Mothering and Attention Deficit Disorder: The Impact of Professional Power

Thesis submitted by

Dianne Rogers

Bachelor of Arts, Master of Social Policy.

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The Centre for Women's Studies
School of Social Work and Community Welfare
James Cook University

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STATEMENT ON THE CONTRIBUTION OF OTHERS

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ABSTRACT

In this country and overseas the debate on what causes Attention Deficit Disorder (ADD) and the interventions necessary is conducted fiercely along with claims and counterclaims as to the validity of the disorder. It appears that everyone has an opinion on the real-ness or otherwise of ADD. What is missing from this debate, which takes place in the media, in academic circles and in the general community, is the day to day reality of living with ADD, as a woman or as a mother. This thesis explores the relationship between power and knowledge in the competing discourses on Attention Deficit Disorder (ADD). It also examines the ideology of motherhood and the construct of difference.

The research for this thesis took place in North Queensland and tells the stories of women affected by ADD, primarily the mothers of children with ADD. In telling their stories, the women identify their children as different, in that they learn and experience the world differently. They articulate that their child's difference attracts stigma and blame, not so much to the child, but to the mother of the child, as she is seen by many in the general community and by professionals as causing her child's difference. The women also report that their families are different and that they live different lives from commonly accepted norms.

This thesis demonstrates that these women struggle, usually unsupported, to parent their children and that some women are also supporting husbands who may have ADD, thus revealing that they endure enormous physical and emotional workloads. These workloads and the isolation and marginalisation that occur within their families and in the general community affect their physical and mental health. This thesis also reveals that some mothers are subjected to verbal and physical abuse from their children. This research demonstrates that abuse is not confined to the home as women experience abuse from by both professionals and governments which seek to normalise the mothers and their children.

Not content to be labelled as bad mothers, the women challenge professional discourses which hold them responsible for having different children and different

families. These women create their own discourse on ADD which is based on their experience of having ADD or parenting children with ADD. Their knowledge is used to advocate for families and individuals and to provide, where possible, practical strategies or support.

This thesis recommends that a strengths based focus needs to be implemented, especially within the education system and professional practices to prevent abuse. It also calls for professionals to work alongside families to implement programs and strategies that support family members. Additional research is called for to explore what it means to be different and how difference impacts on all members of the family. Another area of crucial further research would be to determine how fathers can contribute more fully to raising their children and supporting their partners. In conclusion this thesis argues that difference is a currency that runs through our society and that society has choices to make regarding difference. It can choose to pathologise difference, or it can embrace difference as a vital part of humanity.

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INTRODUCTORY CHAPTER

Introduction

This thesis seeks to explore the power relationships which surround and are embedded in the experiences of women, primarily mothers, who have children with Attention Deficit Hyperactivity Disorder (ADHD) and Attention Deficit Disorder (ADD). For the purpose of this study the term ADD will be used, even though technically ADHD, in the *Diagnostic and Statistical Manual of Mental Disorder, 4th edition (DSMIV)* (American Psychiatric Association, 1994) covers three categories:

❖ Attention-deficit/hyperactivity disorder, combined type

❖ Attention-deficit/hyperactivity disorder, predominantly inattentive type

❖ Attention-deficit/hyperactivity disorder, predominantly hyperactive-impulsive type.

ADD has been chosen since, as will be demonstrated in Chapter Two, the term ADHD has focused both research and community attention on anti-social behaviour in boys, at the expense of conceptualising ADD as a difference in learning which can affect both males and females (Tannock, 2004). However the term ADHD will be used when referring specifically to ADHD or ADHD characteristics.

Background to the Thesis

I discovered ADD when a family member was diagnosed at the close of 1993. The diagnosis helped me make sense of the last few years and in time it helped me make sense of my life as a mother and the life of my family. In 1994, I joined the North Queensland Attention Deficit Disorder Support Group in Townsville. I met many women, most of them mothers and they shared their experiences with me. Some of their experiences were similar to my own. However each story had its own dimension and there were differences.

One story had a profound impact on me. In the car park, as women were leaving to go home from a support group meeting, one young mother in her early twenties told me about her experiences and her frustration. She had four young children, her eldest was about five and had ADD. She also suspected the toddler, a little girl, had ADD and she described a very defiant child. She then told me about her own

childhood. She was a very disruptive teenager, had little education and left home or was asked to leave home at an early age. She said that one day she had taken one of her son's Ritalin tablets and that it was the first time that she found peace. She actually knew what it was like to sit down and gather her thoughts. The young woman, in describing basic ADD characteristics, caused me to wonder if she had ADD as an adult. Despite my education, I had difficulty in locating non-judgemental professionals in relation to ADD and negotiating a system which offers little or no support to mothers. In light of my own experiences I thought, "How does this woman cope? Who would help her"? This caused me to reflect on what it might be like to have ADD as an adult woman and to question what impact, if any, ADD might have on mothering.

Regardless of the diversity of the women in the support group, most felt blamed for their children's difficulties. Many mothers had sought assistance when their children were young but only discovered that they were dealing with ADD when their child was in late adolescence. These adolescents posed enormous problems for their mothers. Other mothers had children who were younger and their situations, although difficult, were not fraught with as much frustration, abuse, crisis and poor health. Nevertheless, the stories had a common theme; mother blame, lack of services, and disbelief from their own families and/or the general public. Often, they found themselves alone, except for the support of women friends within the group.

In my search to find answers during the next few years, I read publications on Attention Deficit Disorder and learnt a considerable amount about the disorder. However the scientific material, usually written for professionals, medical practitioners or psychologists, was often very negative and the prognosis for ADD children was not good. The publications rarely spoke about the achievements of children and adults with ADD; instead I read that they had a greater chance of failing school, becoming an alcoholic, committing a crime or developing a mental illness. In more recent years a number of books have been written which seek to moderate this profile, but in the early days such texts were few and far between. While I did not doubt the statistics, I suspected that a true representation was not being allowed to develop. Maybe the picture was skewed?

The disparity between the lives of the women and what was written in the lay and academic literature was very disturbing, in particular, the mother blame that pervaded many texts. Families and mothers were described as dysfunctional, rather than stressed and coping as best they could. Children with ADD were described as coming from broken homes, the implication being, "What else could you expect"? Mothers were seen as depressed and contributing to, or causing their children's problems. I did not read of the struggles that women encountered, the successes that they had achieved. Mothers' stories were absent from the discourse on ADD. The portrait of ADD was clinical and cold; women's experiences were rendered invisible.

The invisibility of women's experiences was a primary consideration as in the late 1990s there was little information available and from my own experience, many women felt that they were in a siege situation unable to express themselves clearly to anyone outside of the support group. As my thesis was taking shape, I became aware of Carpenter's (1999) unpublished thesis and Malacrida's (2003) work, which examine the experiences of mothers. Late in 2004, I also located a number of other texts which sought to explore the reality of families, notably the work of Kendall (1999, 2003), Muslow, O'Neal and McBride Murry (2001) and Harborne, Wolpert and Clare (2004). I have used these works in the literature review and refer to them where appropriate in the data analysis.

Values and Research

Throughout history we see events that shape people's lives and influence their academic pursuits.   A case in point is Foucault who grew up in the shadow of the Second World War. He tells of his fear as the Nazis assassinated people in his town and as refugees arrived from other parts of Europe. Foucault asserts that these experiences had a profound impact on his life and his generation:

I have very early memories of an absolutely threatening world, which could crush us…the impression of spending one's entire childhood in the night, waiting for dawn. That prospect of another world marked the people of my generation, and we have carried with us, perhaps to excess, a dream of Apocalypse (Cited in Miller, 1993, p.39).

A number of experiences influenced Foucault's world view and academic aspirations. As a young man he tried to commit suicide a number of times. He was not well liked as his classmates found him to be difficult and abusive. Some believed that his mental health was not robust; *"all his life he verged on madness"* (Eribon, 1992, p.26). Foucault held a passionate interest in the fields of psychology, psychiatry and psychoanalysis. He read Freud, listened to presentations on psychiatry and had access to Rene Beauchamp, a family friend and a man who was at the forefront of psychoanalysis in France. Therefore it is no surprise that Foucault's experience with madness informed his work:

> *Whenever I have tried to carry out a piece of theoretical work, it has been on the basis of my own experience, always in relation to processes I saw taking place around me....that I undertook a particular piece of work, a few fragments of autobiography* (Cited in Eribon, 1992, pp.28-29).

Foucault was not alone in using personal experiences as a catalyst for the development of his work. Bruno Bettelheim's experience of living in Austria from 1938-1944 had a profound affect on his world view and may have influenced his theories on autism:

> *some victims of the concentration camps had lost their humanity in response to extreme situations. Autistic children withdraw from the world before their humanity ever really develops* (Bettelheim, 1967, p.7).

Bettelheim went on to employ psychoanalytic theories to explain autism. After the Second World War others were motivated to employ psychoanalytic frameworks. It has been suggested that the unhappy childhoods of Mary Ainsworth and John Bowlby influenced their careers in developing psychoanalytic theory in relation to child rearing (Eyer, 1996; Karen, 1998). Attachment theorists have been criticised for allowing *"their own values to skew their work"*(Karen, 1998, p.249). Therefore it can be argued that our experience and values have an effect on what we study, how we study (Kanpol, 1998) and how theories or disciplines develop.

Although there are many different *"categories"* (Kensinger, 1997) of feminist theory, nonetheless, what most feminist researchers have in common is that they acknowledge the importance of personal experience. Furthermore, feminist

researchers understand that often women will be motivated to undertake research in an area which has had a profound impact of their life (Fonow & Cook, 1991; Reinharz, 1992). Moreover, the knowledge gained from personal experience and research can be used to bring about social change.

My Values in Relation to the Research Topic

I consider that in any research it is important to be aware of one's personal value base and the value base of the theoretical frameworks underpinning the research. Moreover I hold that these values should be stated clearly.

As a feminist I do not place myself in any particular framework (Kensinger, 1997; Young, 1984), instead my focus is directed at exposing the inequalities that women endure. Accordingly I undertook this research because of the pain and abuse that women encountered while trying, often unsupported, to bring up their children who are diagnosed as having ADD. To me these women are resourceful and strong and they challenge the portrait painted of them by some professionals as deficient and in need of instruction. I believe that it is importance for feminist research to expose the structures and systems which do not serve women well. Furthermore research needs to be able to give voice to women's stories so that they can tell *"their truth"* (Ramazanoglu & Holland, 2002, p.64) about the experience of mothering children with ADD and to start to explore the impact that ADD has on mothering.

As a feminist and as a mother I was critical of the way in which the women in the support group had been treated. In the past a number of researchers and students have contacted the North Queensland Attention Deficit Disorder Support Group (NADDS). The women have spoken of their experiences freely. However, when they have asked researchers, *"Do you believe in ADD?"* the researchers often have refused to be brought into the debate, saying it was irrelevant to their research. Even though it could be argued that the researchers were mindful of influencing the interviewees in some way, as a feminist I would strongly assert that researchers need to consider the impact of their research. Just as women who experience violence need to be believed, so too do the women who have children who behave and learn differently.

Another factor of which I was very aware was that women spoke of feeling betrayed; betrayed by researchers and sometimes the media. Usually the women gave information freely, with the hope that their stories would be heard and their experience would be taken seriously and respected. Furthermore, the women hoped that through this process change would occur and things would be made better for their loved ones. It was as if they had given a part of themselves in order to be understood, but their knowledge had either been ignored or not reported. Thus, researchers and reporters have used the pain and trauma, commonly known as data or information, in their projects, studies or government reports, with little thought to the impact on the participants.

I am also mindful of the contribution of women living with ADD and the value of their stories. Thus, I consider I have an ethical and moral obligation to these women, to the research community and readers of my work, to state my values in relation to ADD.

My Values and Beliefs about ADD

From 1993 onwards I read as many books and articles about ADD as I could in order to understand what ADD was and how it affected the individual. Wherever possible I contacted other support groups throughout Queensland and New South Wales to ascertain if the situation in North Queensland was similar to other places and what, if any, strategies or professionals they had been able to find to assist them in managing ADD. In general, I found that both group and individual experiences were similar. Through the information supplied by the network, mothers were able to access ADD *"friendly professionals"* (Malacrida, 2003, p.169). In the following years I attended and organised workshops and seminars. The professionals engaged to present at these functions were mother friendly and tended to present material which spoke of ADD as being, more often than not, passed on from parents, usually the father, to the child, usually a boy.

These professionals' knowledge of ADD and how it affected the individual mirrored my own experiences. This may be because many of the speakers and writers on

ADD, many of whom are men, have been touched in some way by ADD. Even so, I felt that they had overlooked the difficulties that women encountered in dealing with ADD, either as mothers of children with ADD or as adult women with ADD. I started to conceptualise ADD as a disability, using a broad definition of disability: affecting most aspects of your life and something which remains with you during your life time. I did not see the term disability as a negative label, as I believe that a human being is no lesser a person because they are not the same as everyone else. Furthermore, with or without a disability tag, the community still labelled people with ADD as naughty, stupid, or irresponsible. Moreover, the label disability was necessary in order for services to be provided to individuals and families such as respite, assistance in schools and simply understanding.

During this research process I felt my understanding of ADD was challenged, and was broadened. Foucault's concepts, particularly in relation to difference, normalisation and power were illuminating. Additionally, what I found useful was that Foucault does not prescribe a structured analysis or structured plan for social action, as his concepts or ideas are more like tools (Visker, 1995). Thus, I found a tool box, which I could use to grapple with and tease out the controversy surrounding ADD. In particular, why mothers experienced blame and abuse and what this thing called ADD really means for those who live with the disorder either as a mother of children with ADD or as an adult woman with ADD.

I came to conceptualise ADD as a term which is used to identify people who are different. People with ADD think differently, perceive the world differently and learn differently. The impact that this difference has on the individual or family depends on many factors such as: personality, resources, culture, and time in history. Thus, environment does play a part, not necessarily in causing ADD but certainly, I believe, in the impact that difference brings. ADD does not have to be a negative experience however, at this point in time, in a western industrial culture it has been identified as a problem. Accordingly, in this thesis I do not debate its existence, even though I present various theoretical perspectives, rather I am looking at the struggle that has ensued.

Research Aims

Important aims in undertaking this research and writing the thesis are to tell the stories of women affected by ADD, to document the similarities and the differences, to explore the relationships that surround them and in particular, to examine the reasons why the powerful chose not to believe or take seriously the powerless. Moreover to explore mother blame and the way in which it pervades our culture and to celebrate the determination of women who survive horrendous negativity and damaging encounters.

Theoretical Frameworks

This thesis draws heavily on the work of Foucault and the analysis of feminists such as Ehrenreich and English (1979), Oakley (1986), Smith (1990), Eyer (1996) and Hays (1996). In particular, Foucault's concept of power and feminist theories which expose the reality of women's experiences is used as the foundation for both the literature review and the data analysis. In examining Foucault's work it can be seen that power is multilayered and multifaceted and permeates all aspects of our lives (Foucault, 1980d). Foucault conceptualises power as being neither good nor bad. Nonetheless, he does speak of *"great negative forms of power"* which can, and do develop to form discourses, normalise and discipline populations (Foucault, 1980d, p.122).

Foucault's work on the formation of discourse has particular relevance to the debate on the causation of ADD. It is also useful to use his method of genealogy to trace back in time the point when children with ADD were seen as problematic, since it reveals much about the kind of body that society deems suitable (Foucault, 1972, 1984b). Thus, Foucault's work on power, normalisation and discipline and the formation of discourse and genealogy are utilised to explore both the literature review and the stories of the women.

In an initial reading of the literature on ADD there was nothing on the reality of mothering children with ADD and very little on the impact of ADD on adult women. In order to lay the foundation for exploring the stories of the women affected by

ADD and to examine power structures it has been imperative to draw on the work of feminists who have critiqued the formation of the ideology of motherhood and mother blame (Badinter, 1981; Ehrenreich & English, 1979; Eyer, 1992, 1996; Hays, 1996; Jackson, 1994; Oakley, 1986). Feminist standpoint theory, which views telling and making women's reality visible in order to produce social change, is utilised to enable women to tell their stories in relation to ADD. Thus feminist standpoint is central to this thesis (Ramazanoglu & Holland, 2002; Smith, 1990). The theoretical framework of this thesis will be explored further in the literature review and in the methodology chapter.

Limitations and Considerations

The focus of this research is primarily white, Anglo Saxon and is located in the industrialised west; the United Kingdom, the United States, Canada and Australia. Locating the study within present day western culture does not mean that I am not aware of race or different cultures in exploring the whole concept of ADD. However, ADD as a subject is hotly and fiercely contested and is complex, as the notion of ADD spans across many social science discourses. In broadening the thesis to be more culturally inclusive I felt that I would not have the opportunity to fully explore fundamental issues such as motherhood, mother blame and the formation of the ADD discourse. I have located my data collection in Townsville, North Queensland, with the intention of presenting a rich regional perspective and painting a vivid picture of the lives of women affected by ADD.

This research does not explore in any depth what ADD means for the child who is different, or what their experiences have been. It has been my observation that the pain and trauma that women experience in having children with ADD is no less for the child who is seen as different. Valuable insights are to be gained from listening to children who are labelled different, or see themselves as different.

Overview of the Chapters

Chapter One examines the development of the modern family, motherhood and mother blame. Foucault's (1980d) concept of power and feminists' analysis are utilised to demonstrate that powerful forces have constructed the ideology of

motherhood based on the needs of the nation state, capital and the patriarchy. Furthermore, it will be documented how these forces and child raising experts, whose professions developed in earnest from the early twentieth century, have sought to blame mothers for producing aberrant children; people who are seen by society as undesirable, such as adults with schizophrenia, children with autism and recently children with ADD.

In Chapter Two, the identification of ADD and the history of the discourse on the disorder are outlined drawing on Foucault's concept of genealogy. The conflict within the discourse is explored by presenting the two dominant theories which operate to explain ADD; the genetic theory which asserts a biological basis for ADD and the psychoanalytic or behaviourist theories which argue that difference stems from early childhood experiences. The concept of leper, as defined by Foucault is also explored, since, in a society where difference attracts attention, scapegoats need to be found to explain social ills. It will be shown that in our recent history people with schizophrenia and autism have held the status of leper and it will be argued that the baton of leprosy has been handed now to those labelled ADD.

Chapter Three seeks to explore the concept of difference and how nature and nurture theories have sought to explain difference. Foucault's work on difference, normalisation and correction is used in exploring difference and how people or groups that are different have attracted normalisation or disciplinary policies. This perspective is particularly relevant to people affected by ADD. Thus, normalisation and disciplinary strategies will be explored in relation to those affected by ADD.

In Chapter Four, it will be argued that the conflict within the ADD discourses is not a purely academic debate, as professional practices and interventions are primarily developed from a theory of causation. Thus, drawing on the limited literature available, the affect of theory and practice on the family, particularly the mother will be explored using McLaren's definition of power. Four theory bases and practices will be explored:

- ❖ the two dominant discourses which centre on genetic theories and on psychoanalytic or behaviourist theories,
- ❖ and two minor discourses, diet and the strengths based approach located within grass roots organisations.

Methodology is the Fifth chapter which covers the research process and the theory base used to analysis the data collected.

The remaining four chapters, Diagnosis, Difference and Resistance to Blame, Family Life and the Impact of ADD on the Mother, Power and Knowledge and Support Groups and Political Action revolve around the themes drawn from the data:

- ❖ the importance of diagnosis
- ❖ the concept of difference
- ❖ mother blame
- ❖ the isolation and marginalisation of mothers
- ❖ family life and ADD
- ❖ the impact on the mother which covers what it means to have ADD as a woman, the triple burden, depression, isolation and marginalisation, poor health and violence
- ❖ resistance and political action.

In the concluding chapter, recommendations are developed from the themes drawn from the data and the views of the mothers as to what services they believe they need to bring up children with ADD. In addition, the implications for further research will be discussed drawing on the data from this research.

CHAPTER ONE - MOTHERHOOD AND MOTHER BLAME

"This clash between experience and institution, between the reality of motherhood on the one hand and social expectations of women-as-mothers on the other, has been, I think, one of those conflicts responsible for the very birth of feminism itself" (Oakley, 1986, p.119).

Introduction

In this thesis, the development of the ideology of motherhood in the industrial west and the notion of mother blame will be examined by drawing on the works of feminists and Foucault. To a lesser extent, the role of the father and the development of the nuclear family will also be examined. In exploring the ideology of motherhood, particular focus will be placed on the reciprocal nature and interconnectedness of the nation state, the political economy, the middle classes, patriarchy and child rearing experts. The role of the child rearing expert and the formulation of theories in relation to child mental health will be examined to ascertain the function of mother blame in western society.

THE DEVELOPMENT OF THE IDEOLOGY OF MOTHERHOOD

The nuclear family, idealised in the Industrialized West as natural and a universal truth (Reekie, 1998), has been examined by both historians and feminist writers (Aries, 1973; Badinter, 1981; Hays, 1996; Stone, 1977). Various authors, although differing in many respects, argue that the modern family in industrial countries is far from natural and that the nuclear family has evolved over a long period of time, with rapid and significant development occurring in the last one hundred and fifty years. The development of the nuclear family and the parent's role, particularly that of the mother, is seen as being shaped by culture, and by political and societal needs. Jensen and Kingston (1986, p.26) state that *"societies often rear children in accordance with certain societal goals"* while Jackson (1994, p.79) asserts that *"mothering has been constructed and defined historically, its very forms shifting according to changing economic and political needs"*. In a similar vein Hays (1996, p.19) states that motherhood is a social construct and that *"child rearing, like all*

ideas, bear[s] *a systematic and intelligible connection to the culture and organisation of the society in which they are found"*. Thus, the make up of the family and the development of motherhood is embedded in history and the development of the modern world. The modern concept of mothering and the place given to children within our society is in direct contrast to the child rearing practices of the past.

Child Rearing in the Past

In the middle ages, European practices of child rearing accepted the use of opiates to quieten children, whipping as a form of discipline, the rearing of children by subordinates - servants or other children - (Hays, 1996), and the placing of children over the age of six in apprenticeships (Aries, 1973). Abandonment of babies and young children was often practised in the middle ages for many different reasons; poverty, illegitimacy, incest, the inability of the family to look after another child and disability or ill health of either the child or the mother (Boswell, 1988). Wet nursing; sending a child to be nursed and cared for by another woman until the child could be indentured, was also practised. Heywood (1959) states that the care of children was not uniform or structured.

Unlike today, children and their welfare did not receive a great deal of attention, *"most were provided no special clothes, and none were given special toys or spaces for play"* (Hays, 1996, p.24). The social and economic structure of the time was hierarchical with children only being of value when they could contribute to the adult world in which they lived. Infant mortality was high, their deaths were not publicly acknowledged, affection for children was not highly visible, *"because it would have been silly to lament a creature so incomplete and imperfect, a mere child, as today people often disapprove of those who mourn the death of their dog"* (Badinter, 1981,p.64). Hays (1996, p.24) believes that

> *investing one's time and emotion in these strange and fragile beings was simply impractical, and the socially developed ideologies and rituals of child rearing helped to legitimate and reinforce this reality.*

Aries (1973, p.356) in his history of the family, states that parents may have loved their children, however, the overriding concern was *"the contribution those children could make to the common task"*. The task was closely related to either the family name, family wealth in the case of wealthier families or in poorer families the survival of the community. While there was a great deal of difference in the instruction of child and child rearing practices depending on country, region and class, there were also commonalities, for example the authority of men. Hays (1996), in exploring family structure and child rearing in Puritan New England in the late seventeenth to early eighteenth century, claims that written works targeted fathers as the head of the household and the wider religious patriarchal community. American colonial fathers were seen as the authority on child rearing and instructed their children in moral and religious values (Jensen & Kingston, 1986). Correspondingly, in Western Europe:

> *the discipline of children after a certain age had been pre-eminently a masculine task. Family honour was represented in the father as head of household. Child behaviour reflected upon this honour and hence the father was the appropriate agent for disciplining the new generation for the good of both the family and the society* (Matthews, 1984, p.87).

The Seventeenth and Eighteenth Century

Changes in child rearing occurred during the seventeenth and eighteenth century (Aries, 1973). Children started to become more central to the family unit and this can be evidenced by the increased production of children's clothing, toys and books, the formation of schools, family paintings and children being buried in caskets (Hays, 1996). Changes in ideology and values relating to the family and the rearing of children were documented in the works of various authors such as Philippe Hecquet (1708) and Jean Pierre de Crousaz (1722) (Badinter, 1981). John Locke's work of 1693, *Some Thoughts Concerning Education* (Garforth, 1964) and Jean-Jacques Rousseau's *Emile* of 1762 (Archer, 1964), are recognised as influential contributions. These authors espoused a more child centred approach to child rearing and more nurturing methods of bringing up children (Aries, 1973; Badinter, 1981; Hays, 1996; Jackson, 1994). Thus, it can be seen that while in the seventeenth and the early eighteenth century *"child rearing was not...equated with mothering"* (Hays, 1996,

p.26), some authors urged mothers, *"to feel mother love"* (Badinter, 1981, p.30). While embryonic, the modern day concept of motherhood was beginning to form.

Theoretical Frameworks – Feminism and Foucault

In examining the changes in child rearing practices, feminist writers look to the functioning of powerful bodies in our recent history. Foucault's ideas concerning the forming of power and how powerful bodies shape discourse may also provide insight in examining the development of motherhood. Some feminists have discounted Foucault for a multitude of reasons, in particular for rendering women's personal experiences invisible (Malacrida, 2003; McLaren, 2002; McLaughlin, 2003). However, others argue that Foucault has a lot to offer feminist research, particularly in discussing the formation of knowledge and power (Fraser, 1989; McLaren, 2002; Ramazanoglu & Holland, 2002). While some feminists have viewed patriarchy as the primary source of power and oppression (Hesse-Biber & Yaiser, 2004). Foucault (1980d) maintained that there are many forms of power. In exploring significant changes in history and the concept of power, he stated that *"since the sixteenth century, a new political form of power has been continuously developing. This new political structure, as everyone knows, is the state"* (Cited in Rabinow, 1984, p.14). Foucault (1979, p.92) also points out that the state apparatus became increasingly concerned with *"governing of a household, souls, children, a province, a convent, a religious order, or a family"* and particular attention was paid to *"how to introduce this meticulous attention of the father towards his family into the management of the state"*. Thus the state started to turn its attention to the family.

Pollock (1983), in examining the development of modern child rearing practices, attributes some of these changes to the state and the economy. In a similar fashion, Jackson (1994, p.79) states that the role of women in the family and in child rearing has been shaped for a purpose:

> *full-time, exclusive motherhood is a relatively recent event, a specific doctrine evolved during the eighteen and nineteen centuries to support the sexual and political economy (patriarchal and capitalist) of the newly industrialised West.*

In Foucault's (1972, p.185) work, *Archaeology of Knowledge*, he speaks of the relationship between the political economy, class and capitalism: *"political economy has a role in capitalist society, that it serves the interests of the bourgeois, that it was made by and for that class, and that it bears the mark of its origins"*.

Foucault (1979, p.92) also links the family unit and the newly emerging political economy by saying that the state is concerned with, *"how to introduce economy - that is to say, the correct manner of managing individuals, goods and wealth within the family"*. In order to support both the political economy and the state, focus was placed on the population.

The state and the political economy needed *"a population that reproduces itself in the proper way, composed of people who marry in the proper way and behave in the proper way, according to precisely determined norms"* (Foucault, 1980d, p.124). Accordingly, *"vast systems"* were put in place which had *"the function of surveillance, normalization and control and, a little later, those of punishment, correction, education and so on"* (Foucault, 1980d, p.121). Foucault (1980d) conceptualized the state as powerful, but not all powerful as the state in order to survive and prosper, relies on other networks. Hence, (Foucault, 1980d, p.122) describes the state as *"superstructural in relation to a whole series of power networks"*.

Foucault (1980d, pp.119 & 122) saw power as positive and productive, however acknowledged *"great negative forms"*, which he called a *"metapower"*. *"Metapower"* is described as *"structured essentially around a certain number of great prohibition functions"* and that it *"can only take hold and secure its footing where it is rooted in a whole series of multiple and indefinite power relations"* (Foucault, 1980d, p.122). Accordingly the concept of *"metapower"* is useful in examining the changes that have occurred in the last one hundred and fifty years. It will be argued that the nation state, the political economy, the middle classes, patriarchy and the child rearing experts formed a *"metapower"* (Foucault, 1980d, p.122) and in doing so, constructed motherhood, the nuclear family and the role of the father in the nuclear family, to meet the needs of modern society.

Manufacturing Nations, the Family and Motherhood

Great Britain

In Great Britain during the nineteenth century poverty, homelessness and delinquent children were recognised as issues which threatened the security of society and the State (Woodroofe, 1974). The State acted to *"intervene in economic activities in order to alleviate the worst stresses and strains of the Industrial Revolution"* (Woodroofe, 1974, p.14). During the nineteenth century, the State had conducted a large number of Royal Commissions and formed committees to examine the growing social problems. As a result, many Acts were passed to regulate the excesses of industry and to improve the conditions of the poor (Woodroofe, 1974). Benevolent Societies to assist the poor proliferated in this time period. In England in 1861, 640 institutions existed to address social need (Woodroofe, 1974). In general, the poverty of the working classes was seen by the middle classes to be linked with individual character not with economic systems. Furthermore, many of the philanthropists responsible for establishing services to the poor and their young saw abandonment, delinquency and criminality as a result of poor parenting. This was despite the fact that *"in the late seventeenth and early eighteenth centuries, the rate of child abandonment in London rose in direct proportion to a sharp increase in bread prices"* (Jackson, 1994, p.89).

In the nineteenth century Carpenter (1851), outlined in her work on *Reformatory Schools for the Children of the Perishing and Dangerous Classes and for Juvenile Offenders* the practical and educative principles required to transform neglected children. Carpenter was clear on the reasons behind homeless or neglected children who created problems for society:

> *The parents being in reality the guilty parties, rather than the children, since juvenile delinquency usually originates in parental neglect, every parent should be chargeable for the maintenance of a child thrown by crime on the care of the state, as much as if the child were at large, and should be held responsible for the maintenance of a child in the Reformatory School, or made in some way to suffer for the non-discharge of this duty* (cited in Heywood, 1959, pp.44-45).

Dr Thomas John Barnardo, a zealous worker involved in the care and reform of homeless children, was convinced of the power of environment and education to produce respecting and productive members of society. He believed that the children of the working classes, if taken away from their parents at an early age, could be trained to be upstanding citizens (Heywood, 1959). Thus, the middle classes were active in not only identifying the social problem - the working classes – they joined with the state to construct their notion of a desirable society which clearly centred around the family unit and the raising of good citizens.

United States of America

In the United States of America, although poverty and destitution were not as severe as in Great Britain, the 1820s and 1830s saw a proliferation of reform associations designed to ensure citizens of moral virtue. Child rearing manuals were written and directed towards mothers not fathers as previously had been the practice. The middle class encouraged the poor through various schemes to adopt the methods of child rearing that they considered being of benefit to the nation and society as a whole (Hays, 1996). Hays (1996, p.29) believes that middle class women in the United States were urged to take on the role of mothering and the domestic sphere as a result of the push towards republicanism and the building of the nation: *these women struggled mightily to demonstrate their capacity to raise virtuous citizens for the new nation"*.

Jackson (1994, p.82) states that in both America and Britain motherhood had been sanctified, *"for the first time, then, in the sex-gendered system introduced by capitalism, the home, family and child rearing became one woman's supposedly God-given and sole responsibility"*. Mothers were seen as the nurturers of future generations and the moral guardians of the new nation. Hays (1996, p.31) states:

> *the middle-class child's successful internalization of the demeanor necessary to his or her future position was thus understood to be wholly dependent on the intensity of the mother-child relationship.*

The middle class of America saw itself as a moral vanguard and a builder of a nation, thus, an example to both the upper and lower classes. The working classes did not

and could not share the newly constructed idea of motherhood. Working class mothers continued to work outside of the home, relying on older siblings and the community of women to provide care for their young. Poverty and necessity were forces behind working class women adopting whatever methods were at their disposal to care for themselves and their families (Hays, 1996).

Australia

In Australia, the development of the modern family and the role of the mother within that family were, to a large degree, orchestrated by individuals from the middle classes and the State (Reiger, 1995; Summers, 1975). In *Dammed Whores and God's Poli*ce, Summers (1975) traces the role of women in White Australia. Summers (1975, p.292) states that *"women's status and their allotted functions were always to be tied to national needs"*. During the time of the penal settlement, women were supplied to men as whores. However, as the role of the new land changed from a far away prison to a promising productive colony, the purpose of women also changed. The emerging nationalism of the 1840s demanded that women play a different role – "God's Police" - who would exert a moral, stabilising influence on the men of the former penal colony and who would mother the coming generation within a middle class framework (Summers, 1975). The role reversal from Whores to God's Police shows clearly that the *"nineteenth century ideologies of feminism, was that good women were synonymous with good mothers"* (Knapman, 1993, p.113).

Summers (1975, p.298) demonstrated that the family unit as espoused by the middle class, *"was to provide a framework for a colony designed to suit the moral, economic, political and religious needs of the rising class of mercantile capitalists"*. Edward Gibbon Wakefield, Caroline Chisholm and John Dunmore Lang focused on the immigration of people who would aid the development of the middle class family within the colonies. They devised and implemented schemes which fostered appropriate family migration and migration of suitable single women (Summers, 1975). It has been suggested that Australia was more able than Britain at the time to develop and realise the family ideal of the middle class as the early and mid nineteenth century in Britain was a difficult place for the working classes, beset by

poverty and the daily grind of industrialisation (Heywood, 1959; Jackson, 1994; Summers, 1975; Woodroofe, 1974).

Although colonial Australia presented challenges to all white immigrants it held some advantages for the working classes: affordable housing, half the infant mortality rate of Britain and significantly higher wages than Britain or the United States (Summers, 1975). Thus, the middle class notion of the family and women's place within the family unit was more saleable to the working classes and could be more readily adopted. Women's place within the family was further cemented by the development of the Trade Union movement. In the 1890s, a large number of working class women were in the workforce: they had limited employment potential, as many trades were the province of men, their wages were often very low and their working conditions were poor. Nevertheless, the burgeoning Trade Union movement in the main ignored the plight of working women and ensured the betterment of men's working conditions and wages (Summers, 1975). In England, the situation was similar, as the Trade Union Congress of 1877, *"passed a resolution that women's place was in the home and man's job was to provide"* (Nye, 1989, p.36). Nye (1989, p.37), in examining the development of socialism states that *"working men, just like middle-class men, demanded reassurance that homes would not break up, and that there would be continuity of family life"*. Thus, in the late nineteenth century, the nuclear family and the mother as the primary care giver, was becoming the ideal in Australia and the other Western industrial nations. State legislation further supported this ideal.

Healthy Nations Need Healthy Children

In the late nineteenth and early twentieth century, nation states passed laws governing child labour, child welfare, the family wage and compulsory schooling (Hays, 1996; Matthews, 1984; Summers, 1975). State intervention into the social, economic and educational aspects of family life supported the *"middle-class moral abstractions"* (Matthews, 1984, p.85) of motherhood. In exploring this development, Matthews (1984, p.84) states,

> *with the entry of legislative prescription and professional surveillance into the*
> *family - of teachers, doctors, nurses, social workers, truancy officers, labour*

inspectors - mothering became more uniform, more circumscribed, more
responsible to external judgement, more amenable to expert advice (as distinct
from experience-based advice from relatives and neighbours).

Expert advice abounded in the health policies adopted by the state.

At the turn of the nineteenth century, in Europe, Britain and Australia, infant mortality was high, birth rates were falling and concerns were being expressed about the ability of citizens to take their place in the building of a nation. The French, concerned about infant mortality and the loss of life in the Franco-Prussian War of 1870-71, established the Infant Welfare Movement (IWM) in the 1890's (Thearle, 1996). In Australia, the New South Wales Government's Royal Commission, which investigated the decline in the birth rate, reported that infant mortality was at the rate of *"116 per 1000 births in 1904"* (Knapman 1993, p.113). Considerable loss of young life in the harsh conditions of rural Australia is clearly outlined in *Young in a Warm Climate: Essays in Queensland Childhood* (Finch, 1996). As a result, Australia followed the French example with the establishment of an infant welfare clinic in Sydney in 1904 (Thearle, 1996). In 1918, a number of Baby Health Clinics were established in Queensland. Growth was rapid, within twenty years nineteen clinics had been established in Brisbane while the country areas were serviced by ninety clinics and a travelling railway clinic (Thearle, 1996).

Infant welfare workers from both the state and charities were active in the first decade. Matthews (1984, p.78) states that *"their task was the education of mothers and the surveillance of their mothering"*. Hygiene and the correct feeding of babies were seen as the key to reducing infant mortality. The Infant Welfare Movement's development was assured as World War I highlighted the need to produce healthy citizens. During the war, men were rejected for military duty because of physical ill health due to diseases contracted in childhood. Of those young men who were accepted for military duty, many were killed in the numerous battles of the War (Thearle, 1996). Reekie (1998), in her work *Measuring Immorality,* explores the early twentieth century views on child mortality. She states that in Australia, health experts were *"convinced that lowering the infant mortality rate and improving*

children's health was the key to both national prosperity and maintaining British supremacy" (1998, p.77). Similarly in England after the First World War,

> *George Bisset-Smith, HM Examiner of Registrations, claimed…that leaders in health matters had recognised that the health of children represented the real wealth of the nation and that the child was the one essential national asset* (Reekie, 1998, p.75).

In America, the state and philanthropic middle class women established health clinics to assist and advise working class women. Mothers and young women were instructed in hygiene and the care of infants through various channels; *"well-baby clinics",* the education systems and publications (Apple, 1987, pp.102 & 103). The state published its own pamphlet *Infant Care*, advising mothers on child rearing practices (Hays, 1996). The physical health of the child was the focus of the State Health initiatives. This is evidenced by this extract from Infant Care:

> *in order to establish good habits in the baby, the mother must first be aware what they are, and then how to induce them. Perhaps the first and most essential habit is that of regularity. This begins at birth, and applies to all physical functions of the baby - eating, sleeping and bowel movements* (cited in Ehrenreich & English, 1979, p.182).

Likewise in Australia, mothercraft, cleanliness, discipline, rigid schedules and feeding routines were advocated to ensure the health and well being of the child (Reiger, 1995). This model of infant care was seen by many as white and middle class, and often not addressing the needs of mothers, especially Aboriginal, migrant and rural women (Knapman, 1993). Even so, in the early years of the last century a close link was perceived between the needs of the nation state and the health of children.

Scientific Motherhood

The quest for healthy children and a robust nation state was assisted by the development of science. It was believed, during the mid to late nineteenth century, that science held the key to a better society. Science promised to improve the care provided in the home, through analysis and the implementation of standards.

Accordingly, science was enlisted to transform motherhood and in doing so bring about the salvation of the human species (Apple, 1987; Ehrenreich & English, 1979; Eyer, 1996; Reiger, 1995). Scientific motherhood as an ideology developed between 1890 and the 1920s and was pursued with great rigour. Expectation was high:

> *scientific motherhood means more than a casual thought can grasp. It means a grander, nobler race, an altruistic humanity which shall fit the earth for the Saviour's advent. It means the reformation of the drunkard, the redemption of the criminal, the repentance of the murderer, the abolition of asylums for the blind, dumb and insane….the elimination of selfishness, the death of oppression, the birth of brotherly love, the uplifting of mankind through true spiritual Christianity* (cited in Ehrenreich & English, 1979, p.180).

Scientific motherhood was embraced by the middle classes and the concept spread through various forms of communication. The ideology was evidenced in women's magazines, publications on childcare, and advertisements to sell products (Apple, 1987). Women were advised on every aspect of childcare and domestic life, such as cooking, budgeting and shopping (Apple, 1987; Eyer 1996). House cleaning became *"a sanitary crusade against 'dangerous enemies within'"* (cited in Eyer, 1996, p.44). In fact, house cleaning *"became a moral responsibility. The woman whose child died of a preventable disease, they warned, would, in the coming 'sanitary millennium' be seen as a murderer!"* (cited in Eyer, 1996, p.44).

The Rise of the Experts

Given the enormity of the task, mothers were seen to be in need of instruction (Ehrenreich & English, 1979; Eyer, 1996; Hays, 1996; Oakley, 1986). Grandmothers and other women were no longer considered to be relevant in providing information to new mothers. Ehrenreich and English (1979, p.187) in examining the development of *The Century of the Child* state that

> *the only way to rationalize and standardize child raising, given that it is carried out in the privacy of individual homes, was to train a battery of experts, skilled in scientific methods, to reach out to all the ignorant and isolated mothers.*

Hays (1996, p.40) in tracing the development of motherhood, asserts it was considered that expert advice was needed to guide *"irrational and emotional"*

women on the best methods of raising children. Ehrenreich and English (1979, pp.189 & 166) view the development of the *"child-raising expert"* to be *"a new source of patriarchal authority"* as the *"child-raising science"* which they developed, was based more on their *"judgements and studies...and less on the experience of mothers"*. Correspondingly, Oakley (1986, p.59) views the rise of the expert as a mechanism for controlling women, *"from the start, women were seen as the key to the whole problem"*. These experts were in the main, medical doctors and psychologists.

The medical profession had developed in earnest from the thirteenth century. Male practitioners in the field of medicine had already eliminated, or were in the process of destroying, women's natural networks and expertise in healing and childbirth. Female wise women and healers accused of witchcraft had been burned during the middle ages and midwives were increasingly coming under attack by the scientifically trained doctor (Ehrenreich & English, 1973). In contrast, psychology was a relatively new science which emerged in the late nineteenth century (Ehrenreich & English, 1979).

Early American psychologist G. Stanley Hall engrossed himself in the new field of scientific child rearing, lecturing and offering advice to middle class mothers. Eyer (1996, p.49), in looking at the middle classes and their mission to educate the poor, noted that in the 1920s the Laura Spelman Rockefeller Memorial Foundation recruited and trained would be child rearing experts as *"the foundation's goal was to promote 'scientific' solutions to social problems, and psychology was to be one of its tools"*. Behavioural psychology emphasised the early part of childhood and believed that *"'all human values, attitudes and personal bonds' could be traced to the earliest period of human development''* (cited in Reekie, 1998, p.153).

The field of psychology developed quickly and planted itself firmly in the realm of child rearing. During the early twentieth century, the behavioural psychologist J.B. Watson was influential in America, espousing a *"restrictive"* (Ehrenreich & English, 1979, p.191) model of rearing children.

Watson thought of human beings as machines that could be raised to benefit the western industrialised society. He advised mothers in relation to their children:

> *let your behavior always be objective and kindly firm. Never hug and kiss them, never let them sit on your lap. If you must, kiss them once on the forehead when they say good night. Shake hands with them in the morning* (cited in Ehrenreich & English, 1979, p.184).

Treating children with warmth and emotion would only ruin the child and greatly vexed Watson. He said *"when I hear a mother say 'Bless its little heart' when it falls down, or stubs its toe, or suffers some other ill, I usually have to walk a block or two to let off steam"* (cited in Ehrenreich & English, 1979, p.185).

Models of Childcare Change

Karen (1998, p.270) notes that the *"restrictive"* model of childcare developed by the behaviourists at the turn of the twentieth century became obsolete very quickly and the *"permissive"* model of child care became the model adopted by the experts. Scientific motherhood, with its emphasis on hygiene and strict discipline, primarily focused on saving the lives of young children and improving the health of the nation. As infant mortality fell, the advice of experts turned from hygiene and feeding scheduling to focusing on behaviour and mental health (Ehrenreich & English, 1979). In a similar vein, Oakley (1986, p.60) reflected that:

> *experts' advice to mothers has shifted over the years between the early decades of this century and now. Then it was on physical aspects of childcare: on the simple mechanistic elimination of 'dirt' from the environment, for example. Now attention is focused on the development of the child's psychology and personality.*

Ehrenreich and English (1979, p.191) believe that the very abrupt change from the *"restrictive"* model to the *"permissive"* model reflected the economic needs of our culture. Karen (1998) reflected that the change was brought about by a number of factors, which included the acceptance of psychoanalytic theory in popular culture, changes in education and the observation by anthropologists of other cultures. In a similar fashion, Jensen and Kingston (1986, p.17) believe that Sigmund Freud's ideas in the thirties and forties were instrumental in heralding the *"permissive"* era. Psychoanalysts like the behaviourists believed that early childhood experiences and

relationships were significant in shaping the individual (Reekie, 1998, p.153*).* However, Ehrenreich and English (1979, p.191) state that the emphasis was now different and *"individualism",* which supported the American capitalist culture, drove the development of the new model: *"the experts who had been concerned with discipline and self-control now discovered that self-indulgence was healthy for the individual personality just as it was good for the entire economy".*

The *"permissive"* model of child rearing gradually became the dominant model in the Industrialised West, even though in Australia it grew and intensified at a different rate (Knapman, 1993).   A clinic sister interviewed by Knapman (1993, p.116) summarised the change in focus:

> *in the new era there is less emphasis on the physical aspects of feeding babies, and more emphasis on the emotional and management side of children. In the forties and fifties we were still fighting for babies' lives in many cases, but by the seventies and eighties the service was all management and behaviour.*

Hays (1996), in examining *"permissive"* child rearing states that *"intensive mothering"* is embedded in the model. Hays (1996, p.21) asserts that

> *intensive mothering… tells us that children are innocent and priceless, that their rearing should be carried out primarily by individual mothers and that it should be centered on children's needs, with methods that are informed by experts, labour-intensive, and costly.*

Hays (1996, p.52) believes that the model developed by experts *"is not a measure of some absolute and timeless truth, but is instead a reflection of a specific cultural model that was constructed socially, over time, under particular circumstances"*. Hays (1996, p.165) broadens her analysis, saying that the development of the *"permissive"* model and *"intensive mothering"* was fashioned by the power of *"interconnected systems",* which includes patriarchy, the wealthy classes, the economy and the state.   Thus, Hays is drawing on the concept of *"metapower"* (Foucault, 1980d, p.122) to explain the construction of a model of childcare which relies on the mother as the primary care giver.

The Expert and Child Rearing Manuals

Experts who espouse the *"permissive"* model of child rearing and the *"intensive"* method of mothering have published numerous manuals to instruct mothers. In response, feminists have analysed child-rearing manuals to demonstrate that motherhood, as defined by experts, is a social and political construct which reveals more about the *"professional images of motherhood"* than *"the experiences of mothers themselves"* (Oakley, 1986, p.74). Marshall (1991) studied seven childcare manuals. Six written by doctors and one by psychologist Penelope Leach. These books were as follows:

- ❖ Pregnancy (Gordon Bourne, 1979)
- ❖ Book of Child Care (Hugh Jolly, 1986)
- ❖ Baby and Child (Penelope Leach, 1988)
- ❖ Pregnancy and Parenthood (National Childbirth Trust, 1987)
- ❖ Dr Spock's Baby and Child Care (Benjamin Spock, 1988, 40th edition)
- ❖ The Mothercare Guide to Child Health (Penny Stanway, 1988)
- ❖ Baby Care Book (Miriam Stoppard, 1983)

Similarly, Hays (1996) examined the three best selling authors of child care manuals in America. The authors in question are Dr Spock, T. Berry Brazelton and Penelope Leach. According to Hays (1996, p.57), motherhood is said to be an *"absorbing experience"* as *"the mother's day-to-day job is, above all, to respond to the child's needs and wants"*. Thus, she is required to be constantly watchful, in tune and sensitive. Marshall's (1991, p.68) analysis is similar, as she asserts that the manuals portray motherhood as *"satisfying and important"*, and suggest *"that not only is childbearing the best way to become properly human, but that having a child for a man is emotionally fulfilling for a women"*. Furthermore, *"the key ingredient of motherhood is love between mother and child"* (Marshall, 1991, p.69).

This view is in direct contrast to the experience of many women. New and David (1985) state that *"depression is so common among mothers of young children that it could be called an occupational hazard"*. New and David (1985) are not implying that motherhood is dangerous to women, they are simply stating that the modern day construct of motherhood can impact on the health of women. Many factors

contribute to depression in women (Brown, Lumley, Small, & Astbury, 1994; Dale & Foster, 1986; Matthews, 1984). Mothers speak of the *"great responsibility"* (New and David, 1985, p.184) and the fact that looking after baby as a sole operator is a relentless task (Brown et al., 1994). Other factors contribute to maternal depression; a child's difficult temperament, boredom, isolation, the lack of status and recognition and financial dependence, to name a few (Brown et al., 1994; Dale & Foster, 1986; New & David, 1985). Hence, the assertion by experts that motherhood is *"satisfying"*, *"important"* and *"fulfilling"* is not the reality for many women (Marshall, 1991, p.68). However this does not prevent the experts from espousing this view and they advise against listening to more experienced women.

Like the experts who had preceded them, the authors of these manuals considered that their expert advice was more valid and valuable than the experiences of older women. In page one of his book, Hugh Jolly is quoted as writing:

> *the modern mother takes for granted that she will have the advice of experts and will not have to rely on the advice of her mother. The previous generation of mothers may not necessarily be the best advisers of the present generation* (cited in Marshall, 1991, p.73).

Gordon Bourne in his introduction, warns mothers about listening to *"old wives' tales, horror stories and unfounded advice"*, presumably from the women around her: her mother, grandmother, aunty, friends (cited in Marshall, 1991, p73). The experts clearly articulate that, *"if a mother is efficient and obeys their advice, then her child's well-being is apparently assured" (*Marshall, 1991, p.74). Hays (1996) found that experts expected mothers to be well informed by referring to material written by them and where necessary to consult professionals in the field of childcare. Hence, at every step, mothers are told how to feel, what is natural and proper for a woman and that the expert's advice is indispensable. Furthermore mothers are given dire warning; *"the responsibility of the mother for monitoring her child's progress is emphasized because it is said to affect the child's future physical, intellectual, emotional and moral development"* (Marshall, 1991, p.80).

Experts and the Role of Fathers

Mothers are held responsible for not only the healthy development of their children, but for the behaviour and involvement of the father. Under the guise of *"sharing the caring"* (Marshall, 1991, p.77), the modern day father is encouraged to participate in the caring for the child. However, as Marshall (1991, p.77) points out, the majority of *"sharing the caring"* is not directed at the physical care of the child, as father's work is seen by the experts as being outside of the home. Mothers are still expected to perform the majority of the care, such as cooking, washing and shopping (Brown et al., 1994). Like Marshall, Hays (1996, pp.56 &55) deduced that fathers are considered to be *"merely extra help",* while the mother is considered to be the natural caregiver, responsible for the child and the *"emotional well-being of all family members"*.

Eyer (1996), writing from an American context, states very plainly that in families where both partners work in full time positions, only 20 percent share the domestic work with their wives. Furthermore, those men resist their share of domestic work, even though failure to share the workload can result in divorce. In Australia, the picture is similar with research in the last 15 years demonstrating that women still perform *"90% of child care tasks and 70 percent of all family work"* (Russell & Bowman, 2000). This unequal distribution of labour occurs regardless of the amount of hours that women work. In other words women working in paid employment outside of the family home are still doing the bulk of the domestic work. The unequal distribution of domestic work is cited as a major contributor to marital conflict (Pocock & Wilson, 2001; Russell & Bowman, 2000).

Hays (1996, p163) summarises the situation well by saying that the *"present-day model of appropriate child rearing"* as espoused by experts in child rearing manuals, *"frees men from having to do the grunt work of looking after the dirty, demanding, dependent beings that are their progeny"* and, more importantly, the *"system helps to ensure that men are spared from women's competition in the labor market"*. Thus, the labour market and men benefit from the double burden that women carry in relation to domestic work and child rearing. This beneficial relationship is supported

and espoused by child rearing experts who seek to prescribe the role of the father as *"merely extra help"* (Hays, 1996, p.56).

This assumes that a partner is present. The manuals studied by Marshall (1991, p.75) are written for and directed at the nuclear family, and families which are not classified as such, are seen *"as aberrations or inherently problematic"*. Hays (1996, pp.162) believes that *"an ideological emphasis on particular family forms and models of child rearing may be implicated in attempts to maintain political stability and state power"*. Thus, it can be shown that experts seek to instruct mothers in their duties and tell them how they should feel about their mothering. Experts also reinforce the role of the father in the family and strengthen the expectation that women will take responsibility for both child care and domestic work. Moreover, they strive to construct the family as a heterosexual, two parent, nuclear family and see other forms as aberrant. Advice from child rearing experts is well accepted in our culture and it can be shown that it has served, and continues to serve the *"metapower"* (Foucault, 1980d, p.122) which dictates how and under what conditions women will mother.

Summary

Before moving on to the analysis of mother blame, this section will be summarised. It has been argued that a *"metapower"* (Foucault, 1980d, p.122) developed in a little over one hundred and fifty years, which prescribed the role of the mother and to a lesser extent, the role of the father within a nuclear family. The *"metapower"* (Foucault, 1980d, p.122) comprised of separate units which shared common interests and colluded to meet structural, group and individuals needs. These included:

- ❖ the state needing healthy citizens to pursue the development of the nation politically and economically;
- ❖ the political economy requiring an unencumbered, preferably male workforce;
- ❖ the middle classes sought to extend their moral authority and create an environment which promoted their interests, socially and economically;
- ❖ patriarchy wanted to ensure that men still held economic and political power;

❖ the child raising experts recognised an opening and carved out their own empires.

MOTHER BLAME

"In the age of 'permissive' child rearing the maternal role was given a new significance: her bonding with the infant was seen as vital and bonding had to be conscientiously worked at on a 24 hour basis from the very moment of delivery. As the importance of the mother's influence increased, so she became more blameworthy" (Knapman, 1993, pp.117 & 118).

It will be argued that holding mothers responsible for their children has a long history. It is a theme that has threaded its way through the child rearing literature during the last one hundred and fifty years. Even so, blaming mothers for their children's mental health problems developed in earnest after the 1930s. Instrumental in this development were psychoanalytic theories of the cause of aberrant behaviour or mental health problems in children. In this chapter, the emergence of mother blame and the absence of father blame will be explored. In particular, examples of mother blame in our recent history will be given to demonstrate that mothers have shouldered society's wrath for producing aberrant or different children.

An Overview

As mentioned in the previous section, in the late nineteenth and early twentieth century, attention was primarily focused on saving the lives of young children and improving the health of the nation (Reekie, 1998). However, holding parents accountable for neglecting their children's moral development can be evidenced in the 1850s (Heywood, 1959). Child rearing experts were also concerned with the mental health of children, as can be demonstrated from a comment by a European doctor at the turn of the twentieth century. Joseph Gerard stated that should a woman fail in her duties as a mother:

she condemns all her issue to horrible ills: incurable diseases such as tuberculosis, epilepsy, cancer and madness; not to mention all the terrible neuroses with which humanity is so cruelly afflicted (cited in Badinter 1981, p.237).

Neurosis was an area that particularly interested Sigmund Freud. In 1897 Freud commented on what he considered to be the development of obsessional neurosis in a girl, deducing that overly strict toilet training had caused the girl's symptoms (Cleverley & Phillips, 1976). Cleverley and Phillips (1976, p.57) remarked that *"Freud's analysis would have forced the girl's mother to consider whether regularity was such a virtue if it was purchased at the expense of future mental disturbance"*. Holding mothers responsible for the development of child behaviour and mental health was neither linear nor uniform across the industrial west. However, blaming mothers intensified after the 1930s depression.

The Overprotective and Rejecting Mother

In the 1940s a number of books were published: *A Generation of Vipers, Their Mother's Sons, Modern Women,* and *Maternal Overprotection* which state that mothers were capable of harming their children's psychological and social development (Eyer, 1996; Hays, 1996; Oakley, 1986, 2002). An extract from Dr David Levy's work, *Maternal Overprotection* (1943), demonstrates that mothers were seen as pivotal to a child's development:

> *it is generally accepted that the most potent of all influences on social behaviour*
> *is derived from the primary social experience with the mother...the most*
> *important study of man (sic) as a human being is a study of his mother's influence*
> *on his early life* (cited in Oakley, 1986, p.65).

In 1943, Levy selected cases from the family guidance centre where he was director to develop his theory of the *"overprotective"* mother (Ehrenreich & English, 1979, p.208). Levy's lack of scientific rigour and his analysis have received criticism, however, the image of the damaging and castrating mother found solid ground. Mothers could be shown to be both *"overprotective"* and *"rejecting"* at the same time (Ehrenreich & English, 1979, pp.208 & 209). Dr Joseph Rheingold of the Harvard Medical School asserted that women were by nature destructive and damaging to children and that their femaleness was the basic problem (Ehrenreich & English, 1979). Oakley (2002) describes these attitudes, in particular, the view espoused by Philip Wylie in *The Generation of Vipers,* as women hating and

reminiscent of the middle age witch hunts. Women, portrayed as flawed and dangerous by some professionals and authors, were in a no-win situation.

Eyer (1996, p.57) points out women could not redeem themselves as *"mothers who devoted themselves according to the experts' advice... were still in danger of harming their children"*. One such example is the conflicting advice of experts in instructing mothers on the management of babies and small children. Experts advised that picking up a child when it cried, would only result in *"a ferocious crybaby"* and mothers were warned *"against spoiling children with too much responsiveness"* (Karen, 1998, p.169). In contrast, a completely different message was given as the expert's views changed over time; *"women were told... infants should be picked up every time they cried. Failing to do so would make them emotionally maladjusted"* (Eyer, 1996, p.57). Thus, while the expert's advice was often contradictory, dire warning of the harm that mothers could inflict upon their children has been consistent. In examining the texts from this time period, it can be seen that the predominant theme that emerges is the role that mothers play in the mental development of the child. This theme, and holding women responsible for all manner of social ills, is repeated over and over again in the literature that has emerged in the last sixty years.

