Learning from mothers: How myths, policies and practices affect the early detection of subtle developmental problems in children

Thesis submitted by

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STATEMENT OF ACCESS

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DECLARATION

I declare that this thesis is my own work and has not been submitted in any form for another degree or diploma at any university or other institution of tertiary education. Information derived from the published or unpublished work of others has been acknowledged in the text and a list of references is given.

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STATEMENT ON THE CONTRIBUTION OF OTHERS

This thesis has been made possible through the support of many people as follows:

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KEY TO TRANSCRIPTS

In the presentation of the research findings (Chapter 4, 5 and 6), where excerpts from the participants are included, the following abbreviations and font styles have been used:

Long quotes: All the names used within this thesis are pseudonyms (refer to appendix 2 for further information). Pseudonym name, transcript page and sentence number/s identify excerpts from participant interviews.

E.G.   I became a mum to be a mum, so I don't want to have to pay for someone else to raise him (Kimberley, p. 11, 39-41).

[ ] has been used to indicate where words of sentences have been removed from the middle of the quote (usually for the purpose of brevity).

Short quotes: When a few words, or word, have been applied within a sentence in the main text, this is specified through the use of quotation marks.

E.G. 'neurotic mother' (Nerida p. 1, 30),

Additional information

Additional information is sometimes included within quotes to clarify words or to include a mother's action. Brackets and the use of italics identify these.

E.G.   ….you know, having gone through all the problems I had with Michael (*an older child*) just in the first few months…… I had no worries bringing up a second child…so I didn't worry about going (*to the child health clinic*)…the only time I went was to get him his needles, get him weighed, things like that…but there was no…nothing to worry about…not at the time, she (*the child health nurse*) wasn't overly worried about anything…..(Rebecca, p. 16, 26-32).

. . .   Indicates that the participant paused for more than two seconds.

ABSTRACT

Background

Recent research has revealed increasing concerns over the number of children entering school with unidentified developmental problems even though there are seemingly comprehensive health services available for mothers and their children in the pre-school years. Recognising that early detection and early intervention reduces the likelihood of long-term serious health and educational problems, it is important to understand why so many children have not been detected with developmental problems in their pre-school years. Utilising the knowledge and experience of mothers' whose children had not been diagnosed with developmental delay until school age, this study draws attention to reasons how and why children with subtle developmental problems 'slipped through the net'.

Research Question

What can be learned from the mothers' experiences of their child's development that will contribute to improving the early detection of subtle developmental problems in children?

Aims

This study had four specific aims: (1) to document mothers' stories about their experiences of raising a child with developmental problems that remained undiagnosed until school; (2) to ascertain the extent to which mothers' were 'aware' of developmental problems with their child prior to school entry; (3) to determine the environmental characteristics associated with parent's experiences and their interpretation of these experiences and, (4) to ascertain ways in which child health professionals may utilise the experience of parents to improve early recognition and diagnosis of subtle developmental and behavioural problems in children.

Theoretical framework, methodology & method

Recognising that parenting does not occur in a vacuum, but is influenced by the immediate surrounds, the community and the larger socio-economic, cultural, political and historical environments, a social constructionist perspective was utilised as the framework for this research. A synthesis of interpretive biography and literary folkloristics provided a method of collecting, reading and interpreting the life stories of mothers whose children had not been detected with developmental problems until

school age. The life stories were obtained through individual, in-depth interviews of eight mothers who lived in the North Queensland region of Australia, and were read through the lens of three literary theories, arising respectively from the tenets of semiotics, neoMarxism and Foucauldian poststructuralism.

Findings & Conclusions

Findings draw attention to a number of factors that influence the interaction between mothers, health professionals and community members and how these impact on early detection of children's developmental problems:

- competing messages about motherhood affect how mother's decide on the best course of action when concerned about their children;
- societal myths influence how mothers and health professionals view their roles, the child's problem and subsequent action;
- health professionals' knowledge is valued over mothers' knowledge;
- expectations of the role of the health professional, influenced by mythical ideals and ideological notions, differ between mothers and health professionals;
- communication between health professionals and mothers is distorted due to different approaches to language and understanding;
- competing arguments about the value of diagnosis and labelling delay identification and access to assistance programmes for their children;
- a medical diagnosis plays an important role in how support and assistance is determined.

Significance

This research has raised awareness of constraining social, historical and political factors on how mothers and health professionals interact, and the effect this has on the early detection of childhood developmental problems. Bringing these constraints to the attention of health professionals working with mothers and their young children will hopefully encourage active engagement with parents and the acknowledgement that health professionals and parents can work together to improve the early detection of developmental problems in children.

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Chapter 1: Introduction

The context of this research

Fewer than 30% of children with developmental or behavioural problems are detected by their primary health care provider in the years leading up to school attendance (Hart, Brinkman, & Blackmore, 2003; Palfrey, Singer, Walker, & Butler, 1994). This is cause for great concern as recent research warns that children whose developmental delay remains undetected until formal schooling years are at an increased risk of academic failure, behavioural problems and socio-emotional disturbance (Shonkoff & Phillips, 2000).

Once children with developmental problems attend school, they often find the demand of academic tasks, or the formation of social relationships, to be challenging (Glascoe, 2000a; Lerner, 2000; Levine, 1995). The number of children with behavioural and learning problems in schooling has been highlighted in the results of literacy and numeracy assessments conducted on primary (elementary) level students. In Australia, *The National Report on Schooling in Australia* (Ministerial Council on Employment Education Training and Youth Affairs, 2000) reported that, based on numeracy and literacy benchmarking tests in years three and five, 13% of primary school children are at risk of having learning difficulties. While the document does not specifically define 'at risk', it clearly refers to those students who failed to reach, or maintain a level of learning that was benchmarked as appropriate for the age of the child in the Australian context. This figure is reflected in both the United Kingdom (UK) and in the United States of America (USA) where children commence schooling at similar ages. All three countries begin formal schooling (learning to read and write) after a child attains the age of five years, or turns six in the year attendance commences (Elley, 1992; Zill, Loomis, & West, 1997), although variation does exist in individual circumstances. In 1996 in the UK, 15% of Year 2 and 6 students did not attain level 2 numeracy skills, and only 56% attained level 4 literacy skills (Department for Education and Skills, 2000). The report defines level 4 as the expected standard for a child of 11 years of age. In the USA, 13% of children attending public schools are enrolled in special education programs or, if considered 'at risk' of educational failure, are attending public alternative schools (Kleiner, Porch, & Farris, 2003). These figures are of concern when one considers the high standards usually associated with the educational

provision within these countries and they suggest that current efforts to identify children with developmental problems prior to school age are not effective. While it is likely that there are many pieces to this complex puzzle, it is possible that these children have subtle developmental problems (SDPs) that are not immediately noticeable to people other than the children's mothers, and it is from the experience of mothers that this research draws its perspective.

