandy took Aidan out of playgroup and put him into a half-day nursery school. Aidan’s teacher was “wonderful” and “took an immediate shine” to him. The teacher kept saying to Sandy that Aidan doesn’t sit still, but the teacher felt he was an intelligent child who needed stimulation. Sandy noticed at this time that Aidan was becoming “a bit more difficult” at home - more “defiant – wouldn’t really listen”.

At this stage, Sandy started “doing a bit of research” and she went to a talk on ADHD. Sandy admits she “sort of had a feeling”: “in my heart I sort of knew, because my nephew was an ADHD child”.

The following year, the headmistress of the school said to Sandy that: “there’s definitely a concentration, a focal problem”. Sandy “decided to do a bit of more research”. She spoke to the ladies at the pharmacy and they gave her “all these supplements”, which she tried, but they did nothing for Aidan. Sandy also tried him on “some herbal thing” which someone recommended - again no benefit. Sandy decided to give Aidan “the benefit of the doubt” and decided to “let him cruise” the year.

When Aidan got to Grade 0, his teacher said to Sandy that there was definitely a concentration problem – “he couldn’t sit still”. Sandy and Allan sent Aidan for testing. According to the assessment, Aidan was not emotionally ready for school, but otherwise “he was fine”. Sandy and Allan got consent to keep Aidan back a year. Sandy believes the school was “not impressed”, but she kept him back and she kept him back in the same school.

In the first quarter of Aidan’s second year of Grade 0, Sandy took Aidan to a psychiatrist. He diagnosed Aidan as having ADHD and suggested putting Aidan onto Ritalin.

Aidan was initially put onto the slow release Ritalin, but there was no noticeable improvement. Aidan was then put onto the short acting Ritalin until the end of Grade 0 and for Grade 1. At the beginning of Aidan’s Grade 2 year, Sandy took him back to the psychiatrist for a check-up. The psychiatrist suggested trying Aidan on the long-acting Ritalin. Within the first week of school, Sandy was called in and told “that the wheels had fallen off Aidan”. “He was very anti-social, he was very aggressive, told his teacher he was going to commit suicide”. Aidan was just “generally very unhappy”.

So, it was back to the psychiatrist who suggested putting Aidan back on the short acting Ritalin. Aidan stayed on it for Grade 2 and is still taking it now.

This year, Sandy decided to take Aidan to see an educational psychologist. Sandy feels she does so much work with Aidan, but there “was never **any** (Sandy’s emphasis) improvement”. Sandy has always been told that Aidan has so much potential and is so intelligent, but she sees no results. Sandy worries about Grade 4 – “when they changes classes, they get subjects, the studying starts”. Sandy spoke to Aidan’s teacher and the teacher also voiced her concern about possible emotional difficulties that he’s experiencing. The educational psychologist suggested an EEG.

Aidan has now been diagnosed with epilepsy. Initially he was put onto Tegretol. After five weeks nothing had changed, beside Aidan gaining a lot of weight. The neurologist has now changed him to the Convulex and “it’s still early days”.

Sandy’s feelings about Aidan’s diagnosis

Sandy wasn’t surprised by Aidan’s ADHD diagnosis and admits she “always suspected it”.

“I knew that there was a problem and, with the bit of research I had done, it wasn’t a surprise to me when I was told: ‘Your child is ADHD.’”

Aidan and Ritalin

Sandy didn’t really want to put Aidan onto Ritalin. She decided though that she had to be “very open-minded about it”: “I thought to myself, you know, I’m not going to deprive my child of it – if he needs it, we’ll give it to him.”

Sandy explained to Aidan about taking the Ritalin and told him it would help him to sit still, and to take in what the teacher’s saying, and to concentrate. The Ritalin has never made “a huge difference”. Aidan does have “a lot of side-effects”: he cries a lot, in the afternoon he’s very aggressive, he’s emotional, he’s uptight, and he’s difficult to work with. When Sandy spoke to the psychiatrist about it, his reaction was, “Oh man, just give it to him three times a day.” Sandy did not agree with that and, although the Ritalin was prescribed three times a day, she “never ever **gave** it to him three times a day”.

Sandy attended a parent’s course through ADHASA (Attention Deficit Hyperactivity Association of Southern Africa) this year and the doctor who lectures on the course suggested giving Aidan half a Ritalin in the afternoon. Sandy did this, but “never saw any great difference”. The neurologist has since told Sandy not to “waste your time” giving him the half.

The educational psychologist suggested that Sandy look at forms of medication for the ADHD other than the Ritalin – like the anti-depressants. Sandy however, is “terrified” of antidepressants. Sandy has a sister who is bipolar and Sandy can “see what medication has done to her – it’s ruined her”. Sandy also took anti-depressants after her daughter was born, and she feels they made her “worse – majorly

depressed – I felt sick, I had these out-of-body experiences”. Sandy worries that if Aidan goes onto anti-depressants, he will end up like her sister.

At the ADHASA parent’s course Sandy was also introduced to supplementation, and the diet. Sandy has started to give Aidan supplements and she now checks what she buys: “no tartrazine, and I try and stay away from the colourants, MSGs and things like that”. Sandy feels, however, that she is “**not** over-neurotic as far as the diet’s concerned”. Sandy doesn’t want Aidan to feel that he is “different from society”, and only if “he was one of these extremely allergic, sensitive kids” would she “probably go the full route” with the diet.

Sandy feels she has “gone into this whole thing very open-mindedly”.

“I feel that for my child I have done the absolute everything I possibly can. I don’t feel that I’ve left any gaps and, um, I feel I’ve done what I can now, and now I’m just praying for a miracle.”

Aidan and school

Aidan goes to a private school and he’s in Grade 3. There are 24 children in his class, although from Grade 4 it grows to 26 children in a class.

Sandy feels that Aidan “goes through funny phases where he enjoys school”, but “he hates maths and he hates English”. Sandy believes that Aidan hates maths because he’s battling to grasp the concepts. The teacher feels Aidan “**can** do it, but he gets **very** easily distracted (Sandy’s emphasis). Sandy is now going to have to send Aidan to extra maths classes.

Reading is always a problem and it can take Sandy up to two hours to do two readers with Aidan. After that they still have to do spelling. Sandy has put white boards up in Aidan’s bedroom and each week they write the words for the week on them – “the difficult words, the spelling words he got wrong in his spelling that week. So, he constantly sees it”.

At the beginning of Grade 3, Sandy took Aidan to an optometrist and had “the visio-graph and everything done”. The optometrist found that “Aidan reads words and then moves back again on that sentence and that’s why his reading is not up to

scratch". Aidan now "wears little glasses and he sits in the front of the class". Angela feels she has "done everything" for her child now.

Sandy makes sure she has "as much contact with the school as possible". At the beginning of each year, Sandy has been to see the teacher on the first day and said: "Listen, my child takes Ritalin; he's an ADHD child." Sandy asks that Aidan sit in the front of the class and gives the teacher "guidelines as to what the problem is and things like that". Sandy often writes notes to the teacher in Aidan's homework book, and the teacher writes back. Sandy also meets with the teacher when necessary. Sandy feels she has a good relationship with the teacher "and Aidan absolutely adores her – he absolutely cannot love her enough". Sandy is concerned about Grade 4: "because they grow up next year and it's a very different environment. And the teachers don't have patience for children with ADHD, you know".

Sandy admits: "in my heart, I don't think his school is the right school for children who battle". Although it is a "good school" it is "highly academic" and they expect a lot from the children. Sandy did go to see a lady who does assisted learning from home. Sandy feels this teacher "has got tremendous knowledge of children with learning problems and difficulties", but Sandy can't afford the R4 500 a month it will cost to send Aidan to her. Sandy would love to put him there though, because she knows "he would just excel". Once he has picked up on all the areas where he battles and where he is not coping, he could "go right back" to mainstream.

Changing schools remains a consideration, but Sandy feels that before she makes "any drastic, huge decisions", she wants to let the neurologist sort out Aidan's medication and see if there is any improvement.

Sandy finds it "heartbreaking" though to know that Aidan has so much potential. She wants to see her child reach his potential. Aidan doesn't cope as well at school as Sandy would like him to. Aidan often doesn't complete worksheets. His pace is also a big problem because he's very easily distracted.

"And, from my heart, I want to see him strive and I want to see him grow and I want to see him cope better. And that's, that's where I'm desperate. And that's where it gets to me. That's where I get very sad and I get **very** frustrated."

Dealing with health professionals

Sandy did not find the psychiatrist “helpful at all” and she feels “very disappointed” in him.

“I’m very hurt that I spent **so much** (Sandy’s emphasis) money through him, and I just felt I never got anywhere except the damn medication. And, you know, he never once suggested to me maybe we should go the neurologist route.”

The psychiatrist did suggest that Aidan go for socialising. Sandy felt she “didn’t have that sort of money just lying around”. Sandy does “feel guilty about it”: “Maybe it would have helped.”

Sandy feels the neurologist is “a good doctor – he’s been **exceptionally** thorough; he’s **genuinely** concerned about the kids (Sandy’s emphasis)”.

Being Aidan’s parent

Sandy believes nobody can teach you to be a parent and that you can only “follow your natural instincts as a parent”. Sandy feels that as parents, “you do the best you possibly can; you try not make the mistakes your own parents made with you. But still, as a parent, you make mistakes every single day”.

Aidan and his sister “fight like cat and dog”. There is a five-and-a-half year age gap, but Sandy doesn’t believe that is the issue. It depresses Sandy that the two fight so much. Sandy has tried to explain “extensively” to her daughter why Aidan behaves the way he does. At one time Sandy’s daughter accused Sandy of treating Aidan differently to her.

Aidan has always battled with friends, and Sandy feels it’s been “very hard” for her. Even in nursery school, other parents did not want their child to come over to the house to play with Aidan. Last year Aidan asked Sandy the question she knew “was going to come; it was only a matter of time”. Aidan asked Sandy: “Mom, how come I never get invited to play at other people’s houses?” Sandy felt like Aidan’s question “broke” her. Sandy tried to explain to Aidan “that he can’t always be in control – he needs to be less bossy, he needs to give the other children a turn.” Both Sandy and Aidan cried.

This year Aidan has managed to make two friends. Both of them are ADHD and both take Ritalin. But, other than that, he still battles with friends. Sandy feels that Aidan does tend to get on better with girls because he always says the right things: “And it’s just what girls and women need to hear”. This year Aidan seems to be playing “a lot more on the playground”, whereas before he would make excuses to stay in the class – “he would tell the teacher I’m not feeling well so he could stay in the class, or clean the board, or do duties for the teacher”.

Sandy believes that Aidan has “definitely got vestibular problems”. Aidan avoids anything where he’s got to actually exert himself. Aidan avoids running and only learned to ride a bicycle last year. When the other kids ride their bikes, Aidan just looks at them. He won’t ride his bike – it’s in the back room. Aidan has got roller-blades and roller-skates – but he’s “not interested”.

“He’s never been one to climb trees; he doesn’t climb walls. He’s not one of these children that are adventurous on apparatus and things like that. “

Sandy spoke to the psychiatrist about her concerns and he reassured her that “it’s fine. They’ll grow into it; they do their own thing at their own time.” It still worries Sandy sick though, and she feels she will have to do something about it.

Sandy feels that her own attitude to Aidan has changed since doing the ADHASA parents’ course. Sandy believes she used to feel “this tremendous resentment” for Aidan, because as a parent she felt she was failing: “I felt, no matter what I did, it was never right. I could never make this child happy. And I just did what I **needed** (Sandy’s emphasis) to do. And I felt that I couldn’t get close to him.”

After doing the course Sandy’s “whole outlook” towards Aidan changed and Sandy has “tried very hard to change”. Sandy feels she has a “totally different understanding” of Aidan now. She feels she has more patience with him now, even though there are still times when she will lose her temper. Sandy believes she has more patience now because she knows that what he does, he doesn’t do on purpose: “But I love him **more** now because I understand him and I understand his frustrations (Sandy’s emphasis)”.

Coping

Sandy feels she has “a wonderful husband” and he is her support system. When Sandy was doing her course it “was always great excitement to talk to him in the evenings about what I had learned”. Sandy has passed on a lot of her knowledge to Allan.

Sandy was “hurt” though recently when Allan questioned the amount of money being spent on the neurologist and blood tests and EEG’s. Sandy “got a bit upset with him”. Sandy feels that she has got to do these things: “If I leave this, I feel I’m failing Aidan. And I feel that I’ve got to do it for him. Much more that, I don’t know what more I can do”.

Sandy feels her husband is “adamant against these doctors”. Allan thinks “psychiatrists and psychologists are a waste of time”. Sandy thinks this is because they have had the bad experience with the psychiatrist. Sandy believes Allan will be “more positive about it” when “he can see a change”. Sandy feels “it’s very hard” for Allan to fully understand Aidan’s ADHD “because he’s at work and I’m doing all (Sandy’s emphasis) the work – I’m taking Aidan to here and there and everywhere”. Aidan – when things don’t go right - often says: “I’ll just kill myself. You know what, I just wish I wasn’t born. Maybe it’s better if I just died.” Sandy often hears him talk “about things like that and it scares” her: “My husband doesn’t see it like I see it. (Sandy’s emphasis).” Sandy is “totally neurotic that something’s going to happen” to her children. “I don’t want to live if something happened to my kids”.

Sandy’s advice for other parents

Sandy is always “reading articles and finding things out” about ADHD. Sandy heard about ADHASA through a chat show on SABC. Contact details were provided and Sandy phoned in great excitement:

“And, I don’t know, I think this young girl must have thought: ‘Well this is a really lunatic mother.’ I think my excitement overwhelmed her because I so desperately needed to speak to somebody who could help me (Sandy’s emphasis).”

The secretary at ADHASA suggested that Sandy go in and speak to one of their counsellors. Sandy went through the next day and took Aidan with her. Sandy felt the counsellor was wonderful because she included Aidan in the session as well: “She asked a lot of questions directly to Aidan”. Sandy learnt a lot in that first session, such as the fact that Aidan craves cheese when he gets home, rather than the sugar

Sandy suspected he craved. Sandy and Aidan were with the counsellor for about an hour-and-a-half, and the counsellor suggested that Sandy attend the parent's course. Sandy feels the course "was the absolute turnaround" in her life. The course consists of eight sessions and each session focused on a particular aspect, such as medication, supplementation or education.

"That course was the most incredible thing I've ever done and it's changed my whole outlook about my child."

The parent's course also offers advice on discipline. Parents are encouraged to have rules of the house and a reward system for children. Sandy used to give the children pocket money, but the course encourages parents to make children earn pocket money. Sandy now has a laminated poster in the kitchen with the rules of the house on it. There is another poster that outlines ways for the children to earn their pocket money, for example by feeding the animals, or tidying their bedroom, or getting their school stuff ready for the next day, or being downstairs in time for breakfast. Both children start on zero for the month, and for every task they do they get points. But "if they fight, they argue, they swear – points get taken off".

Before Sandy implemented the whole system, she sat the children down and told them she was going to do it and the reasons why she needed to do it. Sandy feels "it works okay". Sandy still finds she has to say to Aidan: "Don't you want to earn pocket money this month?" "Don't you want to feed the cats before your sister does it – quickly so you can earn the money?" Sandy tries to encourage Aidan, but "it's very frustrating" and "it's an arduous task". "Because I've got to constantly remind him – otherwise he'll have nothing".