Bowlby – Maternal Deprivation

Mother blame has been assisted by professionals working in the child guidance field. An influential figure after the Second World War was the psychoanalyst, John Bowlby (Karen, 1998). In 1948, the United Nations proposed a study into the needs of homeless children. As a result the World Health Organisation undertook to report on the mental health of the children affected by homelessness, including those growing up in institutions. Accordingly, John Bowlby was appointed to the World Health Organisation in 1950 to undertake this investigation (Bowlby, 1952). Before examining Bowlby's work, it is important to turn to the plight of children living in institutions as this influenced the World Health Organisation's decision to commission a report.

Institutions were not necessarily good places for children. Karen (1998, p15) cites a Spanish bishop who wrote in 1760, *"in the foundling home the child becomes sad and many of them die from sadness"*. In the early twentieth century infant mortality in institutions was high, therefore, much attention was turned to improving nutrition and hygiene. However, the best institutions in America and Europe still recorded a ten percent mortality rate due to the *"failure to thrive...accompanied by what looked like depression and lost hope"* (Karen, 1998, p.19). Rene Spitz, a psychoanalyst and psychiatrist in the United States, brought to the attention of hospital administrators and staff in institutions that children were pining for their mothers. Bowlby followed on from Spitz and a number of others (Karen, 1998) to develop his theory of *"maternal deprivation"* (Bowlby, 1952, p.11).

Bowlby (1952, p.11) theorized that

> *what is believed to be essential for mental health is that the infant and young child should experience a warm, intimate, and continuous relationship with his mother (or permanent mother-substitute) in which both find satisfaction and enjoyment.*

If a child cannot experience this relationship, the child is said to be suffering from *"maternal deprivation"* and the present and future mental health of the child is at risk (Bowlby, 1952, p.11). *"Maternal deprivation"* can be *"partial"* - the child lives with the mother but she can not give the child the attention that she/he needs or *"complete"* - the mother is not present to look after the child (Bowlby, 1952, pp.11-12). A child will suffer *"symptoms of neurosis and instability of character"* (Bowlby, 1952, p.12) to varying degrees if she/he is exposed to *"partial"* or "*complete*" deprivation.

In order to develop his theory, Bowlby spoke to workers from the child welfare field, childcare and child guidance in the United Kingdom, the United States and a number of countries in Europe. The report, compiled by Bowlby (1952) was sourced from professionals who presented:

a) direct studies- observations of children living in institutional care;

b) a retrospective study - investigations of factors leading up to the development of mental illness in adolescents and adults;

c) follow up studies - ascertaining the mental health of children who had previously experienced deprivation.

The majority of the findings were taken from direct observations and were according to Bowlby (1952, p.12) *"neither systematic nor statistically controlled"*. However, *"what each individual piece of work lacks in thoroughness, scientific reliability, or precision is largely made good by the concordance of the whole"* (Bowlby, 1952, p.15). While Bowlby claimed throughout the report the striking degree of consensus that *"maternal deprivation"* is responsible for mental ill health, he did acknowledge different opinions:

> *there is a curious resistance to accepting it. Indeed, there are still psychiatrists in all countries who challenge these conclusions, though it is to be remarked that few of them have had training in child psychiatry or experience of work in a child-guidance clinic* (Bowlby, 1952, p.46).

One source of contradiction was German psychiatrists who theorised that *"constitutional and inherited factors"* were responsible for mental illness (Bowlby, 1952, p.13). Indeed, Bowlby had access to three follow-up studies, which did not support his theory of *"maternal deprivation"* being responsible for mental illness or mental instability. However, Bowlby (1952, p.15) stated that these studies were of *"a quality which bears no comparison with that of the research the conclusions of which they challenge"*.

The Bowlby Legacy

Regardless of studies and theories which contradicted his hypothesis, and criticisms from fellow psychoanalysts (Karen, 1998), Bowlby's work was read by many, as evidenced by the extensive publication of his report. The expectation placed on mothers was considerable:

> *it should be remembered, too, that continuity is necessary for the growth of a mother. Just as baby needs to feel that he belongs to his mother, the mother needs to feel that she belongs to her child and it is only when she has the satisfaction of this feeling that it is easy for her to devote herself to him. The provision of constant attention day and night, seven days a week and 365 in the year, is possible only for a woman who derives profound satisfaction from seeing*

her child grow from babyhood, through the many phases of childhood, to become an independent man or woman, and knows that it is her care which has made this possible (Bowlby, 1952, p.67).

If a mother did not enjoy providing *"constant attention day and night, seven days a week and 365 in the year"* the child's mental well being was said to be in danger.

In a similar vein, Winnicott (2001), a psychoanalytic paediatrician, also believed that mothers lay the foundations for mental health: *"we are only just beginning to realize how absolutely the newborn infant needs the love of the mother"* (cited in Badinter, 1981, p.276*).* Winnicott was a popular figure in Britain and he instructed mothers through numerous publications and BBC radio (Badinter, 1981). His message was clear:

> *enjoy being thought important. Enjoy letting other people look after the world while you are producing a new one of its members. … Enjoy being annoyed when the baby's cries and yells prevent acceptance of the milk that you long to be generous with. Enjoy all sorts of womanly feelings that you cannot even begin to explain to a man. … Enjoy all this particularly because any pleasure you can derive from the messy business of infant care happens to be vitally important from the baby's point of view* (cited in Badinter, 1981, p.276).

In contrast, Bowlby did not instruct mothers through radio or publications. However his work was extremely influential and had far reaching consequences in a number of areas of child health (Karen, 1998). Changes to the way in which institutions were run must surely have saved a number of children's lives and reduced a great deal of trauma. Karen (1998, p.65) summarised the influence of his *"maternal deprivation"* theory by saying:

> *the impact of the World Health report can barely be overstated. Most immediate was the effect on public policy, particularly adoption, social work, and hospital practices world wide…It caused new thinking about the causes and prevention of delinquency and the training of young women for motherhood…and it made Bowlby a household name in Britain and a champion of child care workers in many parts of the globe.*

Bowlby also made changes to therapeutic interventions. Bowlby was one of the first psychiatrists to be employed in child guidance clinics in England. At the London Child Guidance Clinic at Canonbury in 1936, Bowlby encountered two social workers who put their psychoanalytical training into practice:

> *Lowden and Fairburn introduced Bowlby to the idea that unresolved conflicts from the parents' own childhoods were responsible for the hostile and deficient ways in which they sometimes treated their children. As a result, the social workers gave therapeutic attention to the mothers as well as the children, a process that struck Bowlby as immensely sensible* (Karen, 1998, p34).

So sensible in fact, that when he started work at the Tavistock Clinic in London in 1946, *"he immediately instituted therapy with both children and parents and pioneered seeing whole families together"* (Karen, 1998, p.71).

Indeed Bowlby believed that to ensure the child's mental health and safeguard his development, the mother must be re-educated: *"parent treatment is an essential part of child guidance"* (Bowlby, 1952, p.71). Thus, it was considered that the mother's problem stems from her-non acceptance of her role as mother. Indeed, some of these problem mothers where unable to be educated in taking on their proper role as mothers. Bowlby (1952, p.77) lamented that the *"ineducability and instability of character"* of the mother, rendered a family unit dysfunctional. Furthermore the detection of deprived children and therapeutic intervention centring on the parents was seen as essential for the good of society (Ehrenreich & English, 1979; Karen, 1998).

The Theoretical Foundations of Mother Blame

Bowlby's (1952, p.11) work went beyond *"maternal deprivation"* theory. Bowlby was instrumental in formally introducing the term *"attachment"* (Karen, 1998, p.90) which refers to the special relationship between mother and child. Bowlby was influenced by the work of Konrad Lorenz, an ethnologist who wrote on imprinting (Eyer, 1996; Karen, 1998), and Harry Harlow, who experimented on monkeys (Eyer, 1996; Karen, 1998; Osmond & Darlington, 2001). Bowlby, drawing on these examples, explored the ways in which infants encourage attachment to their mother and how these attachments can be disrupted or damaged. Eyer (1996, p.80) states

that *"attachment, according to the orthodoxy, is formed essentially by responding to the infant's needs in a sensitive and appropriate manner"* and that it is through this attachment the child will go on to form other healthy relationships. Bowlby hypothesised that disruption of attachment with the mother resulted in mental or emotional disturbances in the child (Karen, 1998).

Mary Ainsworth greatly admired John Bowlby and became one of his research assistants (Karen, 1998). Ainsworth developed Bowlby's attachment theories further while working in Uganda. It was here that she devised the Strange Situation Test to assess how attached infants were to their mothers. Allan Sroufe, a developmental psychologist, was impressed with Ainsworth's work on attachment theory and pursued it with rigour, becoming involved in studies in Minnesota in the 1970s through to the 1990s. Attachment theorists have continued to expand on the theory through research (Karen, 1998). Attachment theories and the Strange Situation Test are still in evidence today and are embedded in practice (Howe, 1995; Howe, Brandon, Hinings, & Schofield, 1999; Karen, 1998; Osmond & Darlington, 2001)

Aberrant Children

In the last thirty years mothers have been blamed for a diverse range of social problems and the creation of aberrant children (Ehrenreich & English, 1979; Eyer, 1996). Delinquency, deviance, autism and schizophrenia, to name a few, have been associated with bad mothering (Allan, 2004; Ehrenreich & English, 1979; Eyer, 1996; Singh, 2004; Stout & Mcphail, 1998). For the purposes of this thesis it is useful to examine the way in which psychoanalytic theories and the concept of the *"overprotective"* and *"rejecting"* (Ehrenreich & English, 1979, pp.208 & 209) mother have been used to blame mothers for producing children with schizophrenia and autism and to explore the emergence of attachment theory to explain ADD.

Schizophrenia

Anne Deveson (1991), in her book *Tell me I'm here*, tells of her own experience of having a son who ends his life and his battle with schizophrenia. Some of the professionals that Deveson spoke to told her that schizophrenia did not exist while others located her son's problem by explaining that early childhood experiences

caused schizophrenia and that her son's behaviour was due to his feeling of rejection. Deveson, like the mothers in Levy's studies in the 1940s, was accused of being both *"overprotective"* and *"rejecting"* (Ehrenreich & English, 1979, pp.208 & 209) at the same time. After one incident, when her son was hospitalised, a social worker spoke to Deveson (1991, p.90) saying, *"I know you are a very busy woman, but try to love your son"*. In contrast, another professional suggested that she had smothered her son. Yet another thought that she was a *"noxious parent"* (Deveson, 1991, p.33). In the mid 1980s, at an International Symposium of Schizophrenia in the United States, Deveson (1991, p.204) listened to a professional who *"claimed he had traced the illness to the suffocating attention of mothers who, by living through their children, prevented them from developing a separate identity"*. Thus, he described the "schizophrenogenic *mothers*" as *"domineering, over-protective, over-involved and hostile"* (Deveson, 1991, p.204).

Autism

A similar portrait has been painted of the mother with autistic children. During the Second World War, Leo Kanner in the United States and Hans Asperger in Austria presented clinical studies describing autism in children (Baird, 2000). The *"maternal rejection syndrome",* which arose primarily in the 1940s was considered to be a catalyst for autism (Hays, 1996, p.48). In the 1950s Louise Despert and Margaret Ribble described the mother who was capable of producing a child with autism:

> *this young woman was compulsive, perfectionistic, narcissistic, immature, frigid, emotionally detached, frightened by body contact, lacking in sensuousness, and capable of functioning satisfactorily only on an intellectual level. Her first child was a clear-cut case of early infantile autism* (cited in Albury, 1993, p.313).

Parent blame was still a feature in the 1970s, as can be seen from these remarks:

> *all reports agree that he is usually the child of intelligent but rigid and undemonstrative parents who may not comprehend the special needs of babies and who may even find it distasteful to minister to so messy a creature as a young baby – or perhaps only this particular baby* (Stone & Church, 1973, p.512).

In the 1980s, the mothers of children with autism were labelled *"neurotic"* when they sought out professional assistance for their children (Baird, 2000).

In the twenty first century most mainstream professionals working in mental health or child welfare would hesitate to suggest that mothers, due to their poor parenting or cold and rejecting nature cause schizophrenia or autism. However there are strong contingents, who draw on attachment theories and strained early care giving to explain the development of ADD in children.

Attention Deficit Disorder

In his 1970s studies, Allan Sroufe, the attachment theorist, identified children who were suffering from damaged *"attachment"* (Karen, 1998, p.90). Some of these children he described as *"the fidgety, impulsive child with poor concentration who is tense and easily upset by failures"* (Karen, 1998, p.186). He went on to say, *"whenever I see a teacher who looks as if she wants to pick a kid up by the shoulders and stuff him in the trash barrel, I know that kid had an avoidant attachment history"* (Cited in Karen, 1998, p187). Sroufe's description is very similar to the descriptions of children with ADD found in the works of Serfontein (1990), Green and Chee (1994), Nash (1994), Dengate (1994) and Polis (2001). Thus, the children he identified in the 70s as having damaged or avoidant attachment histories may today attract a diagnosis of ADD.

Attachment theory is considered by Sandberg (1996, p.14) in discussing hyperactivity in children:

> *the association between disrupted parenting and persistent hyperactivity may*
> *apply especially when the early core attachment relationships have been severely*
> *disrupted, suggesting a sensitive period during which certain cognitive and*
> *social skills are acquired.*

Newman (1996, p.107) a paediatrician working in child health in Australia, also believes that ADD may be a *"metaphor"* for disrupted attachments. More recently, psychologists have stated that there is an *"association between attachment insecurity and ADHD"* and that attachment theory has much to offer in the understanding of ADD and its treatment (Clarke, Ungerer, Chahoud, Johnson, & Stiefel, 2002, p.181).

In 2001, the University of Queensland was commissioned by the Department of Families to produce an information sheet outlining attachment theory and its relevance to child protection: *"given the importance of attachment to healthy psychological and physical functioning, assessment of attachment is vital in child protection work"* (Osmond & Darlington, 2001, p.13). Secure attachment is seen to be essential to the development of the child. If, as a baby, you don't form a secure attachment:

> *you are much more likely to be an irritable baby, a difficult toddler, to have*
> *delayed cognitive development, poor school performance, and low self esteem.*
> *You have major difficulties with peer relations, are likely to be seen as a*
> *troublemaker at school or be a bully...likely to be labelled as having*
> *ADHD...Risk taking behaviour begins earlier than most and you are more likely*
> *to experiment with sex, drugs and alcohol early. You are much more likely to*
> *learn depression early, and you are over-represented among youth suicides*
> (Cited in Osmond & Darlington, 2001, p.11).

It appears that workers in the Department of Families are being encouraged to consider that all of the above, from being a difficult toddler through to ADHD and youth suicide, is due to poor attachment.

In closing, Osmond and Darlington cite other works which urge practitioners to *"remain clear about the limits of the knowledge base"* (cited in Osmond & Darlington, 2001, p.21). They go to say that *"it is essential that attachment theory remain value neutral so that it does not become an excuse for punishing victims or their families"* (cited in Osmond & Darlington, 2001, p.21). However, Osmond and Darlington have already recommended psychotherapy for the caregiver, assumed to be the mother, so that she can examine her own history of attachment and any personal issues that she may have which may impact on her mothering. Education and change is also recommended so that the mother can care for her children more responsively and sensitively (Osmond & Darlington, 2001). These recommendations have a familiar ring and are reworked ideas from Bowlby and the psychoanalytical era. The way in which attachment theory is used to understand ADD in children and

the way in which mothers of children with ADD are viewed will be further explored in the coming chapters.

The Role of the Father

In viewing the literature, it can be seen that mothers shoulder the responsibility for producing aberrant children (Badinter, 1981; Ehrenreich & English, 1979; Eyer, 1992, 1996; New & David, 1985). Thus, the question arises what role do fathers play in the development of children? Bowlby (1952, p.13) clearly stated that the emphasis was on the mother not the father as *"all the evidence concerns the child's relation to his mother"* and that *"little will be said of the father-child relation; his value as the economic and emotional support of the mother will be assumed"*. However, Winnicott (1964, p.116) believed that the assumed or invisible father did have a role to play, *"one of the things that father does for his children is to be alive and to stay alive during the children's early years"*. Indeed, it was recognised that the father may be disinterested or reluctant to play a part in the child's life. If this was the case, Winnicott (1964, p.118) urged mothers on the BBC radio to set up a situation or situations where the father could develop a relationship with his children: *"I should say that it is mother's responsibility to send father and daughter, or father and son, out together for an expedition every now and again"*. Thus mothers were required to enjoy total absorption in the child rearing process and to accept responsibility for their husband's involvement in family life.

Bowlby and the influential anthropologist Bronislaw Malinowski wrote much about the relationship between mother and child, seeing the father as important, but playing a support role (Reekie, 1998). Both Bowlby and Malinowski saw fathers more as a *"helpmate"* (Reekie, 1998, p.155) while it was the mothers who were ultimately held responsible for raising the children. According to Karen (1998, p.105) Bowlby maintained this view throughout his life.

Malinowski, in his work on family structure, parenthood and kinship, puts forward the view that fathers were essential to the family, not as care givers but for maintaining culture (Reekie, 1998). Reekie (1998, p.155), in examining Malinowski's work, points out that Malinowski was rather *"vague"* in describing

how fathers maintain culture. However, some insight can be gained by examining the earlier works cited in this chapter. In *Their Mothers' Sons* and *Maternal Overprotection*, too much mothering put boys in danger of being damaged, which in some instances meant unfit or unsuited for military duty (Hays, 1996). The theme of too much mothering and the need for boys to be boys, with the guidance of fathers, is again repeated in the literature in the 1970s (Edge, 1971) and the 1990s (Biddulph, 1997).

Reekie (1998, p.144) describes how Malinowski's notion of maintaining culture has been taken up by present day conservatives, who claim that it *"is not just that children benefit from the presence of a father, but that they need a father in order to become a fully functioning, mature, happy and well-adjusted adult"*. In citing an Australian example, the ex-director of the Australian Institute of Family Studies stated that *"every child, boy or girl, needs parents of both sexes to learn about the human race and society"* (cited in Reekie, 1998, p143). Reekie (1998, p,142) asserts that in the United Kingdom, the United States of America and in Australia, numerous research studies have attempted to show that social ills, from mental health issues through to teenage pregnancy and family dysfunction are directly related to the absence of the father. This is not to be confused with blaming the father; the research is primarily concerned with demonstrating the ills and dangers of fatherless families. In a similar vein, Eyer (1996) believes that the main purpose of research in relation to fathering, centres on maintaining the authority of the father within the family, and the role that the father plays in making boys into men. Thus research has primarily been concerned with demonstrating the importance of fathers in maintaining the nuclear family, which is seen by many as paramount (Eyer, 1996).

The Politics of Fatherhood

As previously stated in this chapter, encouraging fathers to become involved and building a case as to their importance in raising well adjusted children, while not requiring them to be directly involved in the care of their child, serves to strengthen the nuclear family and enforce the role of the father (Eyer, 1996). In other words, fathers are required to maintain the status quo.

Wearing (1984, p.23) writing twenty years ago, expressed a similar idea:

> *through the ideology of motherhood, men are relieved of the obligation to take*
> *care of children and are in a position to perpetuate this ideology and the aspects*
> *of it which also legitimate their relative freedom from other domestic*
> *responsibilities.*

Bowlby and Malinowski are a good example of Wearing's statement. Both men were supported by their wives' efforts to bring up their children i.e. their wives were the primary care givers, as both men either worked away from home, or were heavily involved in their work. Malinowski's daughter reflected in 1984 that, although her father wrote *"so much about the family unit, he was never quite comfortable with fatherhood and wasn't really a family man" (*Reekie, 1998, p149). Robert Karen (1998, p.105) described Bowlby as *"a non-stop worker himself, whose work was his life, and whose rare displays of temper were occasioned by the intrusions of his children"*. They and society may have considered them to be good fathers, in that they supported their wives in their role as mother but they were not involved fathers. While both men can be seen as products of their time, it is interesting to note that as fathers, they were distant from their children, emotionally and/or physically. This distance is in direct contrast to Bowlby's (1952) insistence that mothers needed to be totally absorbed by their children and that they administer care 365 days of the year. It is also in contrast to Patricia Edge's (1971) insistence that mothers be super patient and tolerant. The ideology of the family, in particular the role of the mother and the father which Bowlby and Maloniwski peddled, not only supported the worldview of the *"metapower"* (Foucault, 1980d, p.122) as discussed earlier in this chapter, it benefited them personally in that they were free to pursue their very successful careers.

Father Blame Versus Mother Blame

In completing this brief section on Fatherhood, it is illuminating to compare and contrast father blame and mother blame. Stout and McPhail (1998, p.53) cite research which reported that

> *they found 72 different types of pathology attributed to mothers, ranging from*
> *arson and depression to incest and phobias. The child's pathology was*

attributed, at least in part, to the mother's activity in 82% of the articles and to

the mother's inactivity in 43%, contrasted to the father's activity in 43% and the

father's inactivity in 39% of the articles

Stout and McPhail (1998, p.53) comment on the double standards that operate in relation to blame: *"women are blamed not only for their own psychopathology, but for inflicting it on others as well"* and that terms and labels have been assigned to them which reflect this psychopathology. In contrast, fathers are not labelled in the same way. Eyer (1996, p.149), in summing up the lack of father blame in the research literature states:

the lack of father blame, it must be pointed out, is once again facilitated by our

favourite voices of authority –child psychologists and pediatricians, who have

failed to view father's personal involvement as central to their children's

development.

Clearly, holding fathers accountable for their children's behaviour or safety is not an important issue for many child rearing experts. In contrast professionals have developed theories in which they seek to demonstrate that mothers are responsible for any maladjustment or deviance in their children.

Feminist Critique of Attachment Theories

A number of feminist writers have criticised psychoanalytical and attachment theories and the way in which they are used to pathologise and blame mothers (Ehrenreich & English, 1979; Eyer, 1992, 1996; New & David, 1985). Both Karen (1998) and Rutter (1972) believe that Bowlby's work was exaggerated and taken out of context. However, it can be argued that his original text (Bowlby, 1952) is clear and that mothers and professionals working in the child welfare field understood his message. Mothers took to heart his advice and many felt guilty leaving their children alone, for even a short period of time, in case they damaged their child (Karen, 1998). Almost thirty years after the publication of *Maternal Care and Mental Health,* Badinter (1981, p.261) stated:

a fair number of psychoanalysts today recommend that mothers whose children

have problems undergo analysis themselves, the essential idea being that treating

the child will be futile if one does not attack, at the same time, the root of the evil

- the mother's problems.

In looking at *"attachment"* Eyer (1996, p70) states:

> *the general concept of attachment is an important one. It is this: Infants are very social creatures; they can distinguish people from one another, and they need to have loving, consistent relationships if they are to thrive. Infants and young children require loving, consistent caregivers. But the distance between this fact and the increasingly distorted doctrines of attachment (and bonding) is interplanetary. Attachment doctrine is so convoluted that virtually every mother is guilty of attachment "crimes", if the experts are to be believed.*

New and David (1985, pp.166 & 167), while expressing the value of some aspects of the theory, such as *"physical contact and closeness",* state that Bowlby and Ainsworth go way beyond their own evidence, when they try to use the findings of attachment theory to argue that the nuclear family, with mother as full-time carer, is the natural grouping for human beings. Eyer (1996), in examining the later work of Bowlby and Ainsworth's *Strange Situation Test,* demonstrates that the theories of *"attachment"* can be interpreted in a number of ways and that scientific rigour is lacking. Correspondingly*,* the bonding theories of John Kennell and Marshall Klaus developed in the 1970s are not proven. However, these theories are used by child rearing experts to instruct and warn mothers: *"the high rate of violent crimes in our society may be related, in part, to the infrequency of close contact between babies and mothers"* (Cited in Eyer, 1996, p.87). The question to be asked, given this criticism, is what purpose do attachment theories serve in the industrial west?

The Blaming of Mothers

Gerald Schoenewolf, a New York analyst, considers blaming mothers and pressuring them to accept responsibility is a good thing. In responding to the concept of different temperament, which counters attachment theory, he exclaimed:

> *to attribute failure to a bad fit is to absolve mothers of responsibility and blame. In doing this... [we] are bowing to a feminist trend of the 1970s and 1980s, a trend that in my opinion has been quite destructive to child rearing* (cited in Karen, 1998, p.288).

Brown, Lumley, Small and Astbury (1994) have pointed out that the motherhood discourse is so powerful that problems relating to the care of children or the children themselves are seen as stemming from the mother. Swift (1995) and Matthews (1984) have examined the way in which mothers have been constructed as either *"bad"* (Swift, 1995) or *"mad"* (Matthews, 1984) when they fail the test of motherhood.

In her book, *Mother-Infant Bonding,* Eyer (1992, pp.47 & 15) argues that the theories of *"maternal deprivation", "attachment"* and *"bonding"* have their foundation in psychoanalysis and are utilised by conservative forces to support their values. In *Mother Guilt,* Eyer (1996) goes further and states that attachment and bonding theories are used by child rearing experts to blame mothers. Clearly, feminist writers like Eyer, believe that attachment theories have been used to blame women and to reinforce the ideology of motherhood and the nuclear family. Other feminist writers believe that psychoanalytical theories are a form of *"social control and dangerous to women's mental health"* (Roth Walsh, 1987, p.20) and that psychoanalytical theories are founded on the assumption that women are inherently inferior beings (Lerman, 1987).

Some feminist authors have argued that blaming mothers, by holding them solely responsible for the well being of their children, is a form of violence which is perpetuated by the state and professionals (Irwin & Thorpe, 1996; Thorpe, 1996). Accordingly, it can be argued that mother blame operates to control and punish women who have failed to perform as good mothers, mothers who have failed to produce a good family and the good child.

Summary

In summary, mother blame while not new, found a footing after the Second World War. Psychoanalysts such as Bowlby, Winnicott, Ainsworth and numerous others, secured their positions in the field of child rearing theory espousing such views. Historically, attachment theories have been used to blame the mothers of autistic children and people suffering from schizophrenia.

Feminists have argued that, while attachment theories have some value, they have been used far beyond their scientific merit and have served to:

- ❖ support conservative views of the nuclear family;
- ❖ maintain the status quo of fathers within the nuclear family;
- ❖ blame the mothers of children who developed mental illnesses, disorders or have a perceived weakness.

It has been demonstrated through examples and drawing on the analysis of feminists that mother blame acts as a form of social control to punish women who have produced aberrant children.

CONCLUSION

In concluding this chapter, it can be seen that the construction of motherhood, the prescribed way in which women mother within the nuclear family and the lack of practical support by fathers, has profound implications for mothers in our society. It has been argued that the construct of motherhood is far from natural and has been shaped to suit the needs of many powerful forces, which include the nation state, patriarchy, capitalism, the middle classes and the child rearing expert. It has been shown that when women fail the test of motherhood, in that they produce children who are different, they are held responsible for their child's difference. This examination of motherhood and mother blame will lay the foundation to both the literature review on Attention Deficit Disorder (ADD), which follows this chapter, and the stories of the mothers of children with ADD which will be presented in the data analysis.

CHAPTER TWO - GENEALOGY OF ATTENTION DEFICIT DISORDER AND THE FORMATION OF DISCOURSE

Introduction

In this chapter the formation of the discourse concerning Attention Deficit Disorder (ADD) will be explored using Foucault's concept of *"genealogy"*. It will be argued that conflict within the discourse is in effect a struggle over power and knowledge as psychoanalytical and behavioural theories are aligned against genetic and biological theories. Within the broader field of psychiatry the two ideologically opposed camps have fought other battles, in particular Schizophrenia and Autism. As the battle for professional power is lost by some professionals, their focus and theoretical perspective is transferred to other discourses which seek to explain difference or deviance in our society. A generally accepted portrait of Attention Deficit Disorder, in accordance with the *American Psychiatric Association's Diagnostic and Statistical Manual* (DSM-IV), will be given before moving on to the formation of the discourse.

American Psychiatric Association's Diagnostic and Statistical Manual (DSM-IV)

The criteria for the diagnosis of Attention Deficit Disorder (ADD), Attention Deficit Hyperactivity Disorder (ADHD) and co-morbidities associated with ADD, are outlined in the *American Psychiatric Association's Diagnostic and Statistical Manual* (DSM-IV) (1994). The Australian National Health Medical Research Council (1997) recommends that a number of other assessments be used in conjunction with the DSM-IV before a diagnosis of ADD/ADHD is determined.

Portrait of Attention Deficit Disorder

Attention Deficit Disorder (ADD) and Attention Deficit Hyperactivity Disorder (ADHD) are said to result "*from a subtle difference in the fine tuning of the brain*" (Green & Chee, 1994, p.19). Recent research supports the claim that there are differences in the brain function of people with ADD and ADHD compared with the non-ADD/ADHD population (Barry, 2004; Frieman, 2001).

Dr Nash (1994, p.35) outlines the differences between ADD (ADD(-H)) and ADHD (ADD(+H)):

- ❖ *they differ in terms of their behaviour and patterns and profiles*
- ❖ *their temperaments are quite different*
- ❖ *the areas of the brain involved are probably different. Research suggests that children with ADD(+H) have a functional problem in the front area of the brain, whereas the area involved in ADD(-H) is located further back in the brain*
- ❖ *there is probably a difference in the type of chemical messengers involved in each type of ADD. It is proposed that there is a reduced supply of dopamine in the affected brain cells in children with ADD(+H). In children with ADD(-H), there is less availability of a different chemical messenger, noradrenaline.*

ADD is currently being conceptualized as a deficit of executive functioning (Barkley, 2003). Dr. William R. Stixrud, (cited in Eberle, 2003, p.1) at the Independent Educational Consultant Association conference described executive functioning as being responsible for *"goal-directed behavior"* which is needed for *"planning, organisational skill, maintaining a mental set, selective attention, and inhibitory control - for which the prefrontal regions of the brain are specialized"*. Dr Stixrud (cited in Eberle, 2003, p.2) also stated that problems with executive functioning *"are responsible for a variety of learning disabilities in reading, writing, math skills and content area learning"*. Accordingly some professions are starting to conceptualize ADD as a disorder that affects a person's ability to learn (Tannock, 2004).

Barkley (cited in Eberle, 2003, p.2) argues that the main problem for people affected by ADD *"is in the inability to self-regulate, or, inhibit behavior by delaying one's response"*. Barkley (2001c) believes that children with ADD know what to do and what is required of them but they can not always delay their impulsivity or display appropriate behaviour, therefore ADD is more an intention deficit as opposed to an attention deficit.

Predominantly, ADHD has been seen as a disorder affecting boys more than girls (NHMRC, 1997). It has (Estronaut, 2004; Solden, 1995) been suggested that females are not diagnosed as they tend to be less aggressive and not come to the attention of professionals: *"for years and years, we've been focusing on the hyperactive, behaviour-disordered little boy who might be restless and fidgety and acting out"* (cited in Weekender, 2002, p.44). Girls, if diagnosed, usually present as having ADD which is not as well researched as ADHD (Arnold, 1996; NHMRC, 1997). Some people have suggested that ADD may not be gender specific (Hartmann, 1999) . Indeed some people believe that there is a *"'gender gap' in the detection of ADHD"* (cited in Weekender, 2002, p.44). Thus, boys are diagnosed while girls are undiagnosed.

Co-morbidity

A number of studies have found ADHD to be co-morbid with Oppositional Defiance Disorder, Conduct Disorder and learning disabilities (Lewis, 2001, p.89; NHMRC, 1997, p.16-17). In contrast there *"is more subtle language impairment related to learning disabilities and more co-morbid anxiety and depression"* found in ADD (NHRMC, 1997, p.46). Other conditions such as, Asperger's Syndrome, Fragile X and Tourettes Syndrome can also be co-morbid with ADD/ADHD (Attwood, 1998; Pauls, Fredine, Lynch, Hurst, & Alsobrook, 2001; Zametkin, Ernst, & Cohen, 2001).

"Who are the Different Kids"?

Dengate (1994, Who are the Different Kids?) characterises both the ADD and ADHD child:

> *These are the children who look like the others but never quite fit in. The babies who don't sleep much become the toddlers who are 'into everything', and then become the kids who have trouble learning to read. Others may be good sleepers and good readers, but have problems with their co-ordination in ball games and suffer from temper outbursts. At home or at school, these children can't remember where they left their belongings or what they were told to do. Some can't sit still, others are withdrawn. In the classroom they may be dreamers or class clowns, 'too quiet' or loud and violent. Many have problems making friends and, later on, finding the right job.*

Aust (1994, p.218) paints a vivid picture of an ADHD child:

AD(H)D children are difficult to rear. As young children, they frequently experience excessive bedwetting, sleep problems, temper tantrums, and stubbornness. They are also considerably more accident-prone and more likely to sustain serious injury or accidental poisoning that the normal pediatric population.

Aust (1994, p.218) outlines some of the difficulties that both ADD and ADHD adolescents may experience as they:

tend to begin alcohol and substance abuse at younger ages and they abuse more dangerous drugs than the non-AD(H)D population. They also have more car accidents, make more suicidal gestures (girls), experience more problems with the law (boys), and have more relationship problems than their non-AD(H)D peers.

The pages of Ben Polis' (2001) book, *Only a mother could love him,* provide testimony to the situations that some ADHD boys create and the consequences for their parents. While on Easter holidays at a caravan park in 1990, his father and his father's friends went skin diving with spear guns to catch fish. Upon their return to the holiday camp, Ben (Polis, 2001, p.32 & 33) said

I grabbed my dad's Hawaiian sling [2 metre long barbed spear gun] *to show cousin Lachlan how it worked, shooting it vertically about ten metres high into the air. I repeated this a number of times, until a strong gust of wind blew the spear onto the power lines. It created a short circuit between the two wires. This happened all in a blink of an eye. The power pole that Lachlan and I were standing under exploded with sparks flying everywhere. It looked like a bad day in Bosnia. The current then flowed through all the other poles, blowing them up, one after the other in a big circle around the caravan park. Every power line connected between the poles fell to the ground, just missing tents, and caravans…I don't know how it was that no-one was killed or injured.*

A repair team was called in to repair the damage and they asked Ben's (Polis, 2001, p.34) father

"Do you know who did this? Now before you answer this I am telling you the repair bill for the damage is around $13,000 and if the parents of the boy who did this had any sense they would pack up immediately and leave the park. Do you know what I mean"?.

Ben (Polis, 2001, p.34) remarks that *"My father may be honest, but he is not stupid. And that's what we did and we have never gone back".* These descriptions provide an overall picture of the children, in particular boys who are deemed to be different.

GENEALOGY – EXPLORING THE PAST AND PRESENT

The history of ADD is complex and has only recently been researched from a community or welfare perspective. In order to analyse the development of knowledge, *"genealogy"* will be used as defined by Nietzsche and Foucault (1984b, p.76) as a tool to explain and make sense of the last one hundred years. Unlike the traditional historical analysis, *"genealogy"* is not linear and does not stress unity of thought (Foucault, 1984b, p.76):

Genealogy... begins with the present and goes backward in time until a difference is located....tracing the transformation and taking care to preserve the discontinuities as well as the connections (Sarup, 1988, p.63).

Thus, the concept is particularly useful in exploring the many different branches and dead ends, of the ADD knowledge tree.

1890-1902 - The First Descriptions of Attention Deficit Disorder

In using Foucault's (1984b) concept of genealogy, we can trace back to the late nineteenth and early twentieth century and locate the first description of children who today would very likely attract a diagnosis of ADD. William James, seen by some as the father of modern psychology referred to the symptoms of ADHD in *Principles of Psychology,* published in 1890,

there is a normal type of character, for example, in which impulses seem to discharge so promptly into movements that inhibitions get no time to arise.

These are the 'dare-devil' and 'mercurial' temperaments, overflowing with animation, and fizzling with talk (cited in Holowenko, 1999, opening quotation)

The first descriptions of the characteristics that we know as ADD by medical practitioners occurred during the same time period (Barkley, 1990). George Still and Alfred Tredgold are credited with *"being the first to focus serious medical attention on the behavioural condition in children that most closely approximates what is today known as ADHD"* (Barkley, 1990, p.4). Still referred to these children as having a *"an abnormal defect of moral control"* and believed that attention needed to be paid to these children *"for the good of society"* (cited in ADDAQ, 2004, pp.1 & 3).

Still presented a number of lectures to the Royal College of Physicians in 1902 during which he described*:*

> *20 children in his clinical practice who were often aggressive, defiant, and resistant to discipline; were excessively emotional or 'passionate'; and showed little 'inhibitory volition'. 'Lawlessness', spitefulness and cruelty, and dishonesty were associated with this disorder. Most of these children were impaired in attention and were quite overactive* (cited in Barkley, 1990, p.4).

He claimed that:

- ❖ males presented with these characteristics in a ratio of 3:1 to females,
- ❖ the characteristics, for example, hyperactivity, were assessed as*"unnatural relative to the behaviour of normal children at a given age"*,
- ❖ the characteristics appeared usually before the child was eight years of age,
- ❖ *"alcoholism, criminality, and affective disorders, such as depression and suicide, were noted to be more common among their biological relatives"*,
- ❖ some children but by no means the majority, displayed brain damage,
- ❖ a number of children had a tic disorder,
- ❖ the condition affected both children with an intellectual disability and children without any apparent intellectual impairment (Barkley, 1990, pp.4- & 5).

Still's description is not very different from current descriptions of children with ADD and a co-morbid disorder such as Oppositional Defiant Disorder, Conduct Disorder and/or a learning disability.

Still believed that these children had a neurological condition, which in the majority of cases was inherited, while in other cases he believed that they resulted from injury before or after birth. In fact, although he noted that some children may have been living in less than ideal family situations, most of the children appeared to come from families with acceptable child rearing practices (Barkley, 1990, p.4). Thus, Still saw the condition as a *"biological"* disorder (Green and Chee, 1994, p.12).

Locating the Difference

In drawing on Foucault's (1984b) work in relation to genealogy, we need to ask, what was happening at that point in time which allowed these children to be studied and to be deemed different or problematic (McLaren, 2002)? Foucault (1980d, p.58) invites us to *"study what kind of body the current society needs"*. Rafalovich (2001a) believes that Foucault's assertion is particularly relevant in examining ADD. Indeed a great number of changes were occurring at the end of the nineteenth century and the beginning of the twentieth century. Science had developed to such an extent that many believed that it could fulfil the dreams of industrialised nations, the modern state and professional disciplines such as medicine, psychology and later social work. Combined these forces conceptualised what was desirable in the population and the methods which would deliver a healthy productive nation state (Apple, 1987; Ehrenreich & English, 1979; Eyer, 1996; Foucault, 1980d; Hays, 1996; Summers, 1975). Some of these changes have been examined in the previous chapter.

In analysing ADD some authors believe that *"the origins of ADHD lie in the particular political and economic climate of the United Kingdom at the turn of the century"* and that *"the formation of the basic principles of the condition was deeply rooted in the values of Social Darwinism popular at the time"* (Prosser, 1999, p.50). Thus, it could be argued that the identification of problem children stems from social, political and economic changes and the ideology current at the time.

Although we can locate the historical point in time that children who exhibited ADD like characteristics were first identified as in need of correction, the conceptualisation of ADD has changed in the last one hundred years. The cause of ADD characteristics has shifted from a purely biological explanation in the early twentieth century to include, in more recent times, psychoanalytic and behaviourist theories of deviant behaviour in children. Foucault (1972, p.147) refers to these processes as *"conceptual transformations", "new notions"* and *"technical improvements"*. These developments will now briefly be examined, beginning with the Influenza Epidemic of 1918-1919.

1918-1919 Influenza Epidemic – Brain Disease

In the years 1918 - 1919 the world experienced an influenza epidemic (Barkley, 1990; Green and Chee, 1994; Dengate, 1994). The epidemic killed over 20 million people and left many survivors suffering from the effects of encephalitis, which, due to high fever, often results in neurological damage (Green & Chee, 1994). The surviving children displayed symptoms typically found in Attention Deficit Disorder; inattentive, overly active and disruptive, lacking in impulse control, and problems with memory (Sandberg, 1996). Children exhibiting these characteristics were diagnosed as having Postencephalitic Behavior Disorder and were often placed in residential institutions or in special educational facilities. Some children with Postencephalitic Behavior Disorder displayed *"symptoms of oppositional and defiant behaviour, as well as delinquency and conduct problems"* (Barkley, 1990, p.6). Thus, Postencephalitic Behavior Disorder and the characteristics of ADD were associated with brain disease.

The findings of this period still have relevance today as Wender's (1996) paper points out. Adults who recovered from encephalitis often showed symptoms of Parkinson's disorder and post mortem examinations of the adults who died from this disorder showed lesions in the brain. It was found that children suffered in the same way. Wender (1996, p.4) remarks that: *"these observations tie in with a later finding that idiopathic Parkinson's disorder is associated with decreased dopaminergic functioning in the brain"* which adds weight to the current theory that ADHD is associated with dopamine depletion.

1930-1940s The Era of Brain Damage

In the 1930 - 1940s investigations began into the link between brain damage - caused by a difficult birth, infections, lead poisoning, head injury - and behavioural difficulties. Research during the 1930s identified children who showed signs of hyperactivity and theorised that they may have had defects in the frontal lobe (Barkley, 1990). Unfortunately the emphasis on brain damage due to injury or disease meant that children who showed signs of hyperactivity were said to be *"brain injured children"* even though in the majority of cases there was no evidence of injury (Barkley, 1990, pp.7 & 9). During this time period, institutionalised children were medicated with the drug amphetamine, which improved their behaviour (Green & Chee, 1994). Many of the children that scientists investigated had an intellectual disability, hence much of the research in the first half of the century, centred on brain damage and or intellectual impairment. Studying children with an intellectual disability and/or serious behaviour disorders caused by brain damage resulted in milder cases of hyperactivity being seen as the product of poor parenting or a delinquent family (Barkley, 1990, pp.6-9).

Psychoanalysts were particularly busy during the 1940s as they sought to explain problem children or troubled adults. A number of books attributed a wide variety of childhood disorders and disabilities to mothers. Thus the message relayed, via these publications, was that mothers were dangerous and could damage the healthy development of children (Eyer, 1996; Hays, 1996; Oakley, 2002).

1950s Minimal Brain Dysfunction (MBD)

In the 1950s psychoanalysts like Bowlby and Winnicott were very active and influential in the field of child guidance and child rearing (Badinter, 1981; Karen, 1998). Bowlby (1952) and Winnicott (1965; 1964) believed that consistent and intense mothering was the key to preventing emotional and mental health problems. During this time period the term Minimal Brain Dysfunction (MBD) was coined to describe children displaying characteristics of hyperactivity. Barkley (1990, p.10) stresses that while the term MBD did not contribute much to the understanding of the disorder it did have value in that it had an *"emphasis on neurological mechanisms"*.

Thus, the concept of MBD prevented, in some cases, blame being apportioned to the mother. In contrast the followers of psychoanalytic theories saw behavioural disorders stemming from parents, in particular the mother, and family(Green & Chee, 1994).

In 1957, Methylphenidate (Ritalin) was used by medical professionals to assist with controlling children's difficult behaviour (Green & Chee, 1994). In comparison, psychoanalysts like Bowlby concentrated on educating mothers or assisting them to come to terms with their own unresolved issues which he believed impacted on their mothering (Bowlby, 1952; Karen, 1998).

1960s Hyperactivity Disorder

Chess in 1960 pursued the concept of the *"hyperactive child syndrome"*. Barkley (1990, p.10) cites Chess's definition of hyperactivity: *"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 and other scientists researching in that era hypothesised that the disorder did not extend in most cases, beyond adolescence. Even so, Barkley (1990) states that Chess's research was significant for a number of reasons in that she emphasised hyperactivity as a characteristic and separated it from the concept of brain damage. Moreover her work acted to remove the blame from parents. However, it should be noted that the questioning of brain damage as the cause of ADD and subsequent research was not common in Europe or Great Britain. These countries continued until the 1970s to view hyperactive children as brain damaged and believed that the disorder was uncommon (Dengate, 1994).

1970s ADD - Sustained Attention and Impulse Control

Throughout the world, this era was one of questioning and change. This world wide characteristic was reflected in the developing discourse. In 1972 Douglas, *"argued that deficits in sustained attention and impulse control were more likely to account for the difficulties seen in these children than was hyperactivity"* (Barkley, 1990, p.13). The research conducted by Douglas and her team was extensive and had a significant impact on the understanding of the disorder. Barkley (1990) and Green

and Chee (1994) believe that this body of research was primarily responsible for the American Psychiatric Association (1980) describing the condition in the DSM-111 as Attention Deficit Disorder. Thus, problems with attention and impulsivity were seen as having more relevance to defining the condition than hyperactivity (Green & Chee, 1994).

However during this decade, the psychoanalytic influence was strong, as can be evidenced from Adler and Terry 's (1972) book, *Your Overactive Child: Normal or Not?* The authors (Adler & Terry, 1972, p.7) state that some professionals have labelled hyperactive children as *"'emotionally handicapped' and held the parents responsible"*. This resulted in parents being questioned about their child rearing methods.

Parents were urged to rethink the upbringing of their children, especially in relation to diet. Ben Feingold (1975) put forward the idea that diet caused problems with learning and behaviour. As a result many mothers carefully monitored their children's diet in accordance with his hypothesis.

In the same year, 1975, Schrag and Divoky published their book, *The Myth of the Hyperactive Child and other Means of Child Control* which clearly deemed learning disabilities and hyperactivity as an *"invention"*. Schrag and Divoky (1981) soundly criticised middle class parents, educators and the medical profession for labelling and drugging children as a means of social control.

1980s – The Decade of ADHD
The years from 1980 to 1989 produced numerous research studies, which resulted in the development and fine tuning of the diagnostic criteria. In this decade the significant characteristics of the disorder were questioned and much work was undertaken in teasing out the difference and clearly defining ADD with (+H) or without (-H) hyperactivity, and Conduct Disorder (Barkley, 1990, p.21 - 23).

Children with ADD(-H) were identified *"as more daydreamy, hypoactive, lethargic, and learning disabled in academic achievement, but substantially less aggressive and less rejected by their peers"* (Barkley, 1990, p.22). As research continued to differentiate between ADD with (+H) and without (-H) a similar approach was being taken to clearly distinguish between ADD (+H) and aggressive behaviour such as Oppositional Defiance and Conduct Disorder.

In 1987 the American Psychiatric Association (1980) revised the DSM -111. The DSM-111-R (American Psychiatric Association, 1987) placed ADD(-H) in the Undifferentiated ADD category and in doing so both ADD(-H) and ADD(+H) became known as ADHD (Dengate, 1994; Green & Chee, 1994). Barkley (1990, pp.23-26) believes that this *"demotion"* of ADD(-H) in part reflected the disparity in research. In other words, ADD had not been researched as extensively as ADHD. ADHD was now listed with Oppositional Defiant Disorder and Conduct Disorder. Importantly it was recognised that a dual diagnosis could be made for ADHD and Conduct Disorder (Barkley, 1990).

Towards the end of the 80s the understanding of ADD progressed further with the recognition that motivation was central to the ability to focus and maintain attention (Barkley, 1990). Children with ADD were known to be able to focus their attention to activities which interested them, thus attention was to a degree selective. A number of research studies in the late 80s *"hypothesized that ADHD arises out of an insensitivity to consequences - reinforcement, punishment, or both. This insensitivity was viewed as neurological in origin"* (Barkley, 1990, p.27).

In the same decade within the United States, the medical approach was being questioned. The church of Scientology, under the title of *The Citizens Commission on Human Rights,* took their opposition to the use of medication to treat ADD to the media:

> *Ritalin…was a dangerous and addictive drug, often used as a chemical*
> *straightjacket to subdue normally exuberant children because of intolerant*
> *educators, parents and money-hungry psychiatrists. Ritalin could result in*
> *violence, murder, suicide, Tourette's syndrome, permanent brain damage,*

emotional disturbance, seizures, high blood pressure, confusion, agitation and
depression (Green and Chee, 1994, p.15).

The anti-psychiatry movement which in essence is against the use of drugs to treat mental disorders (Breggin, 1993) is reflected in the Church of Scientology stance. Their view fed into the psychoanalytic and behaviourist framework which highlighted problematic parent-child relationships as the cause of ADD and other psychiatric disorders (Breggin, 1993).

Summary of the Development of the Discourses

1890-1902	Abnormal defect of moral control
1918-1919	Influenza Epidemic – brain disease
1930s and 1940s	The Era of Brain Damage Medication used to treat problem behaviour *Psychoanalytical theories as to the cause* *of troubled children*
1950s	Minimal Brain Dysfunction – MBD Ritalin used for the first time *Bowlby & Winnicott influential in child health*
1960s	Hyperactivity Disorder
1970s	ADD – Sustained Attention and Impulse Control *Doctors, parents and teachers criticised* *for using medication to treat children*
1980s	ADHD/DSM-IV *Concerns rose about using medication* *to treat behaviour problems in children*
1990 – Present	ADHD & ADD Deficit of Executive Functioning *ADD a metaphor for poor parenting*

THE CURRENT DISCOURSE

Today the discourse surrounding ADD is in turmoil, with claims and counter claims from researchers and practitioners (Rafalovich, 2001b). This is despite ADD being *"the most well-studied childhood psychiatric disorder in existence"* (Barkley, 1990, p.21). Tapping (1996, p.108) describes ADD as:

> a topic which tends to polarise the therapeutic community into two opposing (and at times hostile!) camps – those who adhere to a strictly biological or medical model...and those who view ADD as purely a social construction.

Australia, the United Kingdom and the United States of America recognise ADD as a disorder, however it should be noted that within each country there are variations within the discourse. The following section presents the current theoretical frameworks which seek to explain ADD.

Psychoanalytic and Behaviourist Framework

Many professionals who see ADD as a questionable diagnosis locate their discourse within the framework of psychoanalysis or behaviourist theories which construct child behaviour as the result of early childhood experience (Rafalovich, 200ab). Children who are identified as having behavioural difficulties or having problems coping within our society, be it at school, in the community or in the home, are thought to be the result of inconsistent parenting, poor parenting or a disruption of attachment to the primary caregiver (Bettelheim, 1967; Bowlby, 1952; Breggin, 1993).

The theme of *"poor parenting"* (Smith, 1998, p.23; Tobler & Lalor, 2004, p 11) as the cause of ADD saturates media stories (Dullroy, 2002; Laurie & Cubbin, 2003) and the theme *of "strained early caregiver-child interactions and disrupted primary attachments"* (Sandberg, 1996, p10) is repeated throughout professional literature (Clarke et al., 2002; Haddad & Garralda, 1992; Osmond & Darlington, 2001). In speaking of ADD, Dr Newman (1996, p.107), Clinical Director, Paediatric Mental Health Service, South-Western Sydney states that:

> to develop the ability to focus, attend and control behaviour, the infant requires a caretaker who can attend to the infant. Psychoanalytic accounts talk usefully

here of ths (sic) caretaker's 'preoccupation' with the infant as the basis for the

parents' ability to 'read' and appropriately respond to the infant's affective

state…in many parent-infant relationships this process is less than optimal.

Newman (1996, p.107) goes on to say that *"in some ways ADHD operates as a metaphor for disturbances of parent-child relationships"*.

Biological Condition and Genetics

In contrast to the claims of the psychoanalytic and behaviourist camp, others identify ADD as a chemical imbalance (Serfontein, 1990) and locate their discourse within the framework of genetics and biology. Barkley (2001b), the keynote speaker at the *ADHD in the third millennium* conference in Australia stated that ADD is the most genetically inherited disorder. At the same conference Professor David Hay and Associate Professor Florence Levy (2001, p.20) reported on the Australian Twin ADHD Project and some of their findings. They claim that:

generally the ATAP studies like those overseas show little role for shared family

environment, that is siblings do not learn their patterns of ADHD from each

other or from their parents - the "dad deficit disorder" is inconsistent with all

scientific evidence.

In 2002, Dr Russell Barkley and seventy-four colleagues working in the field of ADD issued an *International Consensus Statement on ADHD* and once again emphasised the heritability of ADD:

The genetic contribution …is routinely found to be among the highest for any

psychiatric disorder (70-95% of trait variation in the population)…One gene has

recently been reliably demonstrated to be associated with this disorder and the

search for more is underway by more than 12 different scientific teams

worldwide at this time (ADDitude, 2002).

Barkley (2002, p.3) and other researchers acknowledge that while small in number, *"nongenetic factors... have been linked to ADHD"*. These include premature birth, alcohol and tobacco use by the mother during pregnancy, lead poisoning and brain injuries in early childhood (Ellard, 1993; Milberger, Biederman, Faraone, Chen, & Jones, 1996; NHMRC, 1997).

Diet

While the psychoanalytic/behaviourist explanation and the genetics theory are the two dominant competing ideologies within the discourse, the diet perspective also seeks to explain the cause of ADD. Feingold (1975) was the first to advocate that diet caused disruptive behaviour in children. Barkley (1990, p.16) states that research in the United States disproved Feingold's claim *"that over half of all hyperactive children had developed their difficulties because of their diet"*. Others believe that the diet perspective may have value however it has been overshadowed by the *"neurological discourse"* (Rafalovich, 2001a, p.10).

The Struggle for Power and Knowledge

Clearly in the last decade, the discourse surrounding ADD is one of claims and counter claims as various factions compete to state the *"truth"* (Foucault, 1980d, p.131) about ADD. Currently ADD is the bone in what can only be described as an ideological dog fight. In his works *Madness and Civilization, The Birth of the Clinic* and *Discipline and Punishment,* Foucault speaks of *"dividing practices"*, the ways in which groups are deemed different and the way in which professional disciplines have evolved to *"control"* or contain these groups through the exercise of their knowledge and power (Rabinow, 1984, p.8). Thus, as noted by other authors, Laurence and McCallum (1998), Prosser (1999) and Rafalovich (2001b) the conflict and hostility which exists within the ADD discourses is essentially a struggle over professional knowledge and power. The battle, which has been raging for some time, is being staged in an attempt to determine which approach, psychoanalytic and behavioural or genetics and biology, will be deemed the *"truth"* and which will be seen as *"discontinuous, disqualified, illegitimate"* (Sarup, 1988, p.64).

It could be argued that the conflict within the discourse on Attention Deficit Disorder is a mirror reflection of a much wider power struggle within the field of psychiatry. Porter and Micale (1994, p.5) in examining the history of the development of psychiatry, state that as a discipline it is *"poised precariously between the medical sciences and the human sciences"* and that *"from its earliest days, psychiatric medicine has been marked by the persistence of competing, if not bitterly opposing*

schools".   In particular they refer to the *"endless dialectical struggle between biologically and psychologically oriented theories"* (Porter & Micale, 1994, p.4).

Alexander and Selesnick (1967, p.183) have noted that the *"psychological approach"* to psychiatry had not taken hold during the early nineteenth century as

> *the stupendous progress of the natural sciences in general, and the advancing*
>
> *knowledge of the central nervous system in particular, during the second half of*
>
> *the nineteenth century overshadowed these psychological interests and cast*
>
> *suspicion and general disrepute on everything that did not fit into the*
>
> *materialistic-mechanistic view that had become synonymous with science.*

However, Sigmund Freud (Alexander & Selesnick, 1967, p.181) did succeed in introducing *"psychoanalysis as a valid method of investigation"*. Indeed it is viewed that psychoanalysis was born out of opposition to *"the psychiatry of degeneracy, eugenics and heredity"* (Foucault, 1980d, p.60; Sarup, 1988, p.78). Accordingly, within psychiatry a battle over power and knowledge has been taking place for one hundred years. This power struggle within the field of psychiatry has directly contributed to conflict in the ADD discourse.

LEPERS OF THE TWENTIETH CENTURY

It is important to recognise that within the field of psychiatry, the psychoanalytic and the behaviourist camp and the genetic and biology followers have battled previously within the discourses of both Schizophrenia and Autism. In the late twentieth century, Dr E. Fuller Torrey, the brother of a woman suffering from Schizophrenia described the stigma associated with the condition: *"people with schizophrenia are the lepers of the twentieth century"* (Deveson, 1991, p.214). The concept of leper is an interesting one and can be found in the works of Foucault (1984a). In *Madness and Civilization,* Foucault noted that *"at the end of the Middle Ages leprosy disappeared from the western world"* suggesting *"a connection between this and some of the attitudes then taken towards madness"* (Sarup, 1988, p.66).   He articulates that *"as leprosy vanished a void was created and the moral values had to find another scapegoat"* (Sarup, 1988, p.66). Madness replaced leprosy as the social evil which needed to be contained and later on cured (Foucault, 1984a). In using the work of Foucault (1984a), it can be argued that in a world where difference attracts

stigma and blame, the status of leper is conferred as a new scapegoat must be found to explain social problems or deviance.

Influencing the Discourse and Passing the Baton of Leprosy

Schizophrenia

As with the ADD, discourse polarisation occurred in forming the knowledge base for schizophrenia. Ann Deveson (1991, p.49) gives an overview of the psychoanalytic theory which competed with the genetic predominance of the early twentieth century to explain the development of schizophrenia:

> *In the 1920s and 1930s, psychoanalysts began questioning whether the basis of schizophrenia was physical, or was caused by traumatic childhood experiences or bad parenting. These theories were further developed in the 1950s and 1960s, when the anti-psychiatry movement saw schizophrenia as a label for scapegoating people who were eccentric or difficult to live with.*

A powerful figure in the anti-psychiatry movement was R.D. Lang, who saw madness as an act of rebellion (Deveson, 1991).

In the 1980s at a conference in the United Kingdom the keynote speaker articulated: *"one hundred years of biological research had led us up blind alleys; schizophrenia was not a dysfunction in the brain; the fault was more likely in the programming than in the hardware"* (Deveson, 1991, p.204). In the United States during the same period the National Alliance for the Mentally Ill (NAMI), were actively looking for high profile and powerful partners, to advocate the biological aspect of schizophrenia. Oil millionaire, Jack Hinckley, the father of the young man who tried to kill President Reagan in 1981, was one man who had the ability to challenge the view that poor parenting caused schizophrenia. Jack and his wife established the American Mental Health Fund *"to educate the public about mental illness and to raise money for research"* (Deveson, 1991, p.217). While Breggin (1993, p.41) criticises the NAMI for becoming *"an institutional embodiment of the kind of parents who can drive a child into helpless despair",* the organisation has influenced the discourse to a substantial degree, in that they shifted the focus from poor parenting to biological explanations for schizophrenia.