This study has examined the stories that mothers had to tell of raising children with subtle developmental problems through their pre-school years. The mothers of special interest were those whose children had not been diagnosed with learning and/or behavioural problems until participation in primary school. This group of mothers was chosen for a number of reasons. Firstly, it is often assumed that developmental problems will be detected and addressed in the early years of a child's life. Secondly, children with developmental problems may have learning problems and social difficulties for the remainder of their lives and it is very much in their interest to be involved in early intervention programmes that help diminish the likelihood of long-term problems. Thirdly, parents are often made to feel responsible for the inability of their child to live up to expectations of the academic and social world.

Western societal expectations of children and parents are considerable, particularly in regard to learning and behaviour. For example, in order to be successful as an adult, it has been argued that children should be given every opportunity to succeed in their scholarly pursuits (Campbell, Pungello, Miller-Johnson, Burchinal, & Ramey, 2001; Campbell, Ramey, Pungello, Sparling, & Miller-Johnson, 2002; Evans, 2001; Kleiner et al., 2003; McCain & Mustard, 1999; Ramey & Campbell, 1984) and that parents can help by providing a stimulating environment (Hauser-Cram et al., 2001; Soriano, Weston, & Kolar, 2001; Wagner & Clayton, 1999). Further pressure comes with the 'technological age', which demands that children be literate and efficient, and effective users of all forms of communication. These are considered essential bases of learning and socialisation skills. For many children learning is straightforward but for some children academic and social demands are bewildering. They do not find it "easy" to learn to read and write, they fall behind their peers in the learning environment, struggle to manage behaviour in the confined space of a classroom, and find school stressful and unrewarding. The long-term consequences

can be equally devastating as these children continue to fail and earn little reward for their efforts.

Educational and health professionals have, in recent years, had their attention drawn to the large number of children who fail socially and/or academically when they tackle the challenges associated with schooling. Early childhood development has been the focus of much research in this area in the past thirty years, with the link between early developmental delay and later school learning difficulties established (Shonkoff & Phillips, 2000). Health professionals working in child health are perfectly positioned to assist in the detection of children who show signs of early developmental problems.

Health professionals working in the area of child health in Australia have the opportunity to assess children's development on a regular basis, yet, despite a plethora of surveillance and screening tools available for use in the pre-school years, many subtle developmental problems remain undetected. Children with undetected developmental problems remain unsupported by intervention programmes until the problems cause them to fail at school or they become socially isolated. It is crucial that we attempt to understand why this is happening, because children with academic and social problems are vulnerable to long-term social and emotional problems, especially in a technologically oriented society that prioritises academic achievement and social engagement. Utilising the knowledge and experience of parents' whose children were not diagnosed with developmental delay until school age, this study attempted to document the reasons how and why their children's developmental difficulties remained unidentified by health professionals.

Background

The issue of early childhood developmental delay is an emotive one. I know, because I have personally experienced a child with a developmental delay that has negatively impacted on his ability to read and his schooling years were challenging and difficult, for both my son and myself. Additional support, in and out of school, was required for both his academic and social skills. Psychological challenges were also ongoing, as the emotional roller-coaster reflected his frustrations in the school environment. While I had been aware of his low muscle tone and delay in speech development, they were never identified as areas of concern when I visited health professionals in his pre-school years. A professional did not identify that my child

had a problem until he attended school. His grade one teacher called me to the classroom within two weeks of school starting, to let me know that she had noticed a collection of learning and task-orientated problems. She set a number of learning exercises for my child to complete at home, in the hopes of catching him up to his cohort during the year. This was the beginning of a long period of both physical and cognitive intervention activities for him. Although he successfully completed high school, the twelve years of education were especially stressful ones. I often wondered if his academic path could have been any easier if his developmental problems had been professionally identified during his pre-school years.

It is difficult to know if my experience is unique and little documentary evidence exists, but anecdotal evidence suggests that it is not uncommon. Parents have not had the opportunity to tell their story, and this thesis has attempted in a small way to redress this situation. The aim of this study was not to lay blame. In fact, if I blamed anyone for missing my son's developmental problems, I blamed myself – a paediatric nurse! I have nothing but thanks to offer to the myriad of educational and health professionals who assisted my son throughout the years. I simply wanted to begin a process that set out to help other parents avoid what can be avoided, to help health professionals see what needs to be seen, and help children achieve when they need to achieve.

I recognise that my background, as a parent of a child with developmental problems, has coloured the way in which I heard and interpreted the experience of the parents who were my participants in this study. This had a three-fold affect. Firstly, it affected how I listened to and interacted with my participants; secondly, it affected how they interacted with me; and, finally, it affected how I interpreted their stories. Recognising that some participants may have felt a degree of wariness about how I interpreted their story, I felt that my experience enabled me to approach the subject with considerable understanding and knowledge. Others may complain that my prior experience influenced my interpretation and outcomes, but I was persuaded by Denzin's (1989) claim that when an individual writes a biography, he or she writes himself into the life of the subject, and this enables the researcher to 'illuminate the phenomenon in a thickly conceptualised manner' that not only takes into consideration the learned phenomenon but also incorporates prior understandings of both the researcher and the participant (Creswell, 1998, p. 206). Cole and Knowles (2001) place great emphasis on the importance of a researcher making

explicit their own understandings: 'the more we understand ourselves as researchers, the better able we are to listen to and understand others' (p. 52). I could not ignore my personal history, and I recognised that my experience would shape how I listened to and interpreted these life stories. However, I believe that my knowledge enabled me to better understand the experience of the participants in this study.

For many of the participants, I anticipated that the empathy and understanding promoted by my personal experience would engender a feeling of confidence that would allow them to tell their story without fear of criticism or doubt. Many participants often felt relief in the opportunity to be heard (Denzin, 1989), particularly mothers who had not previously had an opportunity to talk about their experiences on such a difficult, emotional, subject matter.