Sandy feels that routine is also very important for Aidan: "if you've got a higgledy piggedly life, it just doesn't work with an ADHD child. Routine also helps Sandy keep her "sanity". From a Monday to Thursday, afternoons in Sandy's house always follow a similar pattern. After school, Sandy will make lunch for Aidan while he gets changed and puts his school clothes out for the next day. While Aidan eats his lunch, Sandy will go through his school bag "to see what rubbish he's put in his bag, what he's collected off the playground, and I go through his books". Sandy checks Aidan's homework diary and checks for any notices. Once Aidan has eaten they start homework. Sandy cannot leave Aidan to work on his own: "I'll come back and he is

everywhere. He's checking this out, and he's playing with the cat, and he's doodled on his pages."

Once Aidan has finished homework he has to pack his bag for the following day. Only then is he allowed to go play. At six o'clock Aidan baths, and by eight he is in bed. Sandy usually reads to Aidan and they pray together.

Friday afternoons are "day free" for Aidan, unless there is major homework.

Sandy is very strict with Aidan about the programmes he watches or the play station games he plays. "I try and be on top of it because Aidan also suffers from nightmares and things like that."

Sandy also had the opportunity on the course to meet other moms with ADHD children:

"And we all had something to share. And we're all in the same boat – one way or the other. And it's just nice to know that there's somebody out there who's got problems just like you, if not worse problems. So, from that point of view, it would be my recommendation that people go and do a course."

Sandy admits though that even though she has done the course and has more knowledge now, she makes "lots of mistakes every day of my life".

"I do lose my cool, I think it's very normal, although sometimes I hate myself for the things that I do or I realise that I've said or whatever."

"I'm really trying to do the best things that I can and, much more than that, I can't do. But, ja, it's very tough."

APPENDIX N: CONSTITUENT PROFILE – BETH’S STORY

Beth is divorced and has one daughter, Eve, who is 13-years-old. Beth left her husband two months before Eve was born and went to live with her parents. Eve’s father “has chosen not to have anything to do with her”.

Eve was diagnosed with ADHD at the age of seven, and is not currently taking any medication.

The road to Eve’s diagnosis

Beth feels that Eve “never quite fitted; she wasn’t comfortable to have around”. Eve was particularly difficult at night: “she did the thing at 6 o’clock where she would just go bananas at six o’clock every night, you know, and create havoc until about 11”. Eve was also a “wild” and “aggressive” toddler.

Beth feels the situation was complicated by the fact that she “didn’t know anything about kids”. Beth has always been in the business world and feels she is not really a “baby, baby kind of person”. Beth also never had a younger brother or sister: “I didn’t know what the norm was, which made it worse. I had no comparison.”

Beth’s “gut feel”, however, “was that all was not okay”. Beth started “trying to find out if my gut feel was right”. “But it was difficult because I would go and say to whoever: ‘You know something is not right, but I don’t know what it is.’”

“On top of it all” Eve developed asthma at the age of four. She was forever on antibiotics, either having flu or tonsillitis or bronchitis. “So she was always in and out of doctors until we got her sort of stabilised and everything identified. It was havoc.”

Beth did take Eve to a Children’s Clinic for an assessment before nursery school. Beth feels it was “the worst thing that I ever did”. One particular moment stands out for Beth. As they walked down the passage, Eve was running – “like I used to say that she was like a balloon that had been blown up with air and just let go. I mean there was this wild energy with no point.” Beth drew the doctor’s attention to it and asked: “Is that normal?” The doctor responded that children at that age all have a lot of energy. Beth felt that just made her “beat myself up” because it implied that she “just didn’t have enough patience and whatever”.

The whole tone of the assessment at the Children's Clinic was "almost like accusatory". After the assessment, it was suggested that Beth be the one to attend therapy: "I landed up a basket case". Beth attended therapy three or four times and then felt she "actually couldn't take it".

"They kind of messed me up and they never gave a diagnosis and it was just a waste of time."

When Eve was at nursery school, she would create "such havoc in the nursery school". Beth was actually at the school one day for Eve's birthday and watched her "running on the tables and you know screaming and things". Beth then decided to take Eve for occupational therapy and she feels "that helped".

Eve went to Grade 1 at a little private school, "a small school". The primary school only went up to Grade 3 and there were not a lot of children. Eve's class only had eleven children in it. Beth feels she could see that Eve "needed that". "It was just, again, a gut feel".

Unfortunately, even though the staff seemed "very sweet and understanding", Beth feels the school was run "like a military camp". Eve developed stress migraines, although she did get through Grade 1 "with flying colours, distinctions, and everything for everything".

For Grade 2, Beth sent Eve to a school "where they take children with a cerebral palsy kind of problem, but with at least an average IQ". The school also has psychologists. The school wanted to do a full assessment of Eve, but before the process started Beth had to remove Eve because the older boys were sexually harassing her. Beth feels the headmaster handled the situation "like a donkey", and Eve got depressed.

Beth then put Eve into "an ordinary school, a government school". Eve was put into the aid class, which had 16 children in it. Beth had a "lovely teacher", but it reached a stage where the teacher told Beth, "if she (Eve) doesn't go on Ritalin she is going to have to leave".

Beth then took Eve to a paediatrician who specialises in ADHD. "And I was astounded and it was the best thing I ever did, because she's not out of control all the

time – it’s just this attention deficit thing”. Beth believes Eve “is fine as long, as there isn’t stimulation, then she flips out and becomes impossible”.

Beth’s feelings about Eve’s diagnosis

Beth feels the diagnosis “was a relief, a huge relief”. “I mean I had this child that behaved in no way like any other child that anybody seemed to have even heard of”.

Beth sent Eve to a counselling psychologist for therapy and Beth feels she herself picked up “a lot of tips along the way”: “She gave me practical handles and **that** (Beth’s emphasis) I think is very important.”

“And there were lots of things, I mean you know she (Eve) would go under the bed and the psychologist said that I needed to go under the bed with her, which was wonderful. You know once I did that it was great, you know. And then she stopped going under the bed. Instead of saying to her, you know, get out from there; she needed me to go under there with her. It was a huge relief once I started to get practical advice.”

Beth feels strongly that there “needs to be just a very practical book, not technical, just a practical book on **life**. When an ADHD little child screams, what do you do?” Beth wishes she had been told in the beginning that to “contain” Eve, she needed to hold her: “I really learned that **miles** too late, but I **still** do it”. Even now, when Eve has a bad day, Beth will hold her and she is “much better afterwards. And it’s important”.

Beth recognises that there is likely a hereditary component to the ADHD and personally believes that there is a “very definite connection” between ADHD and the mother’s pregnancy. Beth believes that if there is a “lot of emotional, intense stuff that happened” during the pregnancy the chances are good that your child could have ADHD.

Eve and Ritalin

It was a “massive decision to make” when Beth put Eve on Ritalin. Beth “did a lot of research” and “went to see specialists at UNISA” and spoke to the occupational therapist. Beth feels that, in the end, “it was not an emotional decision - it was a purely practical decision. And it just made practical sense and I was just really glad that she could manage to take it, and the benefits were huge.”

Eve was on Ritalin for “about two years”. The paediatrician’s approach was that “she just took it five days a week, only during school time, and not weekends, school holidays and that kind of thing; that is how he operated”.

It “wasn’t difficult” to get Eve to take the Ritalin; “the doctor was amazing”. When Beth went back for her first assessment of the medication she reported that she was finding the effects of the medication beneficial.

After two years, Eve decided that: “when she was taking Ritalin, she really didn’t feel well, that she felt strange, not okay. Not that she can pinpoint it. Just not herself and in a negative way.” Beth feels she is still trying to see where the truth is in that. Beth feels that Eve is “an **incredible** (Beth’s emphasis) drama queen. And whenever she’s sick and that kind of thing, I always need to give it time and take in all the information before deciding where is she sort of on a scale of perfect health and near death, you know. Where’s the truth?”

Beth feels that Eve should still be on the Ritalin. Beth has decided to try an herbal product with Eve “because it might help”. Beth is not sure how Eve will take to the idea: “You know, she has this thing where she (Eve) doesn’t want to stop being the life and soul of the party; it’s a problem. But you know it won’t be like a drug, so if it can just make her.”

Beth has had not “really gone the diet route” with Eve. Beth has noticed that chocolate has a “direct impact” on Eve. Beth does not use “any MSG and all that kind of thing”. Beth, however, does not want to go the diet route because she does not “want to just put this additional burden on her (Eve), because the problem is that they are made to feel that they are so different. And that’s not good, and they’re different in a negative way, and it’s not good.” Beth prefers to “try to be practical without going overboard so that she (Eve) didn’t land up with another burden”.

Eve and school

From the aid class at the government school, Eve moved to another small private school environment. Beth feels that by that stage Eve was “just so far behind in the basics”.

Eve then landed up at a cottage school with a teacher who is a qualified remedial teacher. Although the teacher was “very lovely”, there were “just no boundaries”. Beth feels “Eve is like any human being, she will only do the minimum that is

required; for the rest she will play her hardest. Eve **wasn't** (Beth's emphasis) achieving her best. Beth also feels that Eve missed the "competition": "I mean she used to love exams, and she thrives on pressure and having to perform". The teacher then immigrated to Canada, and Eve went to another home school, which Beth believes "was very good for her".

In her new school, Eve was "in a mush of grades" and "she was with a range of children - she was the youngest and the oldest was fourteen". Eve was at that stage ten, going on eleven. Beth feels the situation was "quite challenging" for Beth because of the "generation gap". Beth feels the teacher "could see who Eve was, and she got a charge out of Eve's mind and challenged her". The teacher challenged Eve in "many areas, challenges that don't normally come out in schools - like home truth, writing poetry and just the area of her imagination and artistic stuff and that kind of thing, so that was good". At the end of Eve's Grade 5 year, the teacher decided to close the school.

Eve then moved to a school that offers assisted learning. The school initially put Eve into Grade 5, believing it is better to be promoted than demoted. Eve was promoted to Grade 6 after a month or so, "so that was good for her too". Beth feels it was also good for herself: "I want to tell you, it was very good for me. Because of course you know, also being intense, I had this whole big thing that her whole life was going to be a mess now because she hasn't had an education properly and she is not up to where she should be."

Eve is now in Grade 7. Beth feels that Eve "thrives" at the school because the "teachers understand and also she (Eve) succeeded". Beth sees Eve staying at the school for Grade 8 as well: "because of what I'm told about the first year of high school being a major transition; and she certainly needs another year."

On a subject level, Eve still hasn't learned her times tables, even though she has "a superb memory". Beth worries that Eve is "missing the basics" in math, and because she doesn't have the foundation she will never catch up. "Reading is a bit of a challenge and spelling is also a hiccup for her". Beth believes that these "these things will fall into place". Beth has decided to just let Eve "be a happy child without all the other stuff - extra this and extra that".

Nearly every teacher at the school still complains about Eve "distracting all the other children" and they all say: "she's got to learn to concentrate and she's got to focus and all that stuff". Beth does, however, feel that there "could be tighter boundaries

and consequences at the school at this stage” and that the “kids run wild a bit there”. Beth believes that Eve is “a popular child and she has a lot of leadership ability and everybody likes her”.

Beth would like to have Eve assessed again next year some time “just to see where is she really at, what are her competencies on a real level, and see if I can put her into a normal school”. Although Eve enjoys her current school, Beth does not feel Eve is “being pushed enough to produce her best and she’s producing actually pretty sub-standard work, I think, for what she’s capable of doing and what should be expected of her”. Beth feels that Eve did work “two years ago when she was at that little cottage school that is far superior to anything that she produces now”. Beth feels she can’t “nag and perform and carry on and whatever if the teachers aren’t requiring that from her (Eve)”.

Beth has had Eve assessed using a tool called the Structure of Intellect Assessment. The purpose of the assessment is to assess your learning style and to assess “the 25 intelligences needed for success in life, academic success and career success, and it’s amazing”. The system also “provides remediation, so whatever you’re low in or even if you’re high and you want to go even higher, you can bump it up”. Beth feels the assessment “was a wonderful thing” because she could see that Eve “was gifted in some areas and she was lacking in other areas”. Beth believes it has made a difference to Eve’s learning. Beth also feels that the assessment has made a difference to the way she “packages” Eve in her mind and her understanding of Eve and “where she’s at”.

“So that made a very big impact on how I handled her as well. It also gave me a lot of peace too because I knew that she was okay; she was not just dumb.”

Dealing with health professionals

Beth’s experience at the Children’s Clinic “was a shambles”. There were two doctors and a psychologist present at the assessment. Beth’s mom accompanied Beth and Eve for the assessment. Beth remembers the three staff members sitting in a line on one side of the room and herself, her mom, and Eve sitting in a line on the other.

Beth found the experience “dreadful”.

“And you know they made all the nice murmuring noises and things but it was, and you know they had their pens and notepads in front of them. And

Eve was sort of clinging to me a bit, and she had her teddy bear. I mean, I wish I'd had someone to cling to, you know. That would have been quite nice too. And she was little and they said she was too clingy. But she was little. And we were in a very horrible environment and she picked it up and my mother and I felt dreadful too and you know. So it was just; oh it was really, really bad."

The occupational therapist that Beth took Eve to "was amazing" and she "achieved results". The counselling psychologist has also been "very good" and she has "helped". Beth feels that "Eve is five going on fifty" and when Beth is dealing with a situation she has to "ascertain, now am I talking to the fifty year old or the five year old". Eve is never sure where to "pitch" herself. The psychologist confirmed that this is a reality when dealing with Eve, and Beth feels it "was very nice to get confirmation of that". The psychologist also helped Eve "to get a lot of practical handles" on life.

There is also a psychologist at Eve's current school. Beth feels she is "excellent". Beth believes that Eve tends to be "over the top about some things, particularly the emotional issues". "This counsellor just puts a practical handle on it and brings her back down to earth and that kind of thing. But is also very empathetic with her when it's necessary, so that's good too." Beth feels that Eve needs to deal with a lot of "anger issues that have to do with her dad". Beth believes that Eve is "sort of getting herself organised around her issues". Eve "doesn't see herself as having any, what do you call it, self-worth issues" and Beth also believes that Eve "sees herself very positively, which is great." The school counsellor, however, "reckons that she does have" self-worth issues to deal with.

Extended family

Eve and Beth are still living with Eve's parents. Eve's mother now suffers from senile dementia and her father has had two heart attacks and a hip replacement. Beth feels "they need me now", but believes it is not easy for Eve. Beth feels that although "there are a lot of challenges there" Eve is actually "growing through it as well".

Eve has always been "very, very close" to Beth's mom and they had a very "intense relationship". Beth feels that her mother's senile dementia "has actually helped to put distance between that very intense relationship". Beth believes this is a good thing as the "separation forever" will then not be such a "big deal".

No one in Beth's family had a problem with the diagnosis. Beth's brother had ADHD as well, and his son now has the disorder. Beth believes that Eve's father also has ADHD, although it was never properly diagnosed.