Today schizophrenia is spoken about as a disease which has no *"single cause"* (Schizophrenia, 2004, p.1) but results from an interplay of genetic and behavioural factors. Dysfunctional families and trauma in early childhood as catalysts for schizophrenia are absent from the mainstream discourse (Keefe & Harvey, 1994).

Autism

A similar story unfolds in examining autism. Albury (1993, p.312) states that autism was seen as *"a cultural metaphor for the evils of bad parenting"* by psychoanalysts after the Second World War. The anti-psychiatry and social justice movements also adopted this stance in the 1960s. Bettelheim (1967) in *The Empty Fortress: Infantile Autism and the Birth of the Self,* put forward the idea that children were withdrawing from what they considered to be a hostile and threatening world, one in which they received no solace from their parents. Bettelheim's work fitted within a psychoanalytic framework, which saw early childhood trauma producing disorders in children.

In contrast, Rimland (1964), a parent of a child with autism published *Infantile Autism: The Syndrome and its Implications for a Neutral Theory of Behavior*, arguing that autism had an *"organic aetiology"* (Albury, 1993, p.315)*.* This view freed parents from blame and was the catalyst for forming the National Society for Autistic Children (NSAC) in the mid 60s.

The NSAC forged alliances with professionals who supported the *"organic"* view of autism (Albury, 1993, p.315). A strong network developed which sought *"to counteract the theory that autism is the result of a noxious mother-child relationship"* (Albury, 1993, p.316). The professionals who held mothers responsible by their nurture theories were now asked to substantiate their claims scientifically. Eventually blaming parents in relation to autism became *"morally and politically taboo"* (Albury, 1993, p.316). Thus, parents and professionals formed a power base to challenge the dominant nurture theory and in doing so transformed the autism discourse.

The genetic component of autism is now emphasised: *"current thinking suggests there are at least four, and perhaps as many as 10 genes which play a role in autism"* (Anonymous, 2002, p.1). This transformation has practical implications for the mothers of autistic children. The early professional descriptions of a cold rejecting mother, is replaced with a description which is more aligned to the genetic theory*: "the child's mother presents with many identifiable autistic traits indicating a strong genetic component to the child's autism"* (Baird, 2000, p.1). As a mother of children with Asperger Syndrome, Baird (2000, p.12) describes the *"mother from hell"* stance that many have taken in dealing with professionals:

> *If you don't give my child the services he needs or you criticise my parenting skills you have declared WAR between us and I will fight you to the death. Otherwise if you work with me on this and try to help my child I will hold you in high-esteem and remain your loyal friend, cooperative and appreciative of your efforts for the rest of my life.*

Baird's comment is particularly important as theory influences both practice and the way in which professionals and parents view each other. This topic will be explored further in the fourth chapter, *Theory and Practice.*

Lloyd and Norris (1999) examine how the parents of children who are different are either approved of and seen as deserving, or disapproved of and seen as unworthy. In relation to the concept of *"leper"* it can be seen that the parents of children with schizophrenia and autism, through their resistance (Foucault, 1972, 1980c) were able to influence the discourse and remove the blame that had been attributed to them. They did this by championing the biological and genetic explanations for their children's difference. As they became blameless they also became worthy. Therefore their position changed, and they could no longer serve as scapegoats for the social ills of society. However, when voids are created, society has to find other scapegoats so that the baton of *"leper"* can be passed on to others.

ADD and the Status of Leper

Today Ritalin, a medication to treat ADD has been identified as the *"leper's bell"* (Oak, 2004, p.13). Oak (2004, p.13) asserts that the taking of medication marks the children with ADD as being *"different"* and *"inferior"*. Lloyd and Norris (1999)

discuss how the parents of children with ADD have pushed for the acceptance of the biological and genetic cause of ADD. They note that by doing so, they seek forgiveness by trying to remove the blame for having different children. Diagnosis and the recognition of difference, as with autism and schizophrenia, paves the way for parents to advocate for services to assist their children and themselves in the rearing of their children (Lloyd & Norris, 1999; A. Reed, 1999; Shields, 1996). However, at this point in time, a diagnosis of ADD does not necessarily produce services that parents find useful (Malacrida, 2003). Currently these different children and their families struggle to be seen as deserving (Lloyd & Norris, 1999). Therefore, the question needs to be asked, are children with ADD and their families scapegoated to explain social problems or deviance. Furthermore, do they currently possess the status of *"leper",* the unworthy and undeserving?

CONCLUSION

In concluding this chapter, the history of the ADD is one which began at the turn of last century as experts identified children who were different from other children and undesirable to the society of the day. Today these children are likely to be diagnosed as having ADD and other co-morbid disorders. Still's conceptualisation of problem behaviour resulting from a neurological condition has been challenged many times.

Today the theory that ADD is a biological genetic disorder is poised against basic psychoanalytic and behaviourist theories that ADD is the result of poor parenting or adverse environment. While other theories exist, for example, diet, the dominant two theories represent hostile and competing camps. This battle for professional knowledge and power is a reflection of a much wider power struggle within the broader field of psychiatry. The battle over power and knowledge has also been played out in forming the discourses on both schizophrenia and autism. As the battle for power is lost by professionals who hold parents responsible for different or deviant children, their focus is directed to other discourses. Thus the status of leper is conferred as new scapegoats need to be found to explain deviance and difference in our society. The notion of difference will be discussed in the next chapter, *Difference, Normalisation and Discipline*.

CHAPTER THREE – DIFFERENCE, NORMALISATION AND DISCIPLINE

"It has been the construction of difference, and the way in which people have approached difference, that has written much of the history of humankind. Both the potential and the perceived threat posed by difference play pivotal roles in the behaviour of human society" (Carpenter, 1999, p.2).

Introduction

The focus of this chapter is to look at how difference is explained through the lenses of biology and the environment and how difference has often attracted correction. Correction or normalisation and discipline were of interest to Foucault. It will be argued using these concepts that within our recent history a number of powerful bodies have joined forces in order to correct people or groups of people who are seen as different or deviant. These concepts have particular relevance to the lives of people affected by Attention Deficit Disorder (ADD) as they have been labelled different and in need of correction. Thus the policies of normalisation will be examined and where possible, drawing from the existing literature, an assessment made of the impact of these policies on people affected by ADD. It is useful to begin with a general overview of the concept of difference before exploring Hartman's view that people with ADD are different.

Difference

Deciding what is desirable and culturally accepted behaviour has a long history and the concepts of normalcy and deviance have undergone many changes (Chess & Hassibi, 1978). In order to label someone or something deviant or different, a base line must be established which dictates what is normal. Accordingly, Francis Galton assisted the medical and allied health professionals to determine normalcy and difference through the development of statistical concepts (Barry, 2004; Trombley, 1988). Today, psychiatric and psychological difference or deviance is outlined in the American Psychiatric Association's Diagnostic and Statistical Manual (DSMIV) (1994).

Difference and the need to recognise or negate difference, is debated within academic and professional sectors (Carpenter, 1999; Gillman, Heyman, & Swain, 2000; Ho, 2004; Moore, 1994; Ramazanoglu & Holland, 2002). Some authors, such as Plomin, DeFries and McClearn (1990, pp.400-401) believe that *"recognition of, and respect for, individual differences is essential to the ethic of individual worth...Human individuality is the fundamental natural resource of our species"*. Other authors believe that "sameness" is of value in our modern society with conformity and the process of normalisation being hallmarks of our current age (Carpenter, 1999; McLaren, 2002). The great value assigned to normal, as opposed to different, can be seen within Wolfensberger's (1984) theory of normalisation or Social Role Valorisation. Gillman, Heyman and Swain (2000) state that the theory of normalisation has devalued difference and diversity. Adams (1997)is concerned that tolerance for difference is waning and that, in reality, we fear and despise difference. It is precisely the determination of normal and *"not normal"*, (Hartmann, 2003a, p.1) and the value assigned to both, that Hartmann focuses on when discussing the nature of ADHD.

Hartmann (2003a, p. 3) takes to task those who pathologise ADHD when he argues that ADHD is more a matter of difference:

> *the difference perspective assumes that different people may need to utilize different techniques to achieve the same goals. The difference perspective presumes that there are different ways of remembering, and different ways of processing and organizing input.*

In constructing his argument he proposes that *"Farmer"* genes produce a *"careful bookkeeper"* and *"Hunter"* genes produce an *"adventurous explorer"* (Hartmann & Lavallee, 2003, p.3). Hartmann seeks to demonstrate that ADHD traits were advantageous in risk taking societies, which valued adventure and a more active way of life. Prosser (1999, p.38) in examining ADD also reminds us that *"people have the same biological diversity that they have always had"* however, social change has dictated that *"certain characteristics"* are *"socially unacceptable"*. Today those who possess the *"Hunter gene"* are viewed in a negative light while people who have the *"Farmer gene"* (cited in Hartmann, 2003a, p.3) *"don't get into trouble, and tend not to stand out in our society"* (Hartmann, 1999, p.30). Thus, in the tightly

controlled environment in which we live, *"Farmers"* are desirable while *"Hunters"* are a threat. It should be noted that in developing his argument, Hartmann (1999; 2002; 2003b) is not necessarily suggesting that we abandon the identification of difference or therapies to assist with being different. Indeed, in Hartmann's (1999) book, *Attention Deficit Disorder: A Different Perception* and his more recent work, *The Edison Gene* (2003b), he discusses a number of options to maximise a *"Hunter's"* potential in our present culture. The need to recognise and appreciate difference, as opposed to pathologising difference is noted, but not fully explored, in some studies which have focused on the experiences of parents of children with ADD (Kendall, 1999; Kendall & Shelton, 2003; Malacrida, 2003). This stance is in contrast to other writers who see the identification and management of ADD as techniques of correction (Conrad, 1976; Rafalovich, 2001b; Tait, 2001).

Hartmann's theory of difference can be criticised on a number of varied fronts. For example his view of the *"Hunter"*, the adventurer, is framed within a white, middle class male perspective and his hypothesis is not holistic in anthropological terms. Nonetheless, Hartmann has made very pertinent points, for example, he changes the focus from the pathological to the productive by saying:

> *there's still a place for hunters,…they can be found in large numbers among*
> *entrepreneurs, police detectives, emergency-room personnel, racing-car drivers*
> *and of course, those who stalk the high-stakes jungle known as Wall Street*
> (Wallis, 1994, p.38).

In other words, Hartmann is reminding us that our world is inhabited by all sorts of people and that we need diversity in order to function as a society. One man who may appreciate Hartman's *"Hunter"* hypothesis is Steve Irwin, the crocodile man.

Steve Irwin sleeps four hours each night and is described by his wife Terri, as full on, all day and every day (Denton, 2004). The Irwins are well known nationally and internationally for their love of wildlife, in particular crocodiles. Recently the Irwins received severe criticism for taking baby Bob, their son, into a crocodile enclosure. Steve Irwin, while holding baby Bob in one arm, proceeded to feed a large crocodile. Many Australians were horrified including the Queensland Department of Family Services. On the Andrew Denton Show (2004), Steve Irwin defended his actions by

saying, *"I am different, I lead a different lifestyle"*. Irwin goes on to say that as a result of that difference, he needs to introduce his children to wildlife as soon as possible. Whether the Irwins were right or wrong in taking the baby into the enclosure, is not the concern at this point in time. However, this example demonstrates that people who are different, or live different lifestyles, often come under the scrutiny of the community and/or the bureaucracy, thus, highlighting some of the challenges for people who are different, such as *"Hunters"* living in the twenty first century.

Hartmann believes that *"Hunters"* are being damaged and punished by the processes that try to shape and mould them into a farming culture. On a daily basis *"Hunters"* are told, albeit subtlety, what desirable behaviour is and what appropriate goals are. They are expected to conform to a set of rules, which may not make sense to them. On a daily basis *"Hunters"* live in an alien world, a constricted system which offers them little flexibility or creativity. They are damaged when their basic instincts are stifled, when their creative spark is left to die or is deliberately snuffed out (Hartmann, 2003a, 2003b). To prevent damage and harm to people with ADD Hartmann (1999, p.2) believes that a greater appreciation of difference is needed and that through this knowledge

> *we can recreate our schools and workplaces to not only accommodate ADD individuals, but to allow them to again become the powers behind cultural, political, and scientific change which they have so often historically represented.*

In this chapter, the way in which difference is explained and the consequences of being different or labelled deviant, will be explored using Foucault's *"core concepts"* (Chambon, 1999, p.65) of normalisation, governmentality and discipline.

Normalisation, Governmentality and Discipline

Miller (1993, p.32) believes that Foucault's work *"may provide a fresh insight into a host of contemporary debates – over the meaning of human 'right', including 'the right to be different'"*. Foucault (1979, p.103) argued that *"we live in the era of a 'governmentality'"* which is concerned with the *"'conduct of conduct'"* (cited in Gordon, 1997, p.5). In his work, *Birth of the Clinic*, Foucault argues that medicine

extended its knowledge base from looking at ill health and disease to setting the standards for normality (Chambon, 1999). *"Transgressors",* those who are different or aberrant, are paid particular attention as they are seen to be in need of intervention or correction (Rose & Miller, 1992, p.180). Thus, energy and time is expended in extending *"a normalizing influence over individuals and populations"* (Chambon, 1999, p.67). Foucault (1999, p.102) believed that *"normalization"* has become *"one of the great instruments of power"* and that *"it has joined other powers"* to shape the population.

Rose (1996, p.12) highlights the extent of the desire to mould populations:

> *the perspective of government draws our attention to all those multitudinous programs, proposals, and policies that have attempted to shape the conduct of individuals – not just to control, subdue, discipline, normalize, or reform them, but also to make them more intelligent, wise, happy, virtuous, healthy, productive, docile, enterprising, fulfilled, self-esteeming, empowered or whatever.*

The shaping of the population and punishing those who dissent, which Foucault (1979, p.101) calls *"discipline",* is performed by many institutions and by the forming of *"'power/knowledge'"* bases (cited in Gordon, 1997, p.3). Thus, Governmentality is not confined to the nation state.

Rose and Miller (1992, pp.180-181) point out that there are other bodies outside of the state which seek to:

> *modulate events, decisions and actions in the economy, the family, the private firm, and the conduct of the individual person. …Experts who claim to know how to direct business activity, family life and personal morality onto the path of virtue*

develop programs and form alliances with other power bases in order to govern. Thus, a variety of power bases operate to control populations and to determine what is considered normal and what is considered different or deviant and in need of correction.

Nature, Nurture and Locating Difference

In our recent history, both nature and nurture theories have been used to explain deviance or difference (Chess & Hassibi, 1978). Nature theories look towards temperament and inherited traits to explain difference (Kagan, 1994). Therefore, they rely heavily on genetically based research. In contrast, nurture theories are embedded in psychoanalytic and behaviourist theories to explain difference (Karen, 1998). Psychoanalytic and behaviourist theories, particularly maternal deprivation and attachment theories, claim that deviance develops from trauma in the early years of childhood (Hil & Brennan, 2004). Psychoanalysts like Bowlby, Ainsworth and Winnicott saw good mothering as the key to preventing deviant children (Bowlby, 1952; Karen, 1998; Winnicott, 1965). Bowlby and Ainsworth were labelled by nature theorists *"as radical environmentalists and parent blamers"* (Karen, 1998, p.286). Karen (1998, p.313) states that *"the blaming and defending of mothers"* has *"become a central subtext of the nature-nurture debate"*.

Against this background, Chess began her research on child temperament in response to the common practice of blaming mothers for their children's behaviour (Karen, 1998). Chess (1976) undertook a longitudinal study of children and their parents and clearly outlined the problems involved in bringing up children with difficult temperaments. Chess questioned the Strange Situation Test developed by Ainsworth and used to evaluate attachment, believing that it was more a measure of temperament (Karen, 1998). Chess is not alone in her criticism, as Kagan (1984) finds it highly unlikely that the Strange Situation Test measures anything meaningfully, asking:

> *is it reasonable that a history of interaction between mother and infant*
> *comprising over a half-million minutes in the home would be revealed in six*
> *minutes in an unfamiliar room* (cited in Karen, 1998, p.249)?

Kagan believes that mothers have got a *"raw deal"* from both behaviourists and the psychoanalysts (Karen, 1998, p.296). A former environmentalist and now a leading critic of attachment theories, he assesses his transformation:

> *my training, my beliefs, my upbringing all came together when I was a younger*
> *person to lead me to minimize the role of biology. I believed that even if you*

started with a little bit of biology that your will and experience could overcome
it. I've now seen many children for whom that's difficult (Karen, 1998, p.295).

Kagan (1984) is now firmly in the nature camp as he believes that temperament is very influential in determining behaviour. While Kagan may be seen by his detractors as a *"radical genetic determinist"* (Karen, 1998, p.295), he does acknowledge the power of the environment. Difficult children who have access to resources such as money and social standing have a much better chance of being successful in life - finding a profession which can cater for their difference - whereas children who do not have access to these resources stand a greater chance of developing anti-social behaviour, being unemployed and possibly ending up in the criminal system (Kagan, 1984, 1994; Karen, 1998).

Karen (1998, p.294) summarises the ideological divide between the two camps:
where Ainsworth sees ambivalent attachment, Kagan sees the inherited
susceptitibility to stress typical of his fretful children. Where Sroufe sees
children displaying the emotional consequences of secure or anxious attachment,
Kagan sees the unfolding of inborn traits.

NATURE THEORIES AND EUGENICS
Both nature and nurture based theories which seek to explain difference have been used by those who seek to govern, to normalise and to shape populations (Hil & Brennan, 2004; Rifkin, 1998; Trombley, 1988; Tyler, 1993). In the early twentieth century eugenicists played a significant role in the nature/nurture debate as *"they believed that heredity was all, and that social progress depended on the purity of the 'genetic substance'"* (Trombley, 1988, p.31). Indeed the early eugenicists and their detractors assisted in shaping the birth of academic sociology as they debated societal issues. The work of Charles Darwin and Sir Francis Galton contributed significantly to the birth and development of eugenics (Trombley, 1988).

In 1859, Charles Darwin published *On the Origin of Species*, which stimulated a number of debates concerning the development of the human species. Darwin added another dimension to the debate in 1871 when he published *The Descent of Man*, and

commented on the practice of civilised societies to protect the weak, poor and sick thus allowing them to live and reproduce. The cousin of Charles Darwin, Sir Francis Galton formed the Eugenics Society in 1907 (Trombley, 1988, pp.5-10). Eugenics as a term literally means:

> *well born. It refers to the doctrine that humanity can be improved by selective breeding, that is, by ecouraging* [sic] *those with desirable traits to reproduce or discouraging those with undesirable traits from doing so* (Nuffield Council on Bioethics, 2002, p.1).

Eugenicists were usually from the middle/upper classes, white Anglo Saxons who saw others as being undesirable. Eugenicists sought to develop and implement social policy based on the then understood laws of heredity in order to build a nobler race and stronger nation (Trombley, 1988).

Social engineers, inspired by eugenics, sought to *"'prove' that the deplorable conditions of slum dwellers came about through inherent genetic fault rather than bad environment"* (Trombley, 1988, p.8) thus absolving government and industry from finding social solutions to poverty (Rifkin, 1998).   While the poor were targeted, other people were also considered to be unfit to reproduce: the insane, disabled, the immoral, the weak, illegitimate and deserted, criminals and other races. The solution of course was sterilization, segregation or deportation in some instances. Trombley (1988) points out that according to the principles of eugenics a number of supporters of the doctrine would be classed as unfit. This fact seemed to go unnoticed as eugenics grew from strength to strength in a climate of loathing and hatred (Trombley, 1988).

Although eugenics had a number of notable critics, it became a very powerful force after the First World War. G.K. Chesterton used common sense and satire to combat the excesses of eugenics:

> *the eugenists* [sic]…*thought nearly everyone mad, when the truth was that only a very small minority were; and that the mad were much less harmful to society than was the 'intelligent bully'* (Trombley, 1988, p.83).

Despite criticism, the movement grew and before the Second World War, Wing Commander James tried to introduce legislation in Britain to sterilize the defective

children of the poor. James and his supporters did not succeed in introducing this bill, as the government's attention turned to the outbreak of the Second World War (Trombley, 1988).

The war allowed the Nazis in Germany to go beyond sterilization, which they had introduced in 1934 under *The Law for the Prevention of Hereditarily Diseased Offspring,* to genocide. The drafting and implementation of the *Final Solution*, saw the murder of unfit Germans, especially those with disabilities or illnesses and other undesirables, such as the Jews, Poles, Russians, Gypsies, homosexuals or simply those that they just didn't like (Trombley, 1988). More than fifty years later, the atrocities committed by the Nazis are difficult to come to terms with. However Trombley (1988) and Rifkin (1998) point out that the Nazis acted upon eugenic principles which were common though-out the Western World, in particular in the United Kingdom and the United States. It has been estimated that 30,000 people were sterilized in the United States and that countries such as Canada, Switzerland and Sweden continued with sterilisation programs up until the 1960s (Nuffield Council on Bioethics, 2002).

Collusion and the Elimination of Difference

Political parties both in the United States and Britain *"were willing to play the nature/nurture game to suit their purpose"* (Trombley, 1988, p.58). Not only was sterilization a cheap and effective solution to social problems, it preserved the status quo, as any intervention was more likely to affect the poorer classes and the disenfranchised (Rifkin, 1998; Trombley, 1988). In examining the scapegoating and blame employed by eugenicists, Trombley (1988, p.87) employs a perspective common to Foucault, when he states:

> *the medicalization of otherness, of the failure to conform, which had been the task of psychological medicine at the end of the nineteenth century, was now aided by the dubious 'scientific' principles of eugenics. All available means were to be employed in the fight to purify the race.*

In their efforts to eliminate difference and deviance, the eugenicists succeeded in establishing support from many different quarters: western governments, the

bureaucracy, the upper classes and academics. It was even proposed that teachers be enlisted to identify children for sterilization based on poor academic performance (Trombley, 1988). The medical profession in particular were recruited to use their *"professional power"* in the development of eugenics and in the resultant practices; sterilization, institutionalisation and genocide (Trombley, 1988, pp.71 & 74). Hitler relied on prominent psychiatrists in drafting and implementing the *Final Solution* in Nazi Germany (Trombley, 1988; Barber, 2004). Doctors in general practice were also enlisted to assist in Hitler's policies. Almost half of the doctors in Germany were Nazis and used their power to advance the cause. However, it should be acknowledged that doctors in general had little choice in the matter; it was often a case of kill or be killed (Barber, 2004; Trombley, 1988). Thus, it can be seen that eugenic policies were supported by a number of power bases and were used to shape society in the mould which best suited those power bases.

Genetic Research in the Twenty First Century

The acceptance of eugenic policies declined after the Second World War as the horror of the Nazi holocaust was revealed (P. A. Reed, 1999) and as research demonstrated that eugenic policies would not eliminate difference or deviance (Nuffield Council on Bioethics, 2002). However, the quest for biological explanations did not disappear altogether and today documentaries are screened which show that scientists are looking at biological makeup to explain human interactions and experiences (ABC, 2004). Perhaps the largest and most well known project in the area of genetic research is the Human Genome Project. The Human Genome Project has attracted a lot interest as well as criticism and fear and many are questioning, *"is genetics merely the new eugenics"* (Marmoset Media, 2004)? There are concerns that genetic arguments can be used to justify why some people are poor, or become criminals, or encounter family violence (Karen, 1998; Powledge, 1996). Professionals and animal rights activists are at loggerheads over using animals to further genome projects (Collins, 2004a) and the debate continues over stem cell research (Collins, 2004b)

Segal (1999), in discussing the Human Genome Project, believes that the application of genetic research may be misused as had occurred in the past with eugenics.

Plomin, DeFries and McClearn (1990) recognise the violence of the eugenics period and see potential for future abuse. They emphasise that scientists need to be aware of the way in which their findings can be used or interpreted, since, *"powerful findings with important implications for society can create problems as well as solutions"* (Plomin et al., 1990, p.398). However, they do not advocate for genetic research to be abandoned. Those who see the potential good of genetic research believe that we cannot ignore history and that the era of eugenics needs to be acknowledged in order to ensure that in the future we do not repeat the abuse and violence of the past (Nuffield Council on Bioethics, 2002).

In a similar vein, Rifkin (1998), in reflecting on current genetic technology believes that it is of value to humanity. However, he adds a cautionary note; who will decide what is normal or desirable? A similar question is asked in a recent study of difference and disability in Australia (Goggin & Newell, 2005). Many in the community fear that, in the future, genetics may be used to pathologise currently accepted behaviour traits and to label them as *"abnormal"* (Nuffield Council on Bioethics, 2002). Interestingly, ADD has been identified as a disorder that may be profoundly affected by the acceptance of genetic research in determining what is acceptable to modern society (P. A. Reed, 1999).

Genetic Research and Attention Deficit Disorder

In Australia the Twin Attention Deficit Hyperactivity Disorder Project has been working since 1993, with the support of the National Health and Medical Research Council, to locate the genes associated with ADD (Hay & Levy, 2001). A comprehensive account of genetic research within Australia is outlined in *Attention Genes and ADHD* (Levy & Hay, 2001). Many parents of children with ADD have supported the genetic approach (Lloyd & Norris, 1999) as gene research has the potential to release them from the blame that often surrounds them. Paul, a political scientist at the University of Massachusetts, has predicted that *"important social questions about genetics...will arise from the desires and demands of individual families"* (Powledge, 1996, p.4). It is acknowledged that a number of genes may contribute to ADD as opposed to one single gene (Anonymous, 1995; Zametkin et al., 2001). However, research has primarily concentrated on the dopamine genes, in

particular, the dopamine transporter and receptor (Barr, Swanson, & Kennedy, 2001; DiMaio, Grizendo, & Joober, 2003; Hay & Levy, 2001).

Rutter (2001) believes that, as ADD is a highly heritable condition, genetic research and the genome project hold promise for those affected by the disorder. He states that there are challenges in unravelling the *"nature-nurture interplay"*, as well as risks associated with genetic research (Rutter, 2001, p.239). However, Rutter stresses that genes are probabilistic not deterministic and that environmental factors, which influence all individuals, cannot be ignored in the development of social policy or welfare practices. The report on *Genetics and Human Behaviour: the ethical context* (Nuffield Council on Bioethics, 2002), also emphasises that there are other influences in our lives and that, while it may be shown that genes influence our behaviour, human beings have the power to modify or change behaviour.

The Spectre of Eugenics Still Looms

In contrast to Rutter's (2001) view that genetic research will be of benefit to those who have ADD, The Church of Scientology is opposed to genetic research. The history of eugenics both past and present is of great concern to the Church of Scientology as they believe that eugenics was developed: *"to allow only those of a society's upper class to procreate while inhibiting the procreation of the lower class"* (Barber, 2004, p. 3). In particular they cite the research of Wender, which claims that ADD is an inherited disorder predominantly found in the lower socio-economic classes and they fear that in the future families will be screened to detect ADD (Barber, 2004).

In our recent past, genetic research has assisted families who have had different children by absolving them of blame and at the same time placed pressure on them through genetic screening (Hughes, 1998). It should be stressed that genetic research into ADD is in its infancy (Barr et al., 2001). However, it is illuminating to read comments on the internet concerning ADD and genetic screening: *"there is no simple screening test to identify those people carrying genes which might increase susceptibility to ADD/ADHD, and no prenatal screening available"* (Macnair & Hicks, 2004, p.2). Another article commented that the research into the genetic

component of ADD is *"of major social and economic importance"* (Hawi, Daly, Fitzgerald, & Gill, 1999, p.2). It is beyond the scope of this thesis to predict the implications of genetic research for families and individuals affected by ADD. However, it should be noted that ADD support groups in the United Kingdom are debating the *"potential benefits and dangers of genetic research"* (ADDNet, 2005d, p.5). Thus, it appears that genetic research holds promise as well as pitfalls for people affected by ADD.

NURTURE BASED THEORIES AND NORMALISATION

A number of strategies based on nurture theories as to the cause of difference or deviance have been used over time to mould populations and these will now be discussed.

Deborah Tyler (1993, p.39) believes that *"like the 'good mother', 'the child'"* is a modern concept which has been fashioned by history, cultural and political interests. Tyler argues that it is in the best interests of those who seek to govern, to shape good children. As part of a strategy to shape good children, The Lady Gowrie Centre kindergartens were built between 1939-1940 in each capital city in Australia *"as one part of a range of strategies aimed at shaping and maximising the capacities of the population to meet national goals"* (Tyler, 1993, p.45). The kindergartens ran model programs developed in America and designed *"to alleviate the behaviour problems that would lead to adult inefficiencies"* (Tyler, 1993, p.46).

Shaping children for the good of the nation is a theme that has been repeated often in our recent history. Schrag and Divoky (1981) give examples of the desire to locate difference and deviance in the late 1960s. Arnold Hutshnecker, a New York physician, wrote to the government suggesting that they *"should have mass testing done on all 6-8 year old children...to detect (those) who have violent and homicidal tendencies"* (cited in Schrag & Divoky, 1981, p.39). To prevent delinquency, his recommendations included day care and counselling. In the early twenty-first century, preventing antisocial behaviour in young people and adolescents and formulating policy responses is a major concern of Western governments. Governments in the United Kingdom, the United States and Australia, using research

steeped in psychoanalytical and behaviourist theories, believe that the solution to a whole range of social problems, including difference or deviance, lies in enhancing the skills of parents (Einzig, 1999; Hil & McMahon, 2001; Pugh, 1999).

In Australia, Hil and Brennan (2004, p.26) examined a Victorian Study which sought to identify *"antisocial behaviour"* in children. Hil and Brennan (2004, pp.26&29) claim that current research in the area of *"antisocial behaviour"* and delinquency is based on psychological theories of the 1940s and 1950s. In particular, they cite the work of John Bowlby and Donald Winnicott. The authors voice concern about the theoretical underpinnings of the research and the intervention programs employed to regulate children and their families. In contrast, other authors view the impact of Bowlby's and Winnicott's work on current policy and practice in relation to parent education programs as important in securing the healthy development of children (Park, 1999; Pugh, 1999).

Merrett (2004), in her examination of parenting education programs, states that there has been very little *"critical"* analysis of parenting programs and their function in society. However, there are notable exceptions. Moss (1999, p.87) argues that interventions aimed at parents *"are the products of economic forces, political processes and power relationships, dominant discourse and constructions"*. Thus, parenting programs may be more about shaping and normalising populations to suit the needs of powerful forces such as the state and the economy, than about assisting parents to raise their children. Pugh (1999, p.4) also poses the question:

> *is parent education a means of self control, whereby gender stereotypes are reinforced, the family is two married parents with two children, adolescents are urged to conform to socially accepted norms of behaviour, and middle class approaches to child-rearing are promulgated?*

Normalisation in Queensland

In line with other western governments, the Queensland government has introduced a number of intervention programs aimed at families. Wendy Edmond (MLA), Queensland Minister for Health, describes the government's approach to assisting families:

> *our biggest challenge is to harness the necessary resources into evidence-based early intervention strategies, to build a continuum of care, and promote healthy growth and development for all children, young people and their families, particularly those most 'at risk' in our society* (Triple P, 2000, p.1).

An early intervention program implemented by Queensland Health is the Family Community-based Assistance Resourcing and Education (CARE) Home Visiting Program. The Family CARE program is a home visiting program which has been designed to produce eleven outcomes relating to the health of infants. These include:

- ❖ the immunisation of infants,
- ❖ detection of depression in mothers and referral to appropriate services,
- ❖ ensuring *"securely attached infants"*
- ❖ and facilitating *"optimal cognitive development among infants through nurturance and developmentally appropriate stimulation"*

(Armstrong, 2002, p.16)

The author of the program has stated that:

> *the central tenet of the program is the importance of the first few years of life in being protective of poor outcomes throughout the course of life. In essence, a sense of secure attachment in infancy is the glue that holds us together through life's expectable crises*
>
> (Armstrong, 2002, p.ii)

At an information session at the Townsville General Hospital on 30th January, 2001, a representative of Queensland Health claimed that The Family CARE Visiting Project would prevent children developing ADD (Queensland Health, 2001). This statement and the following comment made by the Minister for Health, *"there is…increasing evidence that early childhood experiences are important in how a*

child develops later in life" suggests that the minister, the health department and some professionals, believe that ADD can be prevented by facilitating secure attachments and monitoring families (Unpublished letter 18th March, 2002 to the North Queensland Attention Deficit Disorder Support Group from the Minister for Health, Wendy Edmonds).

Triple P

Currently, the Department of Health, Queensland, runs and supports the implementation of The Positive Parenting Program (Triple P) developed by Professor Matthew Sanders from the University of Queensland (Triple P, 2004a). Triple P is a crucial part of the government's *Early Intervention and Parenting Support Initiative* (Triple P, 2000). Triple P is identified as the *"core business"* of the Health Department (Connors, 2002, p.1) and large numbers of Health Department staff are being trained in the implementation of Triple P in the community (Triple P, 2000, p.6). Triple P *"draws on social learning, cognitive behavioural and developmental theory"* and has five levels of intervention (Triple P, 2004b, p.1). It seeks to change children's behaviour through instructing parents. Triple P is described as *"an early intervention program designed to help parents protect children from mental health problems"* (McTaggart, 2002, p.1). Triple P is offered to families who are experiencing difficulty in raising children and is advertised widely in the community through school newsletters (St. Anthony's, 2003) and health services. The media are also used to convey the message that parent training is desirable and feature stories advertising Triple P: *"Parents to pick up tips from 'expert'"*, *"Learn to be a better parent"*, *"Program aims at bad habits of children"* (Triple P, 1998b, p.8).

Merrett (2004) comments that while Triple P is referred to as an evidence based program, she was only able to find one published study which did not have Professor Sanders as the co-author of the evaluation study. To date, there has been very little critical analysis of the Triple P Program. However, there is some evidence to suggest that a critical analysis discourse is emerging. Connors (2002, p.1), a psychologist employed by Queensland Health, while supportive of Triple P, acknowledges that there has been some criticism of Triple P as not being useful for *"disadvantaged families"*. Paul Harnett (Harnett & Dawe, 2004, p.20) creator of the

Parents Under Pressure program *"developed specifically for multi-problem, high-risk families",* questions the use of universal programs, such as Triple P, to address the needs of all parents and all families. Moreover, Harnett (Harnett & Dawe, 2004) describes the tendency to use so-called evidenced based programs to fix everything as the *"institutional abuse"* of families. Other authors, while supportive of parenting interventions, believe that it is important to acknowledge that many other factors influence the well being of children and families, such as access to employment, housing, child care, education and health facilities (Moss, 1999; Pugh, 1999).

Nurture Theories, Normalisation and ADD

Parent Management Training is considered relevant in changing the behaviour of children diagnosed with ADD (Australian Psychology Society, 2004). Currently, in Queensland, Triple P is promoted as being effective in the treatment of ADD (Bor, Sanders, & Markie-Dadds, 2002). Child and Youth Mental Health Services (CYMHS) refer parents of children with ADD to Triple P (Personal communication with Queensland ADD Support Groups and Northern Region Child and Youth Mental Health Service 2002-2004). Referring families who have children with ADD to Triple P Programs is in line with nurture based theories of deviance as can be seen from an extract, *Causes of ADD*, given to parents by CYMHS:

> *children raised in unstable, dysfunctional families with high levels of emotional and/or physical abuse and/or neglect are more likely to develop the disorder than those who come from stable, non-abusive homes* (Townsville District CYMHS, 1999).

There is little in the academic literature which contradicts Sanders' claim that Triple P is a successful intervention strategy for the parents of children with ADD. However, the use of Triple P (Elms, 2002; P. Harris, 2002) and other parent training programs in treating ADD is starting to be questioned by some grass roots organisations and professionals working with families affected by ADD (Brochin & Horvath, 1996; Harrison & Rees, 1998; Kendall & Shelton, 2003). These issues will be explored in the next chapter, *Theory and Practice*.

Partnerships in Normalising Populations

The Triple P program has also been taken up by other bodies as a strategy aiming to produce normal children, normal parents and normal families. The Every Family Project described as *"a population health approach to the prevention of anxiety, depression and conduct problems in young children and families"* (McTaggart, 2002, p.1), also uses the Triple P program to instruct parents and general practitioners. The Every Family Project is a joint initiative of the Queensland Division of General Practice, beyondblue, the Parenting and Family Support Centre at the University of Queensland and Triple P International. Education Queensland, Queensland Health, Parentline and a number of media outlets are allied with the initiative (McTaggart, 2002). In New Zealand MDB Entertainment and Triple P, in an effort to encourage desirable behaviour in children, screened five minute segments of Triple P over a number of weeks (Triple P, 1998a). The Victorian study mentioned earlier, which seeks to identify and remediate *"antisocial behaviour"*, was a joint initiative of the Australian Institute of Family Studies and the state Department of Justice (Hil and Brennan 2004, p.26). Thus, it can be seen that shaping families and normalising children's behaviour is a goal that many bodies have, including government, professional and community organisations.

Parental Responsibility in Normalising Behaviour

Parental responsibility covers many aspects of caring for children (Hartley & Wolcott, 1994; Hil & McMahon, 2001). However, parental responsibility in relation to monitoring and normalising children's behaviour is increasingly being espoused by western governments (Hil & McMahon, 2001). A few examples will be chosen to demonstrate this apparent trend in Queensland.

In 2002, a mother approached the local media in Townsville. She expressed frustration in seeking assistance for her *"uncontrollable child"* (Mortison, 2002, p.6). The mother at the centre of the story said that she felt a *"lack of community support"* and that parents were:

> *not always to blame for out of control adolescents…everyone says it is the parents who are to blame when kids go off the rails, but my son has had every care possible* (Mortison, 2002, p.6).

It is clear that the mother believed that she had done everything in her power to assist her son. Her view is in stark contrast to the response from the State Member of Parliament, Lindy Nelson-Carr, Member for Mundingburra, who replied that:

> *research showed a child's actions in adolescence could relate back to their first three years of life. The first three years will set the scene for the rest of a child's life. Setting borders (of tolerance of behaviour) and rules then will have an effect on how they act later…children learnt how to behave at an early age* (Mortison, 2002, p.6).

This statement is in line with nurture based research which reports that *" the first five years of children's lives…is of critical importance…for all aspects of later development"* (Pugh, 1999, pp.6-7). Nelson-Carr went on to say that the government provided a number of services to assist families, which included parenting programs. Thus, Nelson-Carr is implying that parents are responsible for not only their children's behaviour, but for taking advantage of government and community programs. More recently Rod Welford, a state government minister, said that he supported the *"use of parenting courses"* as a way of combating the unruly behaviour of children (Lawrence, 2005, p.14).

In a similar fashion, Peter Lindsay the Federal Member for the seat of Herbert, states that parents must be held accountable for their children's behaviour and has put forward a proposal to prevent children from roaming the streets at night. Lindsay has suggested the implementation of *"on the spot fines to parents"* and parenting programs to solve the problem (Lindsay, 2004). In the United Kingdom parents of juvenile offenders are ordered to attend parenting courses under the *Crime and Disorder Act 1998.* Some authors have questioned the efficacy of parenting programs in changing the offending behaviour of children (Pugh, 1999) and suggest that such action by the government *"is premised on imposing social control"* (Jones, 1999, p.144). Hil and McMahon (2001) describe the trend of western governments to hold parents responsible for producing deviant or delinquent children as punitive and blame ridden. Furthermore, Hil and McMahon (2001, p.21) state that parents who fail to produce normal children are easy *"scapegoats"*.

In Queensland, a Consultation Paper, *Education Laws for the Future* (Department of Education and the Arts, 2004), outlines the government's intention to increase parental responsibility in the education of children, in particular their children's behaviour and compliance in the school system. In 2003, expulsion from state schools averaged thirty students per week. Students were

> *permanently excluded from…schools after they attacked teachers or other*
> *students, persistently disrupted classes, refused to do their work, damaged*
> *property, swore or were caught with drugs and alcohol* (Odgers, 2003, p.3).

Anna Bligh, the Minister for Queensland Education exclaimed that there is *"no place for bad behaviour in our schools"* (Odgers, 2003, p.3).

The consultation paper, which is intended to inform changes to the *Education (General Provisions) Act 1989*, outlines the responsibilities of all parties; the student, the school and the parent. What is of particular interest is a proposed agreement, which is based on an example taken from a primary school in the United Kingdom (Department of Education and the Arts, 2004). This agreement seeks to hold parents accountable for their child arriving at school on time, doing their homework, attending parent evenings and their children abiding by the behaviour policy of the school. Hartley and Wolcott (1994, pp.65-66) have remarked that it is unrealistic to expect parents to be solely responsible for *"poor scholastic performance…alienation"* or *"disruptive behaviour"*. Furthermore, holding parents responsible for youth failing to adhere to expected norms is to ignore societal and systemic issues (Hartley & Wolcott, 1994).

Given that this concept and proposed changes to legislation are a recent development in Queensland, analysis of how this will affect the parents of children with ADD is not possible at this stage. However, ADD support groups in the United Kingdom have voiced their concerns over their government's emphasis on parental responsibility in relation to children's behaviour in the school system. Support groups have stated that the government needs to look further for the *"root causes of truancy"* and that the education department

> *demonstrates a high degree of hypocrisy by suggesting a 'tough approach' to*
> *parents unable to keep their children at school, whilst clearly not even attempting*

to fulfil their own responsibility of making provisions for children with AD/HD

who are excluded or truant (ADDNet, 2005b, pp.2&3).

Furthermore they assert that the government's actions will have a negative affect on the parents of children with ADD (ADDNet, 2005b).

NORMALISATION AND DISCIPLINE

Swift (1995) has suggested that Foucault's concepts of discipline and punishment are very relevant in examining the bureaucracy which seeks to normalise mothers and families. The material presented in this chapter indicates that the Queensland Government and other organisations utilise programs like Triple P and the Family CARE Program to ensure the healthy development of children and to prevent deviance. Furthermore, the literature suggests that governments are actively promoting the concept of parental responsibilities and are introducing legislation which holds parents accountable for their children's actions and behaviour. The effect of current programs and policies on the parents of children with ADD is not recorded in the literature to date.

CONCLUSION

In this chapter, Hartmann's concept of ADD and difference has been presented. It has been argued that both nature and nurture theories have been used to not only explain difference but to normalise and control populations. Moreover, in using techniques from Foucault, it has been shown that governments and other power bases have joined together in order to normalise populations and govern through the implementation of programs and policies. In exploring the era of eugenics, it can be seen that, eugenics, based on nature theories, did act as a disciplinary strategy through sterilization and murder. However it has also been argued that nurture theories are also used to control and discipline those who are different.

At present, the Queensland government sponsors a number of early intervention programs, in particular Triple P, in an attempt to normalise the population. It appears that the notion of parental responsibility is also being introduced to govern both children and their parents. At this point in time, there is little in the academic literature to explore the affect of normalisation and discipline on families and

individuals affected by ADD. In the next chapter, *Theory and Practice,* the impact of professional power on families affected by ADD will be examined using McLaren's (2002) definition of power.

CHAPTER FOUR - THEORY AND PRACTICE–

Introduction

In this chapter, the impact of the power struggle within the discourse of ADD will be analysed by exploring the theory base and practice of professionals. Thus, this chapter seeks to explore the affect of professional power and practice on families. Harborne, Wolpert and Clare (2004, p.327) have noted that *"little is known about the individual experiences of those directly affected by the disorder and, in particular, how parents make sense of the variety of different aetiological models"*. However, the works of Malacrida (2003), Carpenter (1999), Mulsow, O'Neal and McBride Murry (2001) and Kendall and colleagues (Kendall, Leo, Perrin, & Hatton, 2005; Kendall & Shelton, 2003) provide valuable information. It should be noted that there are differences within countries and regions in relation to the dominant discourse and resultant practices. Accordingly, a very brief overview of the theoretical framework and resultant practices in both the United Kingdom and the United States will be given before moving on to the Australian context. A more in depth view of the discourse currently operating in Australia, particularly in Queensland, will be presented along with the theoretical framework and the resultant practices.

Perspective from the United Kingdom

In The United Kingdom, ADD is referred to as Hyperkinetic Disorder as outlined by the World Health Organisation (1992)*, in The Tenth Revision of the International Classification of Diseases and Related Health Problems* (ICD-10). Hyperkinetic Disorder *"is a severe form of a syndrome which is referred to in DSM-IV (APA, 1994) and the American literature as attention deficit hyperactivity disorder(ADHD)"* (Cameron & Hill, 1996, p.94). Children with Hyperkinetic Disorder are characterised as *"of average or low average intelligence but an appreciable number will have mild or moderate general learning disability (mental retardation in ICD-10 terms)"* (Cameron & Hill, 1996, p.97). Sandberg (1996, p.11) states that *"a severe and pervasive form of hyperactivity, accompanied by restless inattention, is often associated with neurodevelopmental and cognitive delays"*. Thus in the United Kingdom, Hyperkinetic Disorder is often seen in children who have an intellectual disability.

Another condition associated with Hyperkinetic Disorder is Conduct Disorder, which is listed as a subcategory in the ICD-10. Where both disorders are present, professionals often diagnose Conduct Disorder, thus excluding the diagnosis of Hyperkinetic Disorder. Accordingly Hyperkinetic Disorder is believed to exist in 0.5 to 1% of the childhood population in the United Kingdom (Cameron & Hill, 1996, p.97 & 95). Some ADD support groups have been critical of the use of the ICD-10 in the detection of ADD, as they believe that the ICD-10 focuses on hyperactivity at the expense of other characteristics. Thus, the ICD-10 may be excluding individuals who have greater problems with attention, in particular girls (ADDNet, 2005b).

Medical doctors Green and Chee (1994, p.12) have commented that, at the turn of the last century, mainly due to the work of Still, *"the United Kingdom led the world in its understanding of ADD. Unfortunately as the twentieth century moved along, British researchers became preoccupied with a more psychoanalytical style of psychiatry"*. In her recent study Malacrida (2003, p.230) reported that in the United Kingdom ADD is viewed as *"a behavioural problem...in general stem*[ming] *from family of origin issues"*. Accordingly, family therapy is a popular intervention employed by professionals. Even so, some differences are noted within the overall discourse. Cameron and Hill (1996, p.95) believe that Hyperkinetic Disorder has *"some genetic predisposition"* and *"the role of family factors for pure, severe hyperkinetic disorder is questionable"*. The effect of diet, lead and difficult pregnancy and birth are acknowledged but, believed to be *"small and confined to a minority of tightly defined cases"* (Cameron & Hill, 1996, p.95). Other professionals, like Sandberg (1996, p.10), acknowledge genetics however, locates the disorder within the upbringing of the child:

> *clinically significant hyperactivity is rooted in biological, often genetically transmitted vulnerabilities, upon which environmental disadvantages transact. It may be viewed as a disorder of self-regulation with its roots partly in strained early caregiver-child interactions and disrupted primary attachments.*

Thus, family environment is seen as crucial, even though genetic causes of ADD are recognised by some professionals.

Numerous support groups have formed around the country to provide parents and individuals with information and to lobby for services for children and adults affected by ADD (AD/HD Support Group (S.London), 2005; Malacrida, 2003). Support groups give information on treatments and interventions to assist families, which include medication and diet modification based on the work of Feingold (ADD/ADHD Lincolnshire Support Group, 2005; HACSG, 2005b). ADDNet (2005a) coordinates much of the information coming from and going to support groups and reports on matters of interest such as political campaigns and seminars to increase awareness. ADDNet has voiced concern with the Prime Minister's call for a *"new national moral purpose"* and the tendency to blame *"it all on the parents"* when children display antisocial behaviour, or are expelled from schools (ADDNet, 2005c, p.1). Despite the efforts of support groups to have the government implement a coordinated approach to ADD and offer support for families, ADDNet has stated that the government continues to *"ignore the condition and its social/economic cost"*(ADDNet, 2005b, p.3).

Malacrida (2003) reports that in 1999, the public discourse on ADD was almost non-existent, however, in the following years numerous articles and reports abounded in the media and on television. She concludes that *"the United Kingdom is now well on its way to a climate of controversy"* regarding ADD (Malacrida, 2003, p.67).

The United States of America

Doctors Green and Chee (1994, p.12) believe that "*sorting out ADD* [was left] *to the North Americans"*. Doctor Russell Barkley (1990), a well known researcher in North America articulates clearly that ADD is an inherited biological disorder. The criteria for ADD and co-morbid disorders are determined in accordance with the *American Psychiatric Association's Diagnostic and Statistical Manual* (DSM-IV).

In the United States ADD is regarded as a *"neurobiological disability"* (CHADD, 1997, p.1). Therefore children may be assisted under the *1997 Amendments to the Individuals with Disabilities Education Act* (IDEA) if ADD *"adversely affect* [s] *a child's educational performance"* (AEL, 2000, p.2). Multi-modal treatments are

espoused to assist with learning, behaviour or social difficulty e.g. speech therapy, special education services, medication and individual counselling (Barkley, 2001a).

ADD is recognised as a disorder, which in the majority of cases continues to be experienced in adulthood. A number of books have been published in recent years to assist adults to both understand how the disorder affects their lives and how they may be able to improve some aspects, such as organisational ability and social relationships. The positives of having ADHD/ADD are also explored, for example creativity and high energy levels (Kelly & Ramundo, 1996; Solden, 1995; Weiss, 1993; Weiss, 1997).

The self-help group, Children and Adults with Attention-Deficit/Hyperactivity Disorder (CHADD) was formed in 1987 *"in response to the frustration and sense of isolation experienced by parents and their children with AD/HD"* (CHADD, 2003, p1). CHADD is run by volunteers and operates as a non-profit organisation to assist with information, advocacy and support. The grass roots organisation has assisted many families, however it has been criticised for receiving *"significant financial and other payments in kind from the manufacturers of Ritalin"* (Schmidt Neven, Anderson, & Godber, 2000, p.23), thus implying its complicity with the drug companies.

The Church of Scientology and other associated groups, such as the Citizens Commission on Human Rights (CCHR, 2003) are vehemently opposed to the use of drugs to treat ADD and question the manufacturing of psychiatric disorders as outlined in the DSM-IV. Similarly, the use of drugs and the biological approach is opposed by psychiatrists such as Breggin (1993). Breggin (1993, p.114), in *Toxic Psychiatry* asks the question *"why would parents so passionately desire to believe that their children suffer from genetic and biochemical defects"?* The answer he believes is that *"parents would prefer to think of their children as genetically defective rather than as resentful, rebellious, misunderstood, or even abused"* (Breggin, 1993, p.115).

Overall, however, not withstanding some notable opponents, the biochemical and genetic approach is strong in the United States. Multimodal services are recommended and the provision of educational services is legislated under the *1997 Amendments to the Individuals with Disabilities Education Act* (IDEA).

Overview of Australia

The National Health and Medical Research Council (NHMRC, 1997, p.xi) report on *Attention Deficient Hyperactivity Disorder* stated,

> *Australian studies have found prevalence rates of ADHD between 2.3 percent and 6 percent. Most studies have found a higher incidence of ADHD in boys than girls, with boys scoring higher particularly on measures of hyperactivity and disruptive behaviour scales.*

Recommendation One from the NHMRC (1997) report states that a diagnosis of ADD be considered under the DSM-IV and Recommendations Two and Three call for a comprehensive assessment obtained from a variety of sources.

Legislation and Government Policy

ADD is recognised under the *Commonwealth Disabilities Discrimination Act* (1992). Thus, families and individuals may be able to access some services which are federally funded, such as respite services or the Disability Officer at Universities. However, ADD is not recognised as a disability under the *Queensland Disability Services Act* (1992) as, according to Disability Services Queensland, ADD has not been shown to be of a permanent nature. Thus, in Queensland, as with most other states and territories, families are not entitled to state based disability services. The exception is Western Australia, where the Disability Services Commission provides information, referral and advocacy (van Kraayenoord et al., 2001). In Queensland, ADD is not covered under any legislation or policy, thus individuals and families are not entitled to any specialist services.

Whom Does Discourse Serve?

Currently, within Australia, as in other countries, discourses on ADD are in conflict. What causes ADD and what therapies should be implemented to assist are hotly debated. Harborne, Wolpert and Clare (2004, p.336) have suggested that the experiences of families affected by ADD are grounded in the debate *"about the causes and nature of ADHD"*. Accordingly, in exploring the conflicting discourses and the struggle to own the dominant view within Australia, in particular Queensland, one must ask, *"whom does discourse serve"* (Foucault, 1980d, p.115)?

Foucault stated that *"it is in discourse that power and knowledge are joined together"* (cited in McNay, 1992, p.27) and that *"discourse transmits and produces power"* (cited in Chambon, Irving, & Epstein, 1999, p.272). McLaren (2002, p.48), a feminist who utilises Foucault's (1980d) views on genealogy and power, argues that *"theory and practice are inseparable",* thus, power is embedded in practice frameworks. Therefore, it can be argued that the formation of the discourses of ADD, the theory, for example, the cause of ADD and the resultant practice frameworks form a *"web of power"* (Foucault, 1980d, p.116).

McLaren (2002, p.41), outlines a simple but useful definition of the way in which power can be exercised; *"power over", "power to",* or *"power with"*. Those who practise *"power over"* seek to be dominant and to write the rules on what is normal and functional. The effect of *"power over"* on the individual is negative. Those who practise *"power to",* as in change and transformation, and *"power with",* which involves working alongside others and sharing power, are seen as empowering and positive forces. Thus, power can be seen to operate at a number of different levels.

In order to examine whom the discourse serves, the theory base and the resultant practice will be examined using McLaren's (2002) definition of power and drawing on the limited academic and lay literature. In the following section, two dominant knowledge bases; the genetic approach and the psychoanalytical/behaviourist approach, will be presented, along with two minor but important discourses; the diet perspective and a strengths based perspective arising from support groups.

THEORY, PRACTICE FRAMEWORKS AND POWER

1. Hereditary & Biology

Theory

ADD is conceptualised as resulting "*from a subtle difference in the fine tuning of the brain*" (Green & Chee, 1994, p.19). Professionals whose practice is formed from a biological and genetic framework see the act of diagnosis as *"powerful"* and believe that seventy years of Freudian practices have wrongly blamed mothers for their children's behaviour (Barkley, 2001b). Gordon Serfontein pioneered the acceptance in Australia that ADD was a *"biological problem which was not caused by poor parenting"* (Green and Chee, 1994, p.87). Serfontein and others who held similar beliefs were accused of *'colluding'* with parents and *"in spite of immense opposition from many quarters"* (Nash, 1994, p.vii) set up a clinic in Sydney and later in Brisbane. Serfontein died in the early 1990s. Today there are a number of well known advocates in Australia who view ADD as primarily an inherited disorder. Ian Wallace, Dr Green, Dr Nash, Dr Paul Hutchins, Dr Ah Yui, Associate Professor Steve Houghton, Professor David Hay and Associate Professor Florence Levy, to name a few, regularly speak on the disorder and its treatment from this biological view.

Practice Framework

Diagnosis

Carpenter (1999, p.73) notes that *"there has been a silence in the literature about the positive effects of having a child diagnosed with ADHD"*. However, a notable exception is Barkley (2001a) who states that *"the act of diagnosis is powerful",* and that information regarding ADD and the associated co-morbidities, is crucial (Barkley, 1990; Harrison & Rees, 1998; NHMRC, 1997). A number of authors, for example Wallace (1996), Serfontein (1990), Green and Chee (1994) and Nash (1994) have published books to provide information and suggest strategies to the parents of children with ADD.

In speaking of ADHD children Green and Chee (1994, p.33) remark:

> *these sparky, 'short fuse' children are difficult to discipline as their reactions are so reflex-bound. They learn slowly from experience and along the way cause great pain to their parents, teachers and themselves.*

ADD and Parenting

Parents are seen as the key to assisting the child. The books published by Nash (1994), Serfontein (1990) and Green and Chee (1994) speak of ADD as being highly hereditary, and a disorder which mainly affects boys and adult males. These books do not explore how ADD may affect a father's ability to parent. It is interesting to note that some researchers believe that it is important to explore the impact that a mother's ADD may have on a her ability to parent (Arnold, 1996; Personal Interview with Dr Russell Barkley, 16th March 2001).

Interventions

In the Australian school population, one percent of children are medicated to treat the disorder (Holowenko, 1999; Thorp, 1998), although it has been suggested that this rate is much higher in some states (McHoul & Rapley, 2005). Barkley (2001a) has stated that even though medication is seen as the most effective tool in managing ADD, not all children diagnosed with ADD are medicated. Behaviour management is also recommended for children with ADD. It has been noted that, in the United States, a number of programs have been specifically developed, based on the medical model, to assist the parents of children with ADD, oppositional behaviour and Conduct Disorder (Brochin & Horvath, 1996; Einzig, 1999; Mulsow et al., 2001).

Indeed, Barkley has written at least two parent training programs (1987; 1998). These programs are not available to the parents of children with ADD in Queensland, therefore, they will not be examined. However it is interesting to note that Barkley (1987) has stated that his *"program is not effective with every parent or every child, nor is it recommended for adolescents"* (cited in Brochin & Horvath, 1996, p.51). Furthermore, some authors have suggested that the parents of children with ADD may have difficulty in implementing strategies to assist their children due to their

own ADD (Brochin & Horvath, 1996; Mulsow et al., 2001). Even so, behaviour management strategies are advocated and seen as important.

Barkley (2001a), speaking in Sydney, claimed that behaviour management is more effective at the point of contact, for example, if the problem is in the school ground, the issues should be addressed in the school ground and not in the clinic. There is recognition that many children with ADHD display oppositional behaviour and a significant number develop Conduct Disorder. Thus, strategies to address defiant behaviour take into consideration the characteristics of ADHD and explore different ways of handling day to day problems and defusing difficult situations (Foucault, 1984a; Wallace, 1996). These comments suggest that some programs offered to the parents of children with ADD in Queensland may be of limited value. A number of professionals also recommend speech and occupational therapy.