Justification

Focus on the well-being of young Australian children and their families has intensified in the past decade, particularly in regard to the early developmental years. *The National Health Policy for Children and Young People* (Commonwealth Department of Human Services, 1995), identified that early years play a critical role in establishing the foundations, skills and attitudes needed for optimum health and well-being throughout life. *The National Health Plan for Young Australians* (Australian Department of Health and Aging, 1997) identified several key areas, including the recognition of the role of parents/carers as a vital source of health care and health education, along with support for young Australians with developmental delays and learning difficulties. In May 2002, the Australian Government established the *Government Taskforce for Early Childhood Development and Wellbeing* and committed Commonwealth funding to the *Australian Research Alliance on Children and Youth.* Their purpose was to assist in the development of a national research program whose role was to facilitate the generation and translation of knowledge that enhanced the well-being and life chances of children and young people (Sanson, 2002).

On December 5th, 2002 the Commonwealth Government announced its national research priorities (Department of Health Science & Technology, 2002) [DHST]. One of three priority research goals was to enhance the health outcomes of children by 'reducing the impact of genetic, social and environmental factors predisposing

infants and children to ill health and reducing life potential' (DHST, 2002, p. 2). This priority goal of '*a healthy start to life*' was based on research showing that 'health and well-being in early childhood is predictive of later positive outcomes and that health in middle and late childhood is also crucial' (DHST, 2002, p. 5), and was consistent with the Government's *National Agenda for Early Childhood Initiative*, announced in September 2002 (Anthony, 2002). This agenda and protocol are currently being established with the development of *The Australian Research Alliance for Youth and Children* (2005), a national collaboration of researchers, policy makers and practitioners. Furthermore, Australian Government policy has emphasised the importance of early child health screening and surveillance programmes, identifying that they play a major role in optimising the health of children (Commonwealth Department of Human Services, 1995).

This study took place in the Australian state of Queensland where in 2002, the Queensland Government put into effect a number of '*Smart State'* policies based on the importance of supporting the healthy development of children and role of parents. The *Putting Families First* policy statement identified three key outcomes: giving children the best start; valuing and supporting the nurturing role of families and creating safe supportive communities (Queensland Government, 2002a). A total of one billion dollars over three years, representing 0.02% of total budget distribution, was allocated to support this program, including funding to expand child health centre services, develop new childcare and family support hubs, upgrade school age care facilities and develop a training strategy for existing child care workers. Other key initiatives focused on supporting families whose children had disabilities, adoptive families and children who required protective services (Queensland Government, 2002a). While the policy and funding are much needed, the initiative needs to be considerably 'ramped up' if the government is truly committed to building a 'Smart State'. When the number of children who are considered 'at risk' for educational and social problems is potentially 26% of the children commencing school (Hart et al., 2003), governments need to make substantial financial commitments to improving the opportunities for children. This includes providing funding for programmes that support families of pre-school aged children who have subtle developmental variations that may result in negative long-term consequences.

In a further focus on children and families, the Queensland Government budget in 2002-2003 allocated a further $188 million over four years, a further .003% of budget distribution, to the *Future Direction*s program aimed at instituting a range of initiatives that delivered 'better outcomes for children, young people and families' (Queensland Government, 2002b). Based on the guiding principle that prevention is the key to future direction, a part of these funds was directed towards the *First Years Prevention* projects, which aimed to identify children early in their school life who were at risk of poor educational and social outcomes and gave them the opportunity of participating in early intervention programmes (Queensland Government, 2002b). According to the Queensland Government (Education Queensland, 2005c; 2004), these programmes are proving beneficial, although programmes that provide early intervention opportunities prior to school may be more beneficial as the children would not have to wait until they 'fail' before receiving assistance.

While the increasing government and community focus on the health of young children is timely, the participation of parents in these programmes is notably absent, particularly parents of pre-school children whose developmental problems are subtle, often not identified as 'in need' of support and without recourse to government funded services.

Significance

This study focused on the experiences of mothers whose children were not diagnosed with developmental problems until they started school. In particular, it focused on the relationships between mothers and their family, friends, community members, teachers and health professionals in the years leading up to school attendance. While it was anticipated that health professionals such as child health nurses would have regular contact with many parents and their young children, particularly in the first three years of life, many of the mothers in this study only visited child health nurses occasionally. Mothers took their children to Maternal and Child Health Centres for 'well' child check-ups and immunisations, usually in the first few months of their infant's life. They were far more likely to visit their local medical doctor if they were concerned about their child's health or development. While this gave health professionals an opportunity to hear a parent's concerns and to assess the children's developmental progress this did not always occur. These children 'slipped through the net' (Williams & Holmes, 2004/2005, p. 57) and their developmental problems remained undetected by professionals until later school

problems arose. Helping health professionals to identify these children before they attend school would be of benefit to the child and his/her parents, the schoolteachers and the health care providers, particularly as the latest research identifies that early detection and intervention could diminish later problems and associated long-term consequences (Shonkoff & Phillips, 2000).

Early detection of developmental problems enables the instigation of early intervention, and early therapy reduces the likelihood of long-term serious health and developmental problems that may impact on social and educational achievement (Shonkoff & Phillips, 2000). Implementing surveillance programmes that increase the likelihood of detection of developmental problems in the pre-school years are, therefore, extremely important. Even more importantly, parents need to be included because recent research has shown that combining these programmes with parental consultation will increase the success rate of early detection of developmental delay and behavioural difficulties (Bethell, Peck, & Schor, 2001; Boschert, 2001; Glascoe, 1995; Glascoe, 1999a, 1999b, 2000a; Glascoe & Dworkin, 1995; Oberklaid, 2000). Utilising the knowledge of parents enables a more accurate detection of early signs of developmental delay and allows for the early commencement of intervention programmes.

Aims

The research generally aimed to answer the question: What can be learned from the mothers' experiences of their children's development that will contribute to improving the early detection of subtle developmental problems in children? It had four specific aims: (1) to document mothers stories about their experiences of raising a child with developmental problems that remained undiagnosed until school; (2) to ascertain the extent to which mothers were 'aware' of developmental problems with their child prior to school entry and, if so, when and how they noticed them; (3) to determine the environmental characteristics associated with mothers' experiences and their interpretation of these experiences; and (4) to ascertain ways in which child health professionals may utilise the experience of parents to improve early recognition and diagnosis of subtle developmental and behavioural problems in children.