Beth believes the family did find Eve "difficult", "because she has a strong personality" with the ADHD. Beth feels that only now is Eve beginning to manage her strong personality better and not be so "dominating".

Being Eve's parent

Beth believes she was a "hectically intense parent" to start with. Beth had Eve when she was 33 and she "was just ridiculously responsible about the whole thing". Beth kept a record of "everything" Eve did: "what she ate, how many nappies, what colour the stools were. I was pathetic about it all". Beth would "devour every book" that she could and then beat herself up when she wasn't perfect. Eve feels she has now "grown out of that".

Eve is now a teenager. Beth feels you hear so much about how ADHD children have "had so much negative input and whatever, and that they've become emotional wrecks and stuff by the time they're in their teens and then you know you've got all that to deal with". On the flip side, Eve loves being ADHD because "she **loves** (Beth's emphasis) her energy, she thrives on it".

Up until the last six months, Eve "battled very much" to make friends. "She used to dominate and she really was very bad actually". Beth feels that at times other children liked Eve to be in control "because she had the imagination and she used to make up these wonderful games, but the control she would take it too far". Beth feels Eve has "matured a lot" in the area of making friends. "Ja, she's just becoming a normal, nice person, you know. I'm enjoying who I see her becoming and I'm enjoying getting out of the last ten odd years".

Beth believes that Eve "seems to have really found a lot of peace in the last maybe eight months or so, but prior to that I think there was huge frustration". Beth feels that some of Eve's screaming when she was little was related to that frustration "and she would do childish frustration things". Beth feels that she (Beth) "needed to learn" and believes she "learned too late how to help" Eve.

“I think she would have coped very much better with the ADHD and what it did to her world, and how she experienced her world, if I had of had more understanding”.

On a daily basis, Beth experiences Eve as “a whirlwind still”. “She leaves a wake of sort of ... just **mess** wherever she goes - and I find that very, very challenging.”

Eve and the future

Beth believes that intellectually Eve has the ability to go to university, and also feels that Eve “needs a tertiary education”. Beth has panicked about it: “She’s never going to have what she needs to be able to.” One of the teachers at Eve’s current school did a lot to reassure Beth.

“She said by the time Eve gets to that age she is going to be fine, and she will have to work on her own anyway, and that’s really what she’s best at, and just relax you know.”

Beth believes this advice helped her to relax about Eve’s education. Beth believes “it’s a good idea to get advice from practical people who have been there before”.

Beth doesn’t have any real fears for Eve’s future:

“I’ve spent the last I don’t know how many years intensely fixated with a negative sort of projected outcome for her. But not now -now that I see who she is becoming. And it seems that she’s learning and that she’s actually buying into some of the stuff that I’m teaching her. And she’s becoming accountable, and she understands about consequences, and she’s growing in good areas I feel. I think she will be okay if she carries on like this.”

Beth’s advice for other parents

Beth believes that parents of ADHD children need to go for “good counselling **themselves** (Beth’s emphasis). Beth feels there are three reasons why parents need counselling: firstly so that “they don’t do the guilt thing... because that is hard to live with”; secondly, so that they “get intellectual handles on what’s going on”; and thirdly, “so that they get **practical** handles, and that they have someone who can walk them through the processes, or the manifestation of the condition, through the different stages of development”.

Beth feels that “one huge piece of advice” is to allow your child to have a dummy for as long they it: “If they need it, they need it”. Beth believes that the child finds the sucking motion to be therapeutic: “That’s why also nursing babies are calm.”

Beth feels parents must relax: “their kids are going to be okay... I am just saying that just because you know Eve is now 13 and we’ve come out of this. You know she is more in control of herself; she is more able to read her circumstances and read herself.”

Beth believes it is a good idea for parents to go on a parenting course of some sort. Beth actually went on a step-parenting course, which was very practical and helped her a lot. Beth feels parents should attend a course that is “practical and helps parents to also understand how the world works around them, and how to teach things like responsibility and accountability and choices, and how to teach your child how to make choices, and how to assess situations, and how to give alternatives. And how to discipline - what is healthy discipline or, you know, beneficial discipline. Because I didn’t know any of that.”

Beth was also a member of an ADHD support group, which she “found very helpful” in that she realised that she “was not the only person in the whole world with this challenge, or this child”.

Beth also recommends “having the right professionals and just really to keep it practical and simple and throw away all the intense stuff”.

Beth feels that having an ADHD “must be very difficult on a marriage” and “in many ways” she is really glad that she “was a single parent”. “Because in so many marriages, the **guys** are babies themselves, now they must handle a difficult child.”

“And then I don’t know; I don’t know what happens in the end you know to the marriages. It must create havoc in a marriage. Yes, and if you have only one child that is ADHD, and the others are not.”

On “a more fun note”, Beth and Eve “found a really good way of spending time together”. They used to pack a picnic and then take the map book, randomly pick a piece of open ground, and go.

“It means the destination is always a surprise and we actually discovered quite a few nice places. She would walk and climb and get rid of all her energy. She would pick up leaves and plants and grass, and we would take them home and find out more about them. We would often take the dogs with us as well. As she got older, I would let her help plan for the day: she would

plan and help make the picnic, plan what the dogs would need etc. It was a really wonderful time for us.”

APPENDIX O: CONSTITUENT PROFILE – GILL AND DYLAN’S STORY

Gill and Dylan are married and have two children, Terri (ten-years-old) and Doug (eight-years-old). Dylan and Gill have been married for four years: “we did things a bit arse-about-face - we had the kids first, and they got to be at our wedding”.

Doug was diagnosed with ADHD at the age of five and is taking Ritalin. Dylan too has been diagnosed with ADHD and also takes Ritalin.

Both Gill and Dylan were present for the interview.

The road to Doug’s diagnosis

Gill admits that they “suspected for quite a while that there was something not quite right with Doug”. What they “picked up first” was the hyperactivity, but there was also “obviously” a problem with his concentration. Gill felt there “was something that was just off. You know, in comparison to the way Terri was at that age.”

Doug then went to a play school and when Gill mentioned to Doug’s teacher that she was thinking if having him assessed, the teacher “encouraged” her “all the way. By then she had said to me that she thinks that there may be a problem”.

Gill took Doug to a clinical psychologist and he was diagnosed with ADHD at the age of five years.

Hearing the diagnosis

For Gill, there is a relief in knowing what she is dealing with:

“So, for me, when I heard those words come out of her (the psychologist’s) mouth I thought, ‘Thank you.’ It has a name. Because when it’s got a name you can deal with it. When you’re dealing with the unknown.... “

Gill does not feel there is “any embarrassment” to having the disorder. Her attitude is: “So what. It’s not something you asked for, but you’ve got it, so you deal with it.”

Gill hopes that because they “got it (the diagnosis of ADHD) so early” that Doug “will come right”.

Dylan’s diagnosis

Dylan was diagnosed a couple of years after Doug, but they went on the Ritalin about a month apart. Dylan admits that personally he didn’t think he “had a problem”. Gill did, however, believe there was something wrong and she “pushed Dylan into finally going and getting himself diagnosed. Because it was a huge issue for us – it just about destroyed our marriage.” Dylan’s diagnosis was “a relief” for Gill.

Dylan admits that in the beginning he was “kind of embarrassed” about his diagnosis. He has to come to realise though that he is not the only adult with the disorder, and he now has an attitude of “I don’t care”.

Doug and Dylan and Ritalin

Gill and Dylan “fought against” putting Doug onto Ritalin for almost two years. Gill feels that they “bombarded” themselves with knowledge.

“We read every single thing that we could get our hands on. We listened to every single programme on TV, on the radio, wherever, and ended up feeling completely confused. Totally confused: was it right or was it wrong? “

Gill and Dylan decided to try “everything else first”. First they “went down the whole diet route” for about six months. Doug is not on the diet anymore. Gill feels that “as a normal sort of two-income family struggling to make ends meet” they actually “just couldn’t afford it”. “We couldn’t afford it, what I had to give this child. I can’t afford to do my monthly shopping at specific shops and basically that’s what it all boils down to.” There are certain things that Gill and Dylan still do: like trying to limit his intake of colourants and preservatives. Gill and Dylan agree that there was an improvement while Doug was on the diet, but not so much that they “could have relied on diet only”.

Gill then got a job with a homeopath that specialises in ADHD. Although they never took Doug to the homeopath, Gill did have access to the information on what the homeopath was treating the children with. So, Gill and Dylan “went down that route as well” giving Doug “Omega 3 and all the rest of it”. Dylan “didn’t find that it did anything very much”.

Gill and Dylan decided to try the Ritalin after they had been “down every route that I think was available to us”. The “last straw” for Gill was coming home one day to find the “curtains had been pulled off the wall”. Gill admits that at “this stage in the game I say thank God for Ritalin”.

Dylan feels that taking the Ritalin doesn't “really bother” Doug. Doug has asked Gill why taking the tablets makes him “not hungry”. Gill admits though that they haven't seen “a noticeable change in his weight”. Doug is on the slow release Ritalin, so he generally doesn't eat lunch, but come suppertime “he's starving”. Doug also eats well over the weekends as he only takes the Ritalin on weekdays.

Dylan believes he “can definitely feel a difference” since he (Dylan) has been on the Ritalin. “I can sit down and concentrate a lot more. I'm more positive in my work; I'm not so fidgety”. Gill feels that Dylan being on the Ritalin has made a “huge” difference at home. Gill felt that, at some level, she could still “deal with” Doug. Trying to control an adult was not so easy.

Dylan believes he can explain better than Doug can what it feels like to go onto Ritalin. Dylan can “definitely feel the days” that he hasn't been on the Ritalin. Dylan feels “more in control” when he takes the Ritalin and he feels far more self-confident. Before he started taking Ritalin, Dylan would leave Jacqui to “deal with the problems”. Gill agrees that Dylan “couldn't speak to anyone who he perceived to be in authority”. This extended to Dylan not being able to stand up to a boss who, in Gill's view, “took full advantage of Dylan”. Gill feels that dealing with “every single aspect” was “too much” for her. Now Dylan is “doing a lot for himself. Not everything, but most of it.” Dylan confidence has improved to the point where he is now considering opening his own business.

Doug and school

In Grade 00, Gill and Dylan could “definitely” already “see a difference” between Doug's work and that of his classmates when they looked at their pictures. The teacher also said to them that his “work was not up to scratch with the rest of the kids in the class”. Doug battled “when they started to learn their letters – you know he really battled with that.” Doug was also noticeably “emotionally more immature” than the other children in his class.

When the time came for Doug to go to school, instead of putting him into the primary school where his sister goes, Gill and Dylan put him straight into the special needs school affiliated to her primary school. The school is situated in the grounds of the primary school and they wear the same uniform as the primary school, and participate in the primary school's assemblies and sport. The school is, however, privately owned.

Doug is in Grade 2 now and, with 12 children in his class, the children "get that individual attention". The teachers are "fabulous" and Doug has the same teacher this year as he had last year. There is a lot of contact between the teachers and parents, and Gill feels she can phone Doug's teacher at any time. The school follows the same curriculum as the primary school, "but obviously it takes them a lot longer". Doug "loves school" and Gill and Dylan "the best thing" they could have done is put him where he is. Gill and Dylan are "feeling it financially", but they "wouldn't change it". Gill believes that if they had put Doug into the primary school with it's 34 children in a class, "he would have failed" and it "would have really done him damage".

The school's objective is "to get the kids up to scratch" and then mainstream them into the primary school. Gill and Dylan are hoping that they might be able to "mainstream him (Doug) next year, but who knows – we'll have to wait and see." Doug is in Grade 2 now, and if the school does decide to mainstream him next year, he will start off in Grade 2 in the primary school. "So he will end up being that sort of one year behind but it **really** (Gill's emphasis) doesn't matter."

Gill feels there has been "a huge improvement" at school with the Ritalin, and she has had "nothing but positive feedback from the school". At the end of last term Doug's report card was "wonderful –every single aspect of it". By wonderful, Gill does not mean "that his grades were excellent and whatever", but "every aspect of his report was positive. Which is the first time ever, so that was terrific." Even Doug's reading "is coming along nicely now." Gill feels that "Doug is plodding along, but he's getting there."

Dylan feels that school was "difficult" for him and with the teachers he "was classified as lazy". The saving grace for Dylan was to be able to play sport well: "I don't know what I would have done without sport". "I think that is what kept me going at school. I had a very good self-image at school because of my sport." Even today, Dylan

battles to read a book and would far rather work with his hands: "Give me something to do with my hands, no problem."

Dealing with health professionals

Doug was diagnosed by a clinical psychologist and she was "very keen to put him on Ritalin right then and there", but Gill and Dylan "didn't want to". Once Gill and Dylan decided to go that route, Gill contacted the psychologist again and she suggested that Gill go to her GP. Gill took Doug's report from the psychologist and went to see the GP. The GP "had a chat" to the psychologist and prescribed the Ritalin for Doug.

The GP suggested seeing Doug every three months and he has also asked for a report from the teacher. Gill admits to being "a bit slack" and has not yet got a report.

Extended family

Dylan's father feels that Doug's ADHD diagnosis is "a load of nonsense"; "he didn't believe it at all". Gill feels that her father-in-law has "decided that this is something that someone along the line has made up." According to her father-in-law Doug is "a boy; this is what boys do".

Dylan believes that his mother knew when he (Dylan) was a child "that there was something not right". Dylan was taken to doctors and "had probes stuck all over" him. Eventually he just got called "a lazy child".

Dylan feels his family must now just accept that both he and Doug are on Ritalin "and deal with it".

Gill believes that Dylan's mother might have ADHD, as well as Dylan's sister's daughter. Dylan's cousin's child was diagnosed as ADHD and was on Ritalin: "and so it goes through the family".

Being Doug's parent

Dylan feels that parenting the two children "was difficult" for Gill. Dylan admits that he "can switch off" and "let them carry on", but "Gill is not that type of person, so she was always involved". Dylan feels Gill was "having a hard time" and was "really struggling".

Gill agrees that she found it difficult to deal with “a child who is out of control”. Gill would reach the point where she had “actually just had enough” and “would wallop Doug”. That would cause Gill to “spend the next three hours wallowing in guilt”. “Terrible, it’s the worst feeling in the world.”

Gill started to doubt herself as a parent:

“You actually begin to doubt yourself. You begin to think I’ve got to be the worst parent in the world. How come everybody else can do it and I can’t? Which is really stupid because, like I say, I’d known all along that there was something not quite kosher.”

Gill feels that putting Doug on Ritalin made “a huge difference at home” and that it made “a huge difference to Terri”. Gill feels that Terri is “a very sensitive little child”. Terri came to Gill one day in tears and said: “Mommy I just actually can’t deal with it anymore.” Terri said to Gill: “Something has to be done about that boy.” Gill admits it was the first time that “it actually hit home what it was doing to **her** (Gill’s emphasis)”.

Because Terri is the older of the two children, Gill would expect her to be “the more responsible of the two”. So Doug would do all sorts of things and Terri would get moaned at: “Why didn’t you stop him; why didn’t you do this; why didn’t you?” Gill realises now that Terri is not the parent and it’s not her job to control her brother. Gill realises now that the situation “was affecting Terri badly”: “I think even more than it was affecting me and Dylan”.