Power – "power over"?
Malacrida (2003, p.27) reported that a medical label was often helpful to parents as it assisted in removing stigma and blame and that parents were less likely to *"receive...punishment"* from professionals. In her Queensland study, Carpenter (1999, p.199) found that some of the women in her study who consulted medical doctors felt blamed for their children's *"condition"*. Thus, Carpenter (1999, p.199) *"raises the question of whether doctors dispute the patholological origins of ADHD despite treating it medically"*. Her findings may indicate the strength of the behaviourist and psychoanalytic discourse currently operating in Australia or it may indicate that mother blame is very pervasive within our culture. While it may be argued by some that the genetic approach is less mother blaming (Barkley, 1990; Green & Chee, 1994; Nash, 1994; Serfontein, 1990), at this point in time the difficulty that mothers face if they too have ADD has not seriously been taken into account. Furthermore, acknowledging that the father or other siblings may have ADD does not appear to have altered the practice of treating ADD as a disorder that affects an individual, usually the child.

Medical doctors have been accused of abusing their power by pathologising children and prescribing drugs (Carpenter, 1999; Jacobs, 2002). Indeed some authors have

sought to show that the diagnosis of ADD is *"routine and mundane"* and that medication is prescribed *"merely on presentation for the possibility of the 'disorder'"* (McHoul & Rapley, 2005, p.419). It has been argued that this occurs despite the parents being *"manifestly sceptical about (even resistive to) the diagnosis and its methodological grounds"* (McHoul & Rapley, 2005). This view suggests that medical professionals are operating from a *"power over"* perspective in dealing with parents. In contrast, a number of authors (Glascoe, Altemeier, & MacLean, 1989; Glascoe & Dworkin, 1995; Rodger & Mandich, 2005) have stressed that parental concern is a major factor in diagnosing children with behavioural or developmental disorders. This view suggests that medical professionals are more inclined to operate from a *"power to"* perspective in their practice.

2. Psychoanalytic and Behaviourist Framework
Theory

The psychoanalytic and behaviourist perspective attributes ADD to early childhood experiences within the family unit (Rafalovich, 2001b). The literature, including government publications, contains numerous articles and reports written within a psychoanalytic or behavioural framework, with references to attachment theories, dysfunctional families, single mothers, divorce and the decaying of family values as the cause of troubled children who have been given the diagnosis ADHD/ADD (Chapman, 1996; Mertin, 1998; Osmond & Darlington, 2001; Schmidt Neven et al., 2000).

Some writers, in seeking to counter the genetic basis of ADD, *"place*[s] *the child at the centre"* of their inquiry, as opposed to *"the needs of the parent"* (Schmidt Neven et al., 2000, pp.5-6). Furthermore, they have embarked on a crusade to protect *"the physical health and emotional well-being"* of children from the use of medication and state that they know:

> *putting the clamps on the runaway ADHD train will not be popular with parents, who in large numbers rely on stimulants to control their children and absolve themselves of guilt or responsibility at the same time* (Jacobs, 2002, p72).

Both the psychoanalysts and behaviourists clearly see themselves aligned with the child, a protector of children, especially boys. They warn professionals *"not to collude with parents in blaming the child for having the problem"* as they believe that parents scapegoat the child and in doing so, *"deny the complexities of the difficulties they face as a family"* (Schmidt Neven et al, 2000, p.58). As professionals, they believe that they have the knowledge to assess the *"context of the problematic attentional and self-regulatory deficits"* (Schmidt Neven et al, 2000, p.51). Accordingly, the label of ADD and medication are said to act as screens, which mask family problems and dysfunction (Clark, 1996; Jacobs, 2002).

Although professionals operating from a psychoanalytic/behaviourist framework espouse forming partnerships with parents, they see their role as assisting parents to understand *"how the problem originates in the first place"* and to *"tolerate uncertainty and to contain anxiety"* (Schmidt Neven et al, 2000, p.60 & 59). Parents, especially mothers, are viewed as needing education to understand their children and are spoken of as being "*emotionally inaccessible"* (Clark, 1996, p.109). The absence of fathers is discussed and seen as contributing to the problem (Biddulph, 1997).

Practice Framework

Family therapy is viewed as a tool for families to come to grips with their issues (Clark, 1996). The Positive Parenting Program (Triple P), supported and run by the Queensland Government, is also seen as a strategy for the parents of difficult children or struggling parents. Triple P (2004b, p.1) *"draws on social learning, cognitive behavioural and developmental theory"* and was developed on the understanding that *"poor parenting, family conflict and non supportive environments may increase the susceptibility of young people to major behavioural and emotional problems"* (Australian Institute of Criminology, 2003, p.32). Behaviour management programs like Triple P see positive parent/child interactions as crucial to the development of normal behaviour in children and the elimination of pathology (Bor et al., 2002). Thus, Triple P instructs parents and through that instruction seeks to change children's behaviour (McTaggart, 2002; Triple P, 2004b). The use of the

Triple P program in Queensland is advocated by politicians and professions (Lawrence, 2005).

The use of medication to treat children with behavioural problems has been a subject of concern and has been reported in the media (Bagnall, 2000; Cauchi, 2002; Jaksa, 1999; Lawrence, 1998; Tanner, 2000). Echoing this concern, the peak youth agency, The Youth Affairs Network of Queensland (YANQ), commissioned Dr Robert Jacobs to write the report, *Queensland Children at Risk: The Overdiagnosis of "ADHD" and the Overuse of Stimulant Medication* (Jacobs, 2002). Jacobs (2002), a psychologist and lawyer from the United States, is particularly alarmed at the wide-spread use of medication which he believes turns children into *"zombies"* (2004) and calls for a ban on medication until the cause of ADD can be identified.

Interventions

Malacrida (2003) found that practitioners who saw the child's problem stemming from the mother or the family of origin implemented family therapy and/or counselling sessions. The sessions were described by some mothers as *"invasive, unpleasant and 'useless'"*(Malacrida, 2003, p.132). Malacrida (2003, p.132) reported that mothers often engaged in these sessions, even though they were very unhappy about the therapy, explaining *"Well, what else could I do"?* She gives one example of an English mother's experience of family therapy. The mother reported that the professional insisted on seeing the whole family together, even though she was concerned about *"speaking negatively"* about her child and the impact that it would have on him (Malacrida, 2003, p.230). Eventually, the mother gave in to the insistence of the professional to have her son present, saying:

> *the alternative was – that either we refused to play it their way, in which case we would make no progress whatsoever – because we'd had to wait months. Or, we bent to their way of doing it. So we bent to their way of doing it. But, we did so unhappily* (Malacrida, 2003, p.230).

Malacrida (2003, p.172) found that in the United Kingdom mothers encounter almost universal *"mother blame"* from professionals who operate from a psychoanalytical or behaviourist perspective. Furthermore mothers went along with professionals'

insistence of therapies because to refuse may *"produce negative fallout for their children in the form of reduced services, refusals to refer children to other professionals, or negative reports being passed on to other professionals"* (Malacrida, 2003, p.230).

Carpenter (1999, p.200) gives an example from an Australian context, reporting that many of the mothers who consulted one particular psychologist, employed by a government agency, *"felt that he had emotionally abused them"*. One woman had attempted suicide after seeing him and others reported bad experiences, such as Rose:

> *the psychologist had me in tears. He was telling me that I should leave my daughter's bowl of cereal there for three or four days if she won't eat. His advice is totally unrealistic and he's a total put-down. He doesn't like women. He's got a problem with them. I felt like reporting him but I don't have the time to sit here and write letters* (Carpenter, 1999, p.200).

Triple P

As noted in the previous chapter, there is little in the academic literature critical of the use of current parenting programs, in particular the use of Triple P as an intervention strategy for the parents of children with ADD. However in Queensland, Harrison and Rees (1998, p.vi) in referring to programs offered to the parents of children with ADD, states that programs which focus heavily on *"child management strategies"* have been found to be wanting by parents. Criticism of parenting programs, by parents has been expressed in the Townsville media. Sharon Elms (2002, p.8), President of the North Queensland Attention Deficit Disorder Support Group (NADDS) claimed that current parenting programs, in particular, Triple P are *"at best ineffectual and at worst, escalate the problem"*. Philippa Harris (2002, p.8) from the Mental Illness Fellowship, supported Elms' view by saying that the parents of children with *"ADD or ADHD are well aware of the ineffectiveness of available parenting programs"*. Given these statements, it may be useful to examine the broader literature to explore the efficacy of behaviour management programs, particularly Triple P, for families affected by ADD.

Behaviour management programs, which include Triple P, do not take into consideration difference or possible biological basis of behaviour (Attention Deficit / Hyperactivity Disorder, Psychosocial treatments, Behaviour management, 2004). Mulsow, O'Neil and McBride Murry (2001, p.40) point out that interventions which are used with *"nonimpaired children may not work with ADHD children"*. As noted by various authors (Barkley, 1990, 2001b, 2001c; Green & Chee, 1994; Nash, 1994; Serfontein, 1990; Wallace, 1996), children diagnosed with ADD often have learning disabilities, auditory processing problems and a short attention span. Thus, many children with a diagnosis of ADD, would require, at the very least, modifications to common strategies in behaviour management (Wallace, 1996). Even so, it has been stated that children with ADD will make mistakes over and over again and persist with behaviours for a very long time (Green & Chee, 1994; Wallace, 1996). As Barkley (2001c) points out, children with ADD know what is expected of them however, they have difficulty in carrying out the expected behaviour.

Green and Chee (1994, p.35) give a good example of the behaviour that these children exhibit, day after day, month after month and in many cases year after year: *"'Can I have a slice of bread'? 'No, your dinner is just about ready'. 'Can I have a biscuit'? 'No'! 'Can I have a banana'"?* Green and Chee (1994, p.35) go on to state that children with ADD *"quibble, nag and rabbit on until the calmest parent is close to having a stroke"*. These authors comment that *"parents need to be almost super-human to remain positive and encouraging as they live with an ADD child"* (Green & Chee, 1994, p.143). There does not appear to be anything in the literature to suggest that programs like Triple P acknowledge the stress that parents experience in trying to cope with, and trying to change impulsive or hyperactive behaviour.

Another aspect which may diminish the effectiveness of programs such as Triple P is the families' inability to implement the strategies suggested. A number of authors acknowledge the high heritability of ADD and draw attention to the complexities involved when a family is affected by the disorder (Aust, 1994; Barkley, 1990; Green & Chee, 1994; Macnair & Hicks, 2004; Nash, 1994; Rutter, 2001; Serfontein, 1990). However, there is limited research examining how the family operates as a whole when more than one member is affected by ADD, especially the parent.

One exception is Brochin and Horvath (1996) who have noted that the parents of children with ADD may be unable to implement behaviour management strategies, due to their own ADD. Furthermore, Brochin and Horvath (1996) acknowledge that even when programs are specifically tailored for the parents of children with ADD, the program's efficacy is limited in some cases.

There are other factors which may impact on a parent's ability to implement strategies. It is reported that mothers experience a great deal of stress trying to cope with their children's ADD, sometimes their partner's ADD (Smith, 1998) and sometimes also their own ADD (Arnold, 1996; Daly & Fritsch, 1995; Messy purse girls, 2004). Marriage break up (Green & Chee, 1994; Serfontein, 1990; van Kraayenoord et al., 2001) and depression (Carpenter, 1999; Harrison & Rees, 1998; Kendall & Shelton, 2003; van Kraayenoord et al., 2001; Wallace, 1996) are often the result of this stress. Under these circumstances, common intervention, such as parenting programs, may be difficult for parents, particularly mothers and in some circumstances, may be inappropriate (Kendall & Shelton, 2003; Mulsow et al., 2001). Kendall and Shelton (2003) have argued that for some families a great deal more than behaviour management strategies are needed to assist families. Thus, there may be many reasons that mothers are reporting to support groups and trusted organisations that Triple P does not work for them.

Power - "power over"?
In viewing the information from the limited research that has been conducted, it could be argued that a psychoanalytic or behaviourist approach operates from a deficit base and is experienced by many, in particular mothers, as blame ridden. Some professionals operating from this perspective claim that they are protecting children. While they may believe that they are acting in the best interest of the child, a conflict between the needs of the parent and the professional's assessment of the child's needs may develop. Thus, professionals who operate from this approach run the risk of being criticised for placing their knowledge above the knowledge of parents. While behavioural interventions and family therapy may be of assistance to some families it can be seen by viewing the literature that the psychoanalytical or

behaviourist approach may operate from a *"power over"* position in dealing with stressed families.

3. Support Groups and the Strengths Perspective

Theory

Charles Rapp (1998) defines the strengths model as; valuing and building on existing skills, exploring the environment to locate resources, acknowledging that families often know what they need to assist them, valuing respectful relationships and being proactive. Elliot, Mulroney, and O'Neil (2000, Introduction), in speaking of the issues facing families state:

> *parents start out with hopes and dreams for themselves and their children, yet most parents find that family life is far from simple. For families living in vulnerable circumstances, struggling with issues such as inadequate resources, isolation or disability, it can be all too easy to lose sight of hope and for dreams to fade.*

Accordingly, Elliot et al (2000, p.xvi) urge family workers to adopt an *"optimistic stance"* which builds on *"the strengths and capacities of family members"*. The *"optimistic stance"* involves some key factors; listening and hearing the families' views, respectful relationships, goal setting, practical assistance, developing networks and utilising the strengths and skills that exist within the family.

Practice Framework

A number of support groups have formed in Queensland to offer practical support and information to parents and individuals affected by ADD and associated co-morbidities. Various authors attest to the importance of support groups (Barber, 1991; Butler & Wintram, 1991; Reiger, 1995) and it has been suggested that groups assist women *"to manage stressful conditions"* (Taylor et al., 2000). The value of ADD support groups, in providing a range of supports, is also noted in the existing literature (Brochin & Horvath, 1996; Carpenter, 1999; Malacrida, 2003; van Kraayenoord et al., 2001).

The North Queensland Attention Deficit Disorder Support Group (NADDS) states that it aims:

- ❖ *"To promote positive community awareness regarding the issues and challenges of the condition ADD that impacts upon children and adults*
- ❖ *To provide information about services available, including government and community resources*
- ❖ *To assist in the gathering of resources and information*
- ❖ *To empower members to develop their own learning and expertise to assist themselves to gain recognition and support*
- ❖ *To provide a forum for networking and opportunities to share experiences in a non-judgemental and safe environment*
- ❖ *To consult with professionals and members of the community in diagnosis and to meet the challenges of Attention Deficit Disorder"* (NADDS, 2003).

The ADD Association Queensland (ADDAQ), formerly known as The Attention Deficit Disorder Information Support Services Inc (ADDIS) (2003) which operates in the South East corner of the state, describes itself as *"a committed group of parents, educators, health professionals and interested individuals, whose common aim is to address the needs of ADD and ADHD sufferers and their families"*. The group states that it *"was born out of the frustrations of others"* and that *"it will survive because of yours"* (ADDIS, 2003). Accordingly the organisation supplies information to individuals and regularly organises workshops and seminars to promote awareness and advocate for families.

Both NADDS and ADDAQ promote ADD as a biological disorder, with a strong hereditary component. They offer information in relation to medication and diet. In general they do not endorse psychoanalytic or behaviourist approaches as to the cause of or treatment for ADD. Furthermore both groups have advocated for the recognition of ADD as a disability (NADDS Promotional Flyer, ADDIS Information Sheets).

Power - "power with"?

The NADDS (2003) mission statement clearly outlines the purpose and aim of the group:

- ❖ awareness and recognition of the issues for individuals and families
- ❖ providing information and resources
- ❖ the provision of a safe environment for the discussion of issues
- ❖ and working alongside professionals and the community to assist those affected by ADD.

In a similar fashion the information service, ADDAQ states that it is committed to providing information, advocacy and promoting awareness. Thus, it can be argued that the *"optimistic stance"* (Elliot et al., 2000) and a strengths based approach are reflected in the mission statements of NADDS and the aims of ADDAQ. Therefore, some grass roots support groups and information services have the potential to operate from a *"power with"* approach.

4. DIET PERSPECTIVE

Theory

The Diet perspective is centred on the original works of Feingold (1975), who hypothesised that certain foods and preservatives caused behavioural and learning problems. Accordingly, Dengate (1994) was particularly interested in investigating a link between the preservative 282 (Calcium Propionate) a mould inhibitor and children's behaviour and learning. Subsequent research undertaken in Darwin revealed that the preservative 282 commonly found in bread adversely affected children's sleep, their ability to concentrate and their behaviour (Dengate & Ruben, 2002).

Practice Framework

Dengate (1994, p.196) has written and lectured on diet in relation to behaviour and learning problems common to people affected by ADD and recommends the elimination of *"artificial colours, flavours, preservatives, salicylates, amines and MSG"* from the diet to assist with learning and behaviour. Accordingly, foods containing artificial preservatives such as soft drink, bread and fast foods and some natural foods, such as oranges, grapes and broccoli, need to be excluded from the diet

(ADDIS, 2002). Dengate (2005a) urges parents and professionals to modify a child's diet *"as a first means of treatment"* before any other inventions such as medications or behaviour management are utilised to assist with learning or behaviour.

Breakey (1999) a dietician from Queensland, is another well known advocate of the role of diet in treating ADD. She states that, like other treatments, following or changing a diet is not always easy as all treatments require a commitment (Breakey, 1999). Breakey is convinced that changing or modifying diet can assist many people with ADD (1999). It should be noted that much of the changing and monitoring of diet falls to the mother. Both Breakey and Dengate aim to assist individuals and families who appear to be food intolerant.

Power – "power to"?

Barkley (1990) stated that a significant relationship between ADD and diet had been disproven by scientific research. Accordingly, the benefits of diet to individuals and families affected by ADD are primarily found in the websites of organisations or individuals who support modified diets in the treatment of ADD (Dengate, 2005b; HACSG, 2005a). Parents report that a modified diet has assisted their children, thus their family (Dengate, 2005b; HACSG, 2005a). The diet perspective offers alternatives to the limited options currently available. If diet is a factor in learning or behaviour problems, modifying the diet is empowering to both the individual and the family. Practitioners espousing diet modification do not necessarily claim that all children with the diagnosis of ADD have sensitivity to food. Thus, as long as parents, usually mothers, are not pressured into using diet modification at all costs, the diet framework operates from a *"power to"* framework.

STRENGTHS AND OPTIMISM VERSUS DOGMA

The different theoretical models, subsequent practices and the effects of power produce varied results for families, a summary of which is provided in Appendix 1. Saleebey (1992, p5), in examining the different theoretical models which can be used to assist clients, states that *"the obsession with problems, pathologies, and defects, while productive of an impressive lode of technical and theoretical writing, may be*

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less productive when it comes to actually helping clients". Saleebey (1992, p.7) goes on to say that: *"you can build little of lasting value on pathology and problems, but you may build an enduring edifice out of strength and possibility inherent in each individual".*

While Elliot et al (2000) acknowledge that professionals can use a number of approaches or theories in dealing with families; they believe that all practices need to adopt an *"optimistic stance".* The *"optimistic stance"* centres on the belief that strength and change is located within the family. Elliot et al (2000, p.143) states that dogma, in following one approach, is not seen as being in the best interests of the family and encourage workers *"to look beyond their beliefs about what the family needs and focus on the world from the family's point of view".* Drawing on the work of Nietzsche and Foucault, Irving (1999) asserts that science does not have a monopoly on the truth and that there are many ways of knowing. Furthermore, that *"universal notions of the truth lead inevitably toward dogmatism"* (Irving, 1999, p.34). Accordingly, in dealing with families, professionals need to respect that the family's way of knowing is valuable and that each family has strengths that can be drawn upon.

This point is particularly important in dealing with families affected by ADD. Harborne et al (2004, p.338) found that the parents of children with ADD, in engaging with professionals and trying to *"gain recognition...experienced emotional distress".* Thus, they recommend that professionals need to be *"particularly sensitive"* when working with families (Harborne et al., 2004, p.338). Kendall (1999, p.753) also noted that families experienced a great deal of *"exhaustion and emotional distress"* which had not been apparent to her when working in a professional capacity. In analysing over one hundred interviews Kendall (1999, p.753) has claimed that families affected by ADD who did well and managed to survive, did so because

> *they were moving away from the standards and values of what they thought it meant to have a child and be a family/parent. They knew that society and science had not yet caught up to what they instinctively knew to be true. They came to*

understand that there was no intervention known that could help them or their

children cope adequately with the symptoms of ADHD.

These families came to realise that *"medications, individualized education plans, and behavioural techniques"* did not always work and that they had come *"to terms with the chronicity and limitations of the disorder"* (Kendall, 1999, p.753 & 755).

Green and Chee (1994, p.65) also noted that parents, while accepting that the advice of professionals *"holds great wisdom"*, often smile as *"they know we don't have to live with their child"*. Accordingly, it can be argued that the strengths based approach is particularly useful in dealing with families affected by ADD (Elliot et al., 2000). This is clearly articulated by Glenys, a service coordinator:

> *I struggle sometimes when children are diagnosed as having Attention Deficit*
>
> *Disorder, or ADD. Sometimes I'm aware that the same children have been*
>
> *exposed to domestic violence, and the ADD label can mean that their trauma is*
>
> *overlooked when it may be a precipitating factor to the behaviour that has led to*
>
> *the diagnosis. But I have to go with what the family know at the time, rather than*
>
> *trying to force my view on them. For parents there can be an enormous sense of*
>
> *relief that their difficulties with their children are related to an external*
>
> *diagnosis when they themselves have felt labelled as 'bad parents'. That helps*
>
> *them because they feel more in control. That can then create an opportunity for*
>
> *us to work with them on strategies that are helpful for the child* (Elliot et al,
>
> 2000, 149-150).

Thus Glenys is aware of her own beliefs and values in relation to ADD. However, her aim is to work from a strengths perspective and adopt an *"optimistic stance"* in working with the family.

CONCLUSION

In Australia, discourses on ADD are in conflict, with two competing theories, genetics and the psychoanalytic and behaviourist approach, seeking to dominate. However, two minor but important knowledge bases seek to influence the discourse, the diet perspective and grass roots groups which have adopted a strengths based perspective. The theory base of each camp in turn shapes the practice framework and outcome for families. The outcome for each family depends on the way in

which power is used: to dominate, to assist with change, or to empower. In dealing with families affected by ADD, professionals need to ask, are we working alongside families, *"power with"*, or do we employ a *"power over"* approach where the expert instructs and dictates? There needs to be recognition that knowledge does not reside solely with professionals and that a great deal can be learnt from listening to families. Positive gains are to be had from working alongside families, valuing their experiences and respecting their expertise.

In order for professionals to assist families in ways which families consider beneficial, significantly more research needs to be undertaken. This research should not only analyse the effects of theory and practice frameworks on families, but also ask families what they believe they need in order to function as individuals and as a family. It is hoped that this thesis, in drawing on the stories of mothers, will add a new dimension to the significant research undertaken to explore the impact of ADD on families.

CHAPTER FIVE – THEORETICAL FRAMEWORKS AND RESEARCH METHODOLOGY

Introduction

In this chapter the overall theoretical framework of this research will be outlined before moving on to the specifics of the research method. The chapter will also examine a number of concepts central to research, such as what it means to be an insider, the importance of confidentiality and the limitations of the research.

Overall Aim of the Research

The overall aim of the research is to explore the complexity of power relationships which surround and are involved in Attention Deficit Disorder from the perspective of women, primarily the mothers of children with ADD.

Project Objectives

The primary objectives of this research are:

- ❖ To examine power relationships involved in identifying and living with ADD and to show both the positive and negative aspects of ADD.
- ❖ To enable a number of women from the North Queensland Attention Deficit Disorder Support Group (NADDS) to tell their stories of the impact of Attention Deficit Disorder on their lives.
- ❖ To enable themes and issues to be identified. These issues and themes will be examined in relation to the available literature and recommendations made in order to assist women and families within North Queensland and Australia.
- ❖ To act as foundation for further research which can move beyond looking at the causation of ADD and concentrate on the fundamental question of how people are being affected by ADD and how they survive in the twenty first century?

Research Questions

The research questions in this thesis are broad so as to allow women to tell their stories freely. However the fundamental question is: how has ADD impacted on your life and the life of your family?

Feminist Critique of Research

Feminists (Jayaratne & Stewart, 1991; Lowe & Lowe Benston, 1991; Mies, 1991; Reinharz, 1992; Wertheim, 1995) assert that no person, field of enquiry or discipline is value free. Lowe and Lowe Benston (1991, p.49) argue that *"the quest for objectivity is seen as futile by feminist scholars"* as experience and values influence research and the development of theories. Furthermore we live *"in a competitive society, full of vested interests"* (Lowe & Lowe Benston, 1991, p.52) therefore scholarship and research is often a reflection of a patriarchy which seeks to benefit men and exclude women (Mies, 1991; Reinharz, 1992).

Wertheim (1995), the author of *Pythagoras' Trousers: God, Physics and the Gender Wars* examines the emergence of scientific thought, its development and explains how it has been used to shape our world. Wertheim clearly shows how women were excluded from the so-called logical world of the pure sciences, mathematics and physics. In the sixth century BC, Pythagoras the philosopher founded a community based on a combination of religious and philosophical teachings, and the pursuit of mathematics. Pythagoreans believed that *"the study of mathematics could provide insight into human behavior"* (Wertheim, 1995, p.25). Pythagoras further developed the Greek's concept that femaleness was associated with nature and the earth and maleness with the heavens and the gods. Pythagoras claimed that the pursuit of mathematics belonged to the *"psychic realm"* which, in essence meant the realm of man (Wertheim, 1995, p.29). While women were believed to be active in the Pythagorean society the gendering of maths and science was evident from the beginning*:*

> *odd numbers were considered male and even ones female, the specific properties of odds and evens had moral implications for the sexes. In particular, the Pythagorean perception that odd numbers were good and even ones evil cast women definitively on the side of evil* (Wertheim, 1995, p.25).

Accordingly Wertheim (1995) asserts that the development of the field of mathematics which claims objectivity has its basis in misogyny and to this day the application of science works against women.

Science and Quantitative Research

Eyer (1992) in *Mother-Infant Bonding* gives an example of how the research on bonding was used by professionals to serve a particular ideology which seeks to dictate the role of women in society. Science has often utilised quantitative research to oppress women and support the patriarchy (Jayaratne & Stewart, 1991; Mies, 1991). It has been pointed out that quantitative research does have value however quantitative researchers cannot and should not claim to have a *"monopoly"* in defining reality for women (Mies, 1991, p.67).

Feminist Research

Wertheim (1995) believes that women need to determine the way in which science should be practiced and to decide how science can be used to assist women. Reinharz (1992), in discussing feminist research, calls upon other feminist writers and researchers to describe how feminist research differs from empirical and so called scientific research. Lowe and Lowe Benston (1991) conceptualise feminist research as being rooted in the women's movement which seeks to both identify oppression and to seek out ways to address the power imbalance in society. Accordingly, research by women, consciousness raising and political action to end oppression are the building blocks of feminist scholarship (Hooks, 1991; Mies, 1991; Reinharz, 1992; Sprague & Kobrynowicz, 2004). Feminist research also *"insists on the value of subjectivity and personal experience"* (cited in Reinharz, 1992, p.3). Another important aspect of feminist research is *"finding one's voice",* in the process of research or scholarship and creating a vehicle for others to voice their reality (Reinharz, 1992, p.16).

THEORETICAL FRAMEWORKS

In order to present the experiences of women within a theoretical framework, this thesis draws upon Foucault's concepts of power, and feminist standpoint theory. Foucault's work has much to offer in examining power relationships which are involved in and surround ADD as where feminist standpoint theory opens a space for women to tell their stories of mothering.

Power and Resistance

Foucault (1980d, p.119) maintained that there are many forms of power and believed that power was not necessarily a destructive force:

what makes power hold good, what makes it accepted, is simply the fact that it doesn't only weigh on us as a force that says no, but that it traverses and produces things, it induces pleasure, forms knowledge, produces discourse. It needs to be considered as a productive network which runs through the whole social body, much more than as a negative instance whose function is repression.

Furthermore where there is power there is also resistance:

there are not relations of power without resistances; the latter are all the more real and effective because they are formed right at the point where relations of power are exercised (Foucault, 1980c, p.142).

McLaren (2002) states that Foucault's work enables researchers to examine the many aspects of power, including domination and resistance. In addition, Foucault's notions of power provide tools with which to analyse power at both micro and macro levels (Fraser, 1989; McLaren, 2002). For example, at the macro level, Foucault's notion of power has been used in the literature review to examine professional and state power, their interconnectedness in the formation of the ideology of motherhood, mother blame and their attempts to normalise populations. At the micro level, Foucault's notion of power can be utilised to explore the ways in which the mothers of children with ADD exercise power, including the act of resistance and the formation of discourse.

Knowledge and the Formation of Discourse

In the literature review it has been argued that there is conflict within the discourse as competing professional bodies struggle to own the dominant view on ADD. Traditional professional knowledge drawn from the sciences has been seen as legitimate, true and factual while other forms of knowledge are seen as subjective and unscientific. In using Foucault's ideas it can be argued that there are other ways of knowing (McLaren, 2002; O'Brien & Penna, 1998). Foucault speaks of knowledge which is local or regional (Fraser, 1989). This knowledge which he calls, *"popular knowledge"* comes from marginalised groups (McLaren, 2002, p.31).

Foucault (1972) argued that marginalised groups can and do formulate alternative discourses. Furthermore feminists such as McLaren (2002, p.36) argue that *"Foucault's work is engaged social criticism that advocates social and political change"*. Accordingly the concept of knowledge, the formation of discourse, the exercise of power and resistance are central to this research. However a Foucauldian approach does have limitations (Ramazanoglu & Holland, 2002) in exploring the impact of ADD.

Strengths and Limitations

Foucault's concept of genealogy is useful in that it allows us to pinpoint when children who displayed certain behaviours were identified as a problem and in need of correction. Rafalovich (2001a) states that in examining ADD it is particularly relevant to explore what kind of person *"the current society needs"* (Foucault, 1980d, p.58). In a similar fashion Tait (2001, p.93) states that *"differences are created"* so that *"individuals can be more effectively governed"*. What is missing from this approach is that it does not explore what it means to be different and the reality of being different. Thus this approach ignores the reality of women who are living with the difference known as ADD.

Soper (1993) sheds some light on this dilemma in discussing Foucault's view that the identification of paedophilia is purely a discursive practice. While agreeing with Foucault's analysis of how and when paedophilia was labelled and seen as wrong, Soper (1993) argues that by focusing on the formation of the discourse attention is taken away *"from the reality of what happened"* to the young girl in Foucault's example (Ramazanoglu & Holland, 2002, p.133). Thus, the plight of the child and the effect of child abuse are lost in the academic pursuit of analysing the discourse. Wise also looks at the issue of child abuse and states that the real issue for feminists is not in debating its existence from a sociological point of view, it is in examining the impact of child abuse and countering the abuse (Ramazanoglu & Holland, 2002). Ramazanoglu and Holland (2002, p.134) conclude by saying that *"people live in real bodies, in real social relationships, in a real world"*. In a similar way it can be argued that it is important to locate the time and circumstance in which children with ADD were identified as different and in need of correction. However, viewing ADD

as purely a social construction ignores difference and the plight of people who have ADD and their families. It ignores the reality of living with ADD which is fundamental for the women in this study.

Feminist Standpoint Theory

Feminist standpoint theory is valuable in the debate on ADD as it allows a space to be opened and in that space women are seen as *"agents of knowledge about themselves and their experiences"* (Carpenter, 1999). Brown, Lumley, Small and Astbury (1994, p.5) in their research on motherhood, conceptualise women as *"knowers",* who are able to construct knowledge and reflect on their own reality. It has been said that men live in a world devoid of the many day to day realities which sustain our society; looking after the needs of the elderly or children, cooking and housecleaning. Women usually perform these duties thus men are able to *" live in an ephemeral world of abstract ideas"* where *"their thoughts stay lofty and disconnected from reality"* (Sprague & Kobrynowicz, 2004, p.81). Thus, while men often inform the discourse, the knowledge that is produced often has little to do with the day to day reality of women's lives.

Standpoint theory recognises that women have knowledge which comes from their everyday experiences and that this knowledge is often in contrast to the knowledge base constructed by professionals or experts. It is through reporting and articulating women's experiences that feminists can challenge the view of a particular discourse, which often is constructed by and for powerful, white, middle class men (Sprague & Kobrynowicz, 2004). Thus, it is *"from the standpoint of women's experience"* (Smith, 1990, p.4) that the stories of women affected by ADD will be told. This research has been undertaken so that women can speak *"their truth"* (Ramazanoglu & Holland, 2002, p.64) and through this knowledge challenge the existing discourses in relation to ADD (Ramazanoglu & Holland, 2002). Clearly the experiences of women and the impact on their lives is where feminists need to concentrate their energies.

QUALITATIVE RESEARCH

Semi-Structured Interview and Short Questionnaire

In questioning traditional research, feminist scholars have sought to develop research methods which allow women to analyse the position of women and their experiences within society and assist women to challenge the structures and relationships which do not serve them well (Reinharz, 1992). Mies (1991, p.67) regards qualitative methods of research as being *"more useful for women's research"* because they do not *"break living connections in the way that quantitative methods do"*. Kidder and Judd (1986, p.274) state that less structured interviews *"are self-revealing and personal"* and should *"elicit the personal and social context of beliefs and feelings"*. Reinharz (1992, p.20) comments that women in our society are well placed to conduct and participate in this form of research as we are schooled to relate and respond to people.

As surveys, clinical trials and the observations of professionals have to date been unable, unwilling, or just did not see the necessity to portray the experiences and achievements of mothers of children with ADD, a qualitative methodology was utilised to capture the stories and experiences of the women within the support group (Minichiello, Rosalie, Timewell, & Alexander, 1990). Furthermore, given the trauma that these women had been through and the lack of respect that had been shown to them, it was essential to utilise a semi-structured interview to acknowledge that the participants were the experts on their lives. Open ended questions were drafted to gather general information and allow women to tell their story in their own words and explore the issues that were important in their lives. It also gave the opportunity to seek clarification or further information as the need arose (Reinharz, 1992).

As background to the semi-structured interview, a short questionnaire was used to gather basic demographic information, such as age of mother, educational status, and number of children. This information has been collated to give a clear but simple portrait of this group of women. In addition, written material, such as diaries, emails, reports and letters would be used to provide a rich tapestry and to support the

women's stories (Jayaratne & Stewart, 1991). Jayaratne and Stewart (1991) and Denzin (1989) refer to using a number of methods to collect and support data as triangulation. Included in this thesis is information that was given to me up until the time of writing the final draft.

In interviewing mothers of children with ADD, I was involved in a process of women giving voice to their stories. This process was designed to validate the women's reality, facilitate sharing with other women in similar circumstances and allow others to gain some understanding of the impact of ADD. In doing this I wanted to explore an area that is particularly devoid of understanding and self expression. ADD has been seen as a disorder mainly affecting males (Green & Chee, 1994; NHMRC, 1997). Arnold (1996) in viewing the literature, notes that little has been written about the way in which ADD affects females as opposed to males. There is also a suggestion that females are not diagnosed as they tend to be quieter and not come to the attention of professionals (Solden, 1995; Weiss, 1993). Accordingly ADD may not be gender specific (Hartmann, 1999). Moreover within my own circle, the network of ADD, I was aware of women who had been diagnosed late in life with ADD.

Women who had children with ADD were already engaged in a battle on many fronts in having the disorder recognised and advocating for resources. The mothers suffered many agonies in coping with difficult children, often partners as well. They were criticised from all areas, professionals, family and the general public, but they still had some legitimacy. Women with ADD themselves had none. They did not exist. One woman was told never to come back to a particular doctor because he was so outraged with her suggestion that she may have ADD. Other doctors told her the same story that the mothers of children with ADD were told; the difficulties that you call ADD are in reality the evidence of a dysfunctional family. Clearly women who see themselves as having ADD were struggling to be heard. Thus, this research contains one life history to give some insight into the life of a woman affected by ADD and to place her experiences within the political, social and cultural framework of our society (Minichiello et al., 1990).

In order to examine as fully as possible how ADD had impacted upon the life of one woman (Minichiello et al., 1990) questions were constructed in line with those asked of the mothers of children with ADD. However, the questions were to be used more as prompts than questions and only used if the key areas had not been covered. In a similar fashion, Mary Gilfus utilised this method to examine the lives of women in Massachusetts' jails: *"every woman was encouraged to tell her own life story in her own words as much as possible within a chronological and developmental framework"* (cited in Reinharz, 1992, p.131).

Minichiello et al (1990) give an example of the value of examining a person's life story. They explain that quantitative data such as statistics and material gathered from surveys can give some knowledge of the effect of ageing; however, it is only in reading an account of ageing:

> *that we vicariously experience the meanings of ageing on our society. We gain access by reading from the personal and subjective accounts given by the elderly about their lives and their perception of the progression from youth to old age* (Minichiello et al., 1990, p.149).

Diminishing the Power Relationship

Another aspect which is central to feminist research is diminishing the power relationship inherent in the transaction between interviewer and interviewee (Reinharz, 1992). Accordingly, the terms respondent or interviewee were disregarded and the title participant was adopted in recognition that the women were contributing to knowledge and possible strategies for action. Furthermore, I saw myself in my interactions with them as a facilitator of a process, a vehicle through which women could express themselves. I was aware of my responsibilities as a researcher in an academic endeavour however, as the research was women centred, the term facilitator was a more accurate description of my role. The women also knew that I believed that what they had to say was important.

The Process

Ethics approval H936 was obtained on the 1st July 1999. A number of steps were taken before interviews were conducted. At a meeting of NADDS I outlined to the group my research, the reason for undertaking the topic and my aims. I asked for the support of the larger group in my endeavours. Many of the women already knew of my studies and were supportive. At that time two other women in the group were enrolled in science doctorates. I did not intend to interview all women as not all had children with ADD or had ADD themselves. Some had joined because their partner had ADD. My aim was to obtain a wide cross section of women, for example women with older children and women with smaller children, women with tertiary education and women without.

My aim was to interview ten women, all birth mothers or adoptive mothers of children with ADD and one woman who had identified as having ADD. I approached the women informally first, all women approached agreed to be interviewed. A formal letter was then sent to them explaining once again the research and the aims. Before each interview I gave them a Letter of Introduction (Appendix 2) asked them to sign the Informed Consent Form (Appendix 3) and fill out the Questionnaire (Appendix 4). I estimated that the semi-structured interview for the mothers (Appendix 5) and the semi-structured interview for the woman who identified as having ADD (Appendix 6), would take two hours, however I set no parameters on time. In other words, if a woman decided to speak at length on a particular question, she would not be encouraged to shorten her response. I would return to her home or designated place as many times as necessary to complete the interview (Reinharz, 1992). In general the interview and completing the questionnaire took between two and four hours.

The interviews were conducted between mid 1999 and 2000. The interviews were conducted in an informal manner with the semi-structured questions acting as a guide. The general tone of the interviews was of a miniature support group meeting where one woman asked questions and listened while the other thought about the question before speaking of her experiences. Like support group meetings, the

interviews were a mixture of laughter and tears. I later reflected that laughter and tears were very much a part of the life of women affected by ADD (Reinharz, 1992).

Reflexivity

A fellow researcher at the Centre for Women's Studies spoke of reflexivity in research as a notion:

> *of rotational gardening. Of returning to the plot again and again, examining the progress, weeding out the unwanted distractions, comparing growth in one section with what's happening somewhere else, adding things in and looking to see how they influence what is already there* (Yule, 2001, p.49)

The analogy described the process well, as this research enabled me to reflect on the academic literature, what it said, or did not say, about women's lives in relation to ADD and the way in which the omissions or inclusions affected the lives of these women. Reflecting gave me some *"insight"* (Fonow & Cook, 1991, p.2) into the research process and a deeper understanding of what it means to be a political activist.

Many of the women in the group understood and had as part of their commitment to the group a desire to affect social change. They believed that my research and their participation in my research, was another strategy to get the message out into the community that ADD did have a real impact on the lives of individuals and their families. Fonow and Cook (1991, p.3) refer to this process as *"consciousness raising"*. The search to understand and locate the experiences of the women within a theoretical framework and the desire to affect social change is an integral part of this research. In saying this it should be noted that the participants and I were not of the belief that one PhD thesis would change their lives or the lives of their children. The women in the support group know, as I do, that any change will be slow. Some women commented that it might not help them or their children but it may help their grandchildren. Since interviewing the women, two other theses which sought to tell the story of mothering children with ADD have been completed and both authors have seen their work as a vehicle for change (Carpenter, 1999; Malacrida, 2003).

Moreover, in aiming for social change, I was alert to the hostile climate (Malacrida, 2003) in which the research would be received in Australia, particularly in Queensland. Some professionals, while claiming that the parents of children with ADD, who medicated their children, *"were not 'evil people'"* (Passmore, 2004, p.35), nevertheless advocated that they should accept personal responsibility for the behaviour of their children (Jacobs, 2002). Carpenter's (1999, pp.73 & 27) research, which is sympathetic to the mothers of children who have been diagnosed with ADD, primarily sees the *"disorder as one that has been socially constructed"* and *"that the increase in identification of adult ADHD serves the interests of pharmaceutical companies"*. In reading Carpenter's and Malacrida's work it was obvious that there were similarities as well as differences. It was interesting to examine the approach that both women had taken, one as an insider and the other as a researcher outside the experience of mothering ADD children. This caused me to reflect on the different approaches and the analysis of material presented.

Hesse-Biber and Yaiser (2004) provide insight in looking at difference within feminist research. They state that the position of the researcher and the participants will determine the way in which the research is conducted, the data gathered and the analysis drawn. Foucault (1980d) argues that there are no absolute truths and that there are many ways of knowing. Accordingly, the purpose of my thesis is primarily to speak of knowledge from the perspective of a number of women in the ADD support group in regional North Queensland. The participant's knowledge or ways of knowing and mine do not cover all aspects of having children with ADD or having ADD. Carpenter (1999, p.142) refers to this point as offering a *"partial account of a way of life of a group of people rather than a total picture of the wider world"*. Even so, the research seeks to challenge a number of supposed truths that have been presented to-date in the academic literature. Carpenter (1999, p.143) refers to this in her research as enabling *"a broader understanding of how things are"*.

Empathy and Rapport

Riessman (Cited in Reinharz, 1992, p.26) states that *"gender is not enough"* to develop rapport, empathy or to find meaning especially when dealing with abused or maligned groups. Hesse-Biber and Yaiser (2004) also point out the importance of understanding that *"gender is not enough"* (Reinharz, 1992, p.26) in undertaking feminist research. This is certainly true of the women who had children with ADD as they did not feel free to discuss their issues and concerns with just any other women. Years of experiencing blame, or simply silence when ADD was mentioned, had led many women to develop an acute sense of when it was safe to disclose, or explore, and when not to continue the discussion. Occasionally they continued with conversations, even when the silence spoke volumes, simply because they were sick of being ignored. Furthermore not all mothers who have children with ADD naturally relate to each other or wish to relate to each other, as ADD cuts across class, culture and race. Even so, I have experienced and observed that many mothers of children with ADD sense a kindred spirit. In a similar fashion Mies (1991, pp.69-83) speaks of *"identification"* taking into consideration class, culture and race, demonstrating that awareness of sameness or difference is central to any feminist research.

I was fortunate to have a personal relationship with the women I was to interview. The women and I belonged to a support group, NADDS, and most had been members for a number of years. The support group had written its mission statement (NADDS, 2003) early in 1998 and this was a reflection of the group's operation and philosophy. The support group was committed to supporting women in a non-judgmental way, providing an atmosphere of trust and respect, valuing women's experiences, acknowledging our own expertise and working with professionals to enhance the understanding of ADD. These principles and aims were broad feminist concerns, which members of the group endeavoured to honour, even though most of the women would not identify as feminists.

I consider these women to be my friends; we had shared our troubles and joys for many years. bell hooks (1991, p.30) believes that women *"bond with other women on the basis of shared strengths and resources"* as *" they cannot afford to see themselves solely as 'victims' because their survival depends on continued exercise of whatever personal powers they possess"*. This is particularly true of women who have children with ADD. They are blamed for their children's difficulties, and they are seen as failing their families and society. Many will seek reassurance in a support group. The characteristics of these groups are strength, endurance and the ability to support other women. Given my close relationship with the women, a number of questions arose:

- ❖ How would this research affect our relationship?
- ❖ What were the strengths of knowing these women on a personal level and what weaknesses or problems could arise?

Strengths and Possible Pitfalls

I had already established a relationship of trust and respect with the group members. Oakley (1981) believes that developing personal relationships is often unavoidable and is a strength of feminist research. However, I was concerned that in a more formal research conversation, questions in relation to their partners may prove difficult at times. Some members of the group had often expressed their disappointment or anger at their husband's avoidance or lack of involvement in managing the impact of ADD on the family. While people may disclose to a trusted friend that they resent, or question, the relationship with their partner and wonder about its value, information may not come so freely when the same friend is in the role of researcher and asking you to speak into a microphone. While I believed that some women might hesitate to disclose their feelings and thoughts, I was confident that Riessman's (cited in Reinharz, 1992, p.25) concept of sharing *"cultural patterns in order to understand each other"*, would prevail. In general it did.

I was also concerned that revealing information in a formal way might mar the friendship in some way but I found, like Harris (2002), that it was not the case. Harris (2002, p.50) in examining the strengths and weaknesses of interviewing

women who are friends, states that *"the friendship had life before and after the research event"*. Accordingly, I believed as an insider I was in a position to receive in-depth information pertaining to the experiences of women whose lives have been affected by ADD.

The Insider

As an insider, I did run the risk of the participant or myself assuming knowledge or encountering the *'you know, you understand'*. Yule (2001, p.51) as an inside researcher on the topic of women and Breast Cancer believes that being an insider *"necessitates an added commitment to careful listening"*. If the participant or I suspected that I might already know the answer, I could run the risk of missing the opportunity to explore issues further (Minichiello et al., 1990). Accordingly, I needed to be alert and check for meaning during and after participants had relayed their experiences. I knew after many years of interviewing that I did have good listening skills. I had been employed as a case manager for six years, working with a diverse range of people. My ability to work effectively in this area was based in part on my listening skills and ability to make sense of what was being articulated and what was not said at that point in time. Another issue which I needed to be mindful of was that, I had already identified potential themes, such as mother blaming, since as a group of women we had shared similar painful experiences. Therefore I took great care not to influence their answers.

Van Heugten (2004, p.208) has carefully considered the value and pitfalls of being an insider and states that *"passion must be valued and harnessed",* however she strongly recommends that *"values, beliefs and personal interests should not only be declared but challenged on an ongoing basis"*. Thus a healthy tension between *"passion"* and scrutiny must be maintained throughout the research process. This tension was achieved by inviting feedback from academic staff and professionals working in the mental health and community sector as well as engaging in dialogue with support groups throughout Australia.

Data Analysis

Feminist researchers' views and approach to editing and analysis vary. Reinharz (1992, p.137) articulates the view of one researcher who presents the stories of women without analysis:

> *Nancy Siefer believes that the women are capable of analysing their lives, and that an analysis is contained in what they are saying. Moreover, she believes that if the women are heard directly, without her interference, the reader will be able to identify with them. It is this identification that will produce social change, not the oral historian's analysis of the women's lives.*

In contrast, Elizabeth Hampsten *"suggests we worry less about imposing our ideas and worry more about taking initiative"* (cited in Reinharz, 1992, p.137). The approach taken in this research is to use the words of the women and wherever possible present their experiences as a story or case study. However, in analysing the data, I was informed by the work of Thorpe (2003) and Irwin (2003) who urge researchers to critically reflect on the power relationships and values which shape the narrative. Hence, going beyond the reporting of women's experiences, and locating them within the theoretical frameworks of Foucault's concept of power and feminist standpoint theory.

In compiling the interview questions and the short questionnaire the questions had been divided into related areas. This made reading and analysis of text much easier, although many of the interviews did not precisely follow the format. In reading the collected data, it very quickly became obvious that there was a wealth of detailed information. Thus, it was important to refer back to the original aims of the study, particularly in identifying the positive and negative aspects of power and the impact on the lives of the women. Through this process common themes and differences were identified. Consistencies and variations in the feelings or experiences of the women were explored and contrasted with literature or verbal information from other groups throughout Queensland. Thus it was possible to draw out unanticipated outcomes, such as the level of violence that the women experienced in their lives.

Ethical Considerations

Ethical considerations are imperative to feminist research (Fonow & Cook, 1991; Reinhartz, 1992). Confidentiality (Darlington & Scott, 2002), due to the sensitive nature of stories, is a prime consideration in this research. Accordingly, I made it clear to the women that I would not publish their names and asked them to pick a pseudonym. Choosing a name was met with some degree of mirth. I was also mindful that a pseudonym may not always protect the person's identity, as we live in a regional city and people could be identified by relating a story. I discussed this possibility with the women and gave them an undertaking to protect their identity, as much as possible, in the relating of their stories. While some women were very open about their stories and the issues for their families, some women revealed during the interview that some information they had only ever shared with me. The vast majority of this information they had shared with me before the interview process. Once again, it reconfirmed to me that the impact of ADD had silenced many women and that I held a position of trust.

Scrutiny of the Research.

Before this thesis was submitted I had the opportunity on a number of occasions to present a paper at conferences, seminars and workshops. Many of these presentations were based on the stories that the women had told me and the information that they had given me through the questionnaire. My first presentation was at a major conference in Sydney. I was mindful of the sensitive nature of some of these stories and the issues which had been revealed. Accordingly, I presented my paper to the support group at a meeting and asked them for feedback. The women were not concerned with the information that I had presented, as they felt it was an accurate reflection of their stories. Their main area of feedback, was in the selection and presentation of overheads. In other words, how to make the presentation better. Presenting at the conference, a couple of weeks later, was nerve racking however, I was very happy to have women from the support group in the audience. The response that I received from both them and other mothers in the audience was an affirmation and a desire to speak about the issues that affected their lives so dramatically.

As Anne's story was particularly poignant, I felt that she needed to read the material I was presenting in Chapter Eight. I contacted her and arranged for her to visit my home. Over a coffee Anne read the draft of that particular chapter. As I watched her read, I saw goose bumps rise on her arms. When she finished reading, I asked how she felt about what she had just read? She replied in relation to her story: *"the more parents that know about it, the more chance there is of others getting help. If my story can help one family then it is worth it"* (Personal Communication 28th September, 2004).

Limitations of the Research

This research contains 10 interviews and one life history thus the findings from this research cannot necessarily be seen to be representative. The issues facing women who had experienced ADD at some level are many and complex. In order to bring out as many issues as possible and allow women to express themselves, it is important to favour depth, as opposed to quantity. Similarly, with presenting one life history, the emphasis is on the opportunity to express experiences and open up research questions. Thus, my research is focused on exposing issues and opening up the closed cupboard called mothering and ADD. Where possible, the women's experiences were contrasted and compared with those of other women in support groups throughout Queensland. The women's experiences can also be compared and contrasted in future research.

CONCLUSION

This research is primarily concerned with the power relations surrounding ADD and providing a space in which the women can tell their stories. Accordingly ten mothers of children with ADD and one woman, who stated that she had ADD, were interviewed to provide qualitative research data. The insider status of the research is acknowledged, as are the feminist values which underpin this research. Attention has been paid to the process of research, for example, ethical considerations and the necessity to develop and maintain trust, empathy and rapport. This thesis draws upon Foucault's concepts of power and feminist standpoint theory, in both the presentation and analysis of the data. The following chapters detail the findings of this research.

CHAPTER SIX - DIAGNOSIS, DIFFERENCE AND RESISTANCE TO BLAME

"The need for aliveness is a neurological 'hunger' that must be satisfied" (Hartmann & Lavallee, 2003, p.3).

Introduction

In this chapter the women's efforts to find answers to their child's difference and their conceptualisation of difference will be examined. The blame that the women encountered for their child's difference and the blame that they encountered in relation to medicating children will be analysed along with the their views regarding the use of medication. In addition, the resistance to blame will be explored alongside the perceptions of self. Before moving on to the data analysis a short history of the support group, demographic information and a snapshot of the individual women will be presented to give the reader a foundation upon which to hear the women's stories.

BACKGROUND INFORMATION AND PROFILES

Location

The twin cities of Townsville and Thuringowa lie in the dry tropics of North Queensland. The region has a population of approximately 146,000. The centre lies 1,500 kilometres from Brisbane the capital of Queensland (Townsville City Council, 2004).

Townsville is part of The Northern Zone of the Queensland Health Department which covers 750,000 square kilometres, stretching south to Mackay, West to the Northern Territory border and North through the Torres Strait Islands to the Papua-New Guinea border. Townsville residents have access to a number of health services, which include mental health services for children and adults. However, funding for mental health services in the sparsely populated northern zone has been an issue for many years (Mental Illness Fellowship, 2004).

In the year 2000, the same year that the majority of women were interviewed for this research, a discussion paper was written regarding the profile and resources of the

Child and Youth Mental Health Services (CYMHS), Townsville. The Discussion Paper states: *"traditionally CYMHS has been under resourced and lacked a critical staff level to deliver a service"* (Colley & Park, 2000, p.3). In 1997, four staff covered the region comprising the Townsville, Charters Towers, Mt Isa and Bowen area. In the year 2000, twelve staff from a variety of disciplines covered this region. Furthermore, the Clinical Director of the service was the only child psychiatrist in the public health system North of Brisbane (Colley & Park, 2000). It was noted that traditionally staff ratio has been decided on population however, health services do not see *"a child or young person in isolation... service delivery is to the family. Hence, the need to review the staff ratio to population"* policy (Colley & Park, 2000, p.3).

In 1999 and 2000, while the interviews for this thesis were being conducted, Child and Youth Mental Health staff was regularly involved in community forums and consultancies, which explored the issues for individuals and families affected by ADD. Their commitment to providing a quality mental health service is not in question, however the traditional staff ratio to population policy had a severe impact on their ability to provide a service to people living in North Queensland. It is against this background that the women tell their stories.

Demographic Information

Of the ten women who were interviewed nine had partners. Five out of the ten women were in their mid to late thirties, while the remaining five were older. Of the women who had partners, some of their partners were a few years older in fact three women had partners approximately ten years older than themselves.

In looking at educational attainment it can be seen that seven out of the ten women have tertiary qualifications. In general the women have better formal education than their partners. Between the ten families there are twenty six children. The smallest family had one child and the largest five children with the mean being two children per family. Of the twenty six children only seven are girls. Of those twenty six children, fourteen have ADD - twelve boys and two girls. The average age of the

children with ADD is fourteen. A graphical representation of this data is provided in Appendix 7.

Support Group History

All women interviewed were members of the North Queensland Attention Deficit Disorder Support Group (NADDS). At the time of the interviews the group had approximately fifteen financial members. However many more people attended meetings and information sessions and the executive members reported receiving numerous calls from people in North and North West Queensland.

The support group was formed in 1993 by a number of women. Anne, a founding member of NADDS responded to a letter box drop in the Upper Ross area of Thuringowa. While Anne lives on the other side of town, she was contacted by a friend and told about the group's formation. Originally the organisers thought that just locals would come but were surprised to see *"that people came from all around"* (Personal Communication with Anne 2000).

Anne described her memories of those early days, *"it was a traditional support group, where you could go and talk about your problems"*. The group had to be out of the building by nine o'clock, so:

> *there'd been many a time we'd continue sitting around the table outside, it was just so fascinating to be able to know there was others out there that had ADD children, and talking to them, and everyone had that little bit…little different ideas and I'm one that I like to take a little bit…from here, and here and here, and then make up how it suits my family.*

Roseanne described the ethos of the group:

> *it's a band of women who are very much under stress and have linked together out of a common need. And I think, in times of crisis, relationships and sharing goes quite deep. And that's nourishing, very nourishing really. To have that kind of trust level and care and I suppose you can liken it to when a cyclone comes, hitting a city, the sort of relationships that people have with each other, like all the pretence is gone and there you are,… naked as the day that you were*

born, with none of your uppities or downities and just kind of with each
other,…it's sort of we're all in it together. Helping each other the best way we
can.

In 1999 *"the group became more of a lobbying group"* (Anne). Some mothers felt that the talk of politics and lobbying went over their heads, so it was decided that every second meeting would be a support group meeting and every other meeting would be a strategy meeting. Thus, mothers could choose to attend: an informal support group meeting, a formal meeting where lobbying and government policy were discussed, or they could attend both meetings. This format suited mothers in the support group and others who wished to attend on an ad hoc basis. In general the group worked well together however there were challenges as the impact of ADD had different consequences. Women who had older children, most of whom had not been diagnosed until adolescence or young adulthood, had horror stories of drug abuse, stealing, trouble with the law and violence. For the mothers of young children their stories were often too confronting:

sometimes when we talk about these things, I see they get this look of absolute
panic in their eyes and I don't want to say too much about what the future may
hold because I don't want to be negative…they are flat out coping now and so I
just shut up and say a little prayer for them (Mary Serenity).

Despite differences, the general feeling was that the women were there to support each other. **Joyce** spoke of her experience:

I think that the ADD support group has been the most beneficial support I've got,
talking to people … who have got similar experiences, who've been there before,
have used different techniques, have tried different things, and it's worked
(Joyce).

Snapshots

The women chose pseudonyms which often described how they were feeling about life, for example Number 13 described her life as *"shitful"*. Mary Serenity (A Student of Life*)* was reflecting on her life to date and the journey that it had taken her. Others, like Wild Thing and Mim decided on childhood nicknames.

Feral Cheryl

Feral Cheryl has tertiary qualifications, works for a non government organisation and is well regarded professionally. She has two boys and is a single mother. Michael her eldest has ADHD. Michael's father was nicknamed Gofast. She has not seen him for years. Feral Cheryl's parents assist her with the children but *"don't believe in ADD"*. At the time of the interview Michael was living with Feral Cheryl's parents as she was no longer able to cope with his aggressive and demanding behaviour. Michael is ten years old.

Wild Thing

Wild Thing holds a responsible position in the public service. She has one child, twenty one year old Brett whom she has raised by herself. Brett has recently been diagnosed and with the help of medication has taken up an apprenticeship with his grandfather. Wild Thing reports that professionals treat her and Brett differently now that she is married to a respectable senior public servant.