While this study was exploratory in nature it represents the first step towards a larger agenda, which aims to provide knowledge to frontline health professionals who can assist in the early identification of developmental delay. Early identification

of difficulties may lead to assistance for parents and the implementation of early intervention programmes for children.

Summary of this thesis

Following this chapter, a review of literature provides an overview of the historical and contemporary contextual frameworks in which the mother's stories were experienced. A brief history of childhood and motherhood draws attention to how changing societal environments reconstruct the notions of children and mothers across the ages, leading to a construction that, today, idolises the child, while placing the responsibility for their well-being firmly in the hands of the mother. Attention has been drawn to how childhood is seen today, noting that views of childhood have been strongly influenced by the tenets of scientific study, including psychiatric and medical studies that point to the biological nature of child development, and behavioural, psychological and sociological studies that include consideration of environmental influence on child development.

How parenting, especially mothering, is viewed within Western society today is explored, particularly in relation to the role that cultural, social and political environments play. Understanding how parents go about parenting, and how they know how to parent, is also investigated. A brief overview of child health services in Australia notes how services have changed over the past 100 years and draws attention to the increasing importance of developmental screening and assessment, and the relationship between childhood development and later social and academic success. The role of both mothers and health professionals in identifying children who have developmental or behavioural difficulties in the years leading up to formal school attendance is also investigated

In chapter three, the theoretical framework, methodology and method adopted for this study is introduced and discussed. As this study focused on a poorly understood phenomena a qualitative research approach was utilised (Morse & Mitcham, 2003). Because parenting does not occur in isolation from the community and the larger socio-economic, cultural, political and historical environments, a social constructionist perspective was implemented as the framework through which the parent's experiences were viewed. Social constructionism is fundamentally concerned with explaining the processes by which people use language to describe, explain or account for the world in which they live (Gergen, 1985). This framework

enabled acknowledgment that familial, social, cultural, political and historical environments influenced how mothers talked about and perceived their experiences. Within this framework, a metasynthesis of two qualitative interpretive methodologies, interpretive biography (Denzin, 1989) and literary folkloristics (Stahl, 1985, 1989) were used to inform and guide the research.

Life history is a methodology that provides an interpretive framework for understanding the actions and experiences of people through the examination of narratives, stories or personal accounts (Martin, 2002). In this study, the focus was on the experience of eight mothers whose children had not been identified with developmental or behavioural problems until school age. Focusing on the stories of just a few mothers enabled a broad, but in-depth, understanding of their experiences to be developed. These experiences were then considered in light of historical events and social change at a societal level.

While there exists a number of different forms of life history, Denzin's (1989) interpretive biography, which entails the collection of personal life stories, enabled conceptualisation and characterisation of the life of mothers whose experiences did not conform to existing societal perspectives. Denzin (1989) lays out a set of research procedures for making sense of individual lives. His method of interpretive biography entails the collection and analysis of personal life documents, stories, or accounts that illustrate 'epiphanies' in an individual's life. Such moments play an important role in linking the personal experiences of the mothers with events in the wider social, political and economic environment.

Interpretive biography relies on verbal and written expressions of meaning through which, Denzin (1989) says, we have a window into the inner life of their author. Language is a tool or device for creating texts and, while there are times when, due to mutual understanding of social conventions, the meaning of the text is clear, there are also times when meaning can be ambiguous, particularly in regard to personal intention (Hardin & Allen, 2001). As a biographical researcher I needed to make sense of the mothers' lives, on the understanding that their narratives were ideological statements that reflected certain positions, or stances. Stahl (1989) turns to a variety of literary theoretic strategies in the interpretive stage of her literary folkloristic methodology, and this enabled me to situate and deconstruct the story being told, from a variety of perspectives.

While Denzin's (1989) interpretive strategies provided for macro-cultural analysis of life stories, Stahl's (1985; 1989) literary folkloristics methodology, provided an interpretive framework that utilised literary theory to examine the micro-culture. This enabled the relationship of the personal stories of the mothers and their cultural traditions to be linked to their particular social or cultural environments. Closely aligned with Lincoln and Guba's (1985) five axioms of naturalistic enquiry, Stahl emphasises the existence of multiple, constructed realities and the interactive, inseparable bond between teller and listener. Stahl also acknowledges that contexts and time change perceptions and experiences and that because change is always occurring, all inquiry is value-bound (Stahl, 1989). Most importantly, however, Stahl introduces a sixth element- the existence of a construct of 'tradition'. This tradition influences how a person tells their story, and how a listener interprets a story. In this methodology, Stahl argues that it is the researcher's responsibility to find the hidden clues in the story, and to determine why the mothers told the story they told. This could best be achieved by utilising a number of literary theories to critically deconstruct the text, and to identify themes, attitudes and allusions that reflected existing societal expectations which influenced how the mothers experienced life and told their stories.

In this study, three literary approaches were used to read the mothers' stories, including Roland Barthes' semiological interpretation of mythology; NeoMarxist criticism, particularly Habermas' theory of communicative action, and Foucault's post-structural discourse analysis. A comprehensive overview of the literary theories, linking them to the topic under discussion, is presented in chapter three.

An introduction into the analysis and discussion chapters, four, five and six, gives a précis of the mothers' stories and outlines the three chapters to follow. The chapters take their titles and structure from the three major themes that arose from readings of the mothers' stories: (1) *Recognising the "problem"*; (2) *Getting help: The dialogue between mothers and health professionals*; and (3) *Diagnosis.* Bronfenbrenner's ecological model of development (Bronfenbrenner, 1979) that acknowledges both the immediate and outlying environmental influences on the developing child and how a parent tackles the task of parenting was useful in the identification of these three major themes. The analysis and the discussion are undertaken simultaneously throughout these three chapters, with each chapter containing three separate readings based on the three literary theories. Barthes

post-structuralist/semiotic accounts of mythologies, neo-Marxism, in particular Habermas' theory of communicative action, and Foucauldian poststructuralism were used to 'read' and analyse the mothers' stories within each theme. A summary of the readings is presented at the end of each chapter.

Chapter four, entitled *Recognising the "problem",* focuses on the question if, when and how mothers recognised a problem with their children's development in the years leading up to school attendance. Attention was given to how mother's expressed their concerns, with whom these concerns were discussed and the support that mothers did, or did not, receive when their children's development was considered problematic. Whether other members of the community, teachers or health professionals noticed a child's developmental problems, and if so, what they did about it was also investigated. The concept that mythical ideals and ideologically supported notions of childhood and motherhood influenced how children's development was viewed was considered. In particular, the authority that these ideals and notions carried were analysed in relation to what mothers did when concerned about their children's development, how these concerns were interpreted and how access to resources was regulated.