The Ritalin has also made a difference to the way that Doug behaves at home and at school. Doug used to be “constantly in tears”. Dylan believes it was from frustration. Doug no longer cries every day. Doug also used to be a very angry child and Dylan feels that “has dropped”. Gill can now appreciate the fact that Doug is “a nice kid”, “a good kid”, with an “absolutely wonderful heart”. “And he’s sweet and he’s honest, which just I love about him.” Gill feels that Doug’s self-esteem has also “definitely improved”.

Dylan feels that it is easier for him to deal with Doug than it is for Gill:

“Myself I’ve got a lot of understanding; I know what he’s going through. So I’m a lot more patient with him because of it, where Gill isn’t **as** patient. In that respect it’s to my advantage where I know how and what and where he

wants to go. And how it feels, you know his whole temperament. I can relate to it where Gill can't."

Gill feels that they have now "settled into a normal family routine. Finally. It took us a couple of years to get there."

Gill and Dylan

Gill feels that Ritalin has been "a saviour" for their marriage. Gill found she could not cope with an ADHD child, an ADHD adult and the "fall out" from her daughter. A year ago, Gill was ready to get divorced and had already seen a lawyer. There has been a big improvement and the only time Gill and Dylan fight now "are the days that he forgets to take his Ritalin".

Coping

Gill clearly recalls an incident when she was working for the homeopath. The homeopath wanted to visit local pre-schools and talk to the parents about ADHD. Gill remembers phoning one school and being informed: "Parents don't want to hear that kind of thing." Gill "was shocked; I was absolutely shocked." It shocked Gill that parents "would rather bury their heads in the sand." Gill feels "that's a big problem". Gill feels it was vital for her to be "very open to the fact that this might be Doug's problem", and she had to be "willing to explore it". Gill feels she and Dylan could "have turned a blind eye and ignored it, but we chose not to".

"And I do believe, because people look at their children and they expect their children to be little perfect beings. And I don't know if when they perceive that there is something wrong with the child that they take it as a personal failure. I don't. I look at my child and I think: 'Well, he needs my help.' That's the way I see it. I mean, if my child was a diabetic, you know. To me there's no difference. If there's something wrong, don't bury your head in the sand; do something about it."

Dylan is just as incredulous about parents "who wash their hands of it". Dylan has experienced such improvements since he started the medication and he wonders "what might I have been like, or how would I have fared at school, if they had known about it at that age". Dylan feels he has "only started learning a lot about growing up in the last six months, since I've been on Ritalin".

Doug and the future

Gill and Dylan “have the normal worries” for both their children as to whether they will get a job. Both Gill and Dylan see Doug going into some sort of trade. Gill admits she wants Doug to be a horticulturist. She feels he seems to “lean in that direction” and she will “encourage him” as much as she possibly can. Doug has all his own gardening equipment, and whenever Dylan or the gardener is busy in the garden, Doug is there too. “So if this love of gardening holds then, ja, maybe it’s an option for him”.

Gill concludes: “I reckon that Doug is going to be fine, you know.” “I know in my heart he will achieve.”

Gill and Dylan’s advice for other parents

Dylan advises that parents must go into the situation “with an open mind”. Gill and Dylan advise that parents “don’t write off the possibility of Ritalin”, even if they personally don’t like the idea. When Dylan was diagnosed, his attitude was: “let me try this, let me see what. If it’s going to work - fine. If it’s not going to work that’s also fine.”

If parents are totally against the medication route, then Gill and Dylan feel parents must try the “natural stuff”. They emphasise that parents must DO something and not just “sit there and ignore” the problem. If there is any chance of something helping then parents must try it: “You owe your kids. You were the one that brought the kid there, so do it. It will make their life, and in turn your life, easier.”

Dylan and Gill advise that parents must “ask questions” and “know as much as possible”. Gill and Dylan joined ADHASA and, although they have not felt the need to join one of their support groups, they enjoy reading their newsletter. Gill also uses Doug’s headmistress as a “sounding board” because “she’s been around these kids for the last 30 years”. Gill finds this “very helpful” and if the headmistress cannot answer her question, she will refer Gill to someone who can. Gill also has “open lines of communication” with her GP. Finally, Gill also uses Dylan as a “check point” as he often knows how Doug feels.

APPENDIX P: CONSTITUENT PROFILE – MICHELLE’S STORY

Michelle and Matthew are married and have four children: Gary (12-years), Helen (9-years), Kenneth (5 years) and Megan (2 years). Michelle and Matthew have ADHD and Gary, Helen and Kenneth have been diagnosed with the disorder as well. Gary and Helen currently take Ritalin. Michelle suspects that Megan might also have the disorder.

The road to diagnosis

Michelle and her husband, Matthew, both have ADHD. As a child, Michelle “could never cope at school, but there was no such a thing as ADHD then. Nobody knew about it”. Michelle was labelled as “a **problem** (Michelle’s emphasis) child at school”. Michelle remembers herself as “a ringleader” who “was kicked out of classes for being disruptive all the time”. Michelle “never had a really good school career”.

Michelle ended up leaving school after standard eight (Grade 10) because she “wasn’t coping”. Michelle went to college to study hairdressing, but was allergic to all the chemicals and had to leave. She then went back to school and did standard nine (Grade 11) and Matric (Grade 12). Michelle feels that by the time she was finished she “was a wreck”, and so she’s “never studied further”. She does, however, describe herself as “an eager learner”. At the moment her “fascination is nutrition”.

Matthew didn’t finish Standard 7 (Grade 9) and “studying was not his thing”. Matthew tried to do several correspondence courses, “but he couldn’t cope”. Matthew started working at a very young age and became a chef on the railways. That “suited him fine” because he “could be creative and so on”. Matthew’s “passion has always been electronics - but he could never study”. He has gone into the field and “he’s pretty good at it”, but he is entirely self-taught.

Michelle’s eldest, Gary, not only has ADHD but is also vision-impaired. Gary suffers from optical disc hypoplasia - an underdevelopment of the optical nerve. According to Michelle, there isn’t an operation that can correct it and he can’t wear glasses – “the optical nerve is just underdeveloped”.

When Gary was around five-years-old, Michelle read a magazine article about ADHD. The article mentioned a support group and Michelle contacted them. Michelle

felt that she recognised Gary in the article: the picky eating, the constant interruptions, the nagging and “the wearing down”. Michelle “got to know about ADHD a little bit”, interacted with the support group, and went to lectures.

The support group also gave Michelle a copy of the Feingold diet. Michelle feels that at the time though, they just couldn’t afford it. Michelle feels the diet is “a lot easier” to follow now “because there is so much more available”.

Helen, when she was two-years, had “**chronic** (Michelle’s emphasis) temper tantrums”. Because Helen behaved like Gary, Michelle was starting to feel she just “had naughty children”. Michelle would take Helen to the supermarket in her pushchair and Helen would have “such a bad tantrum she would make herself stiff and throw herself on the floor, pram and all”. People would ask Michelle: “What are you doing to your child?” Michelle “developed such a complex about it”. Helen was diagnosed at the age of two.

Then Kenneth was born. At five months he “just started screaming and screaming” and Michelle “didn’t know what was wrong with him”. Kenneth “would scream for days” and Michelle felt she “couldn’t get anything right with him”. By the time Kenneth was eight-months-old, Michelle felt she “just couldn’t take it anymore”. Michelle took Kenneth to a paediatrician who had been recommended. The paediatrician confirmed that Kenneth is ADHD, and later on also diagnosed him with oppositional defiant disorder. “So I had my hands full”.

When Michelle fell pregnant with her youngest child, Megan, she “felt this urge” to do “things a lot differently”. She took her essential oils religiously and in abundance. Michelle also watched her diet – “I didn’t do the whole preservative, colourant and flavouring thing as far as possible. I ate rice cakes and things like that.” Michelle believes it made a big difference. Michelle feels that two-year-old Megan has ADHD, because both Michelle and her husband “carry the genes”. Megan, however, is “a **lot** (Michelle’s emphasis) less severe” than Michelle’s other three children.

Michelle feels it would have made a difference if she had approached her first three pregnancies the same way:

“Had I known, I would have done it from the word go. The oils especially – for those little brains – fish oils and the flaxseed oils and the evening primrose oil – in abundance I had it. It has made a whole heap of a difference. I always

say she is my consolation prize, because she's not as bad as the others. But she's still a handful."

Megan is still an unknown quantity. She does "have some of the tendencies", but Michelle hasn't taken her "for a formal diagnosis yet, she's still a bit small".

Michelle's feelings about the diagnoses

Michelle felt it "was a relief" to hear her children were ADHD "because I knew it wasn't my parenting skills".

Michelle admits to finding the diagnoses "very overwhelming" though because she "realised just how much work was needed". Last year Michelle went on a parenting course through ADHASA. Although Michelle found the course "exceptionally informative", she is "still feeling overwhelmed". Michelle feels that being ADHD herself makes it "hard" for her "because I can hardly cope with **myself** (Michelle's emphasis), and now I have got these four little people that really need me". Michelle admits that she tends to "shut off a lot, which is so wrong": "I withdraw in myself and live in my head".

Michelle feels that "nothing prepares you for this". Michelle believes that having caesareans "compounded" her children's problems, as well as the fact that both Gary and Helen were in distress at birth. Michelle believes that being "ripped out of" their "environment" really has compounded the ADHD.

Ritalin

Only Michelle's two oldest children are taking Ritalin. Both Gary and Helen went onto Ritalin when they were five-years-old. For Michelle, "Ritalin was really a last resort", but she was "very comfortable" by the time she put them on it.

Michelle is very interested in nutrition as a means of treating ADHD. She is involved with a nutritional group and her children see a nutritional physiologist rather than a GP – both the group and the physiologist give her "a lot of flack" because she has the children on Ritalin. She doesn't get any "flack" from the schools the children attend though – "the school actually want them on it".

People whom Michelle has met socially have asked: "How can you put your kids on Ritalin?" Michelle feels that people question her decision because of ignorance and

because of the sensationalism they have picked up from the media: “It is just something they have heard. They don’t really have an informed opinion.”

Michelle’s mother feels that Michelle knows what she is doing and Michelle’s mother-in-law “is also not too bad”.

Both Helen and Gary are on the long acting Ritalin. This “suits” Michelle because she doesn’t “trust the teachers - they either forget or they give it too late, and I don’t want my kids taking it to school and things like that. So they get it in the morning.” Gary is on the 30mg and Helen is on the 20mg, and they take their Ritalin seven days a week.

The only side effect Gary and Helen have is a lot of abdominal discomfort. Michelle worries because Helen does not eat during school hours, but Gary has actually improved in that respect. Before, Michelle would pack him lunch and it would come home untouched. Now he will eat his school lunch and even ask for food. “But he’s also growing up now – you know he’s twelve already.”

Michelle feels that both the children “are quite happy taking the Ritalin. They know that they need the Ritalin to cope at school and to concentrate.” If on occasion Michelle has forgotten to give Gary his Ritalin, he has had teachers make remarks like: “I can see you haven’t had your Ritalin today because you really are being a brat.” Michelle feels that Gary now “associates the Ritalin with the good behaviour”.

The doctor did try Kenneth on a very small dosage of Ritalin, but “it has the opposite effect on him, it makes him more hyper”. The doctor has also tried him on Tegretol and on Rispadol for a while. Because Kenneth is not at school yet, Michelle has decided to keep him off the meds for the moment. Michelle feels she “can control him pretty well at home on his oils and the diet. And a lot of behaviour modification.”

Michelle “decided two-and-a-half years ago to really make a change” regarding the children’s diets. “The older two were unfortunately already set in their ways” and there “was a lot a wailing and gnashing of teeth”. The younger two though didn’t know what bread and sweets were. Michelle has eliminated all colourants, preservatives and flavourants. Because the children have food intolerances, Michelle also eliminated dairy, gluten, and wheat. Instead the family has lots of rice and soya. Gary is even allergic to soya, so he has to have rice milk and rice cakes.

Michelle has been told that Gary will “grow out of” his allergies, but she feels “he has actually gotten worse as he has gotten older”. Michelle has to be very careful with him.

When there is a class party, Michelle will send a special snack pack to school. If it is a family party, they most often cater for the children. Michelle and Matthew also “follow the diet pretty strictly too, except when it comes to chocolates”. Michelle’s oldest two are not happy being on the diet and are “forever” asking: “When are we going to stop with this lifestyle change, Mom? I’m so sick of this.” Gary and Helen complain of missing certain foods.

Michelle feels that “it’s really gotten easier over the years” to follow the diet. She now has a health shop at the local mall where she can buy the soya breads and the rye breads and the rice milk. Before Michelle had “an endless search” and “had to phone around to find who had certain products, and who didn’t”.

Michelle also has the children on essential oils and a number of supplements. Michelle’s approach is to combine the supplements with the Ritalin, because the supplements “alone are not enough to let them concentrate”. Michelle finds that “financially it’s hellish with all the supplements and things”. Michelle doesn’t work and so “the burden of that responsibility falls on Matthew’s shoulders”. Michelle will never “deviate in the diet”, but sometimes she has to forgo the supplements because of finances. “And it is hard because then they deteriorate, and then when we can afford to again it is this long road before they are back where they were.”

Michelle has taken all four children to a neuro-linguistic therapist. All four were evaluated and they went for about six sessions each. Eventually they stopped going though because it “becomes extremely expensive”.

School

Michelle “really struggled” to find a school for Gary, because he is also visually impaired. Michelle “had so many doors slammed” in her face. Eventually they found a little pre-school that was government run. The headmistress said “she would do what she can”. Michelle said to the headmistress that she was worried about Gary’s “social development and so on”. Gary “didn’t cope at all”. He chewed his nails, he had terrible temper tantrums, and he had training accidents at school. It took Gary about six months to settle down. Gary was at the school for a year before Michelle

and Matthew managed to move to a city that has a school for vision-impaired children.

Gary started Grade 0 at the school for vision-impaired children and “there was a remarkable change”: he stopped biting his nails, he settled down, and he was a lot calmer. “You know he was in the correct environment”. Gary is “brilliant as far as figures go”, and gets a distinction for maths. Writing “is such a laborious task for that poor child” and he “can’t stand writing assignments – it freaks him out totally”. Science is fine and, although he likes English and Afrikaans, they are writing subjects. Gary likes reading, but he is very slow, because he’s literally got to read with his nose touching the paper. “He doesn’t mind reading, but he gets headaches pretty quickly”.

Last year Gary had a problem with other children who were bullying him, “so he had a really hard time”. They have now upped Gary’s Ritalin and Michelle feels he has “settled down quite a bit”.

Helen is in a primary school close to home. Michelle finds that with Helen “homework is a never-ending stress”. Helen is already “in overload” by the time they get home and she (Helen) “can’t still face another two hours of homework”. Michelle does the children’s homework with them: “I can’t leave them to it because then it doesn’t get done. I have to sit and monitor **every, every** afternoon (Michelle’s emphasis).

Helen is a “very average” student and “the teachers don’t have anything really bad to say about her”. Helen is “a very emotional child” and “very clingy” and she “needs constant reassurance from the teacher” and “from her parents”. Helen’s reading and writing is very good, but she struggles with mathematics. Michelle doesn’t “have unrealistic expectations for her (Helen)”; “I cannot put that kind of pressure on her”. Michelle is happy with and praises what Helen brings home, “as long as she is progressing to some degree and not falling behind too much”.