Number 13

Number 13 describes her life as *"a nightmare"*. She says that she cannot think of one positive aspect of family life or having children with ADD. She is married to Gary and they have three children. The eldest Stewart is twelve years old, has ADHD and numerous other co-morbid conditions. The middle child, Jane is nine. Jane is described as *"our saving grace"*. The youngest, Anthony is seven; he also has ADHD and other co-morbid conditions. Number 13 takes on the traditional role of mother although she does work a few hours each week in the paid workforce.

Leanne

Leanne is well known in her chosen field. She is married to Bob and they have three children. The eldest, Julia is twenty. She was diagnosed four years ago with ADHD and a Conduct Disorder. Toby the middle child had speech and language problems as a toddler and threw enormous tantrums. Toby is now nineteen. With maturity the behavioural problems disappeared and Leanne describes him as a great support and *"the one who holds the family together"*. Thirteen year old Tom, the youngest has ADHD and is very defiant.

Mim

Mim is currently working on a science doctorate; *"I went off to University for my sanity, I could not have coped"* otherwise with the demands of bringing up a child with ADD. She has two boys. The youngest, James is fourteen and has recently been diagnosed as having ADD. Mim is in a relationship with a professional man and describes their relationship as less than satisfactory. Mim is assertive and committed to advocating for social justice. She is passionate about the need to change the education system to cater for children who learn differently. Mim has spoken at length with the Education Minister about the needs of children with ADD and auditory processing deficits.

Anne

Anne has two boys diagnosed with ADHD. Her husband Joe was diagnosed during the sixties as hyperactive. At the time of the interview, the oldest son, fourteen year old Clifford was in boarding school as the parents had not been able to find any other school willing or capable of dealing with Clifford's behaviour. Not long after the interview the second boy, Carl, who is twelve, was also sent to boarding school.

Joyce

Joyce has two boys, Nick who is ten and eight year old John. Nick was diagnosed with ADHD at a young age: *"he had absolutely every...* [other] *child terrified. He would hit, kick, spit, bite, grab, shove, push, yell, scream, take toys off them, do anything to create the biggest attention"*. John was diagnosed with learning difficulties. Joyce had left an abusive relationship. The children's step father, Rick, is very supportive. Joyce had recently *"finished up full time employment to sort out the problems the kids were having after the experience of Nick being away for ten weeks"*. Under the direction of the Family Court, Nick had visited his father who lived in Bundaberg. His father initially refused to send him back. After ten weeks, Nick was returned to his mother. Both boys were *"distraught"* and could not be separated for three months after the incident. Joyce is now working casually and studying part time.

Mary Serenity (A Student of Life)

Mary Serenity is married to Keith and has two adopted children, Steven, who is eighteen and thirteen year old Eileen. Mary Serenity described her feelings of being able to adopt Steven, *"when he was handed to me he was the greatest gift I was ever given so I totally fell in love with him"*. Steven was diagnosed with ADHD at fourteen and Mary Serenity and her husband were told by the psychiatrist:

> *as he grows he may test you to your limit, you will have to make rules and stick to them otherwise he will destroy your family,…but [at] the same time you must, always let him know that you love him,…love him because if you don't no one else will.*

Roseanne

Both Roseanne and her husband Lee had come *"from an upper middle class, well educated, fairly wealthy background"* and both worked in professional occupations as their children grew older. However, when Roseanne and Lee experienced problems with their eldest, Joshua, they really didn't know *"where to go for help"*. Joshua is eighteen; he has one sister and three brothers.

Caroline

Caroline has four children; two have been diagnosed with ADD/ADHD. Eight year old Clint is hyperactive and requires constant supervision. Eighteen year old Beth has dropped out of school unable to cope with the work, and has recently given birth to a baby. Caroline receives little support from her partner and is exhausted trying to cater to the needs of her children and grandchild. Caroline has a family history of ADD. Caroline has a strong commitment to her immediate and extended family. She is close to her mother and father and they help out as much as they can.

THE STORIES OF WOMEN

The Journey of Diagnosis

The women in the support group meetings spoke at length of the many visits to health professionals before their children were diagnosed with ADD. This was in contrast to the perception in the media (Dullroy, 2002; Laurie & Cubbin, 2003; Lawrence, 1998; Pirani, 2005; Tanner, 2000) and the statements made in the general

and professional community (Chapman, 1996; Schmidt Neven et al., 2000) that *"doctors were too quick to diagnose a child and parents too quick to accept a diagnosis"* (Mancuso, 2004a,p.16).

Many of the women seemed to have been on a journey. It was this journey that needed to be explored and told. One of the questions asked during the interview was; *"When did you feel that your child may have been different or when did you first experience problems"?* Also, *"What was the length of time"* it took for your child to be diagnosed? The responses were varied, however, the pattern was similar.

Some of the first time mothers described active, demanding and some times difficult children. For these mothers active, demanding babies and toddlers was a part of motherhood and initially they did not see the behaviour or activity as different. However, as time went on many mothers started to become aware that their child's behaviour, lack of social skills or inability to learn, was becoming a problem.

Mary Serenity speaks of her adopted child Steven:

> he was active, always very active and I thought that he was very bright. So I didn't sort of worry about it, I just accepted it and at the age of fourteen months he pulled a pot of tea on himself. And it was then I realised that his activity....was quite dangerous. Age 2, I realised that we had a bit of a problem on our hands...we moved into a new house,...it was near the river and he kept running off to see the neighbours,...I never knew where - quite happy visiting strangers. I was terrified that he'd fall into the river so we built a six foot fence and he learnt to climb it within two days. And I realised that he was quite a hand full and had to be watched twenty four hours a day....I just accepted that,...I thought all little boys were like this.

Mary Serenity's son was formally diagnosed at fourteen.

Wild Thing's story was similar:

being an only child it didn't worry me having just to constantly run after him. …
He would sit and open windows on the second floor when he was 18 months.
Just sit on the edge of the window. …Very hyperactive. Actually to the point
where if I went to the toilet, I had to take him in with me and lock him in.

Problems started to set in for Brett:

after he started to go to school. Preschool wasn't as bad as grade one but from
grade one on it just got increasingly difficult. Teachers were always complaining
about him… not concentrating on what-ever they were doing in the classroom,
trying to raise attention to himself at all times. Ah, being the class clown, ah,
aggressiveness in the playground (Wild Thing).

Wild Thing lamented that:

it took me 13 years to get someone to recognise it and give me a diagnosis and be
willing to actually help Brett to do something about it. Not only is it frustrating
for me it is also frustrating for Brett, not knowing what's wrong with him, he
knew there was something wrong with him. But of course they just put the label
of being anti-social, naughty, delinquent.

Feral Cheryl said of her first born Michael:

he never slept through the day, …even as a little baby, … and I can remember
just sitting there amusing this baby, because he was my first baby, I didn't think
that was any different, … I thought well that was what it was like having a baby.
… And it wasn't until I … had Joey [his brother] that I went back and …
compared, and I thought my God, …the difference in the two of them.

Feral Cheryl sought professional help when Michael tried to light a fire. He was three
years old. Feral Cheryl contacted a number of services and completed the Positive
Parenting Program, Triple P. She found that the services offered to her and Triple P
did not help her. Her frustration with the lack of assistance is reflected in the
statement that she made to the Doctor who finally diagnosed Michael when he was

eight years old; *"do not give me another positive parenting programme,...*[if] *you refer me to a positive parenting programme, ... I'll get up and walk out"*.

Leanne describes her first born, Julia:

> *there was a lot of problems at home because she was a very difficult child, had to be constantly supervised, wanted to be entertained, have activity all the time. ... I just thought it was her .*

Schooling proved very difficult for Julia as she:

> *experienced great difficulties with learning, ... in year 3, year 4, ...she had a lot of trouble with learning to read and needed a lot of extra support, ... and then things deteriorated quite badly in year 6 and year 7...she had difficulties with making friends and keeping them, right throughout her school years. ...she actually got expelled from year 7 for biting someone* (Leanne).

Julia was diagnosed when she was sixteen years old.

Roseanne describes her experience as a first time parent:

> *Our son was our first born, it was hard to know what was different because we had nothing to compare with...we just thought we weren't doing a particularly good job as parents...he never seemed to learn from discipline...he would be hitting other kids on the head in play group, just contrary, testing continually, taking off down the side...when you're hanging out the clothes, didn't matter what you said or did or bribed...he would just be contrary.*

Roseanne's son, Joshua was diagnosed at fourteen years of age.

Mothers who had other children or women who had looked after young babies knew that their child was different from an early age. **Mim** said that she knew her second child James was different from *"the first week of life...when James wanted to feed he wanted it straight away, there was no waiting time, it was immediate gratification, absolutely"*. Mim explained that *"he threw a tantrum on his first day home from hospital"* and that he was *"a crappy baby"* who *"woke regularly"*. Although James experienced difficulty from kindergarten, Mim did not contact Child and Youth Mental Health Services until he was eight and later on when he was twelve. Mim had been told on the first occasion that her son *"did not have ADD"* as *"he was a*

very bright boy" and could read. On the second occasion parenting skills was identified as the problem. He was diagnosed at 14 by a paediatrician in private practice.

Anne said that with Clifford it was *"only a matter of a couple of weeks…I realised he wasn't sleeping, feeding, and doing what I'd consider what a regular child would do"*. Anne sought help when Clifford was a baby due to his demanding nature. Clifford was diagnosed with ADHD when he was seven years of age.

Joyce explained that her child Nick was different:

> *from the very beginning, Nick was a difficult baby, …a lot of sleeping problems, … allergies…never fully well, irritable, always needing to be entertained, never smiling or happy, very rare to have a really good day.*

Joyce had been told by a naturopath when Nick was almost three that he may have ADD. He was diagnosed by a private medical practitioner when he was five years old. Thus, it can be seen that the stories of the women's long and painful journey was in stark contrast to the assertion by some professionals (Chapman, 1996; Mancuso, 2004a; Schmidt Neven et al., 2000) and some stories in the media (Dullroy, 2002; Laurie & Cubbin, 2003; Lawrence, 1998; Tanner, 2000) that a diagnosis of ADD, was too easy to come by.

What Difference Does Diagnosis Make?

To the mothers, diagnosis is an important step. The general view in the academic literature, which centres on a behaviourist or psychoanalytical framework, is that parents seek a diagnosis to absolve themselves from blame (Jacobs, 2002; Schmidt Neven et al., 2000). This stance also views the label, ADD, as a purely negative one. The positive aspects of diagnosis or the label of ADD is hard to find in the literature (Carpenter, 1999). Barkley (2001a) is an exception. During an Australian conference, he stated that the act of diagnosis was powerful, as diagnosis and the subsequent information assists parents to understand why their children behave, think and learn differently. Parents' quest for knowledge, understanding and services is recognised in other areas of disability or difference (Ho, 2004).

Ho (2004, p.87), in speaking of learning disabilities, states that diagnosis is important because it helps children, parents and teachers to *"understand or cope with their condition, and realize their respective strengths and weaknesses in various areas"*. Furthermore, this knowledge can assist in finding new ways for children to learn; may provide resources for schools and offers protection under current legislation (Ho, 2004). This research shows that the mothers of children with ADD also seek out information and wish to help their children through better knowledge and, indeed, appreciation of difference.

Joyce explained her feelings when it was suggested to her by a naturopath that Nick, may have ADD:

> *up until this point in time it had always been my fault and there was something wrong in my parenting skills. And when she said that …he had Attention Deficit Disorder I was very relieved to know that there was a name to it and I asked her how it was cured and she said there was no cure and then I had sense of disappointment because that meant I was now going to have to deal with it for the rest of my lifetime and to do that I wasn't too sure how I was going to cope if it continued to the levels it had for some time. So she gave me this book by Dr Gordon Serfontein called Hidden Handicap …it was the best book I could ever have read because it was a complete diagnosis of what I was having with this child.*

Joyce explained that she sought out a formal diagnosis when Nick was older because she needed to understand:

> *not having ADD myself, or a lot of experience with it, I really needed to know how this child ticked. …I knew the basics, but I needed to know more to help me cope … every year the new challenges were different… and how we deal with those challenges, depends on our understanding of how he's coping.*

Mim said *"knowing about ADD… helped me to understand why James is like he is"*. Knowing about *"learning difficulty or disability"* which often accompanies ADD also helped but *"unfortunately there doesn't seem to be any research about how to*

manage these information processing deficits". However, the basic knowledge that she had been able to glean enabled her to start:

> *to talk to him about some of the problems he has and I am talking about his*
> *information processing problems mainly and trying to talk about tactics of how*
> *to deal with exams. Not so much that it'll help him do a better exam but it'll help*
> *him to understand why he doesn't do a very good exam. So not to feel…you're the*
> *dunce of the class but rather that exams are not the way that I express myself*
> *well. So that it is sort of a self-esteem approach rather than an academic*
> *achievement approach…and trying to channel him into an area where his talent*
> *can come through which the education system doesn't do.*

Knowing about ADD and Stewart's severer learning disability had enabled **Number 13** to seek out, but not necessarily, find services:

> *occupational therapy, speech therapy, paediatricians, got him into youth groups,*
> *got him into Lifeline, anything and everything that I can get my hands on to try*
> *and encourage him to behave like a twelve year old, not a five year old.*

Most of the women interviewed spoke of feeling relieved when their child was diagnosed with ADD. Many of the women had strongly suspected that their children had ADD as they had obtained information from friends or read the Hidden Handicap (Serfontein, 1990). The diagnosis, while it did not produce services for their children, enabled the women to find answers for themselves and their children. It did not make everything better, however, it helped them to survive. In her study of British and Canadian mothers, Malacrida (2003) also noted that the diagnosis did not necessarily produce services which the mothers deemed necessary.

Even so, diagnosis did in some circumstances, produce change in other people's attitude towards the mother and child. **Wild Thing** experienced a real turn around in people's perceptions:

> *now that people know that Brett had, and has been diagnosed having ADD, their*
> *perception of me is totally different and, "Oh, you poor thing", and "What a*
> *great mother you were to put up with all that crap", and "How difficult it must*
> *have been for you", as where at the time people used to avoid me. Cause they*

couldn't stand Brett and [they would say], *"How dare you", "Why do you let him get away with that crap", "That's just crap", you know, "Have some control over him, do something with him".*

Furthermore Brett received support from his grandfather. Wild Thing explained her step father's change of heart:

he started off just gaining Brett's respect and then he did everything he could, being an ex teacher and also being able to access apprenticeships. Did everything he could to shape Brett's future so that he had some sort of qualification. He stuck to it, and put in, safety devices so that Brett couldn't fail. If he didn't turn up [to work as an apprentice], *he was told first thing in the morning, he'd go and find him, he'd make sure that Brett attended.*

Wild Thing, newly married, also received support from her husband when Brett was required to attend substance abuse classes as part of his probation: *"now we knew Brett would never, ever attend every class for 8 weeks! So Ned enrolled himself and went with him".* Thus the value of diagnosis lies in understanding the different child and promoting that understanding to other members of the family and the general community.

EXPLORING DIFFERENCE

Family Members

In speaking to the women about their extended families, they spoke of numerous family members who were believed to be strange or different. A number of family members had mental illnesses which required hospitalisation. Number 13's birth mother had been diagnosed with Schizophrenia. Some had a diagnosis of ADD. Feral Cheryl had an adult sister diagnosed with ADD. Caroline's sister had two children diagnosed with ADD. Caroline spoke of a number of family members who she suspected had learning disabilities and/or ADD as children and that these traits had remained with them throughout their life.

In speaking of her father who had held down two or three jobs to support his family during the 1960's and 1970's, Caroline said *"he has to be on the go, he's slowing a*

lot now, because age is sort of, I think, catching him up". Caroline described a dedicated family man who was not always easy to live with:

> *very pig headed, very sort of "my way's the only way", short tempered...he sort of takes a grumpy approach to everything, but he doesn't mean to, that was just him, but I mean he's got a heart of gold really, I mean if they look under that hard exterior, you know, they find he's very genuine and kind.*

Caroline spoke of her cousin:

> *he's got it as well* [ADD],*...I seen him the other day, and he just can't sit still, his eyes are everywhere...he can read, but he can't spell very well. So his education is down as well...but he still has worked most of his life...he likes to work, as he is hyperactive I suppose, he can't sit still for long, he was working well, but he had a lot of different jobs...if he didn't like something he'd just tell them straight up, you know, where to stick it...he's doing OK for himself, he's got a house...when he's not drinking, he's quite OK.*

Unfortunately when he was drinking he found himself in trouble with the law:

> *at the moment he's going to court about a firearm incident. ...He was up for domestic violence as well. ...He can't drink for two years, he's on probation. ...So he can't drink and that now, but he is a lot better in himself...he needs something though...he does need some sort of help. He's trying to do it on his own...you know, it's hard for him...just doing it by himself.*

Caroline's extended family were a mixture of business people, professionals, blue collar workers and people on welfare payments. The traits of hyperactivity had assisted some members in employment and where their learning disabilities had not been severe they had succeeded in gaining tertiary qualifications. However, the traits of impulsivity and attempts to "self medicate"*, through the use of legal and illegal drugs had tipped the balance for other family members. Caroline's examples graphically illustrate the range of difference within her extended family; desirable citizens and the not so desirable (Foucault, 1980a; Rafalovich, 2001a)

Footnote

* "self medicate" is a term used within the support group. It applies to people who have ADD, diagnosed or undiagnosed who use coffee, alcohol or marijuana to help them cope with life.

Different Children

Difference was a currency which flowed through many aspects of the women's lives and held potency in examining their immediate family. In particular, the women interviewed spoke of their children as being different. **Caroline** felt that people needed to realise that *"not every child's the same"* and that children with ADD were *"different"*. **Joyce** spoke of her son, Nick:

> *he used to head butt walls and all sorts of things at that age, he was quite bizarre in his behaviour and no-one with a normal child would understand what was really happening.*

Wild Thing responded to a professional who refused to believe that ADD was a *"valid diagnosis"*. In Wild Thing's view:

> *there is something wrong in his head. There is something wrong with this child, this is not learnt behaviour, this is not what he is taught, this is not how he is brought up.*

Mary Serenity spoke of her son, Steven: *"he is different and … deals with things differently"*. She said that her local GP *"was a very wise woman"* as when Mary Serenity pointed out to her all the skin rashes and allergies that Steven had as a baby, she said, *"that maybe that was just the way he was made….you treat what you can but in the end you have to accept that is the way the person was made"*.

Mary Serenity realised Steven was different at around two but did not see it as problematic. She knew he had ADD:

> *when he was nine and I read that book, The Hidden Handicap, it hit me like a ton of bricks,…I didn't cry or anything, I just thought oh, that is interesting….well he seems to be coping alright with it, … his environment at home and his environment at school were supporting him and his ADD wasn't a problem.*

However, as he grew older Steven started to suffer *"anxiety attacks …the anxiety attacks got worse …and he felt his life was out of control. He just couldn't cope"* (Mary Serenity).

By fourteen years of age:

he couldn't fit in at school so he was threatening to jump off the roof. And he was smart enough to be - when I think back on it, he was the smart one of all of us. We were all so stupid. We kept forcing him, trying to force him to go to school. The school kept trying to force him to conform. He just said F the lot of yous, I am going because I can't do this anymore. ...

Steven's survival instincts have always been brilliant ... He learnt to smoke marijuana and that sort of eased the pain. And in the end he became more and more defiant because he was taught many things by his new friends on how to cope.   Some of them were really tough cookies... And some of those things they taught him weren't good but some of them were good.   So he learnt what he needed to learn at that time and he survived and we survived. ...When I think back on it we were trying to squeeze this round peg into a square hole and it wouldn't fit. And he was the one who found another way to fit, or another place to fit. And for a while that was on the streets in a gang, " homies"*, you know the "homies" and he fitted in there and people thought he was pretty cool and he was happy and he had a girlfriend ... he was a very smart boy (Mary Serenity).

The women in this research believed their children to be different. They identified that their children behaved differently and learnt differently in comparison to the overall population (Barry, 2004; Hartmann, 1999). However it was not only the women who at some stage identify their children as being different. The children also saw themselves as different.

Footnote

*"homies" is a group of peers who hold different values and attitudes to mainstream youth. The gang shares similar interests and through friendship supports each other thus providing an alternative to the mainstream culture.

Wild Thing's son, Brett as a young man is very aware of the troubled time that he and his mother endured. Wild Thing explains:

> he'll break out in tears because he is so sorry for everything he has done. He, on his own, recognised and apologised for what he had done…What an arsehole he was.

Number 13's eldest son sensed he was different from other children and found it difficult to deal with life:

> Stewart went through a stage where he hated himself, he hated his life, he hated the family, he hated school, he wanted to kill himself, his attitude was that if something went wrong, just get rid of me. …He's not a happy child.

The notion of difference and the impact of ignoring difference is explained by an adult member of NADDS through the website and email list set up by the support group. Brian felt that *"for nearly his entire life …that there was something very different about him"* (NADDS, 2004, p.2) and *"that he was persecuted for having ADHD for 40 YEARS, because no-one knew I had it"* (Unpublished email, nqadd@Yahoogroups.com 11/10/2004).

It has been argued that modern western society views deviance as a threat and is geared to normalising populations (Carpenter, 1999; Foucault, 1999; Gordon, 1997; Rose & Miller, 1992). In others words the desire of modern governments and society is to have a homogenous group of people whose needs and aspirations are the same. The populace must receive the same services and be treated equally. Indeed, it has become politically incorrect to treat people differently, even if their needs are different (Carpenter, 1999; Wolfensberger, 1984).

Using Foucault's concept of power to analysis ADD (Rafalovich, 2001a, 2001b; Tait, 2001) is useful in that it examines how people who are different are identified and punished through normalisation procedures, programs and systems (Foucault, 1979; Rose & Miller, 1992). However, conceptualising ADD merely as a social construct, ignores the reality of those who are different. In hearing the stories of the mothers, it can be seen that identifying difference is not an issue for those who have

lived that difference. Thus, for the mothers of children with ADD or people with ADD, the problem does not lie in recognising that individuals are different, the problem lies in devaluing those who are different and the lack of support in our society for those who are different.

Early in 2005, I was contacted by **Mim**. Mim spoke of her son and what had happened in the years after she had told her story to me. The last few years had brought a lot of sorrow as well as triumphs and she reflected that we live in an *"engineered society"* which is trying to *"make every one the same...*[our] *kids are anxiously trying to fit into society... and it is having an affect on our kids and their mothers"* (Personal Communication 4th January 2005).

Difference, Pathology and Power

Mary Serenity spoke of Steven's *"courage and strength"*, to live and survive in a world where difference is not appreciated or tolerated.

Joyce pointed out that by ignoring difference, life is made difficult. Joyce gave an example of a program on television where a media personality was saying over and over*, "There's no such thing as ADD"*. Joyce pointed out that not only was the man ignorant of difference he was intolerant of difference:

> he hasn't got any recognition [or] *acceptance of other people … they have to be normal, everybody has to be normal. And it's like, if that's* [how] *other people* [are]*, just how more difficult is life going to be for people who are different.*

The women don't want their children to be seen as having a *"disease"* (Conrad, 1976, p.84). All of the mothers except, Number 13, spoke of their child's gifts, their sporting prowess, their creativity, their kindness.

Mim appreciated her son James's *"very active"* and *"enquiring mind...if he doesn't understand it, he'll have to find out what it is about"*. Mim and Wild Thing spoke of their children's charm. All the mothers spoke of their children as survivors in a fairly intolerant and often unsupportive environment. Adams (1997) has suggested

that in reality many Australian's fear and despise difference thus, those who are different can and do encounter a hostile environment.

School was seen by many as a destructive environment. **Mary Serenity** spoke of the *"terrible bashing the education department"* had given her son*, "mentally, spiritually and physically"*. **Mim** experienced an inflexible education system and the reluctance of teachers to listen or heed any advice in relation to her son:

> *they never once did anything that I suggested. They were hell bent on their code*
> *of discipline and I explained to them that while they had this rigid code of*
> *discipline you will never be able to handle someone like James, …you are going*
> *to continue to have problems while you have this rigid code of discipline;*
> *detention will do nothing.*

The school's lack of understanding and unwillingness to recognise difference had produced a *"very unhappy boy"* (Mim). Furthermore, the disciplinary strategies had exacerbated the situation and produced more problems:

> *at one stage he was writing lines, I can recall doing that back in the 1960s. Poor*
> *child is sitting there writing lines because he has got some uncontrollable*
> *behaviour habits and of course what also happened …the behaviour problems*
> *became much worse, so instead of just having, your salient gross ADD symptoms,*
> *of short attention span, impulsivity etc. etc., by this stage at high school, he's got*
> *the defiance, the rebelliousness, he's very strong willed and he will get what he*
> *wants, how he wants, he is cheeky, he is rude and he is swearing and he is doing*
> *all of that dreadful stuff.*

Thus, when institutions like schools assume *"homogeneity"* (Ho, 2004, p.90), prize *"sameness"* (Carpenter, 1999, p.2), and are structured to normalise and discipline (Foucault, 1980d, 1999) they have the potential to destroy those whom they proclaim to value; our children.

Leanne believed that in the school system there needed to be a greater recognition that many children with ADD learn differently:

> *most of them have a developmental delay which means that they are often a*
> *couple of years behind in terms of their cognitive thinking and in terms of their*

learning itself. So it's not that they can't meet their potential but you need to take a different view. You need to take a longer term view and you need to accept the fact that they are not going to keep up with their peers in terms of the same age. But if you can keep them going, and if you can help them understand what's happening then you can support them towards adulthood and towards late adolescence so they can still meet their goals and their potential.

The recognition of difference, appreciating strengths and weaknesses (Ho, 2004), can transform a child's life at school. This transformation is desperately needed as all the women interviewed spoke of the horrendous impact that the education system had on their children.

BLAME, SHAME AND PERCEPTIONS OF SELF

As previously mentioned the women found the journey of diagnosis to be a long and difficult one. This journey had been made all the more arduous by the blame, negativity or accusations that they had encountered along the way. Several women clearly identified that they were being blamed for their child or children's difficulty while others simply described their struggle and the experience of blame was implicit but not articulated.

Blame, negativity or accusations took on many forms and came from numerous quarters: health professionals, social workers, teachers, spouses, ministers of religion, state agencies, the community and also included aspects of self blame. Blame largely centred on their child's behaviour but the women also encountered blame if they medicated their children. While blame predominated it was not universal.

Health Professionals

The message that **Anne** interpreted from Child Health was, *"from day one it was my problem, it was my parenting skills,...my behaviour at home, that he was reacting [to]"*.

Joyce spoke of her feelings in contacting Child and Youth Mental Health with regard to Nick's behaviour problems:

> *you could just tell from the expression of the lady that she thought that I ... was just mouthing off. Like making it up. Just fairyland or something, and that I had a problem as a parent.*

Feral Cheryl vividly recalled painful memories;

> *I remember going to one social worker ...who told me that it was me, "it was my fault" that Michael was like that. He was angry at me. I was in tears when I went in there, and I came out, and I can remember sitting in the car because I was sobbing so much ...I couldn't drive.....This woman ..virtually handed me a box of tissues and then proceeded to tell me.... what was wrong ...the problem with my child was me, and that he was angry at me and that's why... he behaved the way he did.*

She went on to say that, *"Nobody believed me"* (Feral Cheryl).

Other women spoke about not being taken seriously by professionals. **Number 13** was accessing a local paediatrician to treat her son. She found it difficult to get her point across regarding the problems that she was having with her children: *"I don't think he has any respect for mothers. And unfortunately ... 99% of the time it's mothers who are taking their children to paediatricians, not the fathers"*.

Joyce in speaking of the health nurses she visited said,

> *I didn't find them very resourceful or helpful. They would weigh him etc, but when I ventured onto the subject of the problems I was having, they were just passed off..."What a lovely baby", ...cheerful pleasantries but not helpful in helping me to deal with what I was going through ... I was struggling to keep him well.*

Wild Thing first took her child to the guidance unit set up under Queensland Health. She explained that the professional's:

> *first opinion of Brett was that he was a wild child, a wild horse, and shouldn't be tamed 'cause that's the beauty of wild horses. And that we'd just go along and see how it goes, and more looked at what I was doing in the house and looking at you know, for good behaviour we'd give him pocket money and for this we'd take the money away, and we'd do this and do that. In the end he didn't want anything to do with Brett. He said it was just a hopeless case, at the end, after... 10 years* (Wild Thing).

As time went on the situation deteriorated and Brett assaulted her. When Wild Thing told mental health professionals that there was *"something wrong in his head"*, she felt that she was perceived as being *"cold, cruel",* a misguided woman who was grasping at straws.

In contrast **Mary Serenity** felt that sometimes she was blamed for being *"too good a mother, or spoiling my children because they were adopted"*. She was told by a teacher that Steven was *"obviously adopted,...he is so badly behaved"*. Mary Serenity's crime was one of over indulgence, as opposed to **Wild Thing** who was perceived as *"cold"* and *"cruel"*. Thus, like the *"overprotective"* and *"rejecting"* (Ehrenreich & English, 1979, p.208 & 209) mothers in Levy's study, Mary Serenity and Wild Thing were seen as causing their children's difficulties despite different behaviours (Ehrenreich & English, 1979; Eyer, 1996; Hays, 1996; Oakley, 1986).

Schools

In her quest to find answers to her child's behaviour **Wild Thing** had spoken to the school about ADD but the message that she got was that it was *"my fault, I must be displaying inappropriate behaviour at home for a child to come to school and behave like that"*.

Mary Serenity reflected on her experiences with her children's school:

> *when I was called up to the meeting with the headmaster as Eileen's Mum, everything was hunky dory. But when I was called up as Steve's Mum, it was a completely different way I was treated and spoken to and viewed. ... even at the same school, when they were both going to the same school, you were treated differently because one child behaved one way and the other child behaved the other way. ... I was accused of being sexist and all sorts of things because I must have raised my son one way and my daughter another way. It is just baloney.*

> *Parents are judged a lot at school I think. I think parents are judged on their appearance,... and on their children's appearance and, I've been on a P & C committee and..., some of the comments you hear are just shocking. Poor children, Aboriginal children coming to school with no breakfast and no one wants to help. Oh, we can't do that, if we do that for them, everyone'll want breakfast. Things like that, you know. It's not their fault if their parents can't budget their money or can't buy the Vita Brits or forgot to get the milk. No I don't think that just because someone's a teacher doesn't necessarily mean that they`ve much of a brain. Intelligence and common sense don't go together either. I used to work at the uni, OK.*

Spouse

Joyce explained that as a baby Nick had a lot of food allergies and was having problems digesting food, she *"took a lot of the brunt of the responsibility and at that time when I was with his father, he made that situation worse by telling me I was an unfit mother"*.

Joyce separated from Nick's violent father when he was two. On an access visit, Nick's father had taken him to a theme park. Apparently Nick had made life difficult by running ahead and not waiting his turn. Joyce said that Nick's father *"blamed me for him having bad...poor manners"*. Joyce was rather incredulous as he then went on to tell her that Nick had almost drowned and had to be rescued.

She explained that Nick's father:

> *didn't believe that there was anything wrong with Nick and yet he couldn't cope very well with Nick, and anything that Nick did that was wrong it was always my fault because I was his mother, therefore I was responsible for the upbringing of this child.*

Clearly the women were held responsible for their children's aberrant behaviour by professionals. This view by professionals is rooted in psychoanalytic theories which hold mothers primarily responsible for their children's aberrant behaviour (Bowlby, 1952; Winnicott, 2001). However, when women sought assistance from professionals, their concerns were often dismissed as the experts believed that only professionals had the knowledge (Ehrenreich & English, 1979; Hays, 1996) to determine what was normal or abnormal (Chambon, 1999; Rabinow, 1984).

Joyce's situation with her abusive ex husband clearly demonstrates that some men, regardless of their level of involvement or parenting skills, are only too willing to join with the experts (Hays, 1996; Marshall, 1991; Wearing, 1984) and hold mothers responsible for their children's behaviour: *"it was always my fault because I was his mother, therefore I was responsible for the upbringing of this child"*. Singh (2004), in interviewing fathers of children with ADD, also found that some fathers believed that it was the responsibility of their wives to manage the child's behaviour. Furthermore, that some fathers were of the opinion that their son's behaviour was caused by their wives' *"overly indulgent mothering"* or her *"crazy"* behaviour (Singh, 2004, p.11). It is interesting to note that both professionals and fathers are drawing on psychoanalytic theories which seek to locate the child's problem as stemming from the mother.

Mary Serenity gives a good example of the culture of blame and intolerance that exists in our society (Adams, 1997) when she speaks about Aboriginal children coming to school without breakfast and the refusal of parents or teachers to assist in a practical way, for example supplying breakfast. Once again parents, particularly mothers, are held responsible if the conventions of normality (Rose & Miller, 1992), for example, breakfast before coming to school are not upheld.

What Happens When You Are Seen To Fail?

Both **Joyce** and **Anne** spoke of doctors and other professionals not coping well with their children. While these professionals could not cope, mothers were expected to cope. Their perceived failure to cope sometimes resulted in reports to those in authority.

Joyce spoke of the time when they had just moved to Townsville and were staying in units:

> *I got a phone call from the minister* [church] *... saying that he'd received a phone call from a lady who was considering contacting Family Services and putting me in as a child abuser for what I was doing to my child. ... I was in shock, I laughed at first, ...I thought it was a joke. And then when he continued, I just burst into tears and was just totally distraught, ...I know the particular incident which would have sparked it, ... Nick was not very confident in water at that time and they had a pool, and he was screaming "don't drown me, don't drown me" ... it echoed all the way through the units.*

She went on to say *"we were all in one room, and it just about drove us all crazy"* and Nick *"wasn't coping"*. He would wake up in the morning and

> *if there wasn't cartoons when he woke up in the morning he'd throw a full on tantrum, ...I think she thought I was belting him to cause him to be that way. I mean, I wasn't even touching him. ...I...tried to explain* [to the minister] *what was happening and I thought I was being ignored by him which cut me even more, nothing ever eventuated, from the incident, but it was a very painful situation ... we had to live through it, which was living hell.*

Joyce in reflecting on her situation and the child abuse claim said:

> *there was not support offered. There was a lack of support, as has always been. It's easier to criticise than to give somebody support and understand what they're going through.*

Number 13 and her husband were reported to Family Services by Child and Youth Mental Health regarding their eldest child Stewart. They too experienced shock and dismay (Personal Communication 2000). Number 13 said that the incident had traumatised the whole family but Family Services offered *"no solution to the problem, they just stayed in phone contact as that was the only support they could offer"* (Personal Communication 2004).

No practical solutions were offered to help either family.

In 2002, it was noted that in the last five years the Queensland Department of Families had recorded a 43.6% increase in child protection notifications and that of the notification in 2000-2001, just over one third of the children were *"were found to have been significantly harmed or likely to be significantly harmed "* (PeakCare, 2002, p.3). Thus, a number of questions have been raised such as:

❖ Were the needs of the remaining two thirds of children and their families met?

❖ Is the child protection system in Queensland more geared towards notification than providing concrete services for families (PeakCare, 2002)?

Lonne and Thompson (2005) point out that the increase in child protection notifications is in stark contrast to the years of gross under-funding and under-resourcing of both government and community organisations in Queensland. Certainly Number 13 and her family's experience suggests that while the notification system worked well between government departments, practical solutions for families are few and far between. Instead blame was laid at the door of Number 13 and Joyce and they were monitored by people unknown to them or by the phone to ensure that they became good mothers (Swift, 1995). The unseen observer is, according to Foucault, a technique invented to normalise those who are seen as deviant and in need of correction (Foucault, 1980b).

Medication, Whose Shame is it?

Medication is also an issue where parents are blamed for failing to look after their children. In recent years the media has focused on the use of medication to treat ADD (Bagnall, 2000; Cauchi, 2002; Jaksa, 1999; Laurie & Cubbin, 2003; Pirani, 2005; Tanner, 2000). While some articles present a balanced view many refer to the *"drug shame"* and the problem of healthy but *"naughty"* children being forced to take medication for ADD (Lawrence, 1998, p.4). The parents of children with ADD and the community in general read headlines on a regular basis which point to the evils of medication:

> *thousands of Queensland children are being doped with powerful*
> *drugs…parents, teachers and doctors are too quick to apply the attention deficit*
> *hyperactivity disorder label…increasingly people are looking for a quick fix*
> (Passmore, 2004, p.35).

Academics are also critical of the diagnosis and medication of children. Tait (2001) claims that in increasing numbers; *"disruptive students, quiet students, or generally different students are drugged into normalcy"*.

In this research, of the fourteen children diagnosed with ADD, nine were currently on medication and five were not medicated, supporting the claim that not all children diagnosed with ADD are on medication (Barkley, 2001a). The mothers took a fairly tolerant view of medication and felt that medication was an option. All of the women except **Number 13** and **Roseanne** had received criticism or experienced negativity regarding medication. Roseanne's son was now a young adult and his medication for ADD was not Ritalin but an anti-depressant. **Number 13's** two boys took medication from a young age and she reported that people *"would not be game"* to criticise her decision. In contrast **Anne** said that her decision to medicate her two boys had attracted a lot of criticism. She described it as *"too many to count"*.

Mary Serenity reported that *"public and even professional attitudes on this subject are ill informed and unsympathetic"*. Caroline, Leanne and Anne had encountered a negative reaction from teachers. Feral Cheryl, Anne and Joyce reported that parents, family and friends had also responded critically to medication.

The choice to medicate was not taken lightly by mothers. Due to Nick's allergies, **Joyce** always monitored Nick's diet and initially resisted attempts to medicate Nick:

I've always been very anti-medication. ... However ...I started to see ... a lot of children who were benefitting from medication and I realised medication was an option that was available that was safer than I first perceived ...the emphasis is the medication is there to help their learning, and it has improved Nick's learning and his behaviour is still erratic at times, ... past relatives had to battle on with these problems, not reaching their full potential as a result of being held back.

What Could be the Alternatives?

Jacobs (2004) describes himself as a professional who loves children suggesting a contrast between himself and other professionals. Jacobs urges parents to look at alternatives, such as *"counselling", "family therapy" and "better parent education"* before giving their children medication (Mancuso, 2004a).

Roseanne felt that they *"tried it all"* with regard to strategies and found that medication assisted their son, then fourteen greatly:

the first three days of taking Ritalin, we just saw this child that we'd always wanted to see. He was able to start something and finish it, he'd never been able to finish anything really, he was able to concentrate for great long periods and we just saw his incredible creativity. Unbelievable creativity that he had. He was able to actually do something with it.

Roseanne, states that nineteen year old Joshua needs his anti-depressant medication. If he doesn't take it he has told her, *"I just can't think. My head is in a fog. I can hardly do anything"*.

The women stated that while medication was and should be an option, other strategies which were not currently available would assist families and individuals affected by ADD. **Mary Serenity** believed that concentrating on *"valuing individuals for their potential and offering support and encouragement"* was a much better strategy than blame and condemnation. **Mary Serenity** and **Mim**, felt strongly that *"awareness raising & public education programs"* (Mary Serenity)

would go a long way in assisting others to understand ADD and its impact on all concerned. Mim also felt that fathers or father substitutes could relieve much of the stress for both the child and mother if fathers took a *"greater (leading) role in all aspects of managing"* children.

Education, its structure and delivery were identified as in urgent need of remediation as many of the children's differences were exacerbated in the school setting. As several women said:

- ❖ *"improved education facilities"* (Mim)
- ❖ *"learning support and one to one"* (Leanne)
- ❖ *"different learning strategies"* (Joyce).

Caroline felt that much of Clint's behaviour could be improved if he had access to *"anger management"* programs. Likewise **Anne** wanted *"help with behavioural problems"*.

Clearly, from this research, it can be seen that mothers actively seek out alternatives to medication but the strategies they believe may assist them are not to be found in the general community or in the public sector. A recent study stated that some mothers believe that *"medication seemed to be the only option that offered any hope of their sons leading a normal childhood"* (Neophytou & Webber, 2005, p.319). Correspondingly, Professor David Hay, (Radio National, 2005, p.2) stated that medication is widely prescribed and used *"because there's nothing else available"*, pointing out that while *"children and adolescents make up 27% of the population, no state spends more than 10% of its mental health budget on children and adolescents"*. Hence the question needs to be asked, who's shame is it in relying on medication, when so few alternatives exist for families?

Good Interactions with Professionals

Not all women reported bad experiences with professionals. In contrast to the other mothers, **Leanne** asserted that *"on the whole I've had reasonably good experiences with professional people"*.

She did mention that:

> there has been some scepticism when it comes to the condition with the school teaching profession. There has been a little bit of negativity, which…might be voiced in relation to medication, which is difficult.

Leanne also mentioned that she was *"called up to the school with a problem with Julia every week, which made the schooling experience rather a difficult time for me"* and that she had *"gone through a lot of anger"*. The anger developed from the late diagnosis of Julia: *"I was looking for answers when she was three and four years old, and having to wait till sixteen to find out"*.

In general Leanne described herself as a *"positive person"* and was hopeful for the future, *"things are looking positive for 2000, after twenty odd years of chaos and bedlam and high levels of stress"*. However she said that others may perceive her differently:

> I think a lot of people see me as an aggressive person, because I've had to be strong, I've had to fight bloody hard, and so some people may see me as aggressive, but I've always been very assertive when it comes to any issue with my family.

Perhaps it was her fighting spirit which made other people's ignorance and the so called ADHD problem, their problem, not Leanne's.

Some of the women spoke of *"good"* doctors (Joyce). **Roseanne** said:

> when we first started to realise, when we suspected that it was ADD [we] *took him to a paediatrician, he's a brilliant paediatrician, and was really well known in* [another state], *and really the authority* [another state] *on ADD. …he was a beautiful man and very compassionate toward the children and the family so we couldn't have been happier really with our first contact with somebody that knew something about it and he explained it so well.*

Roseanne stated that there was more available to assist families and children in the state that she had come from and that it was *"a little bit further advanced in the whole area of ADD"*. Roseanne was aware of the experiences of a number of women who suspected their children may have ADD and wondered if some

professionals in North Queensland *"had been hiding in a cave"* as *"they don't seem to be very cluey about it* [ADD]".

Even so, both **Caroline** and **Joyce** had a high regard for a visiting paediatrician. He was described as:

> *refreshing … and understanding. No parent blaming… he doesn't force his opinion, he's a very good listener, and he never once said anything to me about putting the children on medication, he gave me that option* (Joyce).

It should be noted that the paediatrician that they spoke of was recognised as *"ADHD-friendly"* (Malacrida, 2003, p.169) and had been encouraged and supported by NADDS to set up a practice in regional Queensland.

Caroline and Joyce also spoke very highly of their GPs who had tried to support them as best they could. **Joyce** explained her situation:

> *the GP was very good, very knowledgeable, and exceptionally good to me in that I was on the verge of a nervous breakdown,…he just said to me that I needed anti-depressants. …which I declined and I just made a lot of changes so that I could get some sleep. …So he was very good to me (Joyce).*

Joyce went on to explain that what made him *"good"* was *"he understood I was doing the best I could"*.

Other than **Leanne's** account, the main ingredient for mothers in perceiving their experiences as positive, was the ability of the doctor to listen and to share information. Carpenter (1999, p.202) has also reported that being *"listened to"* by doctors is perceived as being positive by some of the mothers of children with ADD in her study. This resonates with findings from research in looking at general patient and doctor interactions:

> *positive experiences seemed to be associated with the willingness and abilities of the professional to treat the person concerned with respect, to acknowledge the patient's (and family carer's) expertise in relation to how a particular condition effects them, and to be prepared to share power by providing the person with appropriate information and support"* (Gillman et al., 2000, p. 401).

Thus, professionals who were not caught up in the *"truth"* (Sarup, 1988) of ADD or attempting to construct *"reality"* (Gillman et al., 2000) for the mother based solely on their professionals knowledge, were in a position to *"work with"* (McLaren, 2002) parents. Sometimes as in **Joyce's** case, a sympathetic ear and acknowledgement that they were *"doing the best"* they could was the difference between a *"good"* experience (Roseanne) and a destructive one.

Self Blame

Malacrida (2003) and Carpenter (1999) reported that not only did the mothers in their study experience mother blame but some mothers questioned their own ability as mothers and blamed themselves. In this research, two of the women also reported feelings of guilt for their children's difficulties. **Anne** clearly identified that she blamed herself and felt she should be able to do better:

> *I probably blame myself because it is a hard thing to manage, and there's nothing out there to actually help me manage it, …I don't feel that I cope with their ADD at all. …all my energy basically goes into the kids and Joe and the house and things. …it's a hard life, but it's the life that I've chosen I suppose, I could have quite easily have said this is too hard and walked out on it. But I haven't, I've stuck in there. I suppose it's a very hard thing to talk about, but when you've got a family like this here, nothing seems to go right, it doesn't matter how hard you try either way. Yes I do think about suicide and things like that, and I think well, who's going to be able to do all this for my family? And I realise that there's no-one else out there, …basically this is my family. That's that.*

Roseanne also identified self blame. **Roseanne** said that when Joshua was younger, she and her husband felt that they must be at fault: *"if we'd been better at discipline, or better at training, or better at doing something then we'd have this child that would be able to be really well behaved".* Regret and sorrow were expressed as she felt that they had been given the wrong information to bring up a child. Roseanne explained that the church they belonged to at the time *"prided itself on family life"* and held firm beliefs on *"strictness"* and *"spare the rod spoil the child".*

After their son was diagnosed they felt regret:

> *trying to put this model of discipline on a child that had a disability,…we look back now and feel so, so sorry about* [it], *but we were just young parents, just doing the best we could with the information that we had and the beliefs that we had, and it was certainly with great love for our son, you know, that we wanted the best.*

Rejecting the Blame

While it is clear that **Anne** and **Roseanne** felt despondent about the way in which they had fulfilled their role as parents, most of the women rejected the blame placed upon them. **Joyce** summed up her situation by saying, *"my children have been given the best I can offer them"*. **Number 13** actively rejected any blame placed on her by the community or professionals:

> *I don't really care what they think of me. … they don't live with what I live with, so they have no right to judge. And if they think they can do it better, so be it, they can have the kids, I'll pack their bags.*

Joyce told how she had confronted the principal of a school who:

> *pushed me aside and wouldn't talk to me …he wasn't listening to me. …So I put my hands on my hips and I got quite loud, and I basically stood him up* [stood up to him] *and I said, "is it because I'm female, is it because I'm a woman, is it because I'm a mother that you have no respect for me" ? …I'd been through that sort of experience with the kid's father and I knew the male chauvinistic type way he had conducted himself … he was just trying to stand over me and I had made him insecure because I stood him up* [stood up to him].

Mary Serenity not only rejected blame but questioned the view that parents should be held responsible for the delinquent behaviour of their children (Hil & McMahon, 2001; Lindsay, 2004; Mortison, 2002):

> *I gave up even worrying about what anyone else thought or pleasing anyone else. I had to live with it. I had to understand it and I had to deal with it and it didn't matter. The only time that infringes on you is through a system like the education system…or the neighbourhood, like that taking consequences for actions, for*

instance if your child borrows the neighbour's bike and takes it for a ride and wrecks it.

Who is responsible for paying for that bike?...And my son made my mind up that I could no longer pay for Steven's mistakes....Parents can't always be held accountable for the actions of their children. Prosecuting parents for the behaviour of their children is just ridiculous. Especially after you've have an ADD child or a child with a mental illness, how can you possibly be held accountable?...It is discriminatory, and it's unfair, and it's unrealistic.

My neighbour is beggaring herself, trying to pay for her son's, he has ADD, ADHD, she is beggaring herself trying to pay for her son's mistakes with the neighbours. Where...all she has to do is either write a letter and put it in everyone's letter box, "I will no longer be held legally responsible for any damage my son does to your property, Do not lend him anything. Do not let him on your property". He is 14.

Mary Serenity also rejected the concept that she or any parent was *"responsible for their children's behaviour even at school. ...You are responsible for raising your child the best you can"*

Leanne also felt that she had done her best and rejected society's expectations:
being the perfect mother or the perfect worker or the perfect this or that is an unrealistic expectation. And life's stressful enough without putting those sorts of standards on yourself, even though you do expect yourself to do the best. But you can only do what you can do, and I accepted many years ago the efforts that I made and what I actually did, was good enough for me and it had to be good enough for anyone else, and if it wasn't, well that's too bad. I wasn't going to feel any guilt.

Perceptions of Themselves

It was clear that most of the women had resisted (Foucault, 1972, 1980c) the blame and refused to feel guilty. The women described themselves as:

- ❖ *" strong"* (Caroline, Feral Cheryl, Mary Serenity),
- ❖ *"pig headed"* (Caroline)
- ❖ *"very stubborn"* (Joyce)
- ❖ *"intelligent"* (Leanne, Feral Cheryl)
- ❖ *"happy go lucky"* (Caroline, Joyce)
- ❖ *"easy going"* (Joyce)
- ❖ *"patient"* (Feral Cheryl)
- ❖ *" blessed"* (Joyce)
- ❖ *"a good sense of humour"* (Feral Cheryl)
- ❖ *"inventive"* (Feral Cheryl)
- ❖ *"taking one day at a time"* (Anne)
- ❖ *"friendly…I've got excellent taste in shoes!"* (Roseanne's humour)

In response to the question, *"What are your strengths"?* The women spoke of the qualities that had got them through hard times. **Wild Thing** replied:

> *it would have to be perseverance. The ability to love a child, who, in other cases would be absolutely unlovable, I can see that, yes. Why other people wouldn't be very attached to him .*

Number 13 said, *"I'm a survivor…I fall down, I get back up on my feet again. I keep going I suppose, until one day it'll kill me"*. **Mim** spoke of her advocacy,

> *my persistence, I am determined to get change for people with ADD and I don't care if I have to keep knocking on the ministers' doors, til I am old and grey, I think I'll keep doing it.*

The women's strength and determination was abundantly clear from the interviews although not all women were able to express in words how they had fought for their families. A clear example is Anne's super-human effort to send her two boys to a boarding school in a rural area. In 2001, Anne reported that she was working up to sixty hours a week in order to send her two boys to boarding school. Anne looked

and was exhausted, however, she felt that for the sake of her children and family it was imperative. She explained that public schooling had proved disastrous, both boys had threatened suicide and boarding schools had been their salvation (Personal Communication 2001).

CONCLUSION

In summary, the women found that the journey of diagnosis was a long and often painful one. These women found that the act of diagnosis assisted them in understanding their child's difference. However, diagnosis does not translate to services to assist with difference. The women have given examples of how their children have been punished for being different, especially in the education system. The women celebrate many aspects of their children's difference and acknowledged their courage in an intolerant society. Individuals and society have choices to make; we can, as Hartmann (1999) suggests, celebrate the difference known as ADD or we can pathologise that difference (Rafalovich, 2001b). We can embrace a different way of thinking and learning or we can attempt to normalise (Foucault, 1979) and homogenise individuals and, in doing so, cause them and their families a great deal of harm (Rose & Miller, 1992).

Overall, the women in this study experienced blame and condemnation to varying degrees. Medication was an option that some mothers followed however, the mothers believed that changes needed to take place within society and within structures to assist their children. Guilt was not common amongst the women as most felt that they were *"doing the best they could"* (Joyce). However, it is clear from Anne and Roseanne's interviews that their perceived inability to make things right made them feel troubled and inadequate. In the main, the women actively rejected (Foucault, 1972, 1980c) the blame either by confronting people, refusing to accept the blame or simply not caring what others thought. They were able to counter the blame through their positive perceptions of themselves.

Mary Serenity challenged the policy direction of the government (Hil & McMahon, 2001; Lindsay, 2004; Mortison, 2002) in relation to holding parents responsible for their children's behaviour. She is not absolving parental responsibility but is simply

stating that parents are not omnipotent or omniscient. Furthermore, Mary Serenity is questioning the assumption that the nuclear family is solely responsible for difficult children and challenges her local neighbourhood to accept some responsibility. Mary Serenity's statements reflect a community approach to bringing up children, especially different children. In closing, it needs to be stated that while the mother's experiences were often very negative and blame ridden, some professionals had assisted the mothers simply by listening to and respecting them.

CHAPTER SEVEN - FAMILY LIFE AND THE IMPACT OF ADD ON THE MOTHER

Introduction

The nuclear family is held up as the foundation of our modern society (Reekie, 1998). The nuclear family is seen as a natural environment to provide warmth, comfort, enjoyment and happiness for all its members (Bowlby, 1952; Winnicott, 1964). This research sought to explore these widely held beliefs in relation to families affected by ADD. Accordingly, in this chapter family life will be examined, with particular emphasis being placed on the effect of ADD on the mother.

Happy Families or Surviving the Best You Can?

In response to the question, *"Do you believe your family life differs from that of other families who do not have ADD present in their life,* the women replied, *"yes"*. Some were more emphatic and said: *"very much so"* (Wild Thing), *"most definitely"* (Number 13), *"of course"* (Anne*)*, *"a different sort of family"* (Joyce). In the interview a number of questions were asked relating to *"The impact of ADD on Family Life"*. The ideal family and the reality of having children with ADD were spoken about.

Anne said:

> *I was going to have your Brady Bunch Family. Where everyone got along really well, and it was going to be a picture perfect…dinner on the table at five o'clock every night, you'd sit down and play board games after tea and things like that. But I was in for a rude shock.*

She went on to say; *"I'd looked after plenty of kids, I was going to be the perfect Mum, I eat those words every day"*.

Number 13 lamented:

> *it's not the life that I wanted, it's not the life that Gary wanted, we both wanted normal children, we both wanted to be able to go out, have a fun day, and do things, but it doesn't matter whether we do it as a family, or whether Gary takes*

the kids out, ...gives me a break, 99% of the time there is some minor altercation that just ruins everybody's day. And then I figure, why did I bother going? And... our marriage is not what I expected it to be because of the fact that by the time you crawl into bed at night, you're too tired, you're too exhausted, you don't want to talk to anybody because you've just been ear bashed by the kids, and you spend most of your life telling the children to shut up.

Number 13 went on to add, *"we don't go many places...with our kids, purposely for the fact that our kids are an embarrassment"*.

Anne's situation was similar, *"we've actually stopped all social life, with the kids, we basically don't go out unless we have to"*. **Mim** on the other hand did have invitations to social gatherings providing *"the children don't come"* which she explained meant *"we don't want James around"*.

Roseanne summed up the happy family scenario by saying:

well it's been less than ideal. It's been a great grief...its not that this child has not had any training, or any decent upbringing, or any decent love...I mean we're a highly educated fairly balanced couple really, ...the environment is not the thing that's really lacking...in the end we've taken quite a pragmatic approach, we just do the best we can, and we've put our high ideals out the window.

In their efforts to cope they had

put a caravan in the yard. And that became Joshua's space. So that if he had a wild outburst or whatever, we just sent him straight to the caravan...so I think he was forced into being a little bit excluded from the family, but it seemed to be the only way to sort of manage things and keep the other children safe and stop huge fights that never went anywhere anyway. Could never be resolved. And so I think that that has contributed to him feeling a little bit sad and out of it and not part of things. ...it breaks your heart really.

Leanne dismissed the idea of having a *"normal family life"* saying:

I think family life is very stressful when you have kids with ADD. Basically they are insatiable. They, never let go and when they get an idea in their head they are persistent and they will wear you down and wear you down until you

accommodate what they want. The other problem with kids with ADHD is their activity level, and level of supervision that you still have to provide. ...When you work full time, like I have, and come home and you're fairly tired, the last thing you want to do is be up and down, up and down, that's the reality of your life.

Thus, the dream of family life, and the reality of family life was very different for the mothers of children with ADD. Visiting friends, social outings, family gatherings, birthdays, weekend trips and holidays were often a nightmare. People in general did not understand, or accept that children with ADD were different and tended not to invite, or include the families in social activities. The women's stories in relation to family life were not of happy families, they were ones of grief. Grieving definitely needs to go on the agenda in speaking about ADD. Grieving was experienced by some as a sense of loss for what could have been: *"you hear people talk and you know what you have missed out on. I could not even go to a football match with the two of them* [Julia and Tom]*"* (Leanne Personal communication 26th September 2004). **Leanne** (Personal Communication 26th September 2004) described the loss not as a *"sadness"* but as an *"emotional pain for all the sacrifice that you have to make"*. The concept of *"chronic sorrow"* (Roos, 2002, p.24), a loss or grief that can not be resolved is particularly useful in viewing the reality of family life for many of the mothers of children with ADD.

Motherhood and the Triple Burden

The family and motherhood is no stranger to academic inquiry (Aries, 1973; Badinter, 1981; Pollock, 1983; Stone, 1977). Researchers in looking at motherhood and the nuclear family have often spoken of the double burden that women face: working in paid employment and working in the home (Eyer, 1996; Hays, 1996; Marshall, 1991; Pocock & Wilson, 2001; Russell & Bowman, 2000). All of the women who took part in this research were working part time or full time or were engaged in full time study. Given the demands of looking after a child or children with ADD, it was important to see what supports were available in the home to assist the primary care giver in bringing up her children.

Of the 10 families, one was a sole parent family and at the time of the interview Feral Cheryl's son was living with her parents, one family had adopted children, 3 families had stepfathers and the remaining five families were original families - the two parents were the children's biological parents. The questionnaire required the women to indicate:

- ❖ *"Who manages discipline in your home?"*
- ❖ *"Who takes responsibility for managing conflict in the home?"*
- ❖ *"Who assumes the majority of the housework?"*
- ❖ *"Who works with professionals to assist your child with ADD?"*

In the five original families only two fathers shared, or assumed the majority of the housework, while the mothers were responsible for the discipline, conflict resolution and liaising with professionals. Interestingly, the data obtained revealed that the mothers whose partner was not the children's biological father received more support from their partner. In the family where the children were adopted, and in the 3 families where the father was the step father, the men assisted in or took over some of the above tasks. The men also assisted in:

- ❖ attending substance abuse classes (Wild Thing)
- ❖ speaking to probation officers and explaining about ADD (Wild Thing)
- ❖ driving *"around the streets at night and see if he could see Steven and see if he was alright"* (Mary Serenity)
- ❖ taking *"him to lunch"* (Mary Serenity).