The mothers' stories also provided an opportunity to understand the hidden practices and rules that impacted on the experience of mothers whose children had developmental or behavioural difficulties that remained undetected by all but the mothers, until school age. Reading the mothers' stories through a Foucauldian post-structural lens enabled themes to be identified and discussed in relation to the discourse of childhood development and motherhood. Normalising strategies of society were considered in regard to their affect on the behaviour and responses of mothers, their families, community members, teachers and health professionals. In particular, attention is drawn to the concept of 'difference' and how this led to isolation of both the children and their mothers from the general social group.

Chapter five, *Getting help: The dialogue between mothers and health professionals,* focuses on the relationship between mothers and the health professionals from whom they seek help. While my original intention was to focus on the relationship between mothers and child health nurses, as I began transcribing the mothers' stories, it became apparent that the majority of their interactions with health professionals were with the local general medical practitioners (GPs) and

specialists. Child health nurses were only visited on a few occasions, because when mothers were worried about their children, they preferred to seek the advice of doctors. An exploration of how the mythically driven belief of the 'healer' underscores this faith in doctors, and how this belief drove mothers to constantly revisit doctors even when they did not agree with the doctor's opinion, was undertaken. An analysis and discussion of how this belief affected the value placed on a mother's knowledge about her child, in comparison to value placed on the knowledge possessed by the health professional concludes the first section of chapter five.

Communication is viewed as an important part of the mother-health professional interaction and the mothers' experiences, and their interpretations of these experiences, were read and analysed through the lens of Habermas' theory of communicative action. In particular, an exploration was undertaken of how different communication approaches affected the mothers' perception of their interactions with health professionals and their satisfaction with the outcomes of these exchanges. Understanding why mothers and health professionals communicate the way they do, and the historical statements and practices that are associated with such behaviours is also considered. A comparison between the technically orientated communication of health professionals and the 'experience of life' basis to the mothers' communication style draws attention to the impact that such differences may have had on the outcome of medical consultations. Communication may also have been affected by the value placed on one form of knowledge over another. In this instance, the effect of valuing scientifically validated knowledge privileged by the medical profession over the subjective, intuitive knowledge on which mothers' base their concerns about their children was investigated.

Chapter six, *Diagnosis*, focuses on the role diagnosis played in the acknowledgement that children had a 'problem', and why this was so. The semiotic analysis draws attention to the multiple, socially constructed meanings attached to the act of diagnosis. Diagnosis is variously associated with the legitimation of a child's 'illness', validation of mothers' concerns and the subsequent exoneration of blame, the hope of a miracle cure, and access to support services. A discussion on both the negative implications of diagnosis and the associated labels, and the positive outcomes of diagnosis has been investigated in relation to children who were diagnosed with behavioural or learning problems. Diagnosis has also been

investigated in relation to how it is utilised to demonstrate expertise, legitimating the medical profession's claim to authority. The role that diagnosis plays in the development of educational policy directives is discussed in relation to eligibility for access to educational support services and intervention programmes. Finally, diagnosis is considered with regard to its function in social control, surveillance and self-surveillance. How and why mothers adopted the dominant medical discourses emphasis on diagnosis is discussed in relation to acknowledgement of their concerns, gaining support for their children, and their ability to employ diagnosis as a way of gaining some form of control for both themselves and their children.

The final chapter, *Findings and Recommendations*, draws together the analysis and discussion of chapters four, five and six, enabling the assembly of a multifaceted picture of the socially constructed ways in which people interact with other people, respond to those interrelationships, and make decisions. Reading the mother's stories within the theoretical framework of social constructionism, utilising the life history methodology, particularly interpretive biography and literary folkloristics, and through the lenses of the three literary theories allowed for the development of an extensive contextual interpretation of the mothers' experiences. In this way a number of explanations have been given why some children are not identified with developmental problems until school age. Finally, a number of recommendations are made that focus on improving the detection of children with subtle developmental problems so that they are able to access early intervention and support programmes that improve their chances of social, emotional and academic success.

Chapter 2: Literature review

This literature review has been undertaken using a multitude of sources including: the James Cook University Library and other Australian and overseas libraries via the interlibrary loan scheme, the Townsville Hospital library and government reports. The World Wide Web was searched primarily utilising the Google and Google Scholar search engines when direct addresses were unknown. Materials were also accessed through databases including Medline, Ingenta, CINAHL, PsycINFO, ERIC, Web of Science, Current Contents, the Cochrane database, Joanna Briggs Institute and ProQuest 5000. When searching for materials, key search words included: family, families, mother, maternal, child development, infant development, child health nursing, early intervention, child development assessment tools, role of parents, parent expectation, parent beliefs, listening to mothers and mothering.

The aim of this study was not to explore the neurological and physiological nuances of a child with developmental problems, rather the focus was on the experience of mothers whose children's developmental problems had not been identified until school age. Accordingly, the literature review does not include explanations of the causes and manifestations of specific developmental problems, although certain types of problems will be briefly identified, rather the review focuses on issues surrounding parenting. The review begins with an historical synopsis of childhood and major parenting practices and in particular, the views of mothers and mothering. Because this study took place in the North Queensland region of Australia, an overview of the structure, culture and expectations of Australian families is included, and links drawn to the way children are raised and the way society views the role of mothers is conceived. This leads into a discussion on the historic role that child health services has played in child health care, and particularly the role of identifying children with developmental delay. An historical overview of developmental screening and assessment sets the scene for a discussion of the significance of identifying children with physical and cognitive problems and the link between learning, behaviour and development. Finally, a discussion on the involvement of parents in the process of assessment and identification, and the relationship of parents with health professionals, brings attention to the gaps in knowledge when trying to piece together the puzzle of why children with subtle developmental problems are not identified until school age.