For Michelle “dealing with the school is endless”. Michelle feels it is a case of “constant education”, because as far as the teachers “are concerned it is naughtiness”.

“They can’t believe a child can be ruled by the moods and the highs and the lows. Some days they’re up, some days they’re down; some **minutes** they are up and some minutes they are down.”

At the beginning of every year, Michelle goes to their teachers and talks to them “about what the children can and can’t have, and what they need to do”. Michelle doesn’t feel the teachers “really pay attention”.

“Honestly, I sometimes feel like a real pest. Adults don’t like being told what to do. A lot of them are unteachable and unapproachable.”

Dealing with health professionals

Michelle feels she knows more than the health professionals do because she is “living with it 24/7”. Michelle does not find them to be “understanding or sympathetic”. Michelle would go to the doctor and say: “Look, my kids are on this, so please prescribe meds that don’t have this and this.” Michelle would “get a really funny look”.

Extended family

Michelle feels that family have been very accepting of the children’s diagnoses and friends are “very interested and keen to learn”.

“I fortunately don’t have family who persecute me for the way my children act or react. My mother is very supporting.”

Being their parent

Michelle feels that the children “don’t get on very well”, “especially the oldest two”. “They will be playing beautifully one minute and the next minute there will be an explosion. And screaming. They stand and scream at each other. They lay into each other.” Michelle feels “you cannot try and reason with them when they are in that state. You just have to kind of separate them”. For Michelle the “sibling rivalry is hellish”

Michelle feels that the older two children “have no tolerance for the younger two”. Every now and then Helen will sit and read one of the younger two a story: “She can be very much the mothering figure.” Michelle feels that she can trust Helen “to make tea or something like that”. Michelle feels that Gary is absolutely hopeless though, although it “is not totally his fault” because he is visually impaired. “He can’t really do much and it devastates him because he is so restricted.”

Michelle finds that the boys are in a constant “power play” with the girls: “they want to be in charge all the time”. The boys will actually tell the girls what to say when they are playing.

It worries Michelle that Kenneth “has two older role models and Megan has three older role models”. Michelle feels the “two younger ones are copying the older ones’ behaviour”.

“There’s this transference of behaviour patterns. And even though it’s not part of their personality, they pick it up. Especially if it’s behaviour that can get them something. They are so clever; they don’t miss a bloody thing. So for me to differentiate between what they’ve picked up and who they are is very difficult.”

Michelle admits that “are not quiet people” and wonders what her neighbours think of all the screaming. Helen, in particular, is prone to “howling and slamming the doors”. Once when Helen was young, Michelle had the child protection unit come knocking at the door. Michelle had to undress Helen child and “they examined her”.

“Do you know how humiliating that was?”

When Kenneth used to scream and they were living in flats, Michelle regularly had people come up to her to ask her what she was doing to her child. The family was nearly “evicted because people couldn’t handle this screaming baby”.

Michelle finds that “everything with these kids is loud:

“Even their play is very loud and very noisy and very boisterous. They cry about everything. They’ve got to throw tantrums about everything.”

Michelle feels that the children are defiant and that “is a very hard thing to deal with”. “The third child, Kenneth, has got it particularly bad”. If Michelle tells Kenneth not to touch a hot stove plate, he will “look at” her “and do it”.

“Because he will just show me that he is going to be boss. And I don’t know how to deal with it.”

The neuro-linguistic therapist that Michelle took the children to explained to her that children with oppositional defiant disorder don’t understand the consequences of their actions. Kenneth also has tantrums where “he will fling himself down and invariably hit himself against something”.

“So he’s always got a bruise somewhere. And after what happened with Helen and the child protection unit, I am so scared that somebody is going to come and knock on my door and he’s full of bruises. And it has nothing to do with me; it’s him throwing himself around.”

Family outings are a “nightmare” and are kept to “few and far between”.

“Because if we decide we want to go to the zoo, the majority decide, then the one child – just out of defiance says: “I don’t want to go. I don’t like walking. The animals smell.” They will spoil the whole day. It doesn’t matter what I do, one of them will spoil the whole day just out of defiance.”

Michelle also has to be very careful how she “words things to them”, because they will hold her to what she said. “Ja, but you said that. Yes you did; you said that.” The weekend before our interview Michelle and her husband decided to give the children a treat and take them out for Wimpy food, as they have an ADHD menu. Normally they do not eat wheat, but Michelle reasoned that “once in a while is really not going to kill them”.

“Well, I have not lived it down. I cannot break the routine; I cannot drop my standards, because they are there to tell me: ‘But you said we can’t do this and now look we’re doing it.’”

Michelle also gets frustrated by the children constantly contradicting and correcting her, especially if it happens “when you’re in company”.

“They don’t have the slightest notion of what I’m talking about, but they will chip in and they will contradict: ‘No mommy, it was like that. No mommy, it was like this.’”

Michelle hates the fact that “everything that they have, everything that they enjoy” has to be used as “a motivation to get them to do things”. Michelle finds it “awful” that “there constantly has to be a threat hanging over them”. If she doesn’t do it that way though, she believes she “will get absolutely no co-operation”.

Michelle finds Helen “far more difficult to discipline than the boys”. The boys will adhere to their father’s authority. On the ADHASA parent’s course Michelle was taught to have rules of the house and to do charts where the children get credits for what they do. Helen “gets all heated up” and she actually rips up the chart, throws it

back at Michelle and says: “I will not.” So the chart idea “has come and gone” because “it doesn’t work on Helen”.

When it comes to discipline, Michelle finds that her inconsistency is a downfall: “they know now that if they push my buttons for long enough, I will probably cave in.”

Michelle feels the children “are also very paranoid”. “You know they feel that they are always getting the raw end of the deal, and that people are always looking at them and judging them.” Michelle “suffers with that too”: “If I walk into a room and suddenly everyone keeps quiet, then I’m quite convinced they were talking about me.” The children also over-generalise. Helen will come to Michelle and say: “Mom, **all** the girls are **always** making fun of me (Michelle’s emphasis).” “And it’s always **everybody**”.

Michelle also finds that the children “are very easily stressed”. “Something good stresses them; something bad stresses them”. Michelle can’t tell them beforehand that they are going somewhere, “otherwise it’s a constant time check” and “the pressure is unbelievable”.

Michelle also finds the children are “very, very destructive”. Everything that Michelle buys “lands up tattered and torn, and cut and scribbled on, or stabbed with pens and pencils or something”. “In a bad mood, everything gets broken”. Michelle cannot put anything down that she is busy with. She has to hide all her things away, and carry her stuff with her wherever she goes. Keys are also always disappearing. The children have even ruined the inside of Michelle’s car.

“I’ll leave them in the car and pop into the café to get bread. By the time I come back, something’s broken. And I can’t take them into the shop because then they want everything. “

On the physical side, both Michelle’s boys still wet their beds. The paediatrician has assured Michelle that Gary will eventually grow out of it; physiologically his bladder is fine – “everything works”. They have tried various medications, and now Gary has to wear a nappy at night. The girls are “very, very different”. Helen was trained by the time she was 18 months, and Megan is already fine during the day and only wears a nappy at night.

Michelle finds that when the children are incubating an illness, everything is exacerbated: “Their moods everything. Everything is amplified.” Michelle doesn’t “know how to deal with it”.

“I put them in their rooms and I just go crawl into bed. Or I get into my car and I bugger off for a while.”

Michelle feels that parenting her four children has left her with “less than no ego”.

“My self-esteem is terrible. I am constantly looking for approval from my husband, from everyone.”

There are positives to parenting her ADHD children though. Michelle feels they “are very bright and compassionate and excessively intelligent children. They are very easy to love. They are very open.”

Friends

In general, Michelle feels that “they are not very popular children to play with”. Gary is “very bossy” and always “wants to be in charge”. Gary “has a few choice friends that can tolerate that, but he is not hugely popular”. Helen on the other hand, “makes friends easily”, but Michelle believes she “then loses them easily and then she is devastated – totally devastated”. Helen also tends to be “a bit overbearing”. If she can’t get her own way she will throw a tantrum or start crying and howling. Michelle thinks that “just frightens other children”.

Kenneth “doesn’t make friends at all”. He has “such bad separation anxiety” that Michelle “can’t leave him anywhere for any period of time”. He is okay with Michelle’s domestic worker as long as he knows Michelle is coming straight back.

Michelle and Matthew “don’t have friends”: “We are totally isolated.” There is one couple that Michelle and Matthew see - they also have an ADHD child. However, they “don’t see them very often” because they live quite far away. When Michelle does see people socially, she prefers it to be at her house because “as soon as we get into a different environment, they (the children) are 10 times worse”.

Coping

Michelle has ADHD herself and admits to being “a very moody person”. She finds herself “drained most of the time”, because she is trying to cope with her own ADHD, Matthew’s ADHD, and then the kids. Michelle feels that she doesn’t “cope a lot of the time”. Michelle is currently on anti-anxiety medication.

“And so I am coping with myself as well as the family.”

So, for Michelle, “it hasn’t really made it better” that she is also ADHD: “Because I also have to cope with myself and then cope with them”.

“Looking at them and understanding what they are going through, I suppose I should have more compassion. But I have to go through the same thing all the time myself. It just complicates it more.”

Michelle admits: “I try not to think about how I cope”. The children “have gotten hellish hidings on the bottom and it doesn’t work”. Michelle admits that often she will “just switch off”.

“I honestly switch off. I put on my TV or I put on some CD’s and I blare it. Next thing they’re all in here dancing.”

Michelle has found ADHASA to be “very supportive” and although she doesn’t have time now, she used to attend one of their support groups. “You can also get individual counselling from them.”

Michelle has learnt through the neuro-linguistic therapist and through ADHASA that the children need to be taught that there are consequences to their actions. “They have to know that if they do that, this is going to happen. And if that doesn’t happen, then this happens.” Michelle feels she has to “drum it in”. If the children want an hour of TV, “homework needs to be done, chores need to be done, and school things need to be ready for tomorrow and whatever”.

Something that helped in Michelle’s home was removing the computer. The children wouldn’t play outside and just wanted to sit in front of the computer. It was causing such contention between the children – “fighting about whose turn it was”. Michelle felt that “was just a stressor that I did not need added to this house”.

The future

Michele doesn’t “know what is going to happen to them (the children)”. Michelle “will give them all the encouragement” she can “without putting them under too much pressure”. Michelle believes that “more often than not these children fall off the rails”. “And it’s dealing with that and getting them back on track again”. Michelle is “very anguished about how productive they will be as adults” and whether “they will be able to find their little niche. For any adult it is hard, but for these children.”

Michelle hopes that “if at all possible” her children do not “marry ADHD people”. Michelle feels she will also need to educate her children’s spouses.

For Michelle mothering has become her career. Michelle feels that when the children are “less dependent” on her, then maybe she can help other mothers.

Michelle’s advice for other parents

Michelle believes that it is “a long, long road” that parents are going to walk and they need to “persevere”. She warns that “it’s hard”, but parent must put their shoulder to the wheel and “just keep on pushing”.

“It’s never, never ending. I feel like I climb 20 rungs up the ladder and I’m knocked back 19. Then I get up 19 and I’m knocked down again. So it’s up and down.”

Michelle feels dealing with ADHD is “a process” and parents must know that there “is no ways they will be able to change everything in one go”. Once the child has been diagnosed, Michelle believes that parents should “take the most problematic thing (usually their behaviour) and start there”, because it can be so overwhelming when you get all this literature and you’re confronted with all these aspects. Michelle advises that parent find out about ADHD: “learn about it as much as you can”.

Michelle feels it is important that parents accept the diagnosis: “If parents find that they are in this situation they have to give themselves over to it. They cannot fight it.”

Michelle feels parents must learn to “separate the behaviour from the child”. Always tell the child that you love the child, but don’t encourage the bad behaviour: “I really love you, unfortunately (never BUT) what you did was incorrect.” Michelle admits that in “the spur of the moment that doesn’t happen”: “What have you done you stupid child.” If Michelle does react that way, she asks the child to forgive her.

For Michelle “the diet definitely works”. Besides following the diet, Michelle recommends that parent not microwave their food. She recommends that parents buy their food unprocessed, as fresh as you possibly can, and cook everything from scratch. Michelle believes there are a lot of small changes that you can make that are really effective.

Michelle feels that “if one of you in a couple is ADHD, or both of you, then prepare for the possibility” of having an ADHD child. Michelle feels parents “must read up about it” as they “will be so much more at ease and of course the child will benefit”. Michelle feels strongly that when preparing to fall pregnant and during pregnancy women need to take their oils, whether or not you have ADHD. “Those little brains need those oils”.

A final piece of advice from Michelle is to “tell them you love them”:

“I love you no matter what you do. So don’t try and make me not love you, because it’s not going to work. I love you no matter what you do. Your behaviour is something else. You I love with all my heart.”

Michelle remains very aware of the challenge of having this condition:

“Sometimes when I’m having a moment of absolute lucidity, which is very few and far between, then I will see the little spirit struggling with this whole ‘can’t get out of my head’ situation and this noise. And I can absolutely just break down and cry for them. Because it’s really **hard**, it’s really hard living in this mind. Because you withdraw often and it’s in your head – this noise, and all these thoughts, and you can’t concentrate. So a lot of the time I feel overwhelmed and helpless and hopeless – and I try not to let it spill over onto the kids. So I try to pretend that I do cope when I’m really not. It’s not easy and I’m not going to say that it is. I **understand** the diagnosis, I **understand** the condition, I understand the symptoms, but it’s a challenge from minute to minute. And if I get through the day, I’m grateful. If **they** get through the day, I’m grateful.”

APPENDIX Q: CONSTITUENT PROFILE – CARRIE’S STORY

Carrie is married and she and her husband, Vernon, have three children. Their daughter, Cindy, is 23-years-old and has just got married. Cindy does not have ADHD. Their sons, Luke (17-years-old) and Peter (14-years-old), both have ADHD and both are on the long-acting Ritalin.

The road to diagnosis

Luke was “actually quite an easy baby”. He had the usual ear, nose, and throat “stories from pretty young”, but was “much easier” for Carrie to deal with than her daughter had been, and “he didn’t scream like she did”.

It was only when Luke started nursery school that Carrie “could immediately see it”. Luke had a problem with colours and nursery rhymes. However, he “was never the noisiest and the naughtiest kid at school”. Carrie found there was “very little feedback from the school”. One teacher said she thought Luke “might be a bit colour blind”. Carrie would get comments like: “Oh, you know, he is behind; he drifts off.” But nothing was ever done.

“Nobody ever put me on a very definite path. It was more my own instinct that made me push.”

Carrie found that time to be “the most difficult period” because she knew something was wrong, but nobody could tell her what was wrong. Carrie’s husband was telling her she was “a terrible mother” because she had managed to get it right with their first child, so why not this one.

Carrie did the rounds with the educational psychologists and “all of that”.

“Throughout every one of those assessments, not one of them ever said he was ADHD. They blamed it on the parents. **We** needed to go into therapy; **we** needed to do this; **we** needed to do that (Carrie’s emphasis).”