Mary Serenity spoke of her husband's role as Steven's adoptive father:

I think Keith could have been a more active father but having said that he was a good father. We really wanted our children and we really loved them and appreciated them. …we drove them everywhere; he was in so many activities. I kept him busy 'cause that was the best way to keep him happy. Soccer, golf, Tae Kwon Do, swimming, everything. 'Cause… when he was worn out he went to bed well, didn't he. And I enjoyed it. Keith enjoyed it to. And now that he's older, he's a great Dad. I think he's a better Dad now than he was when he was younger. Yeah, in some ways, they have a beer together and they sit and watch the footy together and I think, all boys need a strong father.

Mary Serenity explained that as Steven grew older she *"backed right off"* because she was *"totally exhausted"* and her husband:

> *realised that he had to be a far more active father. …I think that is what really saved Steven, the fact that his father did take over the major parenting role.*

In a similar fashion **Mim's** ill health was a contributing factor in her partner, after many years, taking a greater interest in his stepson. Keeping James active and taking an interest had assisted Mim and her son:

> *they play football on the beach every afternoon together, they go for long walks, two hour walks every night. They go to the football every weekend. He takes him to tennis, he takes him to golf.*

Caroline on the other hand spent her weekends ferrying the children to and from sporting activities as her husband, the children's biological father, had no patience with them and was not interested in becoming an involved father.

In an ADD household, discipline, conflict resolution and working with professionals is a huge task. However, it was clear that the women, whose partners were the children's biological father, received very little assistance in carrying out these extra tasks. In the step families and the adoptive family the women fared better as they received more assistance in housework, discipline, conflict resolution and working with professionals. Keeping children active and taking an active interest in them, lessened the work load of the mothers. It is clear that due to an increased work load and the lack of support from their partners, the women, especially when their children were young, were carrying a triple burden. Furthermore, the women whose partner was the child's biological father fared particularly badly as they shouldered the bulk if not all of the responsibility of raising their different children.

It is beyond the scope of this research to assess in detail the inability, or unwillingness, of fathers to become actively involved in bringing up children with ADD. However, Kendall and Shelton (2003) found when examining the management styles of families affected by ADD that some fathers, while they

acknowledged that extra time and effort was required to parent children with ADD, felt the responsibility laid with their wives. Even though their wives *"were already overloaded and highly stressed... it was easier [for the men] to disengage as a way of coping with their feeling of inadequacy, hopelessness, and anger",* than to take a more active role in parenting (Kendall & Shelton, 2003, p.269). Singh (2004, p.11) also found that some fathers of ADD children, *"left their wives alone to tackle whatever problems their sons were having"* as it appears that they believed that their wives were responsible for managing their son's behaviour. Furthermore, it is important to note that men's unwillingness to become actively involved in their children's upbringing, regardless of ADD, is spoken about in the academic literature (Eyer, 1996; Marshall, 1991; Pocock & Wilson, 2001; Reekie, 1998; Russell & Bowman, 2000; Wearing, 1984).

Hays (1996, p.163) states that leaving women to perform the *"grunt work"* of looking after children benefits men. Joyce's story provides a good example of the way in which men benefit from being removed from primary care giving and the way in which society holds women responsible for their children's behaviour. **Joyce** had to demonstrate that Nick's behaviour was not her fault and that she was not an irresponsible mother for medicating her child:

> *Family Law Court at that time wasn't very supportive and I went through two counsellors, both males, who mainly saw that it was all my fault, ...I felt that the guys were putting blame on me.*

Joyce explained that her ex-husband had more time and resources to put a case against her and demonstrate that she was a *"unfit mother"* as he:

> *had more opportunity, more time to himself, all he did was work, he didn't have the commitments of the family and I had, he didn't have...like I had work, the commitments of a family, and all the other pressures associated with dealing with ADD. He had all the time under the sun to put together a convincing argument and he was going to that father's group, you know, non-custodial father's group, he knew the Child Support Act back to front, he could quote it to me, ...he's gone to great lengths to make my life as difficult as possible. He had opportunity to do that even through the counselling, because these men weren't aware of the type*

of character he was. They believed they were talking to somebody who had been wronged, and they weren't looking at me being the one who had been hugely emotionally and physically abused for three years that I lived with him. And then living in fear after leaving him, of what he might do to me.

Joyce's child care responsibilities and the added demands of looking after a different child disadvantaged her in the Family Court. The Family Court also ignored two important factors in her case; domestic violence and the *"grunt work"* (Hays, 1996, p.163) of having a children with ADD. If anything, her son's diagnosis of ADD and her choice to medicate him was a mark against her (Jacobs, 2002; Schmidt Neven et al., 2000).

DYSFUNCTIONAL FAMILIES OR SURVIVORS?

Another factor which exacerbates stress for women is living with a partner who also has ADD. Adult ADD, especially ADHD in men, does appear in the literature, primarily in the form of self help books (Weiss, 1993; Weiss, 1997). Although there have been some attempts (Carpenter, 1999; Smith, 1998) to examine and report on the implications for women living with a partner who has ADD, the issue has not been widely explored. Accordingly, it is pertinent to explore in this research the reality for women living with a partner who they believe has ADD.

Three mothers believed that their partner, the children's biological father, had ADD. The families concerned are Number 13, Leanne, and Anne, a profile of which is provided in Appendix 8. Number 13, Anne and their husbands share a traditional view of marriage and their role as parents. Although both women work outside of the home, the men see their roles as primarily the bread winner. Both women's husbands expect their wives to look after the children and the needs of the family. When asked who takes on the majority of tasks in the home and the supervision of the children, Anne replied, *"always me"*. Other than the support group, Number 13 and Anne do not participate outside of the home to any large degree. Leanne has a more independent lifestyle as her husband is prepared to look after the children while Leanne participates in activities outside of the home.

Leanne stated that her independence was:

one of the saving graces of our relationship, which has been great, so going to work, earning my own money, making my own decisions, within reason, I've always considered the whole family situation.

Leanne's husband and middle son assume the majority of the housework, while Leanne manages the discipline and conflict within the home *"most of the time"*. Leanne usually takes on the role of working with professionals to assist her children. A brief snapshot of each family will be given before moving on to examine the impact of having a partner with ADD.

Number 13's Family

Number 13, Gary, Stewart, Jane, Anthony.

Number 13 explained that her husband's contribution to the family was *"the pay packet...plus that he takes the kids out and gives me a break from them, that's probably about it"*. Thus, she receives very little support from her husband. She found his inability to assist in the smallest matters as "*chronically annoying":*

It's bad enough when you have two boys who are continually demanding in one form or another, and then you have a husband... I don't demand anything of my husband... but on the odd day you might ask them to do, pick something up on their way home from work, and you'll remind them at three o'clock before they leave work to pick up this item from the shop, and they come home and they haven't picked it up. So then of course, he gets really shirty because he's forgotten, plus the fact he then tries to turn it around and blame me, that I've expected too much from him, even though I rang him up an hour before he left work, or half an hour before he left work and reminded him, so it's sort of like I'm trapped between the devil and the deep blue sea.

When Number 13 speaks to Gary saying *"you've got ADD too",* he just laughs and says, *"Yeah, I probably do actually"*.

Leanne's Family

Leanne, Bob, Julia, Toby and Tom

Leanne speaks of her husband Bob:

> *I always view him as being someone that's tried to do his best. Basically we've done our best, we've tried to work together, ...but at different times, I could get angry with him because he tended...to let the responsibility fall on my shoulders, you know, which has made it hard at times, but we've tried our best as a family unit.*

Leanne explains what effect Bob's ADHD has had on her and family life:

> *I used to get upset with my husband because he found it very difficult to control his emotions...he spent his whole life trying to deal with his ADHD and controlling his emotions...so more or less I spent my life being the mediator, the moderator, you know that's why I was always on call,..till everybody in the house had gone to sleep and that was when I could probably relax, but it wasn't enough time unfortunately, ...one of the things I used to loath were weekends, because all the family members were together. We loved each other very much, but when all of us were together it was just chaotic. That's how you can describe it, just chaotic family life.*

Leanne is very much aware of the impact of ADD on the family:

> *it's not* [just] *one individual* [that is] *affected... you've got a few individuals affected in the family* [and] *that it makes life very very difficult...often the chaotic aspect of family life often comes because there's more than one family member affected by the condition.*

Anne's Family

Anne, Joe, Clifton and Carl

Anne in speaking of her husband Joe, who was diagnosed in the 60's as hyperactive feels that he has coped well:

> *as far as I'm concerned, he's managing it quite well, there are days when you feel like throttling him, but he's channelled it, and his hyperactivity makes him a*

very good person in the workplace, because he gets out there and he gets stuck

into the work and over the years he's learned how to be able to control it, to be

able to supervise himself, have people underneath him, but he still needs that

reassuring, to make sure he's doing it correctly all the time, he's always scared

in case he's misinterpreted what he has to do.

Anne goes on to explain that much of the reassurance comes from her and that in:

any marriage...you've got to work at it. I think with an ADD marriage it's

probably that little bit harder [as] *you've got to do more than your share of work*

to make up for their ADD.

Anne spends a lot of time and energy supervising and supporting both her husband and her children:

in my family if there was three of me to go around so each one of them could

have a hundred percent attention, it would suit this family life a lot better.

In speaking of her husband and his role as the children's father, Anne said:

my husband does try very hard at times, I can see him biting his lip quite often,

with watching me struggle through, the kids are to a certain extent better

behaved for him, I don't know whether it is because they know that he won't

tolerate as much as I will. But on the other hand the loving bond isn't strong

between husband and the children. ...He does try his hardest, but I think with him

having ADD himself, he can't understand. I always said he wants icy pole

children. Ones that you put in the freezer and pull out when you want them

there. ...he doesn't understand children at all...it does cause a lot of arguments

in the family. Having the ADD and I suppose with Joe being ADD too that's got

a lot to do with it.

Anne explained the consequences of living with two children with ADHD and a husband:

I am very tired, I'm always very stressed out, and I find that causes a lot of

problems at home. If I could, I'd like to wake up one morning and just feel

happy. Feel like I've had a good night's sleep, and you know how you see the

ads on the TV and Mum bounces out of bed and cooks breakfast and does all of

this and that. I'd love one morning to be able to just get up and feel well, today's going to be fine.

Clearly any family affected by ADD is stressed and the majority of stress is carried by the mother as primary care giver. In families where the father is believed to have ADD an added stressor is found as the women are often also supporting their husbands.

The reality for these women is missing in much of the academic literature. The academic literature, especially from a behaviourist or psychoanalytic view point, often speaks about dysfunctional families, single mothers and the decaying of family values (Chapman, 1996; Mertin, 1998; Osmond & Darlington, 2001; Schmidt Neven et al., 2000). Families are not described as coping as best they can under the circumstances. While some authors do encourage men to be more active fathers (Biddulph, 1997; Schmidt Neven et al., 2000), the literature does not speak about the triple burden that women face. Given the sheer enormity of the task and the incredible stress that these women are under, it is surprising that the families, in particular the mothers, survive at all.

The Life of a Middle Sibling

This research also revealed that non-ADD children are placed under considerable stress. Leanne's family and Number 13's family have a middle child who does not have ADD. **Leanne** said that her son, Toby, had a few issues when he was younger and could be best described as a late developer. Now however he is the *"lynch pin"* of the family *"as he holds the family together in a lot of aspects"*. Leanne explained that he spends *"a lot of …time"* with Tom and has been a *"good brother"*. Toby is a good *"son"* and assists in household tasks. Leanne has on many occasions spoke of the strength and humility of her middle child to survive a *"chaotic family life"*.

Number 13 also praises her middle child Jane:

she is our saving grace,…our rock of Gibraltar, and I seriously think if we didn't have Jane we wouldn't still be married. Jane doesn't demand anything, Jane

very rarely gets a word in edgewise between the boys…unfortunately poor Jane does suffer.

She can't have sleep overs, because the last sleep over we had, the girl ended up in tears because one of the boys threw something and it hit her, and so Jane doesn't have a normal life either. We've said to Jane that if she wants to go and stay at a friend's place on the weekends, we're more than happy for her to do that, but don't ask to have them here….She's at a different school to the boys…it's her respite away from the boys…in that respect it's good, because she does get some distance from them. Not having to worry about them embarrassing her at school, or anything.

Number 13 and her husband do *"try to compensate to some extent but unfortunately we're both drained and we don't have that capacity either".*

The experience of the non-ADD child in a family affected by ADD is missing from the majority of academic literature and the general discourse on ADD. With the exception of Kendall (1996) there is little to suggest that the plight of the non-ADD children has been seriously considered by professionals. At this point in time the life of the non-ADD child has not been acknowledged by the community and the issues for these children are not addressed in government policy.

IMPACT ON THE MOTHER

In the previous section, the reality of family life for mothers was explored. In this section the impact of ADD will be examined further to ascertain the consequences of mothering children with ADD.

Stress, Emotional and Social Isolation

In responding to a question concerning the impact of having children with ADD, **Caroline** replied; *"very stressful….Now he's on medication, it helps a great deal. They* [children] *still argue and whatever,… it can be very, very stressful".*

Many of the women spoke of the emotional impact on them as individuals and the isolation that they felt. They were isolated in that they were not able to talk to others about their situation and they could not freely engage in social activities.

The women were often estranged from their families as the families saw their children as *"being naughty"* or *"antisocial"* (Wild Thing).

Mim said that for years she had battled alone, she explained,

> *I had no support...well I do have friends, but...they...had these lovely placid children, I seem to be the only one who's had this monster, they don't understand. It's not worth talking to them about it.*

Mary Serenity said that when Steven was younger her friends and family did not understand:

> *I did a lot of this on my own...you know when the final crunch comes in anything in life you really are on your own and if you don't nurture yourself and support yourself and strengthen yourself you won't survive.*

As a single mother **Wild Thing** spoke at length of her feeling of social and emotional isolation:

> *The impact upon my life was horrific. As a single mother I... usually not only work full time shift work as a nurse, I usually did something part time to earn extra money but it was also an escape to get out of the house as well at times. Also I had no supports as far as any one to look after Brett after the age of 8. My family wouldn't have anything to do with him because he tried to burn the house down....They just saw him as antisocial....It made for a rift between the family because I always supported Brett...I had no supports there. Yes it impacted greatly... you don't have boyfriends or social activities.*

Establishing a relationship was also out of the question for **Feral Cheryl**:

> *I just do not have the time and energy to put into a relationship. If I came home to a couple of normal kids, yeah maybe, but I just don't have that. And as I said to Dad, where am I going to go that I could take Michael that I would meet*

anybody that would ever talk to me? You know, like I can't even take him out in public.

Number 13 spoke of being on:

an emotional rollercoaster, I wouldn't know what the word happy means....I'd planned to have children and be very close to my kids, be able to talk to my children, and that doesn't work out that way....life's very unhappy and draining, and you don't go out because the kids are too much of an embarrassment to take out. I don't take any of my children shopping with me at all. For even the simplest things, because my eldest thinks it would be good to try and shoplift while we're out shopping, or he'll want to push the youngest one in the shopping trolley and they end up playing Frisbees with the shopping trolley in the supermarket, so life, what I had planned, has not turned out anything like I wanted....Life is just a chore.

Leanne (Personal Communication 26th September 2004) spoke of the emotional hurt and pain that she experienced:

for years you push things down, you just continue with the stress and the strain but it wells up from time to time. Sometimes I feel that I could go into a corner, pull a blanket over my head and cry for ten years – there is so much pain that I have pushed down because life is so hectic, you are always dealing with some issue. You don't get many times to confront the issue, deal with it, but deal with it you must, otherwise it will destroy you.

In speaking of the *"enormous"* (Mary Serenity) strain and the social and emotional isolation the women also reported health problems. It should be noted that the interview questions did not seek any information about the women's health. The questions were about the impact of ADD on the family and on them as individuals. However these general questions revealed issues of poor health and abuse.

Health

Fatigue was common. **Wild Thing** said, *"I'm very tired, I'm exhausted"*. She explained that in coping with her child's ADD, she had pushed herself and now she found it hard to stop. She had slowed down but didn't feel rejuvenated and at that stage could not see an end to it.

Many of the women spoke about being depressed. **Roseanne** said:

> when we really needed it there was nobody. I think that was why I sort of had a major depressive episode….There was just nobody….I just stopped being able to sleep. ...I nearly went out of my tree. Wanted to die. Was suicidal. And that went on, just that insomnia went on for probably two and a half years…But it was never diagnosed. No antidepressants were ever prescribed, nobody identified the problem, I went to doctor after doctor, they said it's just in your head…you need to go out and play tennis.

Anne too suffered with a sleep disorder:

> I've been to many doctors ... lot of them put it straight down to depression, I do feel that I'm depressed to a certain extent, but that depression is a part of my life, it's just something that I've got to cope with, it's not something that's going to change overnight living in an ADD family.

One doctor was prepared to look further than depression. He pointed out to Anne the strain she was under in looking after *"three children"*. Anne corrected the doctor saying, *"I've definitely got two"*. To which the doctor replied:

> three children...do you know why you have three children?...you have one little one, …you have another one that's off at boarding school, …you also have that big one that lives at home that you married.

The doctor explained that she was *"overstressed"* and *"overworked"* and having to cope with three high needs individuals had caused her to develop a sleep disorder.

Feral Cheryl reported that the stress of having a child with ADD and the expectations that she and society had of mothering had almost brought her to breaking point:

I got to a really low point with it, about two years ago, I was going to have a nervous breakdown...because I was busily chasing something that's never going to happen. I was chasing an ideal of what a parent should be... and now I've learnt not to be so tough on myself.

The turning point came when she decided that, "*it's OK to lose it every now and then*". Feral Cheryl said that when she needs to have a break:

I will walk out and sit in the middle of my driveway and I don't give a rats what my neighbours think, and I will sit down and have a couple of cigarettes until I calm down.

While fatigue, depression and sleep disorders were commonly reported others, like Number 13, Leanne and Caroline believed that stress contributed to their overall poor health: "*Stress. ...No support from families. ... I'm now a diabetic due to stress*" (Number 13).

Aggression and Abuse

All mothers reported that their children made constant verbal demands. Some described it as nagging and carping, while others described it as verbal and emotional abuse. **Leanne** summed up her situation by saying; "*the most difficult thing was suffering emotional abuse*". She went on to say, "*I didn't realise how much abuse I was actually under until I went to my friend's house and lived there for a week*". **Number 13,** in speaking of her second son with ADD said*, "Anthony's been verbally violent...from a very early age like about three,* [he] *has said that he'll probably stab me through the heart with a knife*".

The general tone for some families was of aggression. **Roseanne** reflected on her son's frustration and angry outbursts:

I think our other kids have suffered. There was always a lot of aggression. And that used to really upset me. I could never seem to find an answer to stop him

from hurting others and hurting his younger sister....Joshua got angry at one of the children and ended up holding him by his ankles and holding him out over the veranda. One storey up. And so what do we do? Send him to a foster home? ...Say child protection comes in because the siblings are being ...really badly battered. What, who do you sacrifice in the whole thing?

In families where children had been diagnosed with ADD and other co-morbidities in early and late adolescence, aggression had sometimes turned to physical violence directed towards the mother and damage to property.

Mim stated:
too many mothers are being left and they're doing it rough, I was being punched, hit....I have had golf sticks swung around my head....He has broken so many things....I had to have something like half a dozen holes in my wall plastered up before we sold [our house].

Mary Serenity spoke of one incident:
he took to me with a screwdriver one day and he was going to stab me....because I wouldn't give him some money to go down town to meet his mates. My mother was in the house at the time, she was on holidays and I could see that he was going to escalate and I just had to get away. And I knew that she wasn't in danger and that Eileen wasn't in danger, but he was doing this power thing with me. So, I got in the car and locked all the doors, so that I was safe, as I was trying to drive away he kept throwing himself on the bonnet of the car, like a mad man. And for that one spilt second I thought of running over him. One split second, I thought well this is it; this is the opportunity to put him out of his misery. Then I thought, "Oh God no", I couldn't live with that and just drove away.

Wild Thing also suffered from physical violence and threats to her property:
the aggression was quite hard to deal with. Being able to get through to Brett because they do take it out on either a sibling or a parent and are aggressive

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towards them, 'cause I was the only one he had, it was me. Trying to

communicate with him was just impossible on most levels. That was quite hard.

She explained that at one stage after a disagreement he threatened to burn her motor bike and the house; *"he just poured petrol everywhere, he didn't actually light it. Thank God"*.

Clearly the stress of mothering in a family affected by ADD has a negative impact on the women's health. The strain of raising children with ADD and women's health problems is noted in two recent Queensland studies (Carpenter, 1999; van Kraayenoord et al., 2001). Even so, the damage to women's health is not discussed in any detail in the discourses surrounding ADD and there is no recognition at a policy level in any Queensland Government Department. Nor is the issue of adolescent violence discussed in the competing discourses on ADD, or addressed in *The Domestic and Family Violence Act (1989)*, or any Queensland government policy. Even so, one study has suggested a possible link between ADD and aggression in relationships (Theriault & Holmberg, 2001). While the authors call for caution in making generalisations, their study has highlighted the role that impulsivity may play in the use of aggression and the need for further research (Theriault & Holmberg, 2001). Other support groups in Queensland confirm that their members suffer poor health due to mothering children with ADD and some suffer abuse from their children (Personal Communication 1994-2004). Discussion and debate in Queensland needs to move away from the myth of ADD, inadequate parenting and dysfunctional families (Jacobs, 2002, 2004; Schmidt Neven et al., 2000; Smith, 1998) and focus on the daily grind of living with ADD.

Who Supported These Women?

Given the bleak circumstances of the mothers of children with ADD it is important to note what practical assistance has been made available to women in coping with stressful situations. **Feral Cheryl's** parents took her ten year old son, Michael to live with them for a while as she said:

I seem to have lost control, any form of control, and he was having really violent mood swings where he would hurt me or my other child, ...he would kick, punch, hit, throw things.

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Feral Cheryl explained that it:

> all culminated one Saturday morning when he just trashed my house…he just
> pulled everything out, all of the books out of the bookcase, everything out of
> drawers and cupboards, threw it all round the house…he started throwing things
> at me. Picking things up off the floor and throwing them at me. Then he walked
> over to the fridge, opened the fridge, took a two litre bottle of coke out, shook it
> up and poured it all over the kitchen. And I rang my mother and told them come
> and get him before I killed him.

Feral Cheryl's parents were reluctant to acknowledge that Michael had ADD; they thought he was a *"mischievous normal boy"* who would benefit from strict discipline. However, Feral Cheryl said that Michael was *"starting to get comfortable in the environment, he's starting to push limits, he's constantly pushing, …they've seen it starting too, it's starting to happen at their place"*. While it was unclear how long Michael would stay with his grandparents, Feral Cheryl was grateful for the respite. **Leanne** had a friend who provided some respite by taking *"Julia every Saturday for about nine or ten months. And I think that that really helped the family survive"*.

Practical support for most of the women was sparse or non-existent however, the acceptance of neighbours and family eased the terrible strain that these women were under. **Feral Cheryl** said, *"I get on really well with my neighbours"* which she felt was a good thing, as Michael is *"always yelling"*. She stated that it was not unusual for him to make up stories of abuse and on one occasion when he was told to get ready for school, *"he ran halfway up the hallway and started screaming, "Don't hit me, you're hurting me""*. Feral Cheryl reminded him that the neighbours were used to his antics by now, as often they had remarked that *"it was quiet"* when he was away from the house.

When **Joyc*e*** was heavily pregnant with John and in need of a break, her mother and sister took Nick:

> *my Mum, she cooked, fed, cleaned him and my sister entertained him, and got him to sleep with her so that she could get him down to sleep, cause that was the only way they could do it.*

It was unfortunate that Joyce's mother and sister were not able to cope with Nick's behaviour and constant demands: "*the two of them were exhausted after four days. Brought him back down to Bundaberg, dropped him off with me and said "see you later"*". However, many women were doing it alone. **Anne** explained that she did not receive any assistance, "*because no one understands...they tend to start putting down the family, more so than actually helping*".

The Trauma of Isolation

Most women in the research were not receiving any external practical support and the women and their families struggled. Roseanne's story is a poignant example. Her story is not just related to having children with ADD, it is an example of the isolation and trauma common to many families when they are left to do it alone.

Roseanne spoke of the trauma that comes:

> *out of ADD. I was pregnant with our third child, Joshua had just turned three, I had a little girl who was fifteen months old...she was a good little baby but she was up all night, and we'd finally got her to sleep, we were really exhausted...and Joshua put on the light first thing in the morning, was singing and carrying on, yelling and wouldn't shut up, wouldn't go back to sleep, and wouldn't quiet down, and nothing we could do would make him do that.*

> *And I used to have a practice of getting up fairly early in the morning to escape the house....Even though I was dog tired. Just to get some time with my own head. That was the only way I kind of kept sane. So I'd go for a walk and I'd pray and I'd take my bible and I'd read down by this little creek....This wasn't a beautiful idyllic crystal mountain creek, this was a little suds infested one, but it was the nearest thing to nature that I could find in suburbia....I was to...spend*

three quarters of an hour before the day started, and I got along the way out to
my little creek and I had a very strong urge to go back and nearly heard [an]
audible voice say to me "go back, all's not well" and I thought this is ridiculous,
my mind's playing tricks on me. And I kept trying to push against it, it was
nearly like a physical force forcing me to go back and in the end I did.

There...was no logical reason for it, but when I went back...found Lee was
sobbing...he'd smacked Joshua really hard across the top of the leg it had
cracked his femur...by that time he'd rung the doctor...we ended up having to
take him down to the hospital,...he was in hospital for seven weeks.

And just the stress of that, because I had nobody to look after my toddler, and I
felt that I had to go down and see Joshua...so he wouldn't be frightened...I had
to leave my little girl at home on her own,...I'd put her down to bed in the
morning for her sleep, and my neighbour two doors up came down an hour and a
half later to get her out of her cot and bring her up to her home. I mean, I was
trying desperately in my head to work it out, organisationally,...but physically
couldn't cope with being pregnant and taking her down when she needed a sleep
and there was nowhere to sleep in the hospital for her...And the only thing I
could think of was for her to just have a sleep in her own bed and my neighbour
who had three little kids...I mean we were all in the same boat. We were all
absolutely lacking all support, there was no [grand] *mothers around,...there was*
just nobody to call on. And so that was a huge, huge stress, just sort of being
pulled apart. I couldn't work out what else to do...it used to tear my heart out.

While the professionals in the hospital thought Lee was *"disgusting"* for breaking
Joshua's leg, no action was taken against him nor was any support offered to the
family. Roseanne and Lee were severely *"traumatised"* and Lee *"went into a*
downward spiral in depression", which left Roseanne to cope alone.

Roseanne's story is by no means unique as can be seen by a story reported in the
local media. A single mother of two children with ADD, aged eleven and fifteen was
charged with *"assault causing bodily harm"* (Lineham, 2004, p.10). Preceding the

assault, the boys had been bickering and locked themselves in the bathroom with their mother's car keys. The mother was fearful that the children *"would drive the car, as they had done so in the past"* and sprayed oven clearer under the bathroom door to force the boys out (Lineham, 2004, p.10). The magistrate, while acknowledging the woman was dealing with difficult circumstances, ordered her, as part of her nine month probation, *"to attend counselling and attend any programs directed by her probation officer"* (Lineham, 2004, p.10). The newspaper article makes no mention of any practical support for the woman to assist her in managing what is clearly a very stressful and difficult home life, for both her and her children.

Kendall and Shelton (2003, p.265) have noted the struggle experienced by a mother of children with ADD, when trying to comply with intervention strategies developed by experts:

> *the added stress of trying to find transportation and child care so she could attend parenting classes and psychotherapy added to her burden of caring for her children, although she attempted to attend these sessions, she expressed how overwhelming it was to be expected to do so much and then see so few results from her efforts.*

In viewing the evidence from this chapter, regarding the physical and emotional work load, ill health and isolation that these women encounter, it is argued that government policy (Hil & McMahon, 2001) and the insistence of professionals (Bor et al., 2002; Clark, 1996; Jacobs, 2004; Schmidt Neven et al., 2000) that mothers of children with ADD attend parenting programs or family therapy is abusive. These women are drowning in responsibility and the drudgery of living in a family affected by ADD. Accordingly, practical solutions are required before any interventions can be implemented.

CONCLUSION

In conclusion, the mothers clearly identify that their families are different. This research demonstrates that mothering in an ADD family is characterised by grief, an enormous workload, and limited or non-existent support. While some mothers may be supported by their partners, fathers are in the main absent from the parenting role

which further adds to the burden of women copying under difficult circumstances. In families where the father may also have ADD, the responsibility of the mother is seen to extend to not only caring for children with ADD but offering considerable support to their partner.

The women often experience isolation and marginalisation due to their different children and their different families. Furthermore, their physical and mental health suffers, due to the burden of caring in a vacuum. While depression has been noted in the literature (Carpenter, 1999; van Kraayenoord et al., 2001; Wallace, 1996), it is not widely spoken about, or acknowledged in policy, or service delivery. Moreover, it has been shown that these women suffer verbal abuse and sometimes physical violence at the hands of their children. The potential for abuse and violence has not been acknowledged in the majority of academic literature or addressed in government policy.

This chapter gives insight into some of the issues faced by families living with ADD and at the same time poses numerous questions, for example:
- ❖ What services would best meet the needs of families?
- ❖ How can non-ADD children in a family be best supported?
- ❖ How can fathers of children with ADD, especially those fathers who may have ADD themselves, be supported to parent their children in a positive and productive manner?

It is clear that talking to families will not only reveal more about their lives, their struggles, it may also help to lay the foundations for effective strategies. At present the strategies in place to assist families, such as parenting programs and family therapy maybe of limited value when families are struggling for their very survival.

CHAPTER EIGHT – POWER AND KNOWLEDGE

Introduction

In this chapter, two stories will be presented to give a graphic illustration of the way in which power can affect the lives of women living with ADD. Susan tells her life history of having ADD and the way in which she used knowledge, while Ann, the only one in her family who does not have ADD, details her lengthy journey to seek out knowledgeable professionals who may be able to assist her family.

SUSAN AND ADD

It can be seen from this research that having a partner with ADD impacts on the mother. However, little has been said of the impact of ADD on women (Arnold, 1996). Accordingly, Susan's life history is presented to give some insight into living with ADD and to explore the way in which individuals can use knowledge to positively influence their lives (McLaren, 2002; O'Brien & Penna, 1998). It is not to suggest that all women with ADD have a similar story. Even so, some women may relate to parts of Susan's story. The following section outlines a short account of Susan's life.

Profile

Susan is an articulate woman who spoke freely about her life. Susan believes that she has had ADD all her life, although she does not have a formal psychiatric diagnosis. However, she has been diagnosed with other psychiatric disorders which she believes developed later in life. Susan is in a steady relationship with Bob who has been her partner for eight years. She works part time and volunteers in a number of organisations which assist people with disabilities. She has two sons who live independently. At the time of the interview Susan was in her early fifties.

This Thing Called ADD

Fours years previously, as a university student, she had participated in a study conducted by the Psychology Department at James Cook University: *"when I was at JCU they had a thing, they wanted volunteers, adults who thought they might have, ...ADD, so I volunteered"*. The university told her; *"You definitely fit the criteria"*.

Even so she said:

it really had no effect on me whatsoever, I still carried on carrying on like a two bob watch....I ended up having a breakdown, total breakdown after about nine months or something. And when I got over that, that's when I stopped and thought about it all, and you know, got it all into perspective and realised that I could control this thing. All my life it's controlled me. And it's just sort of then I decided that, you know, I was going to take control of it.

Like all my life I didn't know what made me do all the weird things I did... you just think you're weird, you just think you're crazy. But you can't do anything about it because you don't know why you're doing it. But then once, you know, you find out more about it, then it just makes life simpler....And you can change it. Which is something I have never been able to do, even with my temper and stuff, you know. And yet now, over the last couple of years, because I sort of feel that I'm in control of it.

Taking control meant understanding ADD, and using that knowledge to reflect on her life.

Early Childhood Memories

I was born:

in England, but... well I was three months when we went to the West Indies, to the Bahamas. ...I must have been to an extent hard to handle, because we had maids. We had coloured maids....We had one to do the washing, one to do the cleaning and one to look after me. Mum and Dad both worked, and... whether it's just my age, or whether it was me, I don't know. But I had this one particular [maid], *she looked after me, and I guess I couldn't have been too easy to get on with even then.*

Susan had an older sister, she had friends, was happy and remembers the West Indies with great fondness:

I was ten when we left there. Under a bit of a cloud, as well, with Dad... Dad's business went bad, and you know, it was... much drama and we were sort of smuggled out on this aeroplane and all that.

Things changed for Susan dramatically:

> *when I was …in the West Indies, I started* [school] *at four, and what memories I have got are fine. But from the time I went to England, ... like they've brought me off this desert island, and they've stuck me in this school... this red brick monster, with these great big walls with glass on top, around... they shut the gates in, you know, and they said, you're in school.*

Life at School in London

Susan said:

> *I never got on with anyone at school, I never had friends at school. I was aggro, you know, I used to bite kids, I was very bad for biting in class…and I did quite a few things that used to get me into trouble...I would lead other kids astray... I didn't have good relationships with my peers when I was young. At all. I just didn't, you know. I couldn't work out why all these other people had friends, and I never had friends.*

> *School was a nightmare …my whole school* [ing] *was a total disaster... I hated schools because I hated the rigid... rigid uniforms and all the discipline... that was no good, that didn't work! That wasn't any good....I could do the work, but just...I wouldn't. Just to be awkward, you know…I'd sit there and draw and carry on, you know. And that's how I actually stopped... finished going to school.*

> *I was fourteen, and this particular maths teacher, I'd been doing this fantastic drawing, she came back in and she walked over and took it off me? And she said you can have it back at the end of class. So at the end of class I went over and asked for it back and she ripped it up in front of my face, so I swore at her. And I left. And I didn't go back for about four days or something, and when I did go back I walked in and one of the kids said, "you're in trouble, you've got to go to the headmistress" and I went, "oh, fine". Put the coat back on and walked out, and I never went back.*

I just refused...Dad couldn't make me go back, and... so he finally took me to a psychiatrist, who gave me indefinite period off, which lasted me until I was fifteen, 'cause I couldn't do anything in England till I was fifteen, so I stayed home and nearly drove my mother crazy for about a year.

Life After School

I got married when I was sixteen. Had John when I was sixteen. And then I had another son the following year, but he died at five months old...Bronchial pneumonia... I blamed the country. The climate. But it wasn't... I don't think it was really the climate, I think it was really the fact that I was only seventeen and didn't really have a clue about what I was doing... I had two kids. I mean, Mum helped me, she came over nearly every day, but I really didn't have the faintest idea....I've stopped bashing myself up about it now,... I do believe that it was a lot of my fault. It's not that I didn't get him medical treatment or anything, it's just that... I was too young and didn't sort of have it down perfectly.... a lot of stuff's happened in Australia... but I still think the eight years I spent in England was probably the worst. I hate that country.

And that's... one of the reasons I came... we came out here, I think... well, I came out here... My sister had come out here nine months before me. She was out here, and um... we had gone through all the... interviews and all this to come to Australia, and my husband decided he didn't want to go. So we just dropped it. And then when my other son died, after a few weeks, I sort of got back on my feet, I want to go to Australia. So I just rang up Australia House, and said, you know, there's three of us, when can we go? And they said, we'll let you know, sort of thing, and they rang me back two weeks later and said you can go next week...went up the road, sold all my furniture to different people in the street, said you can pick it up next week. When he came home from work I said "we're going to Australia, dear." Didn't go down terribly well... he wasn't going to come... well, I said to him, you know, you can stay if you want, but he came. He hasn't stopped whingeing about it yet and that was 1966, and I haven't seen him for years now, but he's in Bundaberg somewhere, and as far as I hear he's still complaining.

Life in Australia

I've traveled a bit, but... lived on the Gold Coast from '66 to '91. I got married a couple of times, and had a few more relationships besides that. ...I had a couple of miscarriages during that time. The doctor maybe thought they might have been girls, 'cause there was no reason for the miscarriage. I might have been that I just couldn't carry girls or something.

Worked in hotels for twenty years, and developed a drinking problem. Which is another easy thing to do when you've got ADD I think...I drank alcohol because I liked the way it made me feel. It made me more sociable. I was always very shy... And it helped me feel better and feel social and feel good. Be able to talk to people. Which I couldn't do before that. I don't think... it's never become a physical dependence with me...but it's a mental dependence. And it's also to do with stress... it's like when my stress level goes up, and I get stressed, that's when I start craving for a drink. And that's when I used to drink. That's when I used to totally and utterly wipe myself out...that's how it ended up in the later years.

Susan also abused prescription drugs such as *"Serapax, Valium"* and *"sleeping tablets"*. She saw her use of alcohol and drugs as a way to *"escape"* and said, *"it was like I was daring myself to kill myself"*.

Career and ADD

It [ADD] *made me one of the best barmaids on the Gold Coast, because I was so active and ... well, hyperactive, you know. I worked in bars for twenty years... probably a good fifteen or sixteen of that I was good. I know I was. I've got maths in my head... this is the days before the electronic tills and stuff... you know, you had to add them up in your head. And I can do that. I can do mental arithmetic. So I could do all that whereas everyone else had to get bits of paper, write it down. By the time I got my drinks and taken them back to the customers, I knew how much it was. I was good.*

Very unreliable problem...I changed jobs a lot. I'd get bored...It's true. Sounds stupid I know, but it's... I can't handle... I've never been able to handle boredom. Now, I can handle it better... because I know about it... I know that I can't handle it, so I know how to handle it.

Living with ADD, What Does it Mean?

Susan outlined a number of ADD characteristics and issues which affected her life dramatically:

The reason I'm in Australia [is] *ADD. The reason I have tattoos, ADD. It's all impulsivity. I came out to Australia on an impulse. With my husband and my son. We moved all these thousands of miles away from everything. I remember getting to London airport and sitting there thinking, "God, what have I done this time?" I can't change my mind now.*

A couple of years ago:

one of my brilliant ideas was to buy the ...Fish Bar. And Bob [her husband] *sometimes will stand up to me, but other times it's like, he won't, because he doesn't want a heap of drama...*[by] *saying no to me. So he let me go through with it. I had it for four months, I went totally broke, I haven't got the faintest idea how to handle money. And I went down to forty-two and a half kilos, I was doing fourteen... this is in the middle of summer... fourteen hours a day. He told me he wouldn't help me, and he didn't. And the stress... I ended up selling it, I lost a lot of money. And he was pretty mean. He had a right to be I suppose. But he was pretty bad to me at that time when I first sold it. It was... he was really pissed off that I'd lost this money. And again it was the stress... and the stress level just went up and it went up so far and I started to drink and that was it...I drank ... I don't know, at least a bottle of bourbon a day, you know. I kicked him out. I packed his bags and threw them out the door, changed the locks on the house, and ... sold his boat for two grand... it's worth a lot more than that.*

I'd gone to rock bottom, I mean, that was it, you know? There was two ways out. There was the bathroom and cut my wrists. Or...go back, you know, try to start back again.

What Turned it Around for Susan?

I asked Susan, what prevented her from committing suicide?

A couple of things. One is the fact that before I didn't know why... I felt the way I did. So... it's virtually impossible to handle something when you don't know what it is. So the more I've got to know about these things, the more I've got to know about myself, that's made it a bit easier. One was knowing what I was up against, and the other one was letting myself admit to myself that I wasn't this big strong person that I'd always said I was and independent, and didn't need anybody and this, that and the other. Which is what I've told myself all my life. I realise now it's been total rubbish. It has! It's never been true!

Susan stopped abusing alcohol and prescription drugs from that time and asked Bob to return to the house.

Family and Relationships

I asked, *"How has ADD affected you and your family"?*

Oh, it's definitely had effects. And my parents ... all my family ... my partners ... definitely had a drastic effect on the whole thing! On my whole life!

I had:

a strange childhood, because my father, I'm sure my father's ADD too, my Dad has had so much, he's been a millionaire in his life, a couple of times, and then he's been right at the other end of the scale, and he's ended up at eighty-one years old with three boxes and a suitcase.

Susan has been married four times.

I know all my past relationships and husbands and whatever, have always been ...fairly full on....But then when that wears off and boredom starts, that's when I get stressed and that's when I ... usually just leave whatever I'm doing ... jobs, husbands ...Move on.

My older son spent many years not talking to me, because of the way ... things had happened, and my youngest son loves me dearly, more than anything in the

world, which I know, but because he's so much like me, we clash. Something terrible. But also because I know him. I know him better than he knows him.

In speaking of her youngest son Susan said:

Well my relationship with Jerry ended at five and started again at twelve. He went to live with a friend because I got to the stage where I was about to put a pillow over his head. And suffocate him. I had a friend ... we were on the Gold Coast and she was moving…about an hour from the Gold Coast ... and she offered to take him for a little while. And a little while turned into seven years or something.

He… wasn't the same as other kids. He still had problems at school, you know, he liked to jump off the roof at school, and things like that. He still did really weird things.

He came back a couple of times for a couple of week's trial here and there, and he'd start,…mucking around, and then he'd always get really vicious, and have to start hurting me. I think a lot of it was jealousy, you know, the fact that he lived ... didn't live with me. But he was resentful that he didn't live with me. But I used to go and visit him a lot, and I spoiled him rotten probably, to make up for not ... well, I couldn't look after him. I'd have killed him.

I stopped hitting him when he was about four, three or four. Because I realised, I had this mental picture of me beating him to a pulp. And I knew that I was quite capable of it, and I probably would do it. So I just stopped hitting him….he used to say I was weak, because I didn't hit him. And I said to him when he was a bit older, you shouldn't look on that as a weakness, you should look on it as a strength, because, I said, had I continued hitting you, you would either now be brain damaged, or dead. Because I dare say I would have killed him.

Susan explains that Jerry returned to live with her when he was twelve. Susan found this time very stressful, due to his abusive behaviour, drug taking and problems with the law. Jerry first went to jail at seventeen. As a young man in his early twenties he

avoided going to jail for the third time by becoming involved in a rehabilitation program. He has since been diagnosed as having a psychiatric disorder (Personal Communication September, 2004).

Susan explains that her granddaughter, Jerry's child, eighteen month old Joanne *"is exactly the same"* but Joanne's mother does not have ADD:

She's more placid and everything than I am, and Joanne gets to her as well. She gets to me. I've got to have Joanne in small doses. Which is good, because I can. Cause she doesn't live with me.

By the time Joanne was six she had been diagnosed with ADD (Personal Communication, December, 2004).

The Way Forward

The label ADD, understanding and knowledge promoted Susan to join the support group to assist others:

I do feel for people that have ADD and also for people that have kids with ADD, you know, if I can be of any help, to them,…I'd like to do that. But Joanne is my … main thought these days.

Susan had come a long way in the last year or two. She said:

you probably wouldn't have wanted to know the person I was. I was different. I mean I just was. …I'm quite happy the way things are at the moment. I feel like I'm putting something back into life. All my life I've taken.…So I think the rest of my life is just not to let this ADD…or anything else get the better of me.

In viewing Susan's story it can be seen that while ADD did have a negative impact on many aspects of her life, Susan refused to allow painful experiences to dominate her life. Susan used the label ADD to analyse her life; to understand (Barkley, 2001a) her *"weird, crazy"* and *"impulsive"* actions, and in doing so, this ultimately saved her life. ADD is not seen as a bad thing, after all Susan's *"hyperactivity"* made her one of *"the best barmaids on the Gold Coast"*. For Susan understanding her difference is a liberating experience (Hartmann, 1999). Susan uses her

knowledge in her paid and volunteer work to advocate for people affected by ADD and psychiatric disorders. Foucault (1972; 1980d) argued that knowledge and power are entwined and can be accessed by individuals and groups. Susan, in formulating an alternate discourse in relation to ADD and motherhood, demonstrates the way in which a marginalised and excluded individual can act to bring about change (O'Brien & Penna, 1998).

Susan's story has given some insight into having ADD and the way in which individuals can use knowledge. However, her story raises many questions, such as, do men and women experience ADD differently and how can knowledge be used to support an individual's difference. Susan's story also highlights the difficulty that women may experience as mothers if they have ADD. The effect of having ADD on mothering has come to the attention of other researchers (Arnold, 1996; Daly & Fritsch, 1995; Muslow et al., 2001), however it has not been fully explored to date. Clearly there are numerous questions that need to be examined by researchers, in particular feminist researchers, researchers who identify as insiders as well as researchers who have no or little understanding of what it means to experience ADD as a woman or as a mother. Both qualitative and quantitative research will also add knowledge to an area which, until recently, has been devoid of academic enquiry.

ANNE'S JOURNEY

Another area which further needs exploration is the way in which power is exercised by professionals. In this research, many of the women who sought out professionals to assist them in their mothering reported similar experiences. Anne, in particular, had a detailed history. Accordingly, Anne's story has been chosen as a case study to explore the way in which some professionals use their knowledge and power (Foucault, 1972, 1980d) in their interactions with the mothers of children with ADD.

Profile

Anne told her story of her search for assistance and her experiences with professionals in a simple and frank manner. As previously discussed, Anne is married to Joe and they have two boys Clifford and Carl.

Early Intervention

Anne stated that due to Clifford's demanding nature, she had been involved in Behaviour Management programs since he was three years of age. Anne explained that the program, through the public health system, consisted of role modelling and many common child management strategies:

> *it worked really, really well, Clifford had one on one attention,…well, he just flew through the program, they couldn't believe how well he flew through the program, but at home you could not bring that into reality because at home …you couldn't give him one on one, you'd have dishes to be done,…and that's when the behaviour problems would come in, as soon as the attention was wavered,…it was like a hard battle the whole time, I had been told to just keep giving him the extra attention, to try ignoring the bad behaviour, praising the good, forget when he was having a temper tantrum, that was very, very hard.*

Anne kept searching for answers to her son's difficult and demanding behaviour as *"doing the praising and ignoring…wasn't working for Clifford"*. She said, *"I was just lucky enough to pick up the book, The Hidden Handicap, [when I visited the clinic]…a patient had accidentally left it at child health"*. Reading this book on ADD, written by Gordon Serfontein (1990) was like a light being switched on for Anne:

> *I just kept chasing up someone else who knew more and more…I've been told many a time that my children aren't ADD, they just need a good flogging, basically, one doctor told me to just put locks on their doors, lock them in…I've been told to remove everything from their bedroom…so…they can't break anything, they can't harm themselves, but like my walls – I'm sick and tired of repairing holes in my walls.*

Anne sought assistance from paediatricians in the private sector. Eventually Clifford was diagnosed with ADHD at seven years of age and his brother, Carl at four and a half.

Family Sessions

After the children were diagnosed, Anne once again contacted the public health service to help her manage her children. Anne said that she was told by a doctor that:

> there was nothing he could do for my family, even if like the kids were running riots in his office, writing swear words all over the blackboard, and everything else,...no nothing they could do.

Eventually she was assigned to a different doctor within the agency who said her family:

> had to have family sessions because she said that there was nothing she could do without us being a family. And it was hard, my husband can work up to twelve hours a day, therefore its hard to be able to get in there. But my husband made sure he knocked off work.
>
> We went into this family session one day,...we were sitting down and he [the psychologist assigned to conduct the session] wanted us to tell our life history and all,...he was so over the top about wanting to know my past,...my husband came from a family where he was the only child with mother and father intact [still together] so that went down as a normal family, so that was fine, but then he wanted to know about my family, and well my family wouldn't be what I'd call the normal run of the mill family as my mother had been married three times, and my father had been married three times...and with that Clifford [at nine and a half years of age] stood up and [said] "Well I don't have to listen to all this crap" and walked out. And as he walked out the one door, the next door was opened and it was side by side, and he said; "Hey look Mum, here's all these people sitting in here" and I said, "Come away sort of thing", as I'm trying to get him back in, thinking he was approaching on another meeting, to find out that the mirror in our room, that we'd been sitting in, was actually a two way mirror, and all of these people, there was probably about between eight to twelve people sitting there, with the speaker on, listening in, watching everything that we do. We hadn't been told that this was happening...I would have preferred to have known that was going on beforehand.

Anne said that the event made her feel uneasy and she was concerned about the line of questioning in relation to her family of origin. Anne had told the psychologist in response to his in depth questions about her mother, father, brother and sisters, *"look, this isn't my life, that was many years ago…Yes, that is what I've come from, but I can move on".* Anne valued her relationship with her husband and children saying:

> *as far as I'm concerned, married life is very important to me, probably more so because of the way that my mother and father were, so if anything that should make my family life stronger, not weaker, as* [he was] *trying to make it out to be. So, after that there session, me and my husband had a big talk about it, and said… it was just a waste of time and effort, Clifford was allowed to speak…in any tone of voice, anything he wanted to say, both me and my husband both jumped up and down basically trying to tell Clifford to sit down and be quiet and you don't speak to an older person like that at all. We got told to sit down, while we were in the session, he was allowed to say and do whatever he wanted, and we said no, that behaviour is not accepted by us, wherever, definitely not in a meeting, not with other adults around, and it wouldn't even be tolerated in our own home. So after that session we left.*

I Need to Take a Valium Before I See Your Children

Anne continued to seek help in the private sector. Anne said that she found that the attitudes of professionals to her and her family were very hurtful. She told the story of the children's treating paediatrician who had said to her:

> *make sure that when you book the children in for appointments with me, book them in separately, because I can't handle them together, and don't forget to phone my receptionist to remind her that that's the day you're booked in so I can take a Valium before I see your children. …I just put it down to a joke…but actually a few weeks ago I was there and I heard him say to his receptionist, "Oh no, not the Jones family again. My life was going well until now!" And sitting in the waiting room I'm thinking my God sort of thing, I just felt like bursting into tears and saying look, just don't worry about us. But I'd like the children to be checked on once every three months, they need their medication foremost, for*

myself and themselves, and the other ones around them....My family wouldn't be
here today without the medication.

The same paediatrician encouraged her to return to the public health system saying that in the past three to four years the service had changed; *"go back, go back* (I) *can't help with the behaviour problems, so that's the only avenue you've got left".* Clifford was by this time at boarding school as family, friends and the local school were unable to deal with his disruptive and defiant behaviour. Anne accepted the paediatrician's referral as:

Carl was talking about suicide, and other things like that, and I really didn't
know how to cope, I'd already gone through that with Clifford, and I'd coped
then, but you get tired and you find it very hard to keep finding different things to
help the children with. The doctor phoned while I was there for the appointment
and said it was very urgent.

We Can't Help Martyrs

Anne and Carl attended the interview with the psychologist, explaining that she was concerned about Carl's anger and the talk of suicide. The psychologist:

basically kept telling me that I'm acting like Carl's sibling, not as his parent, I
should take that role back,...I thought well maybe...I'm doing the wrong thing, so
I tried to take that parenting role back...within reason,...Carl's tempers were
flaring even more, because I was trying to get more authority, where...I think
Carl needed more friend than an authority figure, with this suicide tendencies,
and the way his explosion of behaviours was happening, we went back again, it
must have been, oh, it was within a month,...and my other son Clifford was home
from boarding school, and I thought this was a good opportunity for [the
psychologist] *to meet both boys and all, and my boys were on a roll. They just*
played up no end, ... [the psychologist] *had told me to ignore their behaviour, so I*
had, and I thought well this is what I've been putting up with at home, therefore
this is what [the psychologist is] *finally seeing.*

Anne said the interview concluded with the psychologist saying to her:

seeing how my husband couldn't attend the meetings [and] *because I don't like leaving my children with my husband, because my husband cannot understand their behaviour a lot of times, so it causes a lot of friction in the household, my husband won't tolerate a lot of their silliness behaviour, and if they hit him, he's quite happy to hit them back. But I don't blame him sometimes, Carl's got a good mean right hook on him when he wants to, so* [the psychologist] *basically said that's it, he can't do anything at all for my family, unless we all take behaviour management, he said the only way he'd accept Carl doing behaviour management was if the child asked for it himself, because he felt the whole family needed management in their anger.*

Anne said that she felt there was a lot of anger in the family. She found it hard to cope with the situation:

with one child that's just so out of control, he can't control himself, but you can only put up with that to a certain level, and then you do explode, and I must admit I'm a yeller, I'd prefer to be a yeller than smacker, because if I started smacking I don't think I'd stop. It does do the children harm with me yelling at them, I can see that, but…there's not a day that goes by, or an hour that goes by that one of them aren't absolutely swearing their head off, yelling, screaming, I've got to pull the boys apart because they physically get into punch ups and things, and normally it ends up with one of us in tears and basically feeling it's our fault, between the four of us, so it's not the ideal situation to have a family in at all. I don't know whether that all comes with the ADD, or the frustration over the years of having ADD, and not being able to get the help for it, especially when the children are younger. … So we're back at the bottom of the fish bowl again, just floating around and hoping and praying that what I can pick up as far as behaviour management goes [will help us]*.*

A Critic of Professional Power

Anne passed on to me the two letters which had been sent from the psychologist to the paediatrician, regarding the interviews and any possible assistance. She had requested a copy of the letters and after some discussion between the psychologist and the paediatrician about possible *"discrimination",* copies were given to her. The initial three page letter written in August 1999, described the family as *"an intact, working-class nuclear family".* It was identified that Anne *"suffers with chronic fatigue"* and is *"not well supported".* The letter also gave information on Anne's family, mentioning that her mother had had an affair. The key issues that the psychologist identified during the first interview was that Carl needed *"to feel/act his age"* and that Anne needed to establish *"a mutually supportive partnership with her husband".* The plan of action was *"to administer and score behaviour checklists from parents and school"*, to support Anne in *"developing a mutually supportive marital and parenting relationship with her husband"* and to support Anne in *"reviewing her expectations of Carl & making age appropriate demands of Carl".*

The second letter was written after the interview attended by both boys and Anne. The psychologist stated in the letter to the paediatrician: *"I have been overly optimistic in the report of my assessment I sent to you".* He commented that Anne's authority is undermined by the *"paternal grandparents"* and was not receiving support from her husband. He went on to say that Anne *"is not able to establish a mutually supportive marital/parenting relationship with her husband…or to essentially stop being a martyr".* Therefore, if *"there is nothing she can change/do different",* in relation to enlisting her husband's support or the support of her parents-in-law, he was not prepared to arrange *"any further appointments".* The psychologist stated in response to Anne's request for anger management training for Carl:

> *I have said I would be willing to do this if Carl asked for his own sake…aside from this, I think it unwise to single Carl out for treatment in this regard as all family members seem to have problems with their anger management.*

Anne's story is a good example of the experiences that some women have in trying to find services for their children and family. It is clear that from an early age Clifford and his mother were involved in programs which were developed from a behaviourist approach, which sees deviant or problematic behaviour developing from experiences in the home or with the mother (Rafalovich, 2001b). Anne participated in these programs but found them wanting; they did not work for her.

Later on family therapy, which is advocated by some for the treatment of ADD (Clark, 1996; Schmidt Neven et al., 2000), was deemed necessary for the family. Once again the focus was directed at Anne as she did not come from an intact, nuclear family. The professionals concerned chose to work from a deficit point of view (Saleebey, 1992), seeing Anne's family of origin as problematic, instead of working from a strengths perspective, taking into consideration Anne's commitment to her family and her strong desire to help her children (Elliot et al., 2000). Both Anne and Joe were disturbed with the intrusion into their family history and the undermining of their authority as parents, when they were told that the children could say and do what they liked in the family therapy session.

The professionals who implemented the family therapy sessions treated the family with disrespect and acted unethically by not asking the family's permission to observe them through a two way mirror (AASW, 1999). The image of the Panopticon is conjured in examining this practice. Foucault (1980b) notes that before Bentham's Panopticon, glass cells were used in 1751 in Paris, to observe military personnel in their barracks. The observer is unseen, however, through this process the individual, or groups can formulate knowledge, and the ability to control and discipline those they observe. This form of surveillance was later introduced in institutions like prisons, schools and hospitals. In this example, the professionals through their invisibility could observe the hapless family; formulate their theory of deviance with the intention of formulating a plan of action which would redeem the dysfunctional family.

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Professionals in their positions of privilege and power had found it difficult to manage the children, even one on one. Hence, the paediatrician asked Anne to book the boys in separately to see him. However, while the children's behaviour was too difficult for the paediatrician to handle, the professionals that Anne contacted still expected Anne to manage their behaviour; indeed not only manage the children's behaviour but to enlist the support of her husband. This view reflects the work of Winnicott (1964) who asserted that mothers were responsible for the involvement of the father. When Anne could not enlist the support of her husband or stop her parents-in-law from undermining her in her role she was castigated as a *"martyr"*.

The psychologist in the public health system had identified Clifford's immaturity as an issue. He described Clifford as *"enmeshed with and to an extent infantilized by his mother"*. Immaturity, especially in the areas of demanding attention, persistence, organisation and self control is a common characteristic of children diagnosed with ADD (Barkley, 2001a). Barkley (2001a) notes that the later development of children with ADD needs to be taken into consideration when assisting families. However, the psychologist preferred to see Clifford's immaturity stemming from his upbringing and identified Anne as the culprit. Furthermore, the psychologist did not want to single out Clifford for any intervention even though he was threatening suicide. Thus, the psychologist was implying that the child had been scapegoated (Schmidt Neven et al., 2000) for the family's dysfunction. The offer of *"behaviour management"* for the whole family was a futile gesture on the part of the psychologist. Anne had sought help for ten years and all programs offered to her did not assist the family in any way, indeed some of the strategies worsened the situation.

In summary, Anne's story demonstrates the unethical practices of some professionals. Moreover, her story shows how mothers suffer through systemic normalisation practices which seek to produce normal mothers, who raise normal children in normal families. When women fail the programs developed by the experts, they are demonstrating their *"ineducability and instability of character"* (Bowlby, 1952) and are punished (Rose & Miller, 1992). Anne was left suffering from chronic fatigue, no visible support from her partner or parents-in-law, and to raise a child of ten who was threatening to commit suicide.