A brief history of childhood and parenting

A study involving parents and children could not begin without a brief look at the history of childhood and parenting practices. The study of the history of children and childhood has been a recent phenomenon across most disciplines, including anthropology and archaeology where studies focusing on children have, until very recently been almost non-existent (Baxter, 2005). It was not until the early 1960s that an attempt to describe the life and role of children in society was made, with much of the credit for moving the study of childhood into the realm of scholarship going to a publication by Philippe Ariès (1962) and his book (translated from French) *Centuries of Childhood*. Although Aries work has been criticised for his 'explanatory weakness and chronological vagueness' (Wilson, 1980, p. 152), it none-the-less provided an historical analysis of childhood and family that had not existed previously. Ariès paints a gloomy picture of childhood from the middle ages until the eighteenth century. Analysing the depiction of children in paintings, Ariès concluded that the concept of childhood was non-existent in medieval civilization (p. 125). Children were portrayed in paintings as small replicas of adults and Ariès proposed that from the age of seven they were also treated as such. Children were described variously as 'young vipers and (to God) infinitely more hateful than vipers' (Gesell & Ilg, 1943, p. 287) and, in the early nineteenth century, as precious and worthy, although childhood was still seen as a preparation for adulthood (Heywood, 2001). Until the turn of the nineteenth century, the main issue for parents was not how to raise their children, but whether they would raise them. Unlike today, parents had little time to consider the psychological aspects of child rearing, being more concerned with survival and the perils of illness (Connell, Edgar, & Hopkins, 1989).

More recently, in Western middle class cultures, childhood is seen as a time when children need to be raised in a nurturing and loving environment, while being protected from the vagaries of adulthood. Cunningham (1995) considers that the most influential change that transformed the experience and meanings attached to childhood in Western societies was the introduction of compulsory schooling in the late nineteenth century. 'It was this which eventually brought about an emotional valuation of children much greater than anything accorded them in previous centuries' (See, 1985 cited in Cunningham, 1995, p. 17). Schooling released children from the workforce and thereby separated them from the adult society and the associated work. In Australia, legislation introduced in New South Wales and Victoria in 1896 tightened control over the employment and exploitation of children

in the industrial workforce and provided protection for children from having to provide income for the family (Sanson & Wise, 2001). However, an interesting snippet from the *British Medical Journal* in 1903 (ii, p. 1164) suggests that many children were not released from the bonds of the workforce merely because they attended school. A report prepared for the Manchester Education Committee identified that 'over 3,000 school children were at work, and their hours of labour ranged from a minimum of one hour a week to a maximum of 68¼' (Smith, 2003, p. 535). In fact, in 1899 in Great Britain, approximately 300,000 children combined paid work with school attendance, probably 50,000 worked 20 hours per week and a considerable proportion of this number worked 30, 40 and 50 hours per week *(Report of the Inter-Departmental Committee on the Employment of School Children appointed by H.M Principal Secretary of State for the Home Department, 1902)*. A comparison with the number of school children who work today would indeed be interesting, particularly as large corporate bodies are employing young people on rates of pay considerably lower than their adult counterparts. While laws do exist to limit working hours and places of employment, British children aged 14 to 15 years can legally work up to 17 hours per week while 16 year olds can work up to 20 hours per week outside school times (Shaw, 2005). Wages for children, however, remain unregulated, with no minimum wage for children specified in law (Shaw, 2005). In Australia child employment laws vary from state to state although, generally, children cannot be employed for more that six hours a day and these hours must not interfere with schooling. Mourell and Allan (2005) suggest that child labour is a growing concern in Australia with increasing numbers of children working in causal and part-time positions. In Queensland in 2004, almost half of all school children were engaged in paid employment (Commission for Children and Young People and Child Guardian, 2004). It is arguable that, for some children today, school has not freed them from exploitation.

Significant improvements in health due to social reform and the end of the belief in 'infant depravity' also had a strong influence on society's attitude towards children (Heywood, 2001, p. 171) and provided children with an increasing opportunity to participate in a long and enjoyable childhood period. The control of physical diseases and the increasing ability to control reproduction, which occurred in the early decades of the twentieth century, also altered concepts of parenting. Not only did children survive but they became members of smaller families in which parents had correspondingly increased emotional investment (Connell et al., 1989). It could

be construed that this change in how parents viewed their children was a direct reflection of the societal needs at the time. When society no longer needed children as part of the workforce, children were projected as vulnerable and in need of care. As adult wages increased, parents were encouraged to provide their children with the opportunities to play, learn and grow-up without the pressure of needing to earn an income. Changes in political thinking also had an effect on how children were viewed. The rise of socialism, which embodied equalitarianism and the concept of universal human rights, bought enlightenment ideals into the forefront of the political agenda, especially after World War I. During this period there was also an increasing research focus on child development.

Much of the research in the early twentieth century was focused on the physical development of the child; for example, Binet and Simon (1916 cited in Binet & Simon, 1973) and Gesell (1925) documented, for the first time, the sequential emergence of discreet child development skills. The early, widely influential writings on parenting by the American behaviourist John Watson (1924), in the early twentieth century, exhorted parents to avoid contact with their infants except for meeting their basic physical needs. Watson advocated leaving babies alone as much as possible so they could grow healthy without adverse influences of maternal smothering (Gelfand, 2001, p.590).

It has been suggested that these early child development theorists were mostly interested to prove their argument that either nature or nurture played the most influential role in the development of children (Hauser-Cram et al., 2001), rather than an altruistic notion about the importance of understanding child development. This nature-nurture debate has strongly influenced child development studies for the past century. Those in the nature camp, such as Gesell (1925), focused on the primacy of biological determination (Meisels & Shonkoff, 2000, p.10) or genetic links to developmental disorders (See, for example Stevenson, 1999). In the nurture camp, a wide range of environmental influences are considered to impact on how a person develops, including: relationships with family and community, environmental teratogens, including cigarette smoke, chemicals, radiation, alcohol and lead poisoning, as well as dietary deficiencies, poor sanitation, germs and physical injuries (Neugebauer, Hock, & Susser, 1999). As a result of these opposing views, approaches to early childhood studies varied considerably. Researchers belonging to the biological determination camp focused on adverse perinatal events and the

impact on later neurodevelopmental disorders while those in the behavioural camp favoured examining conditioning and environmental manipulation (Meisels & Shonkoff, 2000). However, the nature-nurture argument was, and is, not at all clear-cut. For example, John Watson's claim that children are influenced by environmental 'handling' is based on the premise that children have inherited certain characteristics, that 'come to the fore' when left to develop 'unsmothered' by mothers. This is really a proposition that supports both the nature and the nurture argument.