Carrie believes that the reason that they were never told Luke is ADHD is because these children behave so differently when you test them one-on-one than they do in a classroom situation or a group situation.

Carrie eventually ended up going to a paediatrician. He did the Connors forms and diagnosed Luke as ADHD at the age of five years. The paediatrician monitors the boys “**extremely** (Carrie’s emphasis) thoroughly – they still now see him every three months”. Luke started Ritalin and “they could see the difference”.

Luke did “all the occupational therapy” and, as he progressed with school, the remedial therapy. Carrie also worked with the diet, right from his diagnosis and if the boys went to a party, they took their own sweets and things. Basically the boys went on an elimination diet where you cut out certain fruits and vegetables, and the artificial flavours, colourants and preservatives for a period. And then you start to reintroduce the foods “bit by bit”. By doing that Carrie figured out that some of the preservatives don’t bother them at all, but artificial flavourants and colourants do.

With Peter, Carrie believes she “knew right from the start” that he had ADHD.

“He was irritable in my stomach. He came out screaming. He was a nightmare of a baby. He just screamed, screamed and screamed. Ear, nose, throat; ear, nose, throat. It was just.... We nearly got divorced because of him.”

When Peter started Grade 0, they tried him on the Ritalin, but he couldn’t tolerate it at all. So Peter was put on Reactivan “for a good couple of years”. Peter also has Tourette’s syndrome – “he has the tics and he makes the vocal sounds as well”.

Carrie’s feeling about the diagnoses

For Carrie the diagnoses were “a relief” because it “actually confirmed” her suspicions. “I had known something was wrong, but I didn’t know what”.

Medication

Carrie feels they had “tried everything” besides the Ritalin. They did “the homeopathic route” and “the supplement route” and the “herbal stuff”, but “no luck”. With both the homeopathic products and the herbal products, they helped initially, but the improvement was not sustained. Carrie has found one herbal supplement, Schizandra, helps with aggression for Peter. However, it didn’t work for Luke. Carrie finds the boys “are totally different in how they manifest and also in how their bodies deal with the medication”.

Carrie feels her husband had more “issues” than she did with the Ritalin. She kept saying to him: “If it doesn’t help, we can stop it. It’s not like it’s the end of the world.” The paediatrician told them: “If your child was a diabetic, would you deny him the insulin?” So “with a heavy heart” Carrie’s husband agreed to it.

With Luke the effect “was literally instantaneous”. Luke was on the short acting Ritalin until they brought out the slow release version. “That didn’t last as long, for Luke” and by just after lunchtime that it was “wearing off”. When the long acting Ritalin came out, Luke went onto that. At times, Luke was also put on Rispadol, to try and keep him “on more of an even keel”.

By the time Peter was ten or eleven-years-old, the Reactivan wasn’t doing what it needed to do, even for the morning at school. They decided to try Ritalin again, and “he coped with it fine”. Initially he was on the slow release, but now he too is on the long acting Ritalin. The boys have never been given a break from the medication in the holidays.

Carrie feels the Ritalin definitely does make a difference in “how they socialize”, and “how they concentrate”. Luke doesn’t enjoy taking the medication. He is now in Grade 11, and “about once a year”, he will say: “No, it’s time to stop this.” Each time he has decided he needs to go back on it. He realises he can’t concentrate at school without it, and Carrie has drawn his attention to the fact that there are more fights at home when he is off the medication. “So he has seen the benefits”.

Carrie has had run-ins with the school about the medication. When Luke went to high school, his grade tutor said to Carrie that, “under no circumstances should a boy in puberty be on Ritalin”.

Carrie believes both boys also know the benefits of following the diet. As they have got older, they do cheat, but she feels they can see the effect on their behaviour and they can see it in their schoolwork. Carrie does tend to give them “a bit of a gap” in the holidays though, because they are “not concentrating or doing formal learning”.

When Luke started on the Ritalin, Carrie “wanted to see what it did”. And so she took it too. Carrie “can tell you how Ritalin works”, because it worked for her: “It was unbelievable”. “All of a sudden all those extraneous sounds are gone”. Carrie’s own inability to “switch off” has “caused friction” in her marriage: “I can hear the boys up

there; I can hear the birds out there. And if the boys are making too much noise there, and the parrots are screaming, it's too much for my brain. I cannot shut off.”

Carrie sees the similarities between her and the boys. She hates shopping as much as they do. Before they go shopping she has to tell them exactly where they are going to shop, and how long they will spend in each shop. When they were smaller, if she changed “the order of what we had said we were going to do, it would freak them out”. Shopping with them “was pretty much a nightmare”, but Carrie could understand that because she knew exactly how they feel. Because of the noise in the shopping centre – the boys would just up their volume to drown out all that other noise. Carrie and the boys also hate the tiny cubicles for trying on stuff in the shops. When Carrie took them shopping and they got “fractious”, they would just go home.

School

Carrie has never wanted to send her boys to a remedial school and does not believe it would do “anything for them”. It would only be an option “if they were really not coping within a normal school environment”. Carrie feels she has seen “too many children who do the remedial school route”.

“They struggle at school, and by the time they leave the normal school their confidence is down. They are way behind on their work and they go to a remedial school. And eventually they slot in, they fit in, and they love it – everybody is on a par with them; it's cool. And then the school says no actually you have gone as far as you can go. You are ready for mainstream again. And once again, within a little while, they are back to square one.”

So, the boys are in a government school and “they are sitting in classes of 30 odd”.

Luke is a highly erratic student- he can get 80% for one test and 20% for the next. Luke doesn't tell the teachers he is ADHD; “he doesn't like them to know”. When he was in primary school, Carrie would normally set up an appointment early in the year to discuss Luke's ADHD. Carrie feels, however, that it was wasted effort: “They will listen to you and that is the last they actually think about it”. Carrie feels that teachers make no allowances for ADHD children and do “not take into consideration the disorganization, the distractibility of these kids”.

In the primary school “every teacher had a book” – Carrie “gave them a book on these children and dealing with them at school”. When Carrie was having problems

with one of the teachers, she asked the teacher: “Have you even bothered to read the book?” The teacher had not and Carrie told her: “Then I don’t think we actually have anything to discuss”.

Carrie finds that especially with the high school, “there is no interaction between the teachers and parents. The teachers are not interested. They are there to do a job and they don’t want to get involved”.

Carrie and her husband go to parent’s evenings and they “very seldom get any positive feedback”. They have been going to parent’s evenings for eleven years now “and it hasn’t helped a thing”.

“The teachers all sit there and they make little notes: ADHD, on medication, battles with this, battles with that. And they all sit there and smile and say: ‘Yes, we’ll do this and that.’ And the minute I turn my back... It’s a waste of time to go and stand in those queues, to have 5 minutes with the teacher, to be told just how bad your child is. I as a parent have actually taken a tranquilliser before every parent’s evening that I’ve ever been to. By the time I get to the teacher, my mouth is so dry that I can hardly talk.”

Carrie has never been called to the school for bad behaviour and, if anything, Luke is too quiet. Carrie has warned the teachers that when Luke is “dead quiet and he’s not involved, when he looks like he is staring out the window, he **doesn’t understand** what is going on (Carrie’s emphasis)”. Carrie has been told, however, that the teachers “can’t keep track of every child in the classroom”.

Luke goes for extra science and math lessons, but Peter has got “far more learning difficulties” than Luke: “He’s just more difficult all round”. Carrie feels the boys are lucky that she hasn’t had to work and she has always been there to do homework with them.

“I have seen children whose parents do work full day. They are lost. The parents are lost; the kids are lost. It just doesn’t work.”

Carrie has always bought all the textbooks that the teachers use and the extra workbooks that go with them. “That is how I’ve got them through school”. Carrie used to “get a lot of flack” about doing “too much” and she was told to let the boys “learn on their own.” Carrie did that for one term - “when Luke was in Grade 7, I left

him". When parent's evening came round, the first thing his teacher said to Carrie was: "You really ought to be more involved."

"And I stood there and said: 'But you are the same people who accused me of being over-involved.'"

Luke has stopped doing sport at school because "he battles to do school, and then the sport, and then the homework". Peter "is very sporty" and when he gets home at seven o'clock at night "there is no Ritalin left in him". "He's tired and then he has got to do homework". As a result, Carrie has "stayed a lot more involved with him". This is the first year that Carrie hasn't done any work with him for school. Up till now, she has had to work with him "constantly all the way through". This year, his Grade 8 year, she has purposely left him "to see what he could do by himself". He has done "quite well". Carrie still helps him out on projects though. She feels projects are "an absolute waste of time" and so she "**will** (Carrie's emphasis) help them": "Because if they can score a better mark on a project, it buffers them for a test where they don't so well".

Luke, for nearly two years now, has done his own stuff. In Grade 7 he went on a course to teach him how to study and "that seemed to work quite nicely for him". He "still works with that system". Luke also has his "own little study" in the house. With Peter they "haven't found his way yet". Peter can read everything perfectly, but he doesn't always understand what he's reading. Not one of the teachers picked it up at school. Carrie would send him away to learn something, and an hour later he would come back and say he had done it. Carrie would ask him questions and he would "not have a clue". This would result in "big screaming matches". Carrie would end up "sitting writing it out for him, trying to summarize it, and teaching him at the same time". After that Peter "could go and repeat half of it". Peter also battles if questions are rephrased and multiple-choice questions are "not very practical" for him. Carrie makes both boys "start learning for a cycle tests a lot earlier than the other kids. So they do more repeats of the actual work - for some of it to go in."

The future

Luke's friends are all talking about going to university. Carrie is not sure that Luke is going to be able to get the marks to get into university, and if he does go she is not sure he will cope. Carrie finds it "heart sore" to have to, on the one hand, "show him what reality is", but on the other hand, "not to shatter their dreams". "Luke works

really well with his hands not with his brain". Carrie feels there is "nothing wrong with that, but he doesn't see it like that".

The next big step for Luke is his learner's licence. Carrie worries about him driving "because it has been proven that these children have more accidents than others". Drugs remain a concern for the future. Luke has experimented with drugs already, "because he is very easily influenced", and Carrie does not "think it will be the end of his experimentation. To this day, Carrie has a drug test in her cupboard. Luke also "likes alcohol" and Carrie finds that "scary" because she knows "that alcohol is exactly the same as drugs". Carrie feels that her boys "don't know when to stop".

"If they have a drink, they feel all cool and calm and in control. Then they will go over the top. So that is a worry as a mother, watching them."

Family and friends

Carrie's mother does not understand what ADHD means for the family and will make comments like: "Don't worry; it will pass." Carrie's family "don't like" the boys being on the diet and the medication. Even to this day, Carrie's mother will still say things like: "So when are they going to come off the medication?" Carrie tells her that "they may still be on the medication when they're 25; they may always be on the medication". Carrie has "long ceased to worry" about what her mother "actually thinks".

Vernon's mother "just won't acknowledge" the "children have a problem".

"But she's got a friend, a much younger friend that has got a son who is **so** ADHD. And she will harp on about how difficult it is for this woman to raise this child and the whole bit. And I think: 'There's two of them in your **own** family.' So I actually, long ago, ceased to worry."

Being their parent

Carrie believes that you learn to be a parent "by trial and error": "Nobody teaches you how to do this". More importantly, "nobody teaches you what to do when you have got children that are not the same as everybody else". Carrie believes that "in some ways" you are also "determined not to do what your parents did".

When the boys "were younger they got on quite well". Carrie used to pride herself on "how well they got on". Now "they don't like to be together" and they "don't like to do things together". The boys "only tolerate each other" and "they don't connect". Carrie

believes it is an “age thing”: “It’s like Luke just got that little bit too old for Peter and his peers”.

Carrie like the boys to have their friends over to her house and very often has “a household full of boys”. “I would rather have them here and I know where they are.” Carrie also worries when they get invited to somebody else’s house that they might misbehave, or eat the wrong foods and their behaviour could escalate.

Luke has always been quite sociable and makes friends quite easily. Luke’s two best friends are both gifted. Luke works 10 times harder than either of them and his marks are still way below their marks. So, to fit in with his peers is difficult. Luke is not very sporting and Carrie has “never forced it”. Recently he has started sailing with a friend. This surprised Carrie as her first thought when he wanted to go sailing was “he can’t sit still in a classroom; how is he going to stay on a boat for hours?” But he took to it immediately.

Peter does not make friends easily and “holds back”. Peter tends to stick to one friend. And yet, Peter has always played team sports and when Carrie listens to some of the other boys talk, she believes Peter is very much an integral part of the team.

Carrie prefers that the boys have different interests: Luke the sailing and Peter the team sports. Carrie found it “very difficult” to watch the two of them compete in different teams at school because Peter was always that much better, and it affected Luke’s self esteem. As a parent, Carrie does “try and keep their interests totally different. It just works better like that”.

“You can praise the one and it has got nothing to do with the other one. So I mean Peter has got the hockey and cricket stuff stuck on the wall; Luke has got sailing stuff stuck on the wall. And that works for me.”

Peter is very different to Luke in that he “always sees the negative side” of things. Carrie finds him “a very difficult child in that respect to handle”. Carrie feels that he “won’t even try” things and “it’s because of this fear of failure”. The sport definitely helps his self-esteem though.

Carrie feels that as a mother she is “probably harder on them than any other mother” she knows. Carrie insists on sticking to the rules and “will make sure they are

enforced". Although Carrie is "hard on them" she will "always back them". She "**will** (Carrie's emphasis) "stand and argue with their teachers. Who else is going to come out to bat for them?" At the same time she has "**never** (Carrie's emphasis) allowed them to use ADHD as an excuse".

They boys are aware they are "different" and Carrie has had to deal with that. Carrie remembers sitting in the kitchen when they were smaller and Luke sobbing: "Why am I different? Why can't I learn this?" Carrie has tried to explain to them that their "brains are just wired differently" and that they have to "learn it differently".

"You have to learn it more times than anybody else, like the spelling words. Then you go to school and you can only remember half of those spelling words. And I know it is not because you haven't learnt. I know it is because of the way your brain works. You just have to accept that you have to do it differently, and it is going to be a lot harder. "

Carrie believes the boys need a lot of input and feels that her "husband does not give any input". She doesn't believe it is because he doesn't have the patience. In fact, she feels he has "10 times more patience" than her. Carrie feels he "actually ducks out of it". Carrie believes that her husband "doesn't like to acknowledge that it's part of the family". She also feels that he subscribes to the stereotype that "the mother must do the kids and he brings in the money". Carrie feels it has caused problems within the relationship because she resents it. "And to this day he still doesn't get involved". When it comes to discipline issues; Carrie's husband also tends to be inconsistent and he "keeps giving them another gap".

Carrie feels that being a parent of an ADHD child "sucks". "And you look at the other parents and their perfect kids."

"And it's hard; it's hard. And it's soul destroying. It knocks your own confidence: 'What am I doing wrong?' And so many people out there blame the parents: 'They just need discipline; they just need this; they just need that'"

Carrie believes the boys are lucky that she is "aware of how they feel – all of it". Carrie feels it is only now that she can actually begin to pat herself on the back "a little bit".

"I still don't get the pats on the back from my husband."