Anne's story * is by no means unique. Many of the women I interviewed and other women in the support group, reported similar experiences in dealing with professionals. They either were treated with disrespect or their needs as a family were ignored in favour of what the professionals felt they needed in order to achieve normalcy. Foucault (1979), Rose and Miller (1992) and Rose (1996) speak usefully of the way in which professionals seek to normalise populations through the use of their professional power and normalisation strategies. It was through such experiences that the women in the support group started to look for alternatives which would meet their needs and support their families.

* I have known Anne for many years. She was a founding member of the support group in 1993. I have found Anne and her husband, Joe, to be kind and generous people to friends and those in need. I was aware of the difficult family situation however I was shocked by the contempt for Anne in the letter. To maintain the family's privacy and protect the innocent I decided not to include the two letters in the attachment. Anne was advised by others in the support group to write a letter of complaint. Anne declined, saying that she did not have the energy and doubted if writing a letter of complaint would change the attitude or practices of those concerned.

CONCLUSION

In summary, both Susan's and Anne's lives were dramatically affected by ADD, even though their circumstances are completely different. The impact of adult ADD on women has not been fully explored by researchers. However, Susan's story demonstrates that ADD had a considerable impact upon her school experiences, life choices, career and the ability to mother in a society which has espoused *"intensive mothering"* as the best model of child rearing (Hays, 1996, p.21). Furthermore, understanding and knowledge of ADD did have a positive impact on Susan, as it helped her to make sense of her life and feel that she was *"in control"*.

Understanding ADD was also crucial for Anne however, in her search for assistance, Anne was often seen as the problem. Professionals were all too ready to blame Anne for her children's behaviour and the lack of active involvement from her husband in rearing the children. The story of Susan, and Anne's journey and the way in which power can be used, lay the foundation for the next chapter, in which women's resistance to the negative impact of professional power is explored.

CHAPTER NINE - SUPPORT GROUPS AND POLITICAL ACTION

"Hope gives you power" (Roseanne*).*

Introduction

In the previous chapters, it was shown that ADD had an impact on family life and the health and well being of women. In this chapter, it will be shown that while ADD may have a dramatic effect on women's health, the experience can transform some individuals into social change agents. The value of women's friendships and the support that can be found within groups will be examined, along with the political activities of the support group. Some examples of political advocacy have been documented in this chapter and will be analysed using Foucault's concept of power and feminist standpoint theory.

ADVERSITY – CHANGE OF WORLD VIEW

It is evident that the impact of having a child or children with ADD is profound. However, while the mothers reported poor health and abuse some also spoke about the experience as a positive one. Adversity forged the women's strength, compassion and changed their world view. **Mim** explained:

> *I am not the person I was 15 years ago, I don't mean that I am a little greyer, I mean that I'm a very different person. I think in ways there have been some positives because it has made me grow and mature in ways that I wouldn't have done before.*

Wild Thing believed that if she had not experienced her son's ADD her *"entire life would have been totally different"*. In looking back at her life and seeing the difference that diagnosis had made to her son she reflected that her experiences were:

> *ninety nine percent positive now. Where I am at in my life, looking back I'd say that it was all positive. Because I came, I came out of it, probably, a better person, I was probably always going to be the same person, I don't know, probably makes you a stronger person.*

Leanne also felt that:

adversity makes some people stronger, I think I'm a stronger person as a result of it. I think I have more compassion and understanding for people that don't have a fair go in our community. …Even though it could be seen as basically a negative life experience…it can be a positive one. Even though it is very stressful, very difficult, I think it's made me a better professional.

Joyce believed that she had become a better person for the experience: *"I never would have accepted anyone like Nick into my little world…it's made me a better person. I understand myself better. …I understand people better".*

Compassion, patience and perseverance where the qualities which **Roseanne** gained:

I think it's produced a lot of compassion in me…that's what trials and tribulations can do for people really, it can make you bitter and twisted or give you a great deal of maturity and compassion. …I've had to learn patience and getting up when you feel like lying down.

Steven's ADD and the shattering of **Mary Serenity's** dream of being a mother was described by her as:

the best thing that had ever happened. …I would have stayed in my little, safe little world. I never would have extended myself. It has changed everything, the way I look at everything, it, it sort of, opened my eyes to the stupidity and the discrimination and the unfairness in our society. It made me reevaluate everything.

Mary Serenity spoke of her son Steven as life's teacher:

he has been the best teacher I have ever had. He has taught me so much. …Painful, painful lessons,…he has taught me how to cry, more than anyone I have ever known and he has taught me how to laugh more than anyone I've ever known. …He taught me how to walk away, that's, that's, a very valuable lesson. Because if you can really love someone and then turn your back and walk away that means that you stand alone. He taught me how to stand alone…it is about living and understanding and letting others live. It is also about, we each have to find our own way and live our lives the best way we know how. Not judging each

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other and all that sort of stuff. And it's, it's really about growing up, growing up and some of us never will. He taught me that. …I'm a student of life, I'm still learning. A work in progress.

Stirling (2004, p.2) speaks of *"the gift of brokenness",* the way in which some individuals emerge from painful or traumatic experiences as more rounded, insightful human beings. Thus, like the phoenix rising from the ashes these women were reborn.

Support from Other women

In looking at the dire circumstances of the women, isolated, marginalised and suffering ill health and abuse, it is clear that the friendship of other women acted as a lifeboat. However, it was not just any woman, it needed to be a woman that understood and accepted without judging:

> *standing outside the steps of Centrelink and talking with a woman* [from the support group]*, and that was sort of a precipitous or momentous sort of mark for me because I felt, hell, I'm actually talking with someone that really understands what I'm going through. So that was a special event marked in my mind, that I finally found I was communicating with someone whom I developed a very close rapport with late on, to say yes, I understand what's happening and I, for the first time, I felt that I was talking to someone who really understood where I was coming from. …I had never had that before…getting acceptance and understanding from someone was very important to me* (Leanne).

Thus women in the support group, through their shared experience, could support others and find support for themselves.

Number 13 explained that NADDS:

> *has got me through the majority of it. …You can go there and have a whinge about your life and family and everything, and everybody knows exactly where you're coming from, you're not prejudged, and everybody is sort of been there and done the same.*

Mim also expressed her relief at finding other women in the support group:

and that was…a lovely relief. 'Cause I was allowed to get out a lot of frustration that I had to bottle in for many, many years and, of course, you know you walk around with this big guilt complex that you've made this monster and of course my monster was growing. So the support group helped.

Two other Queensland researchers (Carpenter, 1999, p.26; van Kraayenoord et al., 2001) have spoken of the function of ADD support groups. In her study Carpenter (1999, p.252) concluded that support groups were valuable as they enabled mothers *"to communicate with other mothers who understood their concerns, and to feel a sense of belonging and community with other mothers of ADHD children"*. Furthermore in her study the mothers, *"who did not belong to a support group were unable to find similar support"* (Carpenter, 1999, p.252). Barber (1991) also attests to the value of people with similar issues coming together to support and share their experiences.

Resistance and Personal Advocacy

Many of the women interviewed recognised that advocacy was needed to change the lives of their children and their families. **Joyce** said that through her contact with the support group she was able to talk to others about her experiences with the hope that she may be able to help:

I give my perspective as a parent. I say to people; "I'm not a professional, I don't have a degree in this, but I have an opinion as a mother and I can give you words of experiences that I've been through, but not everybody's experience is the same".

Wild Thing spoke of her willingness to:

show people that you [have to] look at it from a different point of view, when people see them as social misfits and deviants, I always advocate that no, this is not so. It's because of the condition; a lot of this stuff has been brought on by society not recognising the condition. …These people need help and assistance and support, not to be frowned upon and talked about.

Some women were comfortable with personal advocacy and exchanging stories. In exchanging stories they learnt which professionals to avoid and which professionals to approach to assist them with the issues in their family. However, others within the group thought "*of using the support group as a way to get change*" (Mim).

Leanne echoed these sentiments:

I think it's an important structure in the community,...the opportunity to do something positive, the opportunity to make changes is important. ...Lately we've been lobbyng ministers to try to make some positive changes, and that's been good because that's been proactive.

In identifying the support group as a vehicle for social change, **Mim** explained:

it is no use whingeing and moaning, you have to be a doer. ...I think that it is a mammoth task. ...I think unless you are prepared to lobby our politicians you will get nowhere, I am afraid the politicians run our lives. Their policy dictates to us, I mean we do not have a choice about sending our kids to school. It is the government that make us send our kids to school and so it is the education system that is having this enormous negative affect on our children and making them a social problem. So it is the education system that has to be changed.

Accordingly, a core group of women within the support group took on the role of political advocacy with the view of improving the situation for individuals and families affected by ADD.

Foucault (1980c) in exploring the function of power, states that *"there are no relations of power without resistances"* and speaks of the importance of local struggles to challenge dominant power bases. While a core group of women were recognised as the prime movers of this political strategy, other women and men joined in as they felt comfortable and had the resources to allow them to participate. Their activities will now be discussed using the written records of the support group and information gained from attending forums, workshops and support group meetings.

Political Advocacy

Between 1998 and 2002, NADDS was very focused on strategies to influence government policy. These strategies were well planned and sought to be holistic: meeting with and writing letters to local members of parliament, federal and state government ministers, attending community consultation forums, making representation at Community Cabinet Meetings, accepting positions on steering committees, approaching Regional Forum members, and approaching government departments. Many of these strategies are espoused by Barber (1991) as useful and necessary in attempting to influence policy. It is not possible to explore every act of political advocacy however, it needs to be said that the women's activities were numerous, and that there is a plethora of written information to support this assertion.

In viewing the documentation it can be seen that the support group had written their own discourse on ADD based on their own experiences and sought to influence the current discourse operating in Queensland and nationally - a process which Foucault (1972; 1980c) called resistance. Foucault (1980c) stated that within the dominant discourse of the day lie the seeds of resistance as the marginalised fight to change the status quo and bring about change. Thus, this chapter is primarily concerned with *"the politics of resistance"* (O'Brien & Penna, 1998). In addition, NADDS pursued collaboration between themselves, government departments and community organisations, and espoused a *"power with"* approach to the issues facing families and the broader community in relation to ADD (McLaren, 2002, p.41). A few examples have been chosen in order to explore the many dimensions of power operating within theses exchanges between the women and the numerous government representatives, the bureaucracy and community groups.

Seeking to Influence Policy

The women were aware that influencing policy was an important step in seeking to provide services for their families. Given the social justice platform of the Labor Party the women felt that the party may be sympathetic to their cause. Accordingly, women from NADDS attended a forum organised by the Labor Federal Status of Women Caucus Committee (17th November, 1999) to discuss issues of concern for local women. Members of the support group spoke of their plight and the need for

services to assist them and their families. The women who attended were told that *"the information would be used in the formulation of Labor's policies"* (A. Reed, 1999, p.2). The support group secretary followed up with a letter to Senator Jan McLucas thanking her for her attendance and stating that they *"were heartened by the responsiveness of those present to our difficulties"* (Unpublished letter 26th November 1999). A number of issues were covered in the letter and in closing the group requested that as

> the Australian Labor Party conference is scheduled for Hobart next year…our group would be interested in ensuring that Attention Deficit (Hyperactivity) Disorder is raised and a policy decided on by the party (Unpublished letter 26th November 1999).

Members of the support group who were active within the Labor Party locally, enforced this request through branch meetings. Furthermore, the women put forward a proposal that the state party conference also formulate a policy on ADD. To date, the women have never received an indication that their requests were carried out, or that their issues and concerns have been raised through the policy process of the party machine (Personal Communication with NQADD, 1998-2004).

NADDS also sought to influence state government policy. Based on their own knowledge of ADD and drawing on research which emphasises that ADD is a biological condition, the members meet frequently with local members of parliament, attended a Community Cabinet Meeting where they requested to speak to the Ministers of Education, Families, Health, and Disability Services and contributed to a number of departmental discussion papers. After numerous exchanges, some members met with Dean Wells, the Minister for Education, on the 29th July 1999. The members of the support group came away from that meeting with Dean Wells believing that *"a firm commitment to include the recognition of ADHD/ADD in Education policy"* had been made by the Minister for Education (Ahearn, 1999, p.8).

The group wrote a number of letters to Dean Wells and his department after the meeting in July 1999, including passing on to the minister's office the names of academics working in the area of ADD. The group became extremely frustrated as

time passed, as no further acknowledgement was given by Wells or the senior bureaucrats within his department.

Hence the group wrote one more letter to the minister:

Approximately 12 months ago, members of our group (NADDS) met with you in Townsville to discuss the educational needs of children with ADHD. At the conclusion of this meeting we felt confident of your commitment to progressing this issue in a number of ways. Firstly, the need to have ADHD recognised in policy was to be put in progress and we were to expect communication with your policy writers. Since that meeting we have received no evidence of this happening nor have we received any communication from your staff relating to the writing of policy.

We have, however, received a letter from Tim Eltham, dated 17th May 2000 which purports to outline the educational needs of students with ADHD. The contents of this letter are both disappointing and frustrating to say the very least. Within it, there is no reference to the commitments made by you at our meeting. In addition, the information, presumably sent to schools by the department, emphasises our belief that ADHD is not being treated seriously as a learning disorder. Without proper formalised guidelines ADHD will continue to be seen solely as a behaviour disorder.

What is contained within this letter does not show encouraging signs for progressing the needs of children with ADHD. Indeed, our lengthy discussion with you regarding our concerns with Appraisement and Ascertainment do not seem to be recognised by Mr Eltham. Furthermore, I believe that we spoke at length with you about the learning difficulties associated with ADHD, which signify that these children have not only literacy problems per se, but learning difficulties in the conventional classroom, especially one that is predominantly text/whiteboard/chalkboard based.

A recent publication by Susan Moore (2000) identifies the need to focus on the abilities of children with ADHD to obtain successful outcomes. This was the result of 3 years of federal literacy research.

I reiterate, these children are suffering as a result of exclusion within classrooms and while governments continue to dither over whether ADHD is truly a disability or not, we as parents watch another generation of children slide into a trough of despair, depravity and dysfunction. We urge you to honour your commitment and move forward so that our children can receive a democratic and just education (Unpublished letter from NADDS to Dean Wells, 12th July 2000).

The group's understanding of Dean Wells' commitment to the group is outlined in a letter from Mike Reynolds, Member for Townsville, to Dean Wells:

You would remember a meeting held at the Premier's Office in Townsville on 29 July 1999 which included representatives of the Association. A number of the representatives spoke about their serious concerns and in particular the lack of recognition that ADHD has within the education policy framework. As Minister, you indicated that an instruction would be given to ensure that this disability was defined and recognised in departmental policy. ...I would appreciate you advising me of the progress that has been made in this matter (Unpublished letter from Mike Reynolds, to Dean Wells MLA, 10th August 2000).

Once again members of the group who were also members of the Labor Party sought assistance through their local branch. They requested the branch to:

ask why Dean Wells has appeared to have a change of heart and to ask the government in general what is it doing to address the needs of families and individuals affected by ADD (Briefing notes from NADDS).

Dean Wells never honoured his undertaking to the group and after one year the group believed that their energies needed to be directed elsewhere.

Barber (1991), stated that there are *"powerful vested interests in the construction of social policy"*. It has been argued in Chapter One, *The Development of Motherhood and Mother Blame* that a *"metapower"* (Foucault, 1980d) has formed to construct

motherhood and hold women responsible for their children's difference. The material presented in this chapter, demonstrating the unresponsiveness of those who seek to govern federally and those who govern in Queensland, strongly suggests that a discourse may have been adopted which holds mothers responsible for producing children with ADD.

In Chapter Three, *Difference, Normalisation and Discipline*, the tendency of western governments to scapegoat parents for producing deviant children and their reliance on parent training programs to normalise families and children (Hil & McMahon, 2001), was discussed. Dean Wells gives clear evidence of his government's policy towards families and individuals affected by ADD, in a letter he wrote to Lindy Nelson-Carr: *"as you mentioned these children and their parents face complex issues on a daily basis. Programs like Triple P are in place to assist the community"* (Unpublished Letter from Dean Wells to Lindy Nelson-Carr, Member for Mundingburra 23rd November 1999). Thus, the women's assertions to Dean Wells that ADD is in essence a difference, in particular the ability to learn within the current education system, as opposed to being a behaviour problem brought on by poor parenting, has been ignored. It is clear that the solution for Dean Wells is not to change any aspect of the education department's policy to assist children who learn differently but for parents (read mothers) to undertake parenting programs like Triple P, so that they can normalise both themselves and their families. Accordingly, it is argued that bureaucrats and elected members of parliament have rejected any notion of sharing power (McLaren, 2002) with *"bad"* (Swift, 1995) or *"mad"* (Matthews, 1984) women. Furthermore, they believe that they know what is best for children and families affected by ADD.

In Chapter Two, *Genealogy of Attention Deficit Disorder and the Formation of Discourse,* the question was asked*,* do children and their families affected by ADD currently possess the status of leper? The leper, as defined by Foucault (1984a) acts as a scapegoat to explain social problems or deviance. These social problems are seen to be in need of correction and normalisation policies are adopted (Foucault, 1979; Gordon, 1997; Rose & Miller, 1992). It can be seen from this chapter that currently families and individuals affected by ADD are expected to conform at

school and participate in normalisation programs like Triple P. When they fail to conform, they are viewed as the problem and take on the status of leper.

Political Action and the Machinery of Government

Community consultation is widely practised by the Queensland Government:

> *The Queensland Government encourages individuals, groups and communities to be involved in the business of government. It recognises that Queenslanders have diverse opinions, innovative ideas and a wealth of life experience – and this information allows government to better understand issues and provide services that are tailored to community needs* (Queensland Government, 2003).

It is within this framework of community engagement that the group participated in consultation forums for women. The Queensland Government's Office of Women's Policy conducted a Community Outreach Forum in June 2000. Seven main themes were identified by the ninety women in attendance, one of which was *"Mothering and Support for Families"* (Rogers, 2000, p.1). NADDS members attended this forum and called for *"co-ordinated support for parents"* of children with ADD and told the forum that:

- ❖ *"few services exist to support families,*
- ❖ *parents/carers are not encouraged or supported in locating services/organisations to assist them,*
- ❖ *respite care for carers/parents is urgently required,*
- ❖ *information is required by families to assist their children"* (Rogers, 2000).

It was also noted in the report which was generated from this forum, that at the Regional Area Planning meetings conducted by the Department of Families, Youth and Community Care, respite and flexible family supports were identified as the needs of parents who have children with ADD. Furthermore the Women's Health Centre's community consultation had identified that mothers of children with special needs *"reported higher levels of stress and ill health"* (Rogers, 2000, p.2) due to caring for their children.

In the year 2002, the Office for Women, located within the community engagement division of the Department of Premier and Cabinet, consulted with the women of Queensland by holding a number of community consultation meetings throughout the state. In *Mapping the future: a discussion paper for Queensland women and girls* (Department of Premier and Cabinet, 2002, p.4)*"supporting women in family and caring roles"* and *"well being for women and girls"* were two of the four listed discussion points. Once more NADDS members attended forums in North Queensland outlining their concerns and needs in relation to their children and their families.

The Office for Women also encouraged communities to report initiatives that had worked in their area. The President of NADDS wrote to the Office for Women once again, listing their needs and concerns and reported on the partnership that had been formed to assist families living with ADD in North Queensland; an ADD information folder and the development of an alternative Parenting Program, Learner's Permits for Parents. The Parent Support Program, Learner's Permits for Parents, was also mentioned as a positive and effective community intervention for families affected by ADD at the Women's Roundtable in 2002 by a group representing young mothers.

The Office for Women have since published their *Strategic Plan 2004-2009 Making things better for Queensland Women* (Department of Local Government, 2003). In viewing this document there is little to suggest that the Office for Women has taken on board the issues raised by the mothers of children with ADD. Certainly the women have never received any feedback from the Office for Women, the Health Department or the Department of Families in relation to the numerous consultations in which they have taken part.

Michael Hogan the Deputy Director-General, Community Engagement Division, Department of the Premier and Cabinet states that:

> *the amount of influence citizens can exert on decision-making increased in*
> *accordance with the level of engagement with active participation providing*

maximum opportunities for citizen influence. However responsibility for the final

decision rests with government (Hogan, 2003, p.3).

While it can not be assumed that political advocacy will influence government policy, the lack of acknowledgement and the silence experienced by these women from an agency which proclaims to enhance the status and well being of women is worth noting. Furthermore, we have to question the meaning of community engagement with its apparent message of *"power to"* (McLaren, 2002, p.41) change our society for the better and its suggested *"power with"* (McLaren, 2002, p.41) approach to solving complex issues. The question needs to be asked, is community engagement a device to give an illusion of open and accountable government, while at the same time acting as a propaganda machine to give information to the masses but blocking any meaningful two way exchange of information?

"Attention Deficit Hyperactivity Disorder: Impact and Implications for Queensland".

In 2000, in response to support group advocacy, Anna Bligh, the Minister for Families Youth and Community Care and for Disability Services commissioned a report: *Attention Deficit Hyperactivity Disorder: Impact and Implications for Queensland.* Two parent representations were asked from the ADD community to be part of the steering committee overseeing the selection of researchers and the compiling and writing of a report. The committee consisted of: one representative from each of the departments of Families, Disability Services, Health and Education, one parent representative from Attention Deficit Disorder Information and Support Services (ADDISS), located in Brisbane and one parent representative from NADDS. The representative from NADDS was the only regional person on the Brisbane based committee.

The two ADD parent representatives networked widely and encouraged support groups throughout Queensland and professionals working in the area to attend and contribute their stories to the consultations in their local community. The NADDS group responded by attending the community session on Tuesday 6th February 2001 and presenting a written six page response.

The report was a short but comprehensive analysis of their needs, some of which are cited below:

- ❖ *"huge increase of funding to Child Adolescent Mental Health in regional areas"*
- ❖ *"awareness raising and training for professionals"*
- ❖ *"research ...on the impact of ADD on girls"*
- ❖ *"diagnosis and management of adult ADD"*
- ❖ *"case management needs to be holistic, taking into consideration the whole family unit as well as the individuals within the family"*
- ❖ *"ADD needs to be recognised as a disability and written into the policy Documentation of the Education Department"*
- ❖ *"the issues of abuse and violence need to be recognised in government policy"*
- ❖ *"recognition of the complexities of the family unit affected by ADD"*
- ❖ *"men need to be educated and encouraged to undertake a positive role in their families"* (Unpublished submission presented to Don Rice – Focus Group – Impact of ADHD/ADD Tuesday 6th February 2001).

The parent representatives described the experience as *"challenging"* for numerous reasons. However, the most *"challenging"* aspect of the parent representatives' participation was the process, and the contrast between the Draft Report Recommendations and the Final Report Recommendations (Personal Communication with Parent Representatives, ADDIS and NADDS). The major difference was in the recommendations regarding accepting ADD as a disability. It is not the intention of this research to validate the claims of the women within NADDS, or the wider ADD community, that ADD should be seen as a disability, or to debate the quality of the report. What is of interest here is to examine the exercise of professional and bureaucratic power in negating the voices and reality of women.

The change between the Draft Report and the Final Report was a huge disappointment to the parent representatives, since if ADD were to be recognised as a disability, under the *Disability Services Act*, the government would be required by law to provide services. Thus respite, access to funding and support in the education

system would be available to families affected by ADD. The Draft Report Recommendation One stated:

That Queensland Government departments recognise ADHD as a disability under the Queensland Disability Services Act, 1992 with access to government sponsored services and support dependent on a diagnosis in accordance with criteria established under Recommendation 2.

This recommendation was in line with the comments from the majority of parents and some service providers and was one of three mentions of recognising ADD as a disability in the executive statement. The two parent representatives responded to the draft report and told the Steering Committee that *"the parent representatives are supportive of the recommendations in the report"* (Response from Parent Representatives, 7th August, 2001).

The Draft Report Recommendations also met with favour from some sections of the Health Department. A memo written by a representative from the Department of Health stated: *"Queensland Health endorses the majority of the Report Recommendations as expressed in the Executive Summary"* (Unpublished Memorandum, Response to Draft *"ADHD: Impact and Implications for Queensland"* Report, 27th July, 2001). Furthermore, Queensland Health pointed out that the current interpretation of the *Queensland Disability Services Act*, was an impediment to families affected by ADD:

Queensland Health identifies as fundamental (and endorses) the articulations within the Report that the Queensland Disability Services Act 1992 legislation and/or its implementation under regulation/procedure can provide an unreasoned and unreasonable bureaucratic barrier between clients with significant clinical need and their access to appropriate service provision – especially in regard to respite services (Unpublished Memorandum, Response to Draft "ADHD: Impact and Implications for Queensland" Report, 27th July, 2001).

This view did not prevail and the Draft Recommendations were severely criticised by the Departmental representatives. A letter was written to the researchers concerning the Draft Report's recommendation that ADD be seen as a disability:

The Steering Committee [except for the parent representatives] *has had extensive discussions regarding the draft report and provides the attached comments for your consideration. The Steering Committee acknowledges your professional independence and provides the comments to assist in making the final report an important policy document"* (Unpublished letter from Andrew Davis, Executive Director, Children and Families, 31st July, 2001).

Disappointingly for the two parent representatives and the majority of the ADD community, the Final Report Recommendation One, was changed to read:

That the Queensland Government make provision for relevant Departments to provide access to government services and support for individuals diagnosed with ADHD. This may require changes to the Queensland Disability Services Act, 1992 and/or departmental policies and procedures, such as Education Queensland Ascertainment and Appraisement procedures. Documents would need to be developed to ensure a consistent understanding of ADHD across all service agencies (van Kraayenoord et al., 2001, Volume1, p.11).

The change in the two reports came as a shock to the parent representatives as they had supported the draft report recommendations and provided written feedback to the research team and the Departmental representatives.

The objections of the government departments to the Draft recommendations will not be discussed in detail. However, it was clear from the meetings that were held and the written feedback that a number of individuals and groups were critical of the methodology used to collect information and were concerned about the *"truth"* (Foucault, 1980d, p.131; Sarup, 1988, p.64) in relation to ADD.

Although it had been agreed at the beginning of the project, that the views of individuals and families affected by ADD was essential and formed Volume Two of the Four Volume report it was remarked that:

> *the attempt to capture within the Report the spirit of anxiety, disquiet, frustration, and anger manifest by consumers has resulted in an unbalanced document with an unfortunate 'anecdotal flavour'. This is not appropriate for an evidence-based review designed to give direction to government and clinical practice* (Unpublished Memorandum, Response to Draft "ADHD: Impact and Implications for Queensland" Report, 27th July, 2001).

Thus consumers, in particular, mothers' experiences are not considered objective, whereas government rhetoric in relation to service provision and professional discourses (Smith, 1990) are seen as valid.

This is a clear example of the way in which professional knowledge or, the knowledge of those in power, such as senior bureaucrats and politicians, is considered superior to those who live the day to day reality of being different. It also demonstrates how bureaucrats and professional power is used to negate the experiences of parents, in particular mothers (Badinter, 1981; Hays, 1996; Marshall, 1991). Thus, it could be argued that the negating of women's experiences and knowledge is part of the *"metapower"*'s (Foucault, 1980d, p.122) function in Queensland, which seeks to give voice to professional and bureaucratic knowledge over the knowing of mother's affected by ADD.

Not only were women's experiences irrelevant, the contribution that they made to the overall project was also considered irrelevant. NADDS felt betrayed, as support groups had rallied to provide the researchers with as much information as possible and to encourage professionals in their local area to attend. At no time did the researchers indicate to the parent representatives that there were major changes to the final report. In speaking to one of the researchers after the final report had been read, the message conveyed was that the researchers felt that if they had recommended in the Final Report that ADD should be classed as a disability, the government would reject the report. The researcher felt that their report had left room for the women to

negotiate further with the government in relation to supports for families and individuals affected by ADD.

It must be asked why the researchers involved in *Attention Deficit Hyperactivity Disorder: Impact and Implications for Queensland,* who hold reasonable positions of power and authority, believed that their power was insufficient to stick by a report that called for the recognition of ADD as a disability, while at the same time encouraging the women in the support group to continue their fight with the government? In exploring this example, it could be argued that a number of power bases were instrumental in changing the draft report recommendations. Furthermore, it is evident that the government and bureaucracy ignored the reality of the families interviewed for the report and that some researchers are aware of power bases and will side with the powerful (Foucault, 1980d). To date, no action has been taken by the Queensland Government to implement aspects of the report or to engage with support groups regarding service provision.

In looking at the systematic way in which the women advocated through the prescribed channels to bring about policy changes, it can be seen that a considerable amount of time was expended. However their efforts either fell on deaf ears, or were negated as not being real or factual. The women have expressed considerable disappointment that their knowing, or standpoint has been totally ignored (Smith, 1990) and that individuals and groups have used their professional and bureaucratic power (Foucault, 1980d) to prevent any change to the status quo. Butler and Wintram (1991) and Barber (1991) have stated that groups in lobbying for social change will encounter resistance. Nevertheless it has been argued that grass roots organisations and *"local struggles"* (Foucault, 1980d, p.125) are essential to challenge the status quo (Barber, 1991; McLaren, 2002).

PARTNERSHIPS AND CONSTRUCTING DISCOURSE

Fill the Gaps

The women of NADDS did not confine their political advocacy to government departments, or the lobbying of politicians; they were also active in the general community. The women found that when they joined with other women at a

personal and professional level in a spirit of sisterhood, or the desire to change the lot of women, goals were achieved. Butler and Wintram (1991) note that it is important for groups to reach out to other groups, as the women's combined knowledge of local issues and experience can act as a catalyst for action. The support group worked with workers from Life Line, the Domestic Violence Unit and government workers to conduct two Fill the Gaps Forums. The forums were called to discuss the issues for parents and service providers and where possible to work towards developing services for families which fall through the gaps in service provision. The public liaison officer for NADDS reported that the parents of children with ADD were struggling: *"there's nothing to provide extra help and support at home"* and that the only program offered to parents *"was the Positive Parenting Program* [Triple P]*...that placed blame on the shoulders of the parents, which was unfair and not very constructive"* (Anonymous, 2000, p.26)

The first meeting, 22nd February 2000, was attended by parents and paid workers who were concerned about the lack of services to children who had been sexually abused, children who had been traumatised, children with ADD and more serious mental health issues, such as bipolar disorder. Each interest group documented what needed to be done to bring about change. At the second meeting, 5th September, during Child Protection Week, the Children's Commissioner was invited as a key note speaker. The various groups also reported back on their activities to date.

The Fill The Gaps Forums achieved a number of outcomes. One important outcome for NADDS was demonstrating to the general and professional community that mothers of children with ADD were not *"bad" (Swift, 1995) or "mad"* (Matthews, 1984) and the strengthening of relationships between the group and mental health professionals. Also, it was at this forum that the Department of Disability Services Queensland announced that their minister, Anna Bligh, was to commission a report on the impact of Attention Deficit Disorder. While this was thought to be very promising at the time, recent history, as documented in this chapter, has shown otherwise. Although the report *ADHD: Impact and Implications for Queensland* (van Kraayenoord et al., 2001) released to the public in 2003, has done little to change the circumstances of families affected by ADD, these forums did lay the

foundations for other working relationships, in particular an Information Folder (NADDS, 2002) and the development of Learner's Permits for Parents which will be discussed in the following section.

Information Folder

The information folder was made possible by a donation of money from the Townsville Soroptimist Club and the work of James Cook University Students, members of NADDS, staff and volunteers of the Mental Illness Fellowship, members of Soroptimist International and the support of Sheila Park, the Director of Child and Youth Mental Health Services. The front page of the folder stated:

> *the purpose of this folder is to provide a broad range of information on Attention Deficit Disorder. It is anticipated that the information provided will enable people to make an informed decision on the management and treatment of this chronic condition that may continue into adulthood (NADDS, 2002).*

In viewing the folder it can be seen that the NADDS women provided information on ADD which was free of mother blame. The folder was intended not only to give information about ADD but to enable individuals to make sense of their reality (Smith, 1990). The women also saw the folder as a political act (Foucault, 1980d):

> *The aim is to exercise power through informed choice. This is in line with Soroptimist International of Townsville Inc and North Queensland ADD Support Group's common aim of awareness, advocacy, action and empowerment* (NADDS, 2002).

The information folder was distributed to schools and agencies within the local Townsville district. The folder had an impact as evidenced by calls from agencies and individuals living outside of Townsville. Through their networks they had heard about the folder and contacted the support group requesting the information. Modified versions of the folder were sent to rural areas in Queensland and one copy was sent to Papua New Guinea. The ability to network and reach out to other women as noted by Butler and Wintram (1991) and Taylor and colleagues (Taylor et al., 2000) is clearly evident in the actions of the women involved in this project.

Challenging Discourse

In 2002, the Youth Affairs Network of Queensland, commissioned Dr Robert Jacobs, Psychologist and Children's Lawyer from North America to write the report, *Queensland Children At Risk: The Overdiagnosis of "ADHD" and the Overuse of Stimulant Medication* (2002). After the release of Jacob's report, the ADD Association Queensland Inc. (ADDAQ previously known as ADDISS) and NADDS had questioned the government about the material contained in the report and the government's funding of YANQ.

In 2004, NADDS members were informed through various networks that Dr Jacobs was being sponsored by the Youth Affairs Network of Queensland, to tour Queensland presenting his view that ADD *"doesn't exist"* (Doostkhah, 2004). Both ADDAQ and NADDS were concerned with *"the state's peak youth agency"* (Doostkhah, 2004), YANQ's support of Jacob's view. They believed that Jacobs' message, which had a flavour of scientology (Barber, 2004) labelled parents, at best as misguided, while at the same time asserting that Jacobs was a credible expert. Furthermore, ADDAQ and NADDS questioned why government workers and professionals through the dissemination of emails to networks were advertising a view which they perceived to be very parent blaming.

NADDS members decided to stage a peaceful protest outside the Lifeline premises in Townsville where Jacobs was to speak. Group members carrying placards, *"Denying ADHD is Ignorance of Knowledge"* (Mancuso, 2004a, p.16; 2004b, p.2) were invited by Jacobs to come in and hear his view. Jacobs later reported to the media that *"for the first time in his 20-year career he was confronted with disgruntled protesters during a seminar"* (Mancuso, 2004a, p.16). The Mental Illness Fellowship, ADDAQ and NADDS also approached the print media and radio and television stations. Barber (1991) speaks about the value of involving the media in any campaign geared towards bringing about social change. It should be noted that while the group had used the media in the past, primarily in letters to the editor, it had in the main avoided the media due to the stigma and negativity associated with ADD.

In general the media reports on the conflict between Jacobs and NADDS was balanced and supportive of families:

> *it is easy for those who don't live with the ongoing daily battles related to ADHD behaviour to give advice, and much harder to put it into practice, particularly when families are already overstretched. Giving parents a helping hand, therefore must be the key issue here. Parents must be made to feel comfortable about coming forward to discuss their children's situation and they must also be made aware of every avenue available for them after they have made that initial step. Open and honest discussion will bring benefits to families and the whole of society* (Editorial, 2004).

Open communication is certainly required when discussing the issues for families. Jacobs' view that ADD is a myth is a provocative one and his call to celebrate *"diversity and uniqueness"* (Mancuso, 2004a, p.16) is appealing. However, it can be argued that Jacobs, in stating that children are different, is ignoring the reality of being different for the individual and the family. Furthermore, by implying that parents are intolerant of difference, Jacobs is labelling them as *"poor parents"* who need to undertake *"family therapy and better parent education"* (Mancuso, 2004a, p.16). His views and beliefs, which give a clear example of the conflict within the discourse, are not lost on parents. The women and men of NADDS have questioned his views, thus, challenging his professional power and asserting their *"truth"* (Sarup, 1988, p.64) from their standpoint (Smith, 1990).

REALITY, RESISTANCE AND THE DEVELOPMENT OF LEARNER'S PERMITS

It is the conflict between the women's *"truth"* (Sarup, 1988, p.64), in other words the reality of living with children with ADD, and the *"truth"* (Sarup, 1988, p.64) of some professionals and their insistence on family therapy and or behaviour management to assist families which provides the back drop for the next section of this chapter.

The women interviewed experienced desperation, failure and despair when they sought assistance for their child's aggressive behaviour such as lighting fires,

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damage to property, physical fights with their siblings, swearing and abusive behaviour often directed at the mother. The women encountered blame, disrespect, condemnation, silence or they simply found the services they were looking for were not available in the community. In the previous chapter, Anne's journey was used as an example of the mother's experiences.

Research and Action

In 2001, some of the preliminary findings from this research were presented at the Women's Health Summit in Townsville. A paper titled *The Accused and Abused* (Rogers, 2001) highlighted the difficulties of being a parent of a child or children with ADD:

❖ the women struggled to bring up their children with often little support from their partners, the community or professionals,

❖ many of the women had encountered blame and condemnation and some had experienced violence from their adolescent children,

❖ they reported chronic health problems due to stress and isolation - sleep disorders and depression featured prominently.

At the same health conference, Philippa Harris, Coordinator of the Mental Illness Fellowship and Debbie Tanzer presented a paper called, *When Triple P is not enough* (Harris & Tanzer, 2001). The paper was Debbie's story. Debbie is a single mother living with Bipolar Disorder and struggling to bring up a son with Attention Deficit Disorder:

Most parents seek to be the best parents they can be. But being a parent can be like a rollercoaster bringing the greatest joys and the greatest heartaches. This was never more so than in my case. ...I couldn't control my son. It was hard enough looking after myself – getting out of bed each day, getting something to eat and showering myself. But I knew I had to be there for him. ...I did the Positive Parenting Program – Triple P course twice. I did the Centacare parenting program twice. Yet, try as I might, I couldn't make it work, I just couldn't do it. In the end I just sat there during the classes feeling frustrated and with despair washing over me. My sobs caught in my throat, preventing me from

speaking up. I couldn't talk about my mental illness. It would have made me far
too vulnerable and ashamed (Harris & Tanzer, 2001).

In the fourth chapter, *Theory and Practice*, a number of issues were raised in relation to the efficacy of behaviour management programs, in particular Triple P. In speaking with Debbie during 2001 and 2002, it became clear that her mental illness, her own possible ADD, her son's ADD and the general lack of support in the community, were factors which rendered the strategies suggested during the behaviour management program unworkable (Personal Communication 2001-2002).

The two papers presented at the Women's Health Summit highlighted the complex needs of families affected by ADD and or mental illness, the lack of effective support and how the community will isolate and blame the women and men who find themselves trying to manage these complex situations (Mehigan, Harris, & Rogers, 2004).

Philippa, Debbie, Leanne (a member of the ADD support group) and I met during the Health Summit. It was decided to test the water and see if there were others who were concerned enough to want to change things. The word was spread through individual and collective networks that a public forum had been organised for 14th August, 2001. The meeting attracted a wide range of individuals and professionals from government and non-government agencies. The group assembled was asked the question: *"Are the present parenting programs and responses both highly relevant and potent for families who have a member with ADD or a mental illness"* (Agenda, Discuss Alternatives to Triple P Meeting, 14th August, 2001).

Independent facilitators oversaw two further meetings on the 21st and 29th of August where a number of issues were quickly identified:
- ❖ *"Current services were not enough to meet the needs of parents who had mental illness,*
- ❖ *There was a lack of information and understanding in the community about psychiatric disorders and disabilities,*
- ❖ *There was a lack of expertise amongst professionals,*

- ❖ *ADD did not fit into the framework of many services or government policies and therefore there were no programs to assist the families,*
- ❖ *The Parenting Program, supported by the government, Triple P, did not address the issues of living with an illness that affected your mood, concentration, perception and decision making ability,*
- ❖ *Available programs were not effective for children who experienced chronic pervasive developmental disabilities such as ADD, ADHD, Oppositional Defiant Disorder or Conduct Disorder"* (Harris, Mehigan, & Rogers, 2002).

On the 11th of September an Action Plan was developed focusing on three areas: Practical Responses, Community Education and Influencing Groups. A key component of the Practical Response was to develop an appropriate and effective parent support program. A sub-committee was formed to develop and implement a parent support program which would address some of the fundamental issues of parenting for:

- ❖ Parents with a mental illness,
- ❖ Parents of children with Attention Deficit Disorder,
- ❖ Parents who have children with Oppositional Defiance (OD) or Conduct Disorder (CD).

The sub-committee consisted of women with a mental illness, the mothers of children with ADD and Conduct Disorder, which included past and present members of NADDS, service providers and professionals in the field of mental health. Throughout the development of the program people questioned putting parents with a mental illness and parents with children with ADD and OD/CD into the same program. The questioning mainly came from professionals and public servants who felt uneasy with including seemingly disparate groups and groups which did not fit their criteria for current services. The parents of children with ADD advocated strongly that the program should be developed with these three groups in mind as the disorders are not mutually exclusive. Personal experience had shown that mental illness, ADD and OD/CD are not strange bed fellows.

Accordingly based on research, local, national and international (Barkley, 1990, 2001a, 2001b; Harris & Tanzer, 2001; Harrison & Rees, 1998; Rogers, 2001; Wallace, 1996) and personal experiences it was identified that the sub-committee wanted a program that would:

- ❖ Validate the extreme difficulties that parents face, in particular mothers - *"Parents of children with ADD report more stress in their families. … Most parent programs to date have concentrated on child management strategies with little or no attention been given to the needs of the parent in bringing up the child"* (Harris et al., 2002),

- ❖ Build Self Esteem - *"Mothers of children with ADD report significantly lower levels of parenting self esteem, higher levels of depression, self blame and social isolation"* (Harris et al., 2002),

- ❖ Develop strategies which promote wellness - *"Mothers of children with ADD report higher levels of depression. Distressed parents are unlikely to be able to provide consistent parenting"* (Harris et al., 2002),

- ❖ Provide specific information and education about Mental Illness, Attention Deficit Disorder and Oppositional and Conduct Disorder – *"In addressing our needs it is important to move beyond the teaching of child management strategies as we have used a number of these strategies and found them wanting. It is more important to explain why our child behaves the way they do. We need knowledge and information"* (Harris et al., 2002),

- ❖ Facilitate linking to other organisations and supports in the community – *"Knowledge is power"* (Harris et al., 2002),

- ❖ Provide a smorgasbord of behaviour strategies – *"We are the experts on our children we just need a bit of help"* (Harris et al., 2002).

- ❖ Raise awareness of broad mental health issues - advocacy and prevention.

The group was fortunate enough to secure a small amount of funding and Toni Mehigan, a psychologist in private practice, was asked to write the program in consultation with the sub-committee. Toni was asked because she had experience in writing programs, she had knowledge of ADD and the affects of mental illness on parenting and had been involved in previous activities to improve the lot of parents who have children with ADD (Fill the Gaps, 2000).

The sub-committee met many times. Women contributed to the building of the program by speaking of their own personal experiences and/or presenting material which they felt needed to be included in the program. Toni wrote the program, presenting each section to the sub-committee as it was written and rewriting sections to include or delete information.

It must be stressed that while a great spirit of cooperation prevailed, there were differences of opinion. The beauty of the program does not lie in all people thinking the same, its beauty lies in respecting *"individual differences"* within the human family (Unpublished Mission Statement, Management Committee for Learner's Permits for Parents). Thus, people with mental illness and people identified with ADD are seen as important and valuable members of our community. Furthermore, its efficacy lies in acknowledging *"people's experiences"* and the desire to change the status quo for families affected by ADD and mental illness (Unpublished Mission Statement, Management Committee for Learner's Permits for Parents).

The Program

The program was developed between September 2001 and June 2002. The title Learner's Permits for Parents was chosen as a light-hearted analogy of the journey of life and parenting. Each of the sessions builds on the theme of driving. An emphasis is placed on visual learning and as a result the program is bright, fun and lively (Harris et al., 2002). It was recognised that laughter assists in relieving stress and is considered to be an important component of the program (Laugh With Us.org, 2005). In July and August 2002 two pilot programs were conducted. The program has seven sessions, a summary of which is in Appendix 9. A management committee was set up in 2002 to oversee the program. To date a number of programs have been run in Townsville and other regional and rural centres in Queensland.

Data Collection

The pilot studies confirmed the mothers' conviction that the issues of mental illness, ADD and OD/CD should be included in the program as evaluation of the pilot studies revealed a 75% comorbidity rate. Participants have reported *"that this*

program is more beneficial than other parenting programs that they have attended"(Mehigan et al., 2004). Parents also report that they are significantly less stressed and depressed after completing the program. Participants have said that they

> *have enjoyed the program, would recommend the program to others and most mentioned positive gains in their parenting and emotional well-being. Participants all felt closer to each other as a result of the program and by and large wanted to stay in touch* (Mehigan et al., 2004).

Evaluation of the program is ongoing.

Current Situation

The program continues to flourish, even though the management committee do not receive funding, or support from government agencies to run the program. Child and Youth Mental Health Services, while involved in the early stages of the development of Learner's Permits for Parents, have withdrawn support stating that the government sponsors the Positive Parenting Program, Triple P, and will only endorse evidence based programs (Personal Communication 2003 & 2004). Thus, Child and Youth Mental Services continue to utilise Triple P, even though parents are clearly saying it does not work for them. Both the Mental Illness Fellowship of North Queensland and NADDS support the management committee in their endeavours to assist families.

A Mission Statement (Unpublished), written by the management committee in 2003 reflects the desire to affect positive social change:

> ❖ *"We believe in the value of each individual and family in our community as unique and worthy of acceptance and care,*
> ❖ *Some families are disadvantaged due to the impact of Mental Illness, ADD/HD and Conduct Disorders,*
> ❖ *Due to the present lack of support and acknowledgement of these conditions in our communities we will provide a specialised, strength-based parenting program,*
> ❖ *This program will offer practical solutions and current information and will be collaborative, nurturing, holistic, supportive and enjoyable,*

❖ *Through this program we hope to build resilience and positive life experiences for parents, children and families who may be suffering from stigma, discrimination and isolation".*

The management committee have adopted the strategy of training facilitators, so that the trainers can run the program in their communities. To date, 25 Facilitators have been trained to run the program, including a practitioner from New Zealand. Members of the management committee continue to liaise and negotiate with professionals to train facilitators beyond the Townsville area.

Influencing the Discourse and Rejecting the Status of Leper

Learner's Permits for Parents was born from the frustration and tears of women like Debbie Tanzer (Harris & Tanzer, 2001) and the abuse of women like Anne. It is an example of women resisting (Foucault, 1972, 1980c) the normalising process of those who seek to govern (Foucault, 1979) through programs such as Triple P. Learner's Permits for Parents does not necessarily set out to change the child's behaviour. The intention is to explain why the child with ADD behaves the way that they do and how parents may be able to influence their behaviour in a positive way. One way of influencing the child's behaviour is to nurture the mother as primary care giver and to reduce as much as possible stress and conflict. Mothers are encouraged to map out what is important to them and reject what is not important. Focus is diverted from the child's behaviour, as the health of the mother and her well being is seen as crucial. Therefore, the program does not set out to control the child (Rafalovich, 2001a) but to manage what only can be described as a difficult and demanding situation. Recent research supports the premise of this program, in that it identifies that mothers in their role as primary care givers, need to be supported so that they can assist their children with ADD. Furthermore, the research highlights the importance of mothers in managing stress and conflict in the family unit (Kendall et al., 2005).

One of the fundamental differences between current behaviour management programs and Learner's Permits is that the parents, in particular the mothers, are seen as the experts on their situation and their children (Sprague & Kobrynowicz, 2004).

Learner's Permits for Parents works in the local community because it was developed from a *"power with"* (McLaren, 2002, p.41) perspective, combining the knowledge of mothers and professionals to meet the needs of families. The program works from a strengths perspective, not a deficit model (Elliot et al., 2000).

It is important to acknowledge that Learner's Permits for Parents seeks to influence the discourses on ADD, as Session Two, the information session, is in the main from a biological perspective. It is stressed that ADD is *"nobody's fault"* (Mehigan et al., 2004). As blame loses its potency, families can be viewed as being worthy. The children affected by ADD are also constructed as worthy and productive human beings as parents are encouraged *"to identify those unique interests and motivations in their children"* (Mehigan et al., 2004). Being seen as worthy or deserving acts to challenge the leper (Foucault, 1984a) status of ADD, the current social evil of the 21st century.

CONCLUSION

The experience of having a child with ADD *"changed everything"* (Mary Serenity). Mary Serenity explained that having a child with ADD has *"opened my eyes to the stupidity and the discrimination and unfairness in our society"*. The women sought out the support of other women in similar circumstances and through friendship and advocacy were actively involved in assisting other women. Some women, as members of NADDS took the path of political action. The group sought to influence the ADD discourse (Foucault, 1972, 1980c) through providing information based on their experiences of ADD. Their approach was very much a *"power with"* stance (McLaren, 2002, p.41). They also challenged professional discourses, which seek to label them as poor parents. However, political action did not always produce the desired outcome. After all, if their voices were heeded, professionals, the bureaucracy and elected members of parliament would have to consider sharing power and this would change the dynamics of modern government and society. It could be argued that it is easier to blame, to scapegoat and to destroy than to share power with the community to make our communities more inclusive. However, there are groups that are willing to work together and to challenge the status quo. The women had the most impact on the lives of other women and families when they

worked together, as can be seen from the examples given: the Fill the Gaps forum, the Information Folder and Learner's Permits for Parents.

The catalyst for Learner's Permits for Parents was the stories of women who struggle in a system which attempts to normalise both them and their families. Learner's Permit is just one example of women's resistance to blame and their desire to bring about social change for those groups that are isolated and marginalised (Foucault, 1980c).

CHAPTER TEN – DISCUSSION AND RECOMMENDATIONS

"Pathology lies within the social system and it is there that the remediation is necessary" (Conrad, 1976, p.83).

Introduction

This chapter will provide a discussion on the various issues revealed throughout the thesis. The identified themes of this thesis are numerous:

- ❖ Diagnosis was important as it assisted mothers to understand their child or children.
- ❖ The mothers perceive their children and their family as different to most other children and families.
- ❖ Many of the women experienced mother blame, however, most of the women actively rejected the blame and condemnation.
- ❖ Mothering a child with ADD is characterised by grief and an enormous physical and emotional workload.
- ❖ Depression and ill health are common.
- ❖ The women have sought to influence the discourse on ADD.
- ❖ The women have politicised their experiences and actively seek out opportunities to influence government policy.
- ❖ The government, bureaucrats and professionals are extremely reluctant to listen and act on the day to day experiences of women.
- ❖ Respect, strengths based approaches and the sharing of power are characteristics of successful outcomes for the women and their families.
- ❖ Women living with ADD experience a profound impact on their life.
- ❖ ADD impacts on non-ADD siblings.

These themes will now be discussed before moving on to a brief update of the women and their families and the recommendations. The recommendations are made based on the mother's views of what is needed to assist families and the overall analysis of the data. The data also gives valuable insights, providing a basis for identification of further research questions and enquiry.

DIAGNOSIS

The stories of the women clearly demonstrate that diagnosis did not come easily and that the journey to identify their child's difference was long and painful. **Wild Thing** with much sorrow exclaimed: *"it took 13 years to get someone to recognise it and give me a diagnosis"*. **Joyce** explained that diagnosis was crucial; *"I needed to know more to help me cope…every year the new challenges were different…and how we deal with those challenges, depends on our understanding"*. Thus, for these women diagnosis was important as it helped them to understand their different children and implement strategies. This finding resonates with Ho's (2004) statement that parents of children with learning difficulties, or disabilities seek out a diagnosis as part of a quest for knowledge. Thus, parents like the mothers in this study look to a diagnosis to help them understand and find assistance. However, while the mothers in this study sought out assistance they were unable to locate services which met their needs. This finding is supported by Malacrida (2003) who found that a diagnosis of ADD did not equate to appropriate service provision.

It is worth noting that the National Health and Medical Research Council (NHMRC, 1997, xv & xvi) outlined three recommendations in relation to assessing individuals suspected of having ADD and that these recommendations are supported by NADDS:

- ❖ *"As a minimum, the criteria set down in DSM-IV should be fulfilled before a diagnosis of ADHD is made"*
- ❖ *"A comprehensive assessment of a child with suspected ADHD"* should be made before a diagnosis is given
- ❖ *"Multiple sources of information should be utilised during assessment"*.

Diagnosis also assisted Susan to make sense of her life. In speaking to the women it was clear that they believed that information regarding their children's difference or, in Susan's case, her own difference, was extremely important, not only to themselves but for professionals and the wider community:

I find that the media have portrayed ADD in such a way that people perceive it as only being a disorder, where kids destroy, damage [and are] *violent, loud, abusive…when there's far reaching effect*[s] *that* [ADD] *has on children and*

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people's lives that's not covered... ignorance is the cause of most of the friction, and if professionals as well as... the community at large were aware in a more understanding manner of what ADD [is],*... then we're going to come a long way to helping people develop strategy skills* [and give] *them support in areas that they need it* (Joyce).

DIFFERENCE

Difference is a theme that is repeated in the stories of the women; different children, different lives, different families. The notion of difference has been noted by previous researchers (Carpenter, 1999; Kendall & Shelton, 2003; Malacrida, 2003) and the conceptualisation of difference by mothers, has been recorded by Kendall(1999, p.750) *"ADHD is not a death sentence. It is just a difference"*. Even so, this thesis has significantly broadened the understanding of difference in relation to ADD and highlighted that individuals and families affected by ADD attract stigma, blame and disciplinary measures. Furthermore, that normalising policies and procedures damage both children who are different and the families who are different.

Changes Needed in Education

Malacrida (2003, p.249) found that the school was a battleground as mothers and educators fought over *"the 'truth' of AD(H)D and about children who are different"*. This research similarly showed that one area where a child's difference did attract stigma, blame and disciplinary measures was the school environment. The women spoke of the damage that their children sustained through the school's pursuit of sameness and inability to value difference:

> *They* [schools] *are trying to make everyone fit into their academic role. Their academic model and if they* [children with ADD] *don't they're not valuable and they're more or less told that; they are given that message very clearly. If you are not good at this,... you've not really worth much... we still make our children feel bad if they don't do well at school. Why do we do that? It's wrong. Everyone should feel valued for what-ever their strengths are*
> (Mary Serenity).

The women stated that the education system needs to be improved for children that learn differently:

- ❖ *"improved education facilities"* (Mim)
- ❖ *"learning support and one to one"* (Leanne)
- ❖ *"different learning strategies"* (Joyce).

The women in the group strongly favour conceptualising ADD as a difference in learning (Tannock, 2004), as opposed to a behaviour disorder. This is clear from the letter written to Dean Wells, and other documents produced by the group. While it is beyond the scope of this research to recommend specific changes in education policy it is useful to speak about the way in which positive change may be achieved, for example, adopting a strengths based approach in educating children. If a child is a visual learner, showing a child is better than instructing. Furthermore, rewards work better than punishments. Children can be rewarded for remembering to bring their hat to school instead of punishing them by insisting they write lines. Ignoring different learning styles and punishing children for forgetting and not being organised causes much grief and could be considered abusive.

In addition, the women stated that they need options: *"more facilities available to help kids in the education system"* (Number 13). It has to be recognised that not all schools will suit all children. Children like other human beings have their strengths, their preferences and to truly shine need a supportive, nurturing environment: *"people with ADD...can be productive; they can be really valuable members of society...if we support them"* (Leanne). McLaren (2002, p.36) has advocated for *"an increase in options and a decrease in the hold that normalizing disciplines have over an individual"*. Accordingly, it is argued that changes to the delivery of education and a strengths based approach to educating children is needed to transform negative experiences to positive. Furthermore, to assist in decreasing abusive practices brought about by the pursuit of sameness and regulation, parents and children need choices in relation to schools and school environments. In other words different children may require different schools or school environments.

The Value of Difference

The concept of difference and the reality of being different is a fundamental issue for individuals and families affected by ADD. Much wider understanding of difference and public debate needs to occur in order for our society to become more accepting of those who are different and for our society to become less normalising. McLaren (2002, p.33) has stated that Foucault's method of genealogy and his notion that power can be used to challenge discourses gives hope that in future society will *"be less normalizing"* and that *"social change is both possible and desirable"*. McLaren (2002, p.48) states that feminists *"should be sympathetic to the damage that norms can do"* as *"social norms serve to promote and sustain the values of the dominant group"*. Thus, society can choose to acknowledge a person's difference and celebrate diversity or it can pathologise that difference.

McLaren (2002, p.68) states that Foucault's work is often interpreted as suggesting that all practices of normalisation and discipline are in essence negative and domineering, however, she states*; "I do not believe that Foucault holds that all social norms or even all disciplinary practices normalize in the same way"*. A similar view is articulated by Peters (2004). Thus, it can be argued that living in the twenty-first century we need to strike a balance. One way of doing this is to give people options about how, and in what way they want to live their lives. Therefore individuals and families affected by ADD need to be able to decide what aspects of being different are advantageous and desirable to them and what aspects of being different do not serve them well.

In the post 9/11 international environment in which we live, the call to value difference will be extremely difficult to implement given the perceived threat of terrorism. Nationally, authors like Adams (1997) have argued that we live in an increasingly intolerant society. Moreover, it appears that it will be increasingly difficult to question normalisation policies and programs when, within the bureaucracy (Shallcross, 2003a, 2003b) and even in academia, people's differences (Westhues, 2004a, 2004b) attract stigma and disciplinary measures. In addition, given the strong tendency towards psychoanalytic and behaviourist theories within early intervention policies and programs, it will be very challenging to advocate

giving individuals and families choices about their lives and how they live their lives. It should be noted that psychoanalytic/behaviourist theories in themselves may not be abusive, just the same as genetic theories of difference may not be abusive.

It can be seen that the eugenic policies of the early to mid twentieth century were abusive as governments sought to shape populations by deciding who was desirable and who was not desirable. It is beyond the scope of this research to examine in any detail the ramifications of genetic research for people affected by ADD. Even so, it should be noted that theories and models of practice become abusive when they are used to normalise and or punish populations for being different. The cost to humanity will be high if we continue to devalue difference, enforce policies of normalisation and in some cases pursue the eradication of difference. The way forward is to explore the varying discourses on difference and where possible implement practices and policies which recognise a person's right to be different, in our local communities and globally. This view is reflected in Mary Serenity's statement:

> *we have to accept the differences* [ADD] *and value diversity. … that is the challenge for society. … Just because someone doesn't … see the world as you do, doesn't mean that you can't learn from them or value them. And why do we punish those who are different by putting them in jails* (Mary Serenity)?