There is little doubt that multiple factors influence child development and the polarisation of views does little more than create conflict amongst research groups. More recently it has been acknowledged that both genetic characteristics and the environment play a complementary role in the growth and development of children, as Eisenberg (1999) says, a combination of both:

> Nature and nurture stand in reciprocity, not opposition. All children inherit - along with their parents' genes - their parents, their peers, and the communities they live in. Development unfolds in an ecologic and a social setting which, just like genes, is decisive in shaping the organism (p. 1031).

In fact, Meisels and Shonkoff (2000) comment that 'research findings have even led some scholars to adopt the paradoxical position that all behaviour is completely inherited as well as completely determined by experience' (p. 11). A combination of both influences makes sense. No person is isolated from either the influences of genes or the impact of environmental experience.

During the mid twentieth century a prodigious amount of child focused research was undertaken. Studies in physical (Brazelton, 1973; Frankenburg, Dodds, & Fandal, 1975; Gesell & Amatruda, 1947), mental (Binet & Simon, 1973; Griffiths, 1954) and personality growth (Erikson, 1968; Freud, 1977; Thomas & Chess, 1977) and studies of language (Chomsky, 1957; Ferguson & Slobin, 1973; Skinner, 1957), motivation (Freud, 1946), emotions (Ainsworth, Blehar, Waters, & Wall, 1978; Bowlby, 1951; Erikson, 1950), perceptions (de Lorenzo, 1973; Piaget, 1954; Rheingold, 1985; Uzgiris & Hunt, 1975), learning (Bandura, 1986; Blurton Jones, 1972; Piaget, 1951, 1952; Skinner, 1938; Vygotsky, 1962) and moral development (Gilligan, 1987; Kohlberg, 1973; Piaget, 1932) were conducted.

One of the most important child development researchers was Sigmund Freud. Freud's work had a profound impact on theories of childhood and child development in the period 1920-1950. He suggested that the child's relationship with his/her

parents were the key to achieving adulthood. Freud's studies (Strachey, 1955) placed the focus on sexuality, love, pleasure and pain, arguing that the process of emotional development began when the child was an infant. It painted a picture of torrid, emotional-driven and fragile, yet powerful, forces that played a fundamental role in the child's ultimate adult emotional state. For Freud, a child needed to develop a deep attachment to his/her parents for survival reasons. He saw children as both biologically and physically dependent on the parents, and, as a result, how parents interacted with the child influenced long-term emotional states (Poster, 1978). Most importantly, Freud's theories made people look beyond the obvious, into the secret world of the unconscious, providing very sophisticated 'explanations' for what was previously inexplicable or taken for granted and child development was at its core. Freud's psychoanalytic theory formed the basis for European and American psychology until the 1950's, and it still shapes popular and professional understandings and discourses about children. One such commentator, Mark Poster (1978), argued that while Freud's interpretation of how families influence the emotional development of children was immensely significant, he suggested that Freud focused very much on the individual, giving little regard to the influence of the social environment upon children and their families.

Over the past forty years, much of the research into child well-being has focused on the role that environment plays on the functioning of the family and the development of the child. Bronfenbrenner (1979; 1972; Bronfenbrenner & Morris, 1998) and more recently Bowes and Hayes (1999) and Lerner (2002) believe that how parents approach child-rearing is fundamentally influenced by their interactions with the social environment. These named authors are representative of a whole mass of researchers, particularly anthropologists and social psychologists, who have shown how parenting practices are directly influenced by the cultural and social milieu, and the practices, discourses and other influences which surround them (for example, Belsky, 1984; Bradley, 1995; Brookes-Gunn, Han, & Waldfogel, 2002; Fox, 1995; Goodnow, 1995; Harkness & Super, 1995; Hoff-Ginsberg & Tardif, 1995; Luster & Okagaki, 1993a, 1993b; McLoyd, 1990; Meyers, 1999; Okagaki & Divecha, 1993; Taylor, Spencer, Baldwin, & Sturge, 2000; Vondra & Belsky, 1993).

The proposal that the environment influences how parents parent is supported by the social constructionist view that perceived changes in childhood and parenting has not occurred because children, adults and their relationships have undergone

significant change themselves, rather, the changes are based on historically significant factors which have influenced the way people behave and view their behaviour (Gergen & Davis, 1985, p. 5). James and Prout (1990) expand on this argument, suggesting that childhood itself is solely a social construction: 'Childhood, as distinct from biological immaturity, is neither a natural nor universal feature of human groups, but appears as a specific structural and cultural component of many societies' (p. 8). However, caution is warranted with this statement, as James and Prout (1990) appear to be counterposing a social construction (childhood) with a fixed, indisputable, matter of scientific fact (biological immaturity). A genuine social constructionist position would argue that this is a false dichotomy, because the 'fixity', 'objectivity' and scientific certainty of biological immaturity are also socially constructed. Therefore, childhood is 'just as real' regardless of whether it is viewed through the construction of a biological status or a cultural one.

Ochiltree (1990) proposed that the ever increasing research in child development led to greater recognition of the needs and rights of children and contributed to the legal changes concerned with their physical welfare and the 'right of all children to the opportunity for optimal development not only in the physical realm but in the intellectual, emotional and social ones as well' (Sears, 1985 cited in Pollock, 1988, p. 23). This has been reinforced on an international level by the United Nations Declaration of the Rights of the Child, ratified in 1959, that states that the child 'has a right to a happy childhood and enjoy for his (her) own good and for the good of the society the rights and freedoms as outlined….' (United Nations resolution 1386 (X1V), 20 November, 1959 cited in Commonwealth of Australia, 1980). However, it is arguable whether the rights of children have been improved as a result of World Health Organisation rhetoric. Daily reports on the devastating circumstances of children around the world, in both developed and developing countries, are a stark reminder of the realities of the modern world. Children are probably more vulnerable than ever before, open to exploitation and abuse, even in Western countries where child abuse is considered to be the great 21st Century epidemic (Gilbert, 1997).

Juxtaposed with rising commentary and concerns over child health is the drive for scientific guidance to enhance the well-being and competence of children. As a result of scientific research, increasingly clear-cut developmental stages, and expectations for individual achievement within these stages, have been delineated (Modell & Siegler, 1993, p. 73). When these expectations are represented as

'scientific facts' both children and their parents are placed under increasing pressure to perform at these specified levels of accomplishment (Hauser-Cram et al., 2001). Parents are motivated to search for intervention strategies to improve the potential of a child with disabilities, but they are also seek the key to the competitive advantage of their healthy children (Hauser-Cram et al., 2001). Children who are high achievers in both (or either) physical and academic domains are seen by parents and society to be the most successful.