Coping

Carrie feels that the support groups have a role to play, “particularly for those parents who are just starting out on this road”. Carrie was involved in a support group and being involved gave her “a sense of knowing that I was on the right track”. Carrie does feel that you have to take what they say and “adapt it to your own situation”. Carrie tried the “whole points system with the kids” that the support group recommends, but she found “it only worked in the beginning”.

“Down the line I discovered my boys were lying horribly and they had figured out ways to circumnavigate this little system, but were still getting all the points and the money.”

Carrie did find that you could get affordable counselling through ADHASA.

“Parents don’t often have money for that. These are expensive children – the medication if they are on it, the diet, the extra therapies they need. Very often parents just do not have that money.”

ADHASA also has a holiday camp for ADHD children. Carrie feels that as a mother of ADHD kids, she “never gets a break”. She sent her boys on the camp, and they always enjoyed it. Eventually one year Carrie asked them what was so good about the camp compared to school tours. And they said: “We were all the same.” Carrie asked if they feel different when they go on school tours, and they said yes.

“So they know they are different. Instinctively they know. And that is the sad part for me as a parent.”

Carrie no longer attends support group meetings, but she still enjoys getting the ADHASA newsletter because it has very good articles in it. As the children have got older, Carrie has found she doesn’t need “as much support”. Every now and then she will contact them about something.

“At the bottom of it, for me, I trust my gut instinct now more than what I used to. And I can help other people, especially those with children younger than mine, because I’ve been there. Especially now with two of them that are different – they fall under the same broad banner, but they are two totally different children.”

When Carrie was involved in the support group, schools would request courses to be run at their schools. “And the teachers would all sit there and make copious notes and buy all the books.” Carrie feels though that teachers are not prepared to implement what they learn. Carrie feels that teachers are not prepared to look “at alternative methods” of dealing with these children and consider the other 26 children in the class as more important than the three or four who have a problem.

Carrie’s advice for other parents

Carrie feels that as a parent you “need to trust your own gut instinct” and “you definitely need to be prepared to try different alternatives”. She feels that parents must look “at how the Ritalin works and look on how many **levels** (Carrie’s emphasis) the medication works”.

“That is what so many parents do **not** see; that it **doesn’t** just work on the academic level - it works on the social level and the emotional level.”

Carrie feels parents should “give it (Ritalin) a try – it doesn’t have to be for life”. Carrie insists that parents “owe it to their children to try **everything** (Carrie’s emphasis). Carrie warns that parents should “not believe everything they read or hear” about Ritalin. She also cautions that it is important to realise “that the Ritalin is a trial and error process”.

“Go back; fill in the forms. There must be proper monitoring. You don’t just let them give you a script and say see you in 6 months time. Especially when they start off, you have to figure it all out. It might not be the right medication. You have to go through this process of trial and error to find out where they fit in on the scale. You also need to see a doctor who specializes in ADHD, not just a GP. You need someone who really knows what they are talking about.”

Carrie also recommends that parents consider the diet as it works for some children. Carrie believes that if her boys do not follow the diet, she might as well not give them the Ritalin – “that is the effect that it has”. Carrie has found that if her boys are on the diet, the medication works better.

Carrie concludes: “And you have to accept the condition. It’s not going to go away; you have to deal with it. And if you think it’s difficult **now** (Carrie’s emphasis), just leave it untreated.”

APPENDIX R: CONSTITUENT PROFILE – ROSE’S STORY

Rose is married and she and her husband, Mark, have one child, Eugene, who is 19-years-old. Mark was married previously, and has two sons from this marriage, who unfortunately are estranged from him.

Eugene was diagnosed with ADHD at the age of six, and until recently was taking Ritalin. Mark believes that he himself is attention deficit.

The road to Eugene’s diagnosis

In the year that Eugene was born Mark lost his business, and the family moved in with Rose’s mother. Rose and Mark thought it would only be for a few months, until they got back on their feet again. Rose had always earned good money, so when the time came she would go back to work. Instead, they ended up living with Rose’s mother “for six very long, painful years”.

Eugene was born, with an AGPAR ten out of ten, when Rose was 42-years-old. They took him home and “everything seemed fine”. He was beautiful and very healthy, but he didn’t sleep very well. Rose remembers when Eugene was six-months-old how Mike would walk up and down at 12 at night to try and get Eugene to sleep. Rose used to put him in a pram and wheel him round the neighbourhood all afternoon. They even took him on the highways to try and get him to sleep – nothing worked. “He never slept, that’s all there was to it.” Mark and Rose were exhausted from lack of sleep.

Rose took Eugene to a lot of homeopaths, because she “didn’t want to go anywhere else”. Medical doctors suggested that Rose give Eugene “something” to make him sleep. Rose didn’t want to give a young child “something” – so she “was prepared to rather sit up all night with him”. One homeopath suggested putting him on the breast: “at least it will keep him quiet”. So Rose put Eugene in the bed with them, and put him on the breast: “And that was how we coped”.

Eugene’s sleep problems continued though. He was also scared of the dark - to the point where he “could not be left alone after sunset and was unable to go to his room or the loo”. This put pressure on Rose and Mark and was “exhausting”. They tried sitting beside his bed after bedtime stories, “but by 2 am we were still sitting there and he was still awake”. The only way they could all get some sleep was to allow

Eugene in their bed: “My husband had no objection to having our son in our bed if that allowed us all to get some sleep.”

Later Eugene slept on a mattress in their room until he was able to move to his own room, at about age 8. The fear of the dark only faded away when he was about 13. Rose feels his problems were exacerbated by the fact that he is an only child. “Had he had a sibling in his bedroom it might have been comforting for him.”

Throughout Eugene’s year of battling to sleep, Rose and Mark had people telling them they just did not know how to be firm; and suggesting that they close the door and leave him to cry himself to sleep.

Besides the sleep problems, from the moment Eugene was weaned, he retched up foods. The retching continued for years, but the medical fraternity could give no answers. Rose and Mark now know that Eugene is seriously allergic to wheat and dairy products. The retching up of food seriously impinged on Rose and Mark’s social activities – “we were very reluctant to eat out or with other people for fear he would retch up his food. For us this was the beginning of our isolation.”

Eugene has also suffered from serious migraine attacks since he was a toddler – “he used to bang his head against the side of the cot and later the walls, which was very distressing”. Medical doctors were never able to find the cause. There were times when Eugene would be immobilised for days, unable to go to school, and, because there was no diagnosis, “there was this suggestion that it may be psychosomatic”. Now Rose and Mark are quite sure that it was the wheat allergy.

For Eugene, living with Rose’s mother was wonderful as he had lots of attention. Rose’s mother’s boyfriend, Charles, took a great deal of interest in Eugene and as a toddler would take him into the garden with him every day. Eugene had no desire to go to a playgroup, nor did Rose and Mark think it necessary. When Eugene was four-years-old Rose and Mark found a “nice playgroup”. Eugene “very half-heartedly attended”, but would not allow Rose to leave him “for quite a while”. Unfortunately, just as he started to settle, the playgroup was disbanded and they had to find another.

Rose and Mark now know that Eugene hates change in his life, so this period of trying to find another playgroup was “very difficult and painful” for the whole family.

Eugene could not understand why he couldn't simply stay at home; however, Rose and Mark worried that, as an only child, he would not learn to mix with other children. After some months they found another group. Eugene would not let Rose leave him there, but the teacher was very understanding of that.

Eugene then moved on to a nursery school and there followed "three of the worst weeks" in their lives". Eugene would not let Rose leave him and the principal of the school told Rose "in no uncertain terms" that she was a "useless mother" for not having made Eugene obedient to her instructions by this point in his life. One day, Eugene even refused to get out of the car. And so it was back to Eugene's previous playgroup "where he had been happy".

When Eugene did eventually go to a local nursery school, the principal did not hesitate to let Rose stay the first day. His teacher handled it very well, so that by the second day Eugene was settled and no longer wished Rose to stay with him: "Which goes to show what intelligent and professional handling can do."

The longer the family "went along, the more apparent it became that he (Eugene) wasn't like other children". In Eugene's last year of nursery school, Rose and Mark decided to take him to an educational psychologist to be assessed. When Rose's mother heard of this she objected strongly and even physically tried to stop them from taking Eugene to the appointment. She always claimed that Eugene was behaving as all boys do, and that Rose and Mark "were making problems for him". The family moved into their own home soon after this incident. The move was traumatic and Eugene was very unhappy generally.

The educational psychologist who assessed Eugene wanted Rose to leave the room, but Eugene would not allow it. Rose ended up sitting with her back to him. Eugene, because he was "nervous about being in a strange environment", also insisted that Rose accompany him to the bathroom. The psychologist reported that Eugene had a gifted IQ and that his behaviour was consistent with being bored. She also said that Rose "was an over-possessive older mother who didn't really know what she was doing". She suggested that Eugene play soccer and learns gym or judo.

With regard to playing sport, Eugene is left-handed, and "that also was a big problem": "He's never had a mid-line; he's half left-handed and half right-handed." Eugene can play tennis both ways, and kick a ball both ways. He was chosen for a

soccer team in pre-school, “but it was useless because he couldn’t understand how the game worked on the field”. This made other parents angry.

That was the end of soccer, so next they tried gym. Eugene was always outdone by the girls which “was most dispiriting” for him. That left judo as an option. First of all it was big group, “which is never ideal for these kids”. The instructor was Japanese and spoke strongly accented English. Rose and Mark did not “know at that point that Eugene as an ADHD child would have trouble ‘hearing’, that is hearing as in understanding what was being said and then acting upon it.” With this strong accent in a large class, he was utterly confused and could not follow. The teasing and bullying started and that was the end of judo.

After that, Mark and Rose left Eugene to tell them when he wished to try some sport. Eugene’s father was a very good oarsman and in high school, Eugene took to rowing, joining the Rowing Club immediately. “It gave him invaluable lessons, friends, and wonderful memories.”

Bullying was a problem that Eugene battled with for years. When about 14-years-old Eugene took up Kung Fu with a friend and he loved it. It became known at school that he was competent in martial arts, and this made others think twice about tackling him. It also gave him confidence that he could defend himself if required to do so. “And yet it was this very confidence in the sport and it’s teachings that made him less willing to do so.”

The December before Eugene went to primary school the family consulted a homeopath regarding his allergies and his retching up of food. She remarked, “Eugene is so allergic he is hyperkinetic”: “And that was the first time that we even gave it a thought.” Mark and Rose read up on the subject, but still did not think it applied to Eugene as he could concentrate on Lego or painting for hours on end.

At the age of six Eugene started Grade 1 at a government, co-ed school and that “brought it’s own miseries”. Rose feels that his Grade 1 teacher remains the “most insensitive” teacher he ever had. Eugene was so nervous about “big school” that he retched for two days beforehand, despite the fact that they had attended the sports day the previous year, and had driven him past the school repeatedly to get him used to the idea. He did not settle and he cried every morning. Rose feels “it was just a most painful time” in their lives and just thinking of it makes her tearful to this day.

Eugene's Grade 1 teacher called Rose in and said that he was disruptive and destructive in the classroom, not good for the other children, and that there were a lot of complaints. She added that he would not pass at the end of the year. Rose pointed out that he had been assessed as gifted. The teacher asked to see the report, as she did not believe it possible. Rose was reluctant to hand over the report, as it contained a few family things that she didn't particularly want the teacher to see. Now she "couldn't care less what anybody sees".

At that time another mother remarked that she had been given the name of a highly regarded psychiatrist. Rose booked an appointment and the psychiatrist did all the tests. He diagnosed Eugene as "a classic case of ADHD" and suggested they try Ritalin.

Rose's feelings about Eugene's diagnosis

Rose believes that "when one has a child with problems, one looks for answers." Rose was an older mother and tried to do "all the right things to have a healthy happy pregnancy". She still ended up asking: "Did I do something wrong?"

When Eugene was diagnosed, Rose does not believe they "went through an anger or denial stage".

"We accepted it from the beginning and set about facing it and trying to deal with it. Here I was seriously helped by Mark, who is a practical person who faces things."

Eugene and Ritalin

When the psychiatrist suggested Ritalin, Rose was against it as she had been brought up homeopathically. But Mark, being a physicist, said they must keep their "minds open and that if something helps you must look at it first before you reject it". Mark sat alone with the psychiatrist and asked all the chemical questions he could. He said to Rose that they should try it. At this point Mark also took over dealing with Eugene's "obstructive" teacher.

The Ritalin "was magic". By this time Rose and Mark had also joined THASG (The Hyperactive Support Group of Southern Africa), "which was absolutely invaluable": "They saved my life; my sanity; my everything". The support group gave Rose the

restricted diet, which she started Eugene on, along with evening primrose oil tablets. That had made a “vast improvement”, and now the Ritalin “gave him another boost”.

“Whereas before he had painted with dark red, maroon and black, and whereas his drawings were sombre with the crayon lines tearing the paper, he now started using pale shades. He came home with an angel coloured in pinks and blues, neatly stuck together, and we knew that something very important had happened.”

Eugene’s temperament also improved. The Ritalin did affect his appetite, but Rose and Mike made sure he ate a good protein breakfast before taking it. They also found that protein snacking him through the day, rather than sticking to three proper meals, worked better for him. He did not take medication on weekends, “which made them noticeably harder going”.

School holidays were “a nightmare” for Rose as the family could not afford to go away, and Eugene would be off the Ritalin.

“Those days stretched out before me like an eternity. He would be wild, bored and very angry and by the time he returned to school I was glad, depressed because I was glad, but sad at all the lost opportunities. It was tragic that we could have had such a wonderful relationship and done so many lovely things together, but could not because of his temperament. They say parents who have a child with a problem mourn for the child they never had. I cried every time he returned to school wishing it had been different, but it never was.”

Mike and Rose feel they “would not have survived” without the Ritalin and feel parents should consider Ritalin, and give their child a chance where possible.

Eugene and school

The educational psychologist who assessed Eugene suggested that he join the school for gifted children. When Eugene was in Grade 1, Rose approached the school “never thinking they would accept Eugene as he was not exactly displaying signs of greatness in his first year of academic life”. The resident psychologist insisted that Rose enrol Eugene “right there and then”. Rose went home and said: “Eugene, I think I’ve found a place for you.”

Later, when Eugene returned to choose his courses, no one thought it “odd” that he sat on Rose’s lap throughout the interview. The school was wonderful because “they embraced eccentricity and let the children be”. The school operated after normal school hours, the children dressed as they pleased and relaxed, and the teachers accepted them. The fact that there was a place where Eugene could go and relax and learn was extremely important, and Eugene “**loved** (Rose’s emphasis) it”.

Rose believes that Eugene would “never have gone to school at all if he had any say in the matter”. His primary school years “were fraught with tears every morning just to try and get him up and going”. Eugene had an excuse every day as to why he could not go to school - from tummy aches, to headaches, to just plain misery. Mark took to coming back home for tea after dropping Eugene, as he and Rose were so “fraught” most mornings just from getting Eugene to school. Eugene would come out of school in the afternoon in tears, and he would get in the car and hit Rose. They would fight all the way home and both would be in tears when they got home.

