

Dianne Rogers

Mothering and Attention Deficit Disorder

The Impact of Professional Power

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INTRODUCTORY CHAPTER

Introduction

This research 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

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 work was taking shape, I became aware of Carpenter's (1999) unpublished research 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; Reinhartz, 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 work 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 this book 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 work 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 research (Ramazanoglu & Holland, 2002; Smith, 1990). The theoretical framework of this work 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 research 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.