Difference, a Simple Analogy

It needs to be considered that people with ADD are different from the non-ADD population. Just the same as some people are born with blue eyes and some are born with brown eyes or some people are born with lighter skin and some are born with darker skin. Having darker skin is an advantage for people who live in hot climates close to the Equator, while people with lighter skins can experience difficulties due to their biology.

People with lighter skin who live in the tropics cannot act the same way as people with darker skin. They have to dress differently, for example wear long sleeved shirts and trousers if spending time in the sun and of course wear a hat. However, that might not be enough and some use sunscreen to protect them from the damaging

rays of the sun. If people with lighter skins do not dress differently, and use the knowledge of medical science to protect themselves from the sun, they stand a high chance of developing problems. They may develop rashes from the sun; their skin may dry and become damaged. Many may develop skin cancers or life threatening melanomas.

The fact is that people with lighter skins are different; they are not the same as darker skinned people whom biology has prepared for the tropical climate. People with lighter skin need to acknowledge their difference and act accordingly if they are to remain healthy. The question is, are people with lighter skin sick? The answer, surely, is no. But they can become unwell or perish if that difference is not recognised.

A CULTURE OF BLAME

Mother Blame

It has been argued that the social construct of motherhood and the prescribed way in which children are to be cared for has been fashioned by powerful bodies (Badinter, 1981; Hays, 1996; Jackson, 1994; Jensen & Kingston, 1986; Oakley, 1986). Thus, women as mothers are expected to conform to their position in a nuclear family as the primary care giver of children. Furthermore, women are expected to follow the advice of child rearing experts so that they can produce good children, children who can function within the confines of society (Ehrenreich & English, 1979; Eyer, 1996; Hays, 1996; Marshall, 1991). Mothers who produce deviant or different children fail the test of motherhood and are blamed (Brown et al., 1994; Eyer, 1992, 1996; Matthews, 1984; New & David, 1985; Swift, 1995).

Many of the women in this research encountered blame for having different children and/or from medicating their children. The blame came from many different quarters; professionals, the community, their family and in Joyce's case, her ex-husband. However, regardless of the source, the message that mothers interpreted was *"from day one it was my problem, it was my parenting skills"* (Anne). These findings of mother blame echo and therefore support the earlier findings of Carpenter (1999) and Malacrida (2003).

It was interesting to note that the concept of the *"overprotective"* and *"rejecting"* (Ehrenreich & English, 1979, pp. 208 & 209) mother which took root in the 1940s still has resonance today. **Mary Serenity** was seen as being *"too good a mother"* thus causing her son's bad behaviour whereas **Wild Thing** was seen to cause her son's bad behaviour by being *"cold"* and *"cruel"*.

Indeed, the motherhood discourse is so powerful (Brown et al., 1994) that punishment, in the form of surveillance (Foucault, 1980b) is used if women are seen to be *"a child abuser"* (Joyce). **Joyce** was contacted by her church minister as a parishioner had threatened to contact Family Services. Understanding, empathy and support were missing from both the anonymous parishioner and the minister as Joyce and her husband were left to cope alone with their different child. **Number 13** and her husband were reported to the Department of Families for child abuse. Once again support for the difficult circumstances in which they lived was missing and both families were left knowing that they were being monitored by people unknown to them. Feminist authors, Thorpe (1996) and Irwin (Irwin & Thorpe, 1996) have argued that holding mothers solely responsible for the well being of children is an act of violence.

Lepers

Mother blame and the social and emotional isolation of women due to their different children and different families have been well documented throughout this thesis. Mim, for example in Chapter Seven, spoke of the way in which she was invited to social functions as long as *"the children don't come",* which she said meant *"we don't want James around"*. She said *"I seem to be the only one who's had this monster"* (Mim).

Anne was told by her children's treating doctor to book the children in separately as he could not cope with the two of them together in his surgery.

Wild Thing as a single mother spoke at length in Chapter Seven of the social and emotional isolation, highlighting the stigma of having a child like Brett:

I had no supports as far as any-one to look after Brett after the age of 8. My family wouldn't have anything to do with him because he tried to burn the house down...they just saw him as antisocial.

Some of the mothers articulated that people outside of their immediate family just didn't understand their different children or different family. However, it became clear that it was more than lack of understanding that excluded the women from social or professional acceptance. Lloyd and Norris (1999) have explored the way in which parents of children who are different are either approved of and seen as deserving, or disapproved of and seen as unworthy. Furthermore, Lloyd and Norris (1999) show how biological explanations for a child's difference have served to remove the blame from parents. A graphic example of the way in which *"labels of forgiveness"* (Lloyd & Norris, 1999, p.3) can work for families is given by Wild Thing.

Wild Thing explained that *"a rift"* had been created between her and her family and that *"people used to avoid me"* due to Brett's behaviour. However after he was diagnosed their perception of Wild Thing changed: *"Oh, you poor thing...what a great mother you were...how difficult it must have been for you"*. The family's attitude towards Brett also changed as his grandfather *"did everything he could to shape Brett's future so that he had some sort of qualification"*.

In contrast **Leanne** reported recently that *"no one, including members of her own extended family wanted to touch or become involved with our children* [children with ADD]" (Personal Communication 6th February 2005). Thus, the emotional and social isolation that the mothers experienced was in part to due to the judgments made by extended family members, the community, schools and professionals as to worthiness or deservedness of the mother, child or family. Deemed as problems or problematic, the people, the families that no one wants to know, are blamed and stigmatised. Foucault (1984a) noted that scapegoats are needed to explain social

problems, therefore, it can be seen that people affected by ADD do indeed possess the status of leper.

Rejecting the Status of Leper

The status of leper, in particular the notion of being unworthy, is an important concept to explore as a helping hand is usually only given to those who are seen as deserving. Illegal immigrants who were reported to have thrown their children overboard were said by the Federal Government to be undesirables. Questions have been raised as to whether they are *"genuine refugees"* due to their behaviour (truthoverboard, 2005, p.1). Unworthy to be considered as Australian residents or citizens, their detention in camps in remote locations in Australia does not raise too much concern. In a similar way, if individuals or families affected by ADD are seen as unworthy or to blame for their situation their plight will receive little attention. It has been noted that within the discourse on Autism, parent blame lost its potency (Albury, 1993) and this change drastically affected the way in which parents, particularly mothers, were treated by professionals. Furthermore this change from undeserving to deserving influenced the model of service delivery and eligibility for services. Therefore, it can be argued that, while blame is a part of the discourse on ADD, individuals and families affected by ADD will continue to struggle for recognition and for the services that they deem necessary.

It can be seen that the mothers in this research, through their personal and political advocacy, attempted to influence the discourse on ADD by stressing that ADD is *"nobody's fault"* (Mehigan et al., 2004). The program Learner's Permits for Parents is founded on the rejection of mother blame and is built around nurturing and supporting the mother. Thus mothers of children with ADD are constructed as worthy. Furthermore, the child with ADD is believed to have talents and skills which are to be encouraged. As blame loses its potency families and individuals can be viewed as deserving, thus challenging the status of leper (Foucault, 1984a). The recent work of Kendall and colleagues (Kendall et al., 2005) validates the development of programs like Learner's Permits for Parents, as they have stated that it is crucial to provide support for the mothers of children with ADD.

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Medication an Option?

It is beyond the scope of this research to closely examine the issue of medication. However, what was revealed is that of the fourteen children diagnosed with ADD, nine were medicated and five were not. This finding is in line with Barkley's (2001a) assertion that not all children diagnosed with ADD are medicated. Of the women who medicated their children, most reported criticism and blame. All of the mothers felt that the issue of medication attracted a great deal of negativity and was poorly understood. Even so, they believed that while medication was not a cure all, it needs to be an option for families. **Anne** stated that:

> my family wouldn't be here today without the medication…without the
> medication there's no hope in getting the child even to work with you, I've tried
> so many natural medications, I've tried everything that I can think of.

Some of the other women had also sought out alternatives before deciding to medicate their children, thus challenging the assertion that medication was *"a quick fix"* for families (Passmore, 2004, p.35).

The use of medication to treat physical, emotional and mental disorders or illnesses is a useful debate as it draws attention to the possible misuse of drugs. However, debates need to be holistic and issues examined thoroughly. Any debate on the use of medication to treat children with ADD needs to look at many factors. In viewing the media presentation of the debate within Australia, it could be argued that the debate is skewed and the general portrait depicts uncaring, selfish and irresponsible parents (Lawrence, 1998; Passmore, 2004). This research demonstrates that women are overworked, stressed, and operate with limited or no assistance from their partners, their extended family or the community. Other research data indicates that similar issues exist for the mothers of children with ADD living in south east Queensland, the United Kingdom, Canada and the United States (Carpenter, 1999; Harborne et al., 2004; Kendall, 1999; Kendall & Shelton, 2003; Malacrida, 2003; Mulsow et al., 2001). Thus, it is clearly an abusive practice to add to the burden of mothers by blaming them for using medication to assist their children.

The current debate needs to take into consideration what it means to have ADD, what it means to be different in terms of learning, experiencing the world, employment,

families and relationships. Furthermore, the view that badly behaved children are the product of *"bad"* (Swift, 1995) or *"mad"* (Matthews, 1984) mothers needs to be challenged and the reality of mothering children with ADD needs to be presented to prevent mothers from experiencing blame and condemnation.

It has been argued that mother blame has its roots firmly planted in psychoanalytic and behaviourist theories which developed in earnest after the Second World War. While this research has documented the way in which women have resisted the mother blame through their own personal determination and/or the support of other women in the support group, it is clear that mother blame pervades our culture. Hence, it is imperative that professionals, either as individuals or as a group, support mothers to resist and reject the blame for producing different children.

Re-emergence of Psychoanalytic Theories

It is important to note that in Australia in the late 1990s, psychoanalytic theories of child deviance, or difference, were in general noted in the literature covering ADD. Also, while psychoanalytic theories were implicit in the practice of some professionals these theories were not, in the main, overtly referred to, even though there were exceptions (Clark, 1996; Newman, 1996). Early in the 21st century I observed an increase in publications which spoke of the value of work by Bowlby and Winnicott in explaining the development of child deviance and the value of their work in relation to understanding ADD (Clarke et al., 2002; Osmond & Darlington, 2001; Schmidt Neven et al., 2000).

These publications indicate that psychoanalytic theories are reclaiming ground. This has particular relevance for the mothers of children, given that mother blame is so pervasive in the discourse on ADD. Malacrida's (2003) research gives numerous examples of the way in which some women were pressured into taking part in intervention strategies with a heavy psychoanalytic foundation which they found to be *"invasive, unpleasant and 'useless'"* (Malacrida, 2003, p.132). In this research Anne's case study demonstrates that family therapy and behaviour management programs did little to assist Anne and in some cases only added to her distress. Even so, as psychoanalytical theories are evolving and professionals are looking to the

field in relation to ADD, it is worth exploring the way in which these theories could be used in a positive and productive way.

Drawing on the work of Miklowitz (2001) in assisting families with Bipolar Disorder may give some insight into the way in which some interventions may be very useful. Miklowitz (2001, p.557) states that family therapy based on psychoanalytic theories is grounded *"in a culture that faulted parents for causing mental illness"*. However, he asserts that in contrast, family-focused treatment (FFT) which is comprised of *"psychoeducation, communication enhancement training and problem solving skills training"* (Miklowitz, 2001, p.523) is an intervention which is of value to some individuals affected by Bipolar Disorder and their families (Miklowitz, 2001).

Miklowitz (2001, p.527) asks the question *"what is the role of psychosocial treatment in a disorder with such a heavy biological and genetic basis"*? Before discussing this question it needs to be noted that there is no research that can demonstrate conclusively that particular genes are responsible for the development of Bipolar Disorder, Schizophrenia, or Autism. However, we do know that, as in the case of Autism and the other mental disorders, it became *"morally and politically taboo"* (Albury, 1993, p.316) to blame parents for causing the disorder and that this change in thinking influenced the way in which parents were viewed and the model of service offered to families.

Miklowitz (2001) asserts that by increasing the skills base of individuals and family members the challenges of life and mental illness will be more manageable and the quality of life may improve for all concerned. It needs to be acknowledged that he sees *"psychotherapy and medication as working synergistically"* and acknowledges that FFT is not needed by all individuals and families affected by Bipolar, nor will it benefit all families (Miklowitz, 2001, p.528). Thus Miklowitz (2001) acknowledges the biological genetic basis of the disorder, rejects parent blaming and views FFT as being useful for some families. With this in mind it can be seen that some therapies with their foundations in a psychological perspective can, if applied sensitively and appropriately, assist some individuals and families.

It needs to be acknowledged that the conflict within the discourse on ADD is hostile and that mother blame is a feature, thus any policies or programs that are founded on psychoanalytic theories to explain ADD need to be critically examined before accepting them as possible intervention strategies to assist mothers of children with ADD. However Miklowitz's (2001) work does show what may be possible for families affected by ADD in the future.

Recent Developments in Government Policy

The apparent trend of western governments to implement parent training programs based on psychoanalytic and behaviourist theories to solve a plethora of social ills, from delinquency, to socially unacceptable behaviour, has been noted and questioned by a number of authors (Hil & Brennan, 2004; Moss, 1999; Pugh, 1999). It is clear from the comments of politicians in Queensland that the parents of children with ADD, especially mothers, are expected to attend these programs so that they can normalise their children's behaviour. If parents (read mothers) are seen to fail the program, the program's theoretical base is not questioned as the failure is taken as yet another example of inept parenting. Another trend of western governments which has now appeared in Queensland is to extend the responsibility of parents to their child's behaviour and attendance at school. This is further evidence that theories that hold parents, particularly mothers, responsible for deviant children are driving aspects of government policy. In Chapter Six, **Mary Serenity** clearly rejected notions of parental responsibility:

parents can't always be held accountable for the actions of their children. Prosecuting parents for the behaviour of their children is just ridiculous. Especially after you've had an ADD child or a child with a mental illness, how can you possibly be held accountable…it is discriminatory and its unfair and its unrealistic.

Pointing the finger at parents for producing deviant children is a strategy which diverts attention from other social considerations such as education facilities which do not meet the needs of children. Thus, it is easier for governments to scapegoat parents (Hil & McMahon, 2001), particularly mothers, for producing children who do not adhere to prescribed norms of behaviour or attitude. Professionals who seek

to support individuals and families affected by ADD need to challenge simplistic assumptions in relation to difference and seek out more holistic frameworks in order to understand difference.

THE ABUSE OF MOTHERS

The women agreed to participate in the research so that their stories could be told. As **Anne** said, *"if my story can help one family then it is worth it"*. Hence, the reality of the women's lives must be clearly articulated to their spouses, family members, professionals and the general community. Other researchers (Pocock & Wilson, 2001; Russell & Bowman, 2000) have documented that most mothers carry a double burden in that they care for their children, run the household and often work in the paid workforce. This research has revealed that the mothers of children with ADD share a third burden, as they are forced to shoulder the workload that comes from having children who are different. Furthermore, some women carry a fourth burden by supporting a partner with ADD as well as their children.

It would be difficult to imagine an ethnic or religious group shouldering a workload that was disproportionate to their colleagues or neighbours without some form of protest or call to social action. However, the disproportionate workload expected of mothers is not acknowledged in any meaningful way in government policy, nor is it spoken about in the general community. Thus, all mothers are discriminated against and abused by the society in which they live due to the double burden that they carry. This abuse is further increased for the mothers of children with ADD, as they shoulder huge workloads in caring for their children and some encounter more onerous workloads by supporting a husband with ADD. Many of the women interviewed in this study identified that the workload, physical, emotional and mental stress contributed, if not caused their health to suffer. It was found that the women suffered from fatigue, sleep disorders, depression and physical disorders such as diabetes. Thus, it has been shown that mothering children with ADD has health consequences for women.

Violence

This research has also demonstrated that children with ADD, in particular children with ADHD can, and often do become verbally or emotionally abusive to their mothers and to a lesser extent, non-ADD siblings. Aggression from ADHD boys towards their siblings was also reported by Kendall and Shelton (2003). Another study by Theriault and Holmberg (2001) has suggested that impulsivity may play a part in aggressive responses from people affected by ADD. This thesis clearly confirms that some mothers are the victims of physical violence and damage to property inflicted by their adolescent children. This I believe is an important finding as it has implications for child protection practice and policy and poses questions in relation to the provision of family welfare services.

A case in point is the experience of **Number 13** and her family. Number 13 had spoken of the child abuse notification to the Department of Families, and their subsequent involvement, as a destructive encounter for her and her family. However, this negative experience with government services was further cemented when she realized that while she or her husband could be reported for child abuse, no practical steps could be taken to prevent her son, Stewart, from acting aggressively towards his family.

In 2004, Number 13 called the police to her home on three separate occasions as Stewart, then fifteen, was threatening to kill his family and burn the house down. She explained that he would fly into fits of rage which would last for up to five hours. In frustration and fear, Number 13 told the police to *"take him"* away. They replied, *"We can't do that Madam",* as they explained that they had no place to take him to. In speaking to the police, she found out that they could only act when he had actually carried out his threat. Even so, the police informed her that she could lay charges for damage to property while another policeman informed her son of his right to lay charges against his parents if they *"touched him"*. Number 13 reported that in tears she said to the police:

> *Are you telling me that this kid can do what he likes? Does this mean that I have to sit up all night to guard my other children so that he doesn't burn the house down or kill them as he has threatened to?*

Number 13 said that she felt particularly powerless and afraid for her two other children and wondered at the impact upon them (Personal Communication 15th February, 2005).

This situation is obviously complex, however what is highlighted here is that the rights of one child appear to have overshadowed the rights of others in the family, such as his parents and his brother and sister. Thus, I argue that while the needs of the ADD child are important especially in child protection issues (Lonne & Thomson, 2005; PeakCare, 2002) the other members of the family, especially mothers and other siblings, are equally important as they often bear the brunt of the out of control child's actions. Therefore, the understanding of violence within the family needs to be extended to include violence that young people perpetrate upon their parents and their siblings. Furthermore, both the domestic violence sector and family welfare services need to acknowledge that these complex family situations do exist and there is a need to act to ensure the safety of all individuals.

It is worth noting that the North Queensland Domestic Violence service has made attempts to draw attention to adolescent violence towards their mothers at a conference held in May 2004 (Cannon, 2004). However, as noted by Cannon (2004) there is scant reference in the Australian domestic violence literature of young people under eighteen, being perpetrators of domestic violence. Moreover, it is rare to find mention in the domestic violence literature, of adolescents with a diagnosis of ADD, Oppositional Defiance and Conduct Disorder as perpetrators of domestic violence (Bobic, 2004). Accordingly, the findings of Theriault and Holmberg (2001) which suggests a possible link between aggression in relationships and ADD is of importance, as it provides a new perspective on the issue of violence.

It is particularly disturbing that the focus on child protection appears not to take into consideration the needs of the other children in the family who surely must suffer trauma from experiencing abuse and witnessing the impact upon their parents.

Jane, Number 13's daughter wrote a letter to her parents explaining how she felt about the family situation:

> *To my dearest mum and dad,*
>
> *I know that you are sick of the crap in this house. I am too! If you could change this so-called "family" I know you probably would for your sake. I know I don't get much chance to say something to you both because we are always in continuous battle, usually against the big, sweaty, swearing monster who doesn't know the word hygiene, but I would just like to say I really really love and* appriciate [sic] *you both so very much.*
>
> *If I offended you in anyway before (above) I am really sorry. Usually I can write what I am thinking but can't find enough confidence to say it. If I was confident and more outgoing I would tell the monster, what I really think. Even if he swore at me. I am sick of being told what to do by him, he doesn't even know what to do himself. There are so many things I could yell at him for, but I don't. I am just about to pop because of the anger and disappointment inside of me. I know I've only had to put up with it for maybe ten years of my thirteen year life. But I don't really remember much when I was little, but I am so positive that you remember every ounce of complications in the past sixteen years and I am really sorry. I don't know what else to say except thank you for being with me and helping me through tough times. I love you both very much and again* **thank you.**
>
> *love Jane xoxo*

(Letter to Number 13 and Gary from Jane, February 2005)

SYSTEMIC NORMALISATION AND DISCIPLINE

It has been demonstrated in this thesis that the Queensland government and professionals recommend, urge or refer mothers of children with ADD to behaviour management programs, counselling and/or family therapy. Women in this study have stated that the Positive Parenting Program (Triple P), or similar behaviour management programs, have not assisted them in any meaningful way: *"government child health services I have been disappointed with… I've been to a string of child health services, which haven't been supportive"* (Joyce).

Questions have been raised as to the efficacy of strategies in parent training programs founded solely on behaviourist theories to treat families affected by ADD (Harrison & Rees, 1998; Wallace, 1996). While this research did not ask questions specifically in relation to the efficacy of programs like Triple P, nonetheless the information provided by the women indicated that programs like Triple P are not considered to be effective. This research and evidence drawn from existing literature, suggest that parenting programs based on psychoanalytic or behaviourist theories may not prove to be effective for a number of reasons.

Women who are depressed (Harrison & Rees, 1998; van Kraayenoord et al., 2001) or women who are physically and emotional stressed (Kendall et al., 2005; Kendall & Shelton, 2003) are unlikely to participate successfully in these programs. Furthermore the one size fits all focus of these programs (Harnett & Dawe, 2004) does not take into consideration that individuals and families affected by ADD are different (Harris et al., 2002; Mehigan et al., 2004). Thus, these programs fail to recognise difference; for example children who learn differently, adults who learn differently and families who are different (Brochin & Horvath, 1996; Mulsow et al., 2001) .

Foucault (1979, 1999) has argued that sameness makes populations easier to govern. Hence, governments introduce programs like Triple P to normalise populations. This thesis argues that programs such as Triple P which do not recognise difference and place yet another responsibility upon already overburdened women are in essence abusive. Furthermore, as demonstrated by Anne's case study, some professionals operating from psychoanalytic or behaviourist theories have heightened the distress of mothers by unethical behaviour and attributing the children's problems to the mother's upbringing or her martyrdom. Thus, they have used their professional positions to blame and abuse the mothers of children with ADD. In this way the mothers of children with ADD suffer systemic abuse through the normalisation policies of the Queensland government and programs implemented by some professionals.

SUPPORT FOR FAMILIES AND INDIVIDUALS

The women have called for support for their children and families stating that:

> *the community needs to recognise that having a child with ADHD is as*
> *challenging as having someone with a physical disability, or having someone …*
> *with an intellectual disability* (Leanne).

The way forward is to have:

> *less stereotyping and more getting in and having a look at…the family situation,*
> *looking at the individual, and how that family can be supported, or how that*
> *individual can be supported. That's fundamental* (Leanne).

Accordingly, it is essential to acknowledge the difficult circumstances in which these women mother and service providers need to look at the whole family situation and offer services that are capable of supporting each particular family in a practical way.

Professional Sensitivity and Awareness

This research has highlighted a number of issues which are important for service delivery and in client and professional interactions. Some of the women commented that the experience of having children with ADD, mothering and marriage was very different to what they had envisaged and spoke of *"a great grief"* (Roseanne). Accordingly, this research has recorded that grief is an aspect of the women's lives. The concept of grief is not widely articulated in the ADD discourse, however, where grief is mentioned it is more conceptualised as the loss of the normal child (Rice & Richmond, 1997). This research broadens the understanding of grief to include, grieving for what could have been and is best articulated by **Leanne** in Chapter Seven: *"you hear people talk and you know what you have missed out on. I could not even go to a football match with the two of them* [Julia and Tom]*"* (Leanne Personal communication 26th September 2004). Leanne described the loss of what could have been as an *"emotional pain for all the sacrifice that you have to make"* (Personal Communication 26th September 2004). It needs to be stressed that this grief is often on going and can be described as *"chronic sorrow"* (Roos, 2002, p.24). The understanding and conceptualisation of grief is starting to be expanded by a number of authors working with families (Thorpe, Thomson, & Wallace, 2004). The term, non-finite (Bruce & Schultz, 2001) describes the grief a parent feels when the child is alive but is lost to the parent, and disenfranchised grief (Doka, 1989, 2002),

where there is limited acknowledgment of grief, are concepts which also could be used to describe the grief that some mothers of children with ADD experience.

Bailey (1997, p.155) has advocated that professionals need to be aware of the *"psychological load"* that parents carry and the stress that mothers encounter in raising children with ADD. Examples from both Joyce and Caroline demonstrate that simply listening to, and validating the experience of mothers can be the difference between a destructive interaction and a positive interaction. However, the overriding message from the stories of the women in this thesis, and the stories of the women in both Malacrida's (2003) and Carpenter's (1999) studies is that mothers in general are not treated with empathy or respect by professionals. Harborne, Wolpert and Clare (2004, p.338) have stated that in the battle *"to gain recognition"* from professionals, parents experience *"emotional distress"*. Thus, this study complements the existing literature which shows that many professionals add to the anguish of mothers of children with ADD. In addition, this research offers some insight into the grief that some mothers experience and introduces the concept of *"chronic sorrow"* (Roos, 2002, p.24) in relation to mothering and ADD. Clearly professionals cannot begin to assist families if they fail to take into consideration the reality of parenting a child with ADD.

Involving Fathers

The active involvement of fathers in the *"grunt work"* (Hays, 1996, p.163) of bringing up children is an issue for all mothers (Goward, 2005). In particular, it is an important issue for the mothers of children with ADD as it has been demonstrated in Chapter Seven, that the mothers interviewed shouldered an enormous workload in bringing up their different children and sometimes supporting their child's father. While it can be seen that non-biological step/adoptive fathers did become more active in the child's upbringing in general fathers were absent from the *"grunt work"* (Hays, 1996, p.163). This research did not interview fathers however, other research has found that many fathers of children with ADD believe that their wives are primarily responsible for the upbringing of their children. Moreover some of these fathers blame their wives for their child's difficulties (Singh, 2004). Accordingly, the findings of this thesis are supported by other research.

Most of the mothers in this study believed that their children would benefit from a more active role being taken by a father figure, stating the way forward is for: *"fathers/substitute fathers taking* [a] *greater (leading) role in all aspects of managing child[ren] at home"* (Mim). The exception was the three women who believed that their husbands had ADD. While they would have welcomed their husbands' assistance, they articulated that their husbands did not have the patience or skill and that their husband's own ADD in some instances inflamed the situation.

Resistance to Active Father Involvement and Possible Strategies

Given that it has been argued that the mother as primary care giver has been shaped by the interests of the state, capital, patriarchy and child rearing experts, it is difficult to see how this will be changed other than through the efforts of feminists and those who wish to support families, in particular families affected by ADD. However, the first step to address the imbalance in parenting roles must be the acknowledgement that most women carry a double burden, and that caring for children who are different increases the workload. The double burden needs to be discussed openly in the community, in the media and it needs to be acknowledged openly by bureaucrats and the government. It is only when the knowledge is widespread that the imbalance can begin to be addressed in any meaningful way.

The second step may be education programs for fathers. Paull (2004, p.13) has stated that:

> *many men are considered to be basically unprepared to assume the active*
> *parental role being asked of them by new societal expectations, having deficits in*
> *such areas as knowledge of normal child development and parenting skills.*

Paull (2004) discusses many reasons for the absence of fathers from most parenting programs, and suggests a number of strategies to better prepare fathers for a more active involvement in parenting. One strategy suggested is to provide programs in schools to prepare adolescent males for fatherhood. While this strategy would not address the issues of bring up children with ADD it would provide males with basic information in order to give them a more realistic picture of fatherhood and child development.

The lack of active involvement of Fathers in parenting children with ADD is far more complex. I am not aware of any research to date that investigates the experiences of fathers in having children with ADD, however, this would be an important step in seeking to support families affected by ADD.

RESISTANCE AND POLITICAL ADVOCACY

This thesis has shown that political action through community engagement activities and advocacy in relation to policy development has to date been unsuccessful. That is not to say that individuals and organisations should cease to lobby government, or bureaucrats, as it can be shown that some individuals, in particular Dr Sheila Parks had supported NADDS, to bring about change in the community, for example: the Information Folder and the development of Learner's Permits for Parents. However, a cautionary note needs to be given, as evidence from this research and information gained from ADD support groups in the United Kingdom, suggests that governments are not prepared to share power, in any shape or form and government policy will not yield easily to accommodate difference.

Strengths Based Approaches

It has been argued that we *"need to reject abstract and universal solutions to political problems in favor of specific local resistance"* (McLaren, 2002, p.50). Accordingly, energies may be better expended in working with groups and individuals in the community to bring about change for families. This local action may, in the long run be more beneficial for families as the time and energy expended in developing and running Learner's Permits for Parents and the development and dissemination of the Information Folder has assisted families in the local community and further a field. These projects, where undertaken with a *"power with"* (McLaren, 2002, p.41) approach and a basic strengths approach in working with families have proved to be productive and positive. Thus, community organisations which adopt a *"power with"* (McLaren, 2002, p.41) and strengths based approach (Elliot et al., 2000; Rapp, 1998) in their contact with families and in the implementation and development of programs are more likely to assist families in meaningful ways.

Feminist Action

Feminist organisations have a role to play in supporting the women and families affected by ADD. The women interviewed in this research have encountered systemic abuse from the *"metapower"* (Foucault, 1980d), as they are blamed for their children's difference, are overburdened and stressed due to enormous workloads and the violence that some suffer from their children is ignored by those who seek to govern. Women with ADD encounter additional problems as can be seen from Susan's story.

In this research Susan was the only woman to identify as having ADD herself. Her story provides some insight into the impact that ADD had upon every aspect of her life: schooling, relationships, mothering, career and health. Her story highlights that women who have ADD and mothers who have ADD face particular challenges given the prescribed gender roles of women and mothers in our society. Susan's story not only demonstrates the difficulty of being different, it also demonstrates that Susan's difference can be an asset. All of these issues mentioned lie within the framework of feminism. Hence, feminist organisations need to seriously consider these issues and seek to support women affected by ADD, either through political action, advocacy or practical support.

Support Groups

Feminists have been aware of, and acknowledge, the benefit of support groups. Both Malacrida (2003) and Carpenter (1999) have noted the role of ADD support groups in both supporting women and in political action. Carpenter (1999) in her concluding chapter called for more research to ascertain the benefit of support groups to women. This research has demonstrated that support groups can provide a safe and supportive environment where women can share their deepest fears, pain and frustration. Furthermore, this research has shown that the mothers of children with ADD may suffer from poor health, enormous workloads and violence however, they are not content to adopt a victim status. Some of these women used their experiences to assist other women at a personal level, others used their knowledge to counter professional discourses that held them responsible for their children's difference and

some used their knowledge to develop and implement practical strategies, such as the Information Folder and Learner's Permits for Parents.

A significant outcome of this research has been to make available information which has assisted in the development of the strengths based program, Learner's Permits for Parents. Thus, social action which has resulted in a challenge to professional power and discourse which blames women for different children has occurred through the process of this research. Furthermore, this thesis has acted as a witness to the women's political advocacy and recorded their efforts to bring about social change. Contributing to social change and the documentation of women's political advocacy is an important aspect of feminist research and action (Sprague & Kobrynowicz, 2004).

HOW ARE THEY NOW?

Most of the women were interviewed in the year 2000. During the last five years much has happened to them and their families. Thus, it is valuable to revisit the women and to look at their current situation.

Number 13

Number 13's situation has worsened as sixteen year old Stewart, has been expelled from school and is home tutored. Stewart was sexually assaulted by another boy and now suffers from post traumatic stress disorder. Stewart is resentful and angry and lashes out at his family. Number 13 feels like the whole family is in a siege situation as they tip toe around Stewart's outbursts and demands. She exclaimed, *"what can you do"*, he rules the roost, and we have *"nowhere to go for help"* (Personal Communication 17th August 2004).

Anne

Anne considers herself lucky as she now only works thirty hours a week. In reflecting on her efforts to send her children to boarding school and working sixty hours a week to support them, she said: *"if you don't do it, what chance do they have…boarding school changed his life around, we were not going to get anywhere the way it was"*. In 2004, Clifford, now eighteen years old, attended university and

is interested in education and psychology. Anne believes that in the future he may be able to assist children who have ADD. At his last visit to the paediatrician, the doctor shook his hand saying, *"I thought you would end up in jail, instead I am proud to see you are heading off to university instead"*. Anne also reported that sixteen year old Carl, his brother, can pull any motor apart and put it back together again and is looking to find an apprenticeship in the motor industry. Carl and his father, Joe share an interest in car racing and spend many hours together fixing and modifying cars. Anne said that her boys still have their problems; low tolerance levels and mood swings but life has moved on. Anne herself still suffers from a sleep disorder but is assisted by medication (Personal Communication 28th September 2004).

Caroline

Caroline is separated from her partner who is reluctant to support the children financially and makes little effort to contact them or see them on a regular basis. She continues to care for her children with some support from her parents and a supportive local GP. Caroline is chronically tired and struggles with poor health. She devotes considerable time to liaising with the school regarding her son, Clint, now twelve. Caroline was concerned about Clint's ability to cope with high school and their ability to deal with his behaviour. She has enrolled Clint in a small Catholic high school that has a good reputation. At the start of the school year in 2005 Clint is enjoying high school, has qualified for a position on the sporting team and has won a weekly student award. Caroline is not sure how she will manage financially. Her eldest daughter, Beth, aged twenty two is coping well with her young daughter who is now in grade one. Beth has spoken of the possibility that her child may have ADD. Caroline urges Beth to return to school or take courses to increase her employability (Personal Communication February 2005).

Leanne

Leanne reports feeling chronically tired and desperately seeking a break from the demands of family. Twenty five year old Julia has had a baby and the baby brings great joy to Leanne and her husband Bob. Julia's partner has assaulted Julia and Leanne has given her shelter on a number of occasions to escape the violence.

Leanne and Bob continue to support Julia and her partner financially. Twenty three year old Toby, Leanne's second child is in his last year of university. Toby has left home as his brother, Tom's behaviour became intolerable and affected his ability to study. Tom, who is almost nineteen, has appeared in court on a number of charges. He is verbally abusive to his mother and damages property when he flies into a rage. Leanne is currently on medication to help her cope with the stress and emotional pain of her son's violence (Personal Communication March 2005).

Mim

Mim left North Queensland not long after I interviewed her and in another state James was diagnosed as having Aspergers Syndrome (ASD). Mim said that he was eligible to receive support services which previously he could not access with a diagnosis of ADD. However, both James and his mother experienced difficult times. Mim reported that James *"desperately wanted to fit into society especially with his peer group"* and this led him to make mistakes, which almost cost him his life. Mim located a psychiatrist *"who was Autism aware"* and things improved for James. At nineteen, James has left home and with the help of his maternal aunt and uncle has found a job in which he excels and enjoys. In speaking with Mim in early 2005, she reflected on her journey as James' mother: *"I experienced a constant battle in trying to build a boy with a strong self-esteem and confident manner so he could become a responsible and happy adult"*. Mim finished her doctorate and is now a grandmother as her eldest son's partner gave birth to a baby boy (Personal Communication 4th January 2005).

Joyce

Joyce has left the district but keeps in contact with members of the support group. Her son Nick, now fourteen is working part time and is in year nine at High School. Joyce said that *"he aspires to finishing a Uni degree but unsure of exactly what"*. Twelve year old John *"is doing well"* at school. Both boys are still under the guidance of a paediatrician and:

> we are continuing with medication to assist in their ability to cope with learning (mainly for John) and behaviour (mainly for Nick). It has been a growing time and we still have the same basic problems to deal with but in continual different

contexts. No more family court at present - no resolution on the access

agreement but their dad now travels to visit instead of them visiting him.

Joyce said that the boys' father has now decided that he will visit them as he had a horrific experience last Christmas when he refused to give them their medication. He found that after stopping their medication he and his new family could not cope with their behaviour. Joyce recently assisted the support group by providing information on possible venues for a conference to be held in Townsville hosted by ADDAQ (Email 27th September 2004).

Feral Cheryl

Feral Cheryl's son, Michael, is now fifteen. He still lives with his grandparents. Michael has regular contact with his mother and they have a good relationship. Michael has been expelled from two schools and currently is not attending any school as *"no public school will take him"*. Michael loves computers; he has built his own website and designed his own games. Next year he wants to attend TAFE and study Information Technology and find a part time job. Feral Cheryl's parents still *"don't believe in ADD"* (Personal Communication 27th October 2004).

Roseanne

Roseanne's son at twenty three has recently become a father. She believes he will be a good father and reports that the new baby is much loved by all family members. Joshua is currently employed and has many ideas for a small business in an area in which he has expertise. Roseanne continues to advocate for families affected by ADD and works hard to support her family (Personal Communication 17th May 2005).

Wild Thing

Wild Thing is divorced from the respectable public servant as she discovered he was not so respectable. Her twenty five year old son, Brett, is employed and is in a long term relationship. He is no longer on medication but Wild Thing believes that medication may be needed in future. Wild Thing continues to support him emotionally, however, acknowledges that he has come a long way from the troubled youth that he was five years ago (Personal Communication November 2004).

Mary Serenity (A Student of Life)

Mary Serenity reported that she now feels that she is in a *"joyful place having raised Steven successfully, to adulthood, I mean still alive… after having a very difficult time"*. Steven, now twenty three, *"is well, happy, employed and in love"*.

He is *"good at his job, people ask for him, he makes people laugh. His loving gentle side has been opened up now that he has found his niche"*. Mary Serenity reflected that when people find their niche, find where they belong and are valued they don't need to become angry, resentful and rebellious. She said that in the couple of years after I first interviewed her, awful things happened and she doesn't know how Steven avoided going to jail. In looking back on her experience she said that the message she would give to other parents is *"never give up, never back down when trying to help your child as every system wants to grind them* [children who are different] *into the earth"* and often you are the only one between them and your child. We as a society need to *"value difference as we have so much to learn from them"* (Personal Communication 17ᵗʰ February 2005).

In reading this updated account it can be seen that some of the different children have not only survived to adulthood, as in the case of Steven, Mary Serenity's son but have, like most other grown up children, found jobs or started families. Clifford, Anne's son, did not end up in jail as the paediatrician had feared instead he enrolled in a university course. However, all of the women acknowledged that regardless of the apparent success, in other words achievement or milestones in a person's life, such as education attainment, joining the workforce and starting their own families, there were challenges and there probably always would be for their different children.

Unfortunately for some families their situation had worsened. I have kept in regular contact with Number 13 and Leanne and their situation can only be described as horrendous. Their health and mental well being has been affected and as can be seen from Jane's letter to her mother, Number 13, the life of the non-ADD sibling is a rather sad one. In viewing the situation for both families, in particular the mothers, it is difficult to envisage positive changes occurring within the short term.

Other women, like Joyce and Caroline have younger children who are just beginning their teenage years. It should be noted that Joyce and Caroline's children are supported by an *"ADHD-friendly"* (Malacrida, 2003, p.169) paediatrician whom they hold in high regard. It will be interesting to revisit their situation in another five years time.

RECOMMENDATIONS

The following recommendations are addressed to the wider society in which we live, government bureaucrats, policy writers and professionals working with families and children, such as teachers, social and community workers, psychologists and medical doctors.

One

To recognise that difference is embedded in our society and that difference does not equate to pathology. Furthermore, in valuing difference, a person's strengths should be recognised, valued and nurtured.

Two

Education reforms to ensure that children who learn differently are catered for in a nurturing and holistic environment. These reforms need to employ strengths based approaches and concentrate on increasing options for parents and individuals affected by ADD.

Three

Professionals' interactions with mothers affected by ADD need to be:
- ❖ respectful,
- ❖ recognise the knowledge and expertise of women as mothers,
- ❖ aware that grief and sorrow are issues for these women.

Four

Rejection of mother blame in all its various disguises.

Five

Support for the reality of mothers to be included in the discourse on ADD. In addition, recognition that ADD is not gender specific and that a mother's own ADD has implications for her as an individual and her children.

Six

The concept of abuse and violence to be extended to include:

- ❖ the enormous work load that women encounter in supporting their children and their partners with ADD,
- ❖ the damage to women's health due to caring for children and or partners affected by ADD,
- ❖ the verbal, emotional and physical aggression women experience from their children with ADD,
- ❖ policies and programs which do not meet the needs of individuals and families affected by ADD.

Seven

Intervention programs in order to avoid abusive practices need to:

- ❖ be developed in consultation with families and individuals,
- ❖ employ a strengths based approach in assisting individuals and families affected by ADD,
- ❖ include copious practical supports as well as therapeutic interventions,
- ❖ recognise the needs of individuals within the family, including the needs of non-ADD siblings,
- ❖ recognise that a particular program or intervention strategy may only be effective for some families – need for diversity of programs and choice,
- ❖ value and support local solutions to local problems.

Eight

Critical examination of programs and polices which are based on simplistic psychoanalytic and behaviourist approaches to difference. In addition, the recognition that current programs and policies implemented by the Queensland Government may not be in the best interest of all mothers or all families.

FURTHER RESEARCH

The story of the child diagnosed with ADD was outside of this research, as was a detailed study of the stories of adults who believe they have ADD. Child advocates (Mason, 2004) argue that children have agency and that they are capable of expressing their feelings and their views articulately. Accordingly, research on the child's experience of having ADD, or being told they have ADD would be extremely valuable. Of equal importance is the experience of the non-ADD siblings as this research reveals that the impact may be profound.

Suzan's story, as an adult woman with ADD, raises many questions and feminist research is needed to explore what it means to have ADD as a woman and what it means to have ADD as a mother. Feminist scholars need to examine the impact of ADD on women as individuals and as mothers. It would also be valuable to have research undertaken by insiders as well as by people who are not affected by ADD.

In addition, the impact of ADD on men needs to be explored. Brian, a member of the ADD support group, stated he knew *"there was something very different about him"* and *"that he was persecuted because no one recognised that he was different"* (Unpublished email, nqadd@Yahoogroups.com 11th October 2004). Therefore research is needed to investigate what it means to be different, and the impact that difference has on a person's life. This research has documented that having ADD impacted very negatively on the ability of fathers to contribute to the raising of their children. It also highlighted that a man's partner is often trying to support her husband as well as bringing up their children.

As the father's lack of involvement within the family affected by ADD has been identified as causing further stress to the mother, more work needs to be done in exploring ways that fathers can support their partners. It would be particularly interesting to see this research undertaken by men as agents for change.

In short, research needs to be undertaken to determine what it means to be different, both the positive and negative aspects, and what strategies have been utilised successfully to assist individuals and families affected by ADD.

CONCLUSION

In this thesis I have documented the journey of a group of strong women who have demonstrated great love for their children. The women on this journey developed an understanding of difference: what it means to be a different family, what it means to have different children and what it means to be, as in Susan's case, different. The experience transformed them. Their lives would never be the same again. However, as painful as their experiences have been, they recognise that through their *"brokenness"* (Stirling, 2004, p.2) they have been transformed into more knowledgeable, tolerant and compassionate human beings. They have used this knowledge to advocate for people affected by ADD and to challenge discourses which abused them and their children.

I am grateful that the women allowed me to share their journey, as a woman affected by ADD and as a researcher. My journey as a researcher has, like the personal experience of ADD, not been smooth or uneventful. Along the way I encountered many challenges, however, in the end felt that I gained valuable insights into the concept of difference and developed a greater understanding of just what it means to be different. I hope that the material found in this thesis will assist others to be more tolerant and accepting of those who are different, particularly those who are labelled or identify as having ADD.

APPENDICES

Appendix 1 – Summary Table

	Psychological Framework	Biological Framework	Diet Perspective	Strengths Perspective
Position on ADD	Difficult or deviant behaviour is caused by early childhood trauma or poor parenting.	Biological condition and strong heritability.	Contributes to ADD, behaviour & learning problems.	Primarily biological & heredity focus but acknowledges that diet and trauma may contribute.
Child	Central to their concern & treatment.	Acknowledge the difficulty of rasing the child.	Food intolerant.	Combination of – concern & hope. Often receives the most attention & time within the family.
Siblings	At risk.	May have ADD or another disorder, need support e.g. respite, camps.	May benefit from modified diet.	May have ADD or another disorder Non ADD siblings need support as they are often left out.
Mother	Needs to be educated and accept responsibility.	Needs information on ADD. Needs to provide structure, undertake parent training, supervise & implement therapy.	Implement & monitor diet. Needs to observe & note behaviour changes.	Often doing it alone, needs validation & support. Often feels blamed & under a lot of stress. May also have ADD.
Father	Needs to play a more active role but not seen as central to the problem.	Acknowledges that he may be absent or have ADD.	Could also benefit from the diet.	Absent physically or practically. May have ADD & contributes to stress in the family. Looks for ways to involve father in a positive way.
Intervention	Family therapy, Triple P, education on child development.	Multimodal: Medication Parent training Behaviour management at the point of contact Other therapies e.g. remedial, speech.	Elimination diet & adherence to diet. Other therapies as recommended by treating doctor.	Multimodal: Medication Parent Support programs Diet if applicable Programs to assist children with their difficulties Other therapies e.g. remedial & speech.
Policy Direction	Strengthen the family.	Provision of intervention strategies in Education & Disability sectors.	More recognition of sensitivity to food.	ADD recognised as a disability & services provided. Recognition that people with ADD are different and have different requirements.
What they want	A society which is more child centred.	Research to assist understanding.	Research. into the affect of diet on children's behaviour & learning	Strengths based interventions

Appendix 2 – Letter of Introduction

Hi, my name is Dianne Rogers, I am contacting women who are involved in the North Queensland Attention Deficit Disorder Support Group and inviting them to participate in research which seeks to tell the experiences of women who have children with ADD or who have ADD themselves. I would like to interview at least ten (10) women who have children with ADD and one (1) woman who has ADD.

I need some basic information, such as the age of your children, time of diagnosis etc and will ask you to fill in a questionnaire. Also I would like to conduct a semi-structured interview session, which may take two hours. The purpose of the questions is for you to tell me about your experiences of having children with ADD or your experiences of having ADD. I will need to tape record the interview however, the tapes will be kept safe in a locked place.

I will ask you to choose another name, a pseudonym, to be used in any written or oral presentations or publications. Your real name will not be used at any time and the information that you give me will be treated with the strictest confidence. If you choose to participate, please be aware that you are free to withdraw from the research project at any time.

It is hoped that the research finding will be used to assist people to understand the impact of ADD on the family, in particular mothers. The research project can also be used to advocate for recognition of ADD and services and resources to assist people affected by the disorder.

If you require any further information I can be contacted by phone, 4781 4111.

Yours sincerely,

Dianne Rogers

Appendix 3 – Informed Consent Form

School: School of Social Work & Community Welfare

Project: Mothering and Attention Deficit Disorder: The Impact of Professional Power

Researcher: Dianne Rogers

Contact Details: Phone Number - 4781 4111

                        Email: **Dianne.Rogers@jcu.edu.au**

Project Description:

Participants are invited to be part of a research project which seeks to tell the experiences of women who have children with Attention Deficit Disorder or women who have Attention Deficit Disorder.

Consent:

I have read the Letter of Introduction, the aims of the study have been clearly explained and I understand what is required of me. I am aware that taking part in this study is voluntary and I can end my involvement at ant time.

I understand that any information I give will be treated as strictly confidential and that in the research findings, any written or oral presentation or published material a pseudonym will be used, not my real name.

NAME(PRINT)……………………………………………………………………….
SIGNATURE…………………………………………DATE……………………….
Witnessed by the Researcher Obtaining Consent
NAME(print)……………………………………………………………………….
SIGNATURE…………………………………………DATE………………………

Appendix 4 - Questionnaire

Participant

Name

Age

Educational Attainment

Employment outside of the Home

Partner

Name

Age

Educational Attainment

Employment outside of the Home

Children

Names and Ages

Educational Attainment

Diagnosis

1   How many people in your immediate family do you believe have Attention Deficit Disorder?

2   Have they all been diagnosed?

3   If so by whom, how long ago and were other disabilities or disorders identified? (Learning Disabilities, OD, CD)

4   What was the length of time from feeling that there was a difference/problem etc to the time that your child/children was diagnosed?

5   If a family member has not been diagnosed, please give the reason.

6   Do you have family outside of your immediate family who you believe have Attention Deficit Disorder?

7   Have they all been diagnosed? If not why not?

8   Is your child on medication? Has your child ever been on medication? If so why did medication cease?

9   Have you received any criticism or negativity from using medication to assist your child? If so from whom?

10   Instead of medication what would you see as a preferred strategy?

Information and Services

11   When did you first hear of ADD?

12   How have you learnt about the disorder and who or what has provided you with the information? (books, journals, friends/library, support groups)

13   Who are the current professionals, agencies or groups that assist your child/children, yourself and family? (medical support, behavioural management, therapy, tutoring, information or support)

14   Do they meet your needs?

The Impact of ADD on Family Life

15   Do you believe your family life differs from that of other families who do not have ADD present in their life?

Supports and Individual Action

16   Who manages the discipline in your home?

17   Who takes responsibility for managing any conflict in the home?

18   Who assumes the majority of the housework?

19   Who works with professionals to assist your child/children with ADD? (visit to the doctor, school, speech therapist etc)

Appendix 5 – Semi-Structured Interview - Mothers

Diagnosis

1   When did you feel that your child/children may have been different or when did you first feel that some aspects of your child/s development was not as you would expect or when did you first experience problems?

2   Can you please tell me how you felt when you where told that your child/children had Attention Deficit Disorder?

3   Describe your experiences with professionals when speaking to them about your child/children? (before diagnosis, after diagnosis, working with teachers, psychologists, therapists etc)

4   How did/do you feel about the use of medication?

Information and Services

5   What services supports would meet your needs?

6   Describe your family life and how ADD has impacted on you family life?

7   Describe the impact of having an ADD child/children/husband on you as an individual (personal level)?

8   How do you think other families or people view you, your family and your child/children with ADD?

9   How does you partner contribute to living in a family with ADD (positive and negative aspects)?

Supports and Individual Action

10   Who provides you with emotional and practical support? (Who do you talk to about problems with your ADD child/children or ADD husband)

11   What action have you taken to assist your child or yourself to manage living with ADD?

12   Has one single individual, group of people or event assisted you above anyone or anything else to cope with having ADD in the family?

13   What has been the value of joining and maintaining the North Queensland Attention Deficit Disorder Support Group?

14   Tell me of the achievement of your ADD child/children. (The things that you are proud of)

15   Tell me how have you have advocated for your child or worked towards your child being seen in a positive light?

16   Tell me what changes in your life have occurred through having a ADD child/children and or husband? (How has having a child with ADD changed your life)

17   What are your strengths?

18   How do you feel about yourself as a person? (What words describe you eg. Happy, tired, strong etc)

19   Is there anything else you would like to speak about or add. (an issue which is important to you or something your feel I may have missed)?

Appendix 6 – Semi-Structured Interview - Susan

1 When were you diagnosed as having ADD?

2 Who by?

3 How did you feel about being diagnosed with ADD/?

   What were your thoughts?

Question to ask if not covered:

1 When did you feel that you were different from other people in some aspect of your life – school, relations with peers?

2 How did it affect your youth – growing up, at school, within the family etc?

3 How did it affect your career prospects – your work?

4 How did it affect your relationship with your familiy members – partner, children, siblings, parents/

5 Has there been one event or person in your life that has impacted on your understanding or acknowledgment of ADD?

6 Who offers you emotional and social supports?

7 What value has the ADD support group been to you?

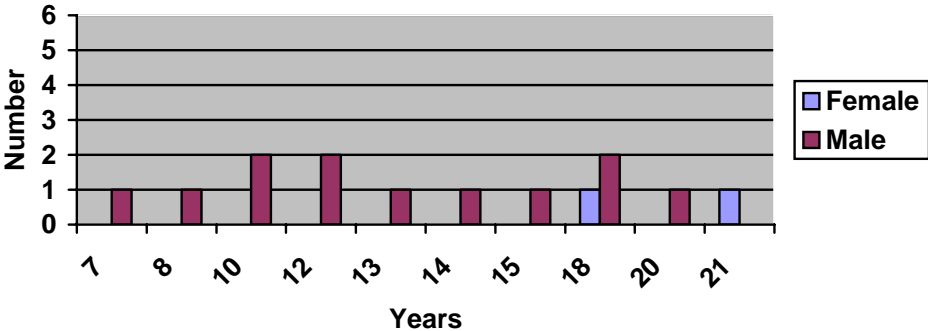8 Where do you go from here – what are your plans?
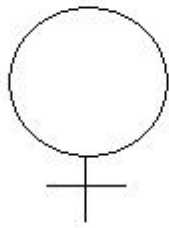
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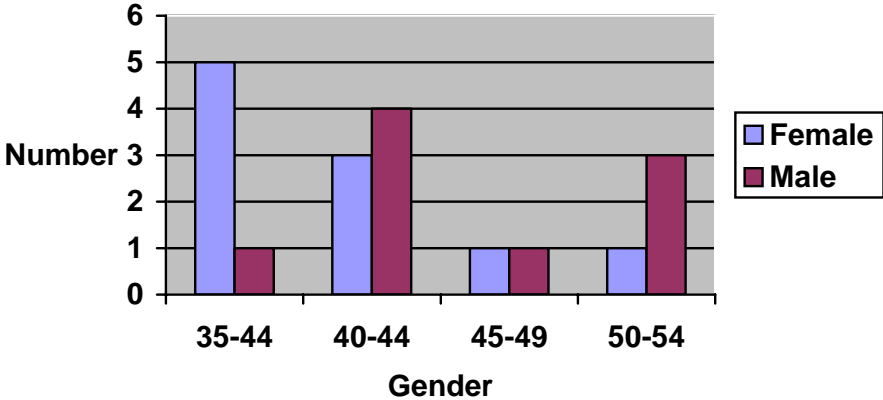
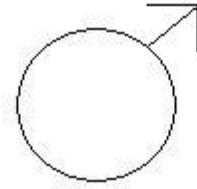## EDUCATION
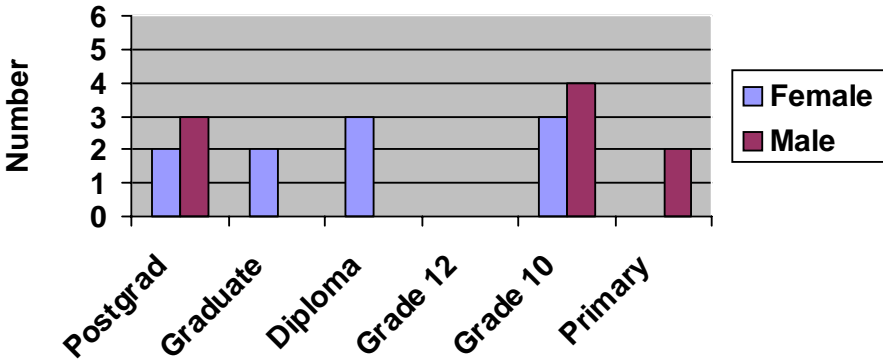
CHILDREN

12 Males and 2 Females

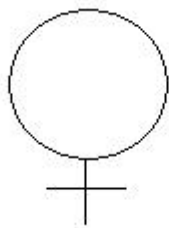**Appendix 8 - Families**

Mother
Leanne

Father
ADHD

ADHD
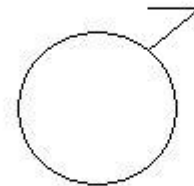CD - Conduct Disorder
LD - Learning Disability

LD

ADHD
LD
OD – Oppositional
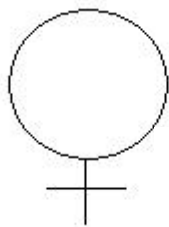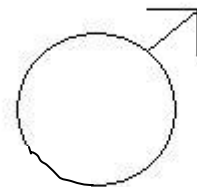Defiance Disorder

Mother
Number 13

Father
ADHD

ADHD
OD & LD

ADHD
OD

Mother
Anne

Father
ADHD

ADHD
OD

ADHD
OD & LD

Appendix 9 – Learner's Permits for Parents

Seven Sessions

First Session - Validation

"Some parents had attended parenting programs, which gave them solutions in the form of strategies, but had not been able to implement these successfully because of biologically based disorders and so felt like failures" (Mehigan et al., 2004). Thus *"the first session seeks to validate the experiences of parents by spending the first session talking simply about the ups and downs of the road... the bumpy road of parenting"* (Mehigan et al., 2004).

Second Session - Information

Up to date information on Mental Illness, ADD and OD/CD is provided in an understandable format. In providing information about these disorders it is emphasized that it is *"nobody's fault"* (Mehigan et al., 2004).

Third Session – Relaxation & Stress Reduction

In the third session a range of affordable relaxation strategies which are fun for the whole family is provided: aroma therapy, laughter, water play, visualizing (Mehigan et al., 2004).

Fourth Session – Rules and Guidelines

"One of the things that parents had fed back to the larger group was the sense of failure when they had tried prescriptive methods of child management. The consensus from all providers and parents was that a smorgasbord of behaviour management techniques should be provided. The program attempts to find strategies that will work for the unique circumstances of the family" (Mehigan et al., 2004). The desired goal is to reduce conflict and distress.

Fifth Session - Support Networks

For parents with a mental illness, *"it is absolutely imperative that they have an emergency plan in place for when they are not well, especially if they have young children. Having this plan reduces the likelihood of crisis, as it identifies the precursors to an episode and triggers a range of responses from their support network"* (Mehigan et al., 2004). The essence of quality human relationships is spoken about rather than the mechanics of control (Mehigan et al., 2004).

Sixth Session – Developing Boundaries

"Parents who are tired often don't know how to say no or put in place healthy boundaries. Help in identifying the most important priorities in a parent's life and reserving energy for emergencies is essential" (Mehigan et al., 2004).

Final Session

In the final session, participants are treated to lunch or morning tea. An emphasis is placed on quality relationships and sharing (Mehigan et al., 2004).

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