The school for gifted children were “just wonderful people who considered the child first”. There was nothing institutional about it, and Eugene got to do things like early electronics and archaeology. “It was the first time he was positive about a learning experience”. Also the classes were very small - never larger than six.

When Eugene was in Grade 4, he started speech and drama lessons. Eugene went on to take three years of exams, and obtained honours for two of those, and Rose feels “it has stood him in good stead all these years”. At this time they also joined the Listener’s Library. Eugene’s reading was “not that good”; but Rose and Mike “wanted him to love stories”. Eugene loved listening to the readings, and eventually he graduated to reading the books himself.

Rose remembers an incident in Eugene’s Grade 4 year where Eugene begged her to ask the headmaster to move him to another teacher, because his teacher had told him she would “eat him up” and he was petrified. Rose and Mike became more aware then of how ADHD children see language and semantics differently to other children, and that the nuances of speech, and body language, seem to stump them. Mike and Rose realised that “the ADHD child will see words differently and we must clarify with them what they think they are saying when there appears to be confusion - which is often”.

Mark and Rose had to make sure that the words they used were “flat”: “They must mean what they say. Do not use two-dimensional words or oblique words.” This did not mean that new words were not introduced to Eugene, but that new words “must be explained and made clear as to what they mean”. Rose believes that “one of the most difficult things in the world is to live with someone and not become like them”.

“In order to get Eugene to understand and do things we had to change our speech patterns and use of words. In fact through our change in language, we became less subtle, using the demand form of speech, became less shady, less oblique, less witty and humorous, less caring and kind and ultimately more aggressive. Not only did our language suffer, but our relationships did as well.”

Rose and Mark also found that not only must the words be flat (“one dimensional”) as their understanding of semantics is poor, but the sentence must also be clear to them. They found if they said, “Eugene would you like to set the table.” the answer from him would be a simple “No.” At first Rose and Mark could not understand this. They came to realise that “whereas it is a subtle instruction to the initiated (there is no question mark after table), to the uninitiated ADHD child it is a choice (there **is** a question mark) and his choice was always: ‘No I would not like to set the table.’” For another child it would be understood as an instruction from a parent to a child who had no choice. Similarly they found that if they said, “Would you close the door,” in all probability Eugene would not close the door. For action Rose and Mark had to demand: “Close the door please.”

Eugene has, however, always had higher than average marks in English. Rose is a qualified English teacher and “Mark has a high standard in the language”, and Rose believes these “factors have played a large part in Eugene being very adept at English, both in writing and speaking it”. Eugene did battle with maths though.

Rose found that reading something to Eugene helped him understand it, and she believes he “learns best when taking it in through his ears”. She read all his notes to him and, “even when he was dancing around and standing on his head when he was young and quite unable to sit still, he still took it in”. In high school, Rose read all his history notes, and set works - English and Afrikaans - to him. “Even when he was dog-tired after rowing practice, he processed it and passed the exams the next day”. Rose even read his computer science notes to him, although she could not “understood a word of it”.

Writing was “taxing for Eugene”, and Rose feels it is because he “never really established his mid-line”. His motor co-ordination seemed to make it difficult for him to write cursive, so he never mastered it. Eugene’s Grade 6 teacher was the first teacher who allowed him to print. His Grade 7 teacher said she could not allow him to print as the syllabus demanded cursive writing, so Mike and Rose had to get permission from the head of department for him to carry on printing.

When Eugene was in high school writing became a problem, as he could not finish his exams. He received high marks for projects and class work, but did badly in exams. Rose and Mike got permission from the school for Eugene to have more time in exams, and, when the time came, applied for “more time in matric”. Although the school were not very supportive of her application, Rose fought on and “Eugene received the most time of any student that year”. Rose feels that parents “have to be prepared to fight for their rights” and must not allow themselves to be intimidated.

Rose believes that when dealing with the school, parents must realise that whatever school they choose, “it will never be perfect”. “Also parents must realise that they will have to monitor the progress of their child and the school the whole way.” Rose also does not agree with changing schools unnecessarily: “We decided that if at all possible we would stick with the school of choice and rather help Eugene adjust to the school, it’s teachers, it’s pupils and the parents.”

Eugene “has come a long way”. He is at varsity now and “seems to be coping”.

Dealing with health professionals

Rose feels she has “never met a paediatrician who actually likes children, who actually knows how to handle them - who treats them as little people”. Rose actually had a paediatrician tell her that she is “a useless mother” that has “no control” over her own child. Years later Rose attended an ADHD seminar and was amazed when this same paediatrician “held forth about ADHD”.

“My courage failed me, but I wanted to get up and ask him in front of all those people if he remembered this ‘useless mother’ whose child who had since been diagnosed with ADHD, when he in his wisdom of only a few years ago had not recognised it at all, when he had ample evidence.... Every time we passed his offices, Eugene would point it out as the place where that horrible doctor lived.”

The family's relationship with the psychiatrist did not prove to be much better. Shortly after they started seeing him, Rose was hijacked and Eugene was extremely upset by the incident. Mark telephoned the psychiatrist for help. He left two messages, but received no reply. Mark then sent him a fax. Two days later he managed to speak to the doctor, who admitted receiving the fax and promised to read it and call back. The psychiatrist never ever returned their calls or answered their fax: "We were aghast and appalled at his behaviour."

The family eventually "turned back to the GP" and he agreed to prescribe Ritalin for Eugene, with the proviso that he would physically examine him every three months. Eugene continued taking Ritalin until the end of his matric year.

Rose believes that when it comes to dealing with health professionals, parents should use their common sense and be outspoken when they feel they are not getting service. Rose also feels that both parents should be present at consultations. Rose and Mike have learned not to let professionals intimidate them and believe that, when in doubt, parents should ask themselves whether the doctor would accept this level of treatment for his own family

Extended family

Rose is convinced that her father "was seriously ADHD, although he made a success of his life and built up a successful business". She is also convinced that her mother and brothers have ADHD.

In Rose's family, with the exception of her eldest brother, Eugene's ADHD is "a matter for denial":

"It was generally felt that Mark and I were not good parents and that Eugene had no problems. We were making the problems; we were not strict enough; we had it all wrong."

Being Eugene's parent

When Eugene was four, "in despair" Rose went and did a Parent Effectiveness Training (PET) course. Rose couldn't understand why she was unable to deal with a four-year-old, when she had been a teacher who never had disciplinary problems in the classroom, and had also been in management positions in business. The counsellor "went mad" with Rose because she "kept saying it doesn't work".

“And she kept saying I was negative and it worked with other people. And I said well it doesn’t work with my child, never realizing that Eugene was hyperactive.”

It has always been a conscious decision for Rose that she did not want to parent the way her parents had, and that she “would break those chains”. Mark and Rose even discussed it.

Rose believes that “without a shadow of a doubt raising an ADHD child places a marriage under the most extreme of pressures - there can be no stronger test of a relationship than something like this”. Rose feels it requires “great maturity from both partners”, as well as teamwork.

Rose found it hard that “just because one has an ADHD child the world does not stop spinning”. Although having a child with ADHD is stressful enough in itself, there is always the usual stress and family problems that have to be handled at the same time. Rose believes parents must face the fact that ADHD places enormous strain on a marriage and the parental relationship, and must discuss this and how to deal with it. Rose feels the parents need to set up some house rules “in order to proceed, and those house rules must suit them and their family and concern no one outside it. If it is an unconventional set of rules but it works for them, then so be it”.

Rose feels that with any child, many of the hopes and aspirations of the parent will be placed on the backburner, “but with the ADHD child this can mean, not indefinitely but forever, and that can be hard to bear”.

Rose believes that having a child had made her “nervous” and reduced her confidence, so that she cannot believe she was once quite adventurous and notched up accomplishments in the working world. Rose believes that having a child with problems “makes you doubt yourself further”. “All in all you are not the person you were. We are not the people we were”.

“There have been times when I have quite understood stories about human combustion - where people have spontaneously combusted and burned up. There have been times when I have felt that I would spontaneously combust from sheer stress.”

Rose feels that having an ADHD child has isolated them. They isolated themselves from the parents at the school and lack of finance isolated them even further. Rose believes this isolation and lack of finances also affected Eugene's ability to make friends and keep them.

Rose believes that ADHD "is one of those things that do not elicit much sympathy for parents".

"Parents of an obviously handicapped child do receive a certain amount of sympathy, and therefore understanding, and maybe even offers of assistance. Parents of the ADHD child receive no sympathy, as they are perceived to be the problem in the first place. They are the ones who are making the problem. The child appears to be misbehaved and it is every parent's duty to raise a well-behaved child. There is no sympathy for a parent who does not accomplish one of the most basic requirements of parental duty."

Far from receiving offers of assistance, Rose feels parents of the ADHD child "are somewhat ostracised and that is a difficult thing to bear".

"The parents can either try to convince those around them that they are not to blame - or maybe they accept they are to blame - or they can turn their backs on critical society and try and sail their ship in lone waters, so to speak. We would fall into this category."

Rose believes "this is where support groups play a very big part".

"For parents trying to negotiate the hostile waters, to just have a place where one can go and talk to people who are living through the same problems, where one can shed tears of relief, pain, frustration, anger, recognition, is beyond belief."

Rose also finds that ADHASA's Pulse magazine "is packed with professional advice and information and news of lectures and seminars."

Coping

Rose feels that Mark is "definitely my greatest source of support". In the five years following Rose's hijacking, her four closest girlfriends emigrated, leaving her "to rely on Mark more than ever".

One door did “open up” when Rose met up again with a friend from varsity. This friend also had a “laat lammetjie” and was friends with two other women in the same situation. Rose joined their group and they would meet once a week, alternating homes or going on an outing. All of the women had boys, and all were the same age as Eugene. Rose feels it was “wonderful for Eugene”.

Eugene and the future

Rose believes that “the ADHD child can be raised successfully” because “there is a great deal of potential and there are possibilities”.

“Our greatest wish is that with full maturity, Eugene learns to understand, control and love himself, that he learns to motivate and organise himself - that he finds something that will give him satisfaction and the minimum of stress and anxiety whilst earning a living - that he finds someone special who will understand, accept and love him and, above all, that he will learn how to unselfishly and gently care for and truly love that person in return.”

Rose’s advice for other parents

Rose feels that if “there is one nugget of advice” she can offer parents of an ADHD child, then it would be” to read as much as you can about the subject, go to as many lectures as you are able, talk to as many people as you can, be they both professional and lay”. The next step is to “set all that information to one side and decide what suits your family the best”. Rose believes parents must “go with a very informed gut feeling”.

For Rose, discipline is the “most vexing question regarding ADHD children”: “They appear to be quite impervious to discipline.” Rose does not believe that negotiation or behaviour modification works with the ADHD child. Smacking Eugene also just made it worse. Rose feels that because ADHD is “a chemical, biological, allergy problem” the best route is trying to restore that chemical, biological balance through medication and staunching the allergies through diet.

Rose and Mark discovered early that Eugene “hated change, so if something was planned there had to be an excellent reason for altering the plans”. Shopping was a nightmare as the crowds, the noise, and the smells drove him mad. Heavy traffic had the same effect. If the family planned lunch at a restaurant, “it was hell just to get him dressed and in the car”. “The anxiety of a planned trip or outing seemed to totally

unsettle him". For Rose and Mark, "discipline was improved when all the points above were taken into account. Trying to keep calm, few people, a lot of planning and warning of what we were planning, no changes, staying out of noisy, air-conditioned places etc."

Rose and Mark found that in more formal atmospheres like the Country Club, Eugene behaved better. "If a place was quiet and structured and yet was interesting - the waiters, the gardens, lovely tables and settings, quiet people - the fascination of it all would keep him calm and quiet." Rose believes that the key is that the atmosphere was quiet, "and maybe that calmed him and kept him quiet". At home, Mark and Rose set up a bird feeder outside the kitchen window, and his interest in watching the birds often helped them to feed him, "especially in the mornings when he is at his worst".

Mark and Rose also learned that if Eugene "did not eat properly and at correct intervals, the aggression was high". Mornings were bad until they got food into him. It took some time for them to realise that Saturdays and Sundays were worse, because they took their time getting up and getting breakfast. They could not think of going out and postponing breakfast, "it was just not worth it". They did find that coffee worked for Eugene; "it had to be quality coffee though". If they did go out they took a snack in the car so they "were ready when he hit a downer".

"Believe me, all this took a long time for us to learn."

Rose believes that repetition seems to help ADHD children. When Eugene started Grade 1 he did not know the alphabet, so Mark and Rose recited four letters every night in the bath, and then only added another two when he knew the first four by rote. At the end of each school term the family would go through Eugene's reports "and list what had improved and what needed improving". They would then "set up a plan for the next term that would hopefully strengthen the weak points".

Rose and Mark have found that Eugene's "biggest fault is procrastination". He leaves everything to the last minute. Rose and Mark would often have to "step in and help out". As Eugene is not a good sleeper, they often landed up working into the night. When Eugene was in high school, he would stay up until the early hours working on a project, and now at varsity he works through the night quite regularly. Rose has learnt to accept and work with what worked best for him.

On a practical level, Mari and Rose found that Eugene “became paralysed if he was given too many choices”. They soon learned that it was better to give only two options. For example, when dressing they found it better to ask, “Which shorts do you wish to wear, the black or brown?” and never to ask, “What would you like to wear today?” The latter was “too open, too confusing”. The same applied to food. Rose believes parents should not “leave the question open-ended as this confuses them”.

A big question Rose and Mark battled with was “whether one should admit that a child is ADHD”. Rose’s mother never wanted them to tell anyone. At primary school, Rose and Mark felt they had to be open for Eugene’s sake: “especially with the teachers - so that people would understand him better - so that other people would learn something from it, maybe their child had similar habits - so that people would become aware of ADHD as a subject etc. and we still feel that we were correct.”

When Eugene went to high school he asked his parents “never to tell” and they tried not to do so. It “complicated” their lives though and when they applied for things like extra time for exams and Matric exams, most of the teachers ended up knowing. Rose and Mark “now know that ADHD is not ‘curable’, that one has to learn to live with it”. Rose still grapples with the issue of who should or should not know that Eugene has the disorder.

A “big point” for Rose “is that one seems to get very little in return with an ADHD child”. Eugene has never been an affectionate child, “which is painful for a mother”. Because he battles with aggression he would say things to Rose, like: “I hate you; I hate you”. Rose feels “we seem to have given, and are still giving so much, but seem to get little in return”. Eugene is “immature” and “still blames everyone else for his failures”. He almost never offers to help Rose and Mark with anything, and when he does he still feels he can do it in his time, even if it is vitally important. “So one lands up doing it oneself anyway, and vowing never to ask again”. At this stage, Rose feels she has “absolutely no desire to be a grandmother”. “Having said that though”, Rose cannot imagine not having Eugene in her life: “I know that if I had never had Eugene I would be a lesser, glacial person. Mark and I have discussed this, and in all probability, I would have damaged our marriage irreparably if we had not had a child.”

In conclusion, Rose feels that animals can be a “saving grace” for families with an ADHD child. Rose and Mark bought a puppy in Eugene’s Grade 1 year and Rose feels that the dog “saved our mental lives many times over”. Eugene said that she “was a human with a snout” and Rose feels the dog “gave us a wonderful dimension and saved our lives”.