Norbert Elias (1982), a social theorist and commentator, describes this drive by parents to seek high achievement for their children as part of 'the civilizing process' in which people constantly strive for self-improvement. Elias proposed that parents in Western societies are continuously concerned about whether their child will attain the 'standard of conduct of their own, or even higher class, whether it will maintain or increase the prestige of the family and whether it will hold its own in competition within their own class' (p. 238). This drive is the product of tensions and pressures placed on parents by the society in which they live. Elias (1991) argues that even though family relationships may be variable in individual detail, their 'basic structure is determined by the structure of the society into which the child is born and which existed before him' (pp. 22-23).

Childhood itself can be seen as part of this civilizing process. Infants and children are expected to behave in certain ways, to develop according to a specified timetable and to learn to read and write at a particular time in life. Parents whose children do not conform to these pre-set societal and cultural standards may feel that their child is not performing optimally. These parents feel the pressure to 'do something' and so search for strategies that will help their child improve to a 'standard set by society'. Many questions arise as a result of this perceived societal standard. One needs to ask whether societies tolerance levels are changing, particularly in regard to developmental expectation of infants and children. Society today demands of mothers that their babies are slim, not chubby, sleep and do not cry, behave themselves in all social settings and follow a pre-established developmental pathway. It's not surprising that young mothers worry when their baby does not confirm to societal expectations of the 'normal' baby. Utilising Norbert Elias's theory within a social constructionist framework, it can be argued that these demands and levels of tolerance are socially constructed expectations driven by a

culture that is representative of a civilising society. How parents go about the task of parenting is inexorably linked to the society in which they live.

Mothers and mothering

While parenting embraces both the involvement of both mother and father in the upbringing of their child, it is clear that in Western societies, mothers undertake the bulk of child rearing (Goward, 2002) and that mothers are held responsible for a child's actions and problems (Allan, 2004). Fathers tend to focus on work and financial responsibilities. Even today with the emphasis on equal responsibility and with many women working; 62% of women with children under the age of sixteen years are engaged in part-time work (Australian Bureau of Statistics, 2002); mothers remain the main source of child rearing and all the activities this entails.

The history of motherhood is fraught with contradictory and bounded interpretations that draw a reader to the realisation that motherhood is a historical construct, influenced not only by the social, political and economic discourses of the time but also by the interpretations that are placed on historical records, literature and narrated experiences. Many of these explanations and understandings have been developed as a result of the feminist movement, which, over the past century, has strived to explain how men have dominated women (Moi, 2002), and how this has influenced the role of women as mothers (DiQuinzio, 1999). While recognising the interpretive influence of this powerful discourse, feminism, I shall attempt to present an overview of mothers and mothering from a broad perspective. However, feminists have written much of the literature on the history of mothering and it is hard to exclude their interpretation in its entirety, and perhaps it would be inappropriate to do so.

Until recently, mothers have been of marginal interest to society. Prior to the 19th century, mothers were mostly viewed as those who provided the nation with future soldiers, workers and heirs (Comacchio, 1992) and, until the mid nineteenth century, mothers had little say and no legal rights over their children (Smart, 1996). Even medicine took little interest in mothers. Up until the late eighteenth century, mothers were considered to be little more than reproduction machines, and women had their own medicine that was scorned by the existing medical authorities (Donzelot, 1980). However, changing political and economic circumstances in many Western countries from the late 18th century bought with it a changing focus on motherhood.

Mothers were no longer considered merely as 'chattels' owned by their husbands, but began to be seen as 'an institution' that could be controlled by the State (Smart, 1996). This change in approach became particularly apparent at the beginning of the twentieth century when mothers were blamed for the alarmingly high rate of infant mortality. No longer were mothers left to raise their children in obscurity. In fact, they were not even considered to be trustworthy in their role of raising children, requiring assistance from the State and extensive guidance from trained experts (Margolis, Cole, & Kotch, 1997). Legal impositions, such as compulsory schooling and child protection legislation, along with increasing obligations imposed by medical and health professionals, such as immunisation schedules, all began to place a strong focus on the importance of being a 'responsible' mother. Donzelot (1980) proposed that this promotion of responsibility as mother, educator and medical auxiliary raised a woman's social status, but also tied her mothering aims to the production of a child that would be of economic benefit to The State. This responsibility was reinforced by the development of the psychoanalytical theory of Sigmund Freud that closely linked the psychosexual relationship between children and their parents, especially mothers (Kaplan, 1992). Freud's theory was instinct-based, proposing that mothers had 'unconscious' drives that influenced their relationships with their children, however, he added a host of other factors that he claimed also affected a mother/child relationship. Badinter (1981) suggests that the psychoanalytical advice that flowed through the mass media or in books written especially for mothers, on one hand supported the ideas that maternal behaviour was instinctual, while, on the other, promoted the idea that mothers needed to be advised and corrected in every aspect of mothering.

Increasing regulation of mothering practices also arose as a result of the attachment theory advocated by Bowlby in the 1950s (Allan, 2004). In fact, Dally (1982) suggests that John Bowlby and his theories on maternal deprivation, loss, attachment and the importance of the mother-child relationship influenced more mothers, professionals, government agencies and governments more than any other. Central to Bowlby's argument was the suggestion that the maternal-infant bond was the most essential factor influencing the psychological and emotional development of infants and young children (Bowlby, 1951). It was as a result of this work that mothers were encouraged to stay at home and provide their children with a stable, loving environment. By doing so, he argued, the affectionate bonds that developed between mother and child would result in a happy, healthy and

emotionally stable child who would, eventually, act in the same way to his or her own children. Mothers became central to their children's well-being.

Bortolaia (1996) argues that in recent times, the pressure on mothers to perform as child raisers 'par excellence' has not diminished. In fact, while mothers have more autonomy and control due to scientific/medical discoveries such as the contraceptive pill and increasing technologies such as washing machines which reduce the need to spend as much time at home, mothers are still facing enormous demands. Societal expectations place even greater pressure on mothers to perform, particularly in the role of raising responsible, achieving and well-behaved children. Margolis (1997) suggests that the mother's role has become central to the development of her children, for she has become the main instructor in every aspect of her child's life – social, moral, physical and psychological. Mothers are now expected to educate their children, not only in the ways of social responsibility, but academically as well. Not only do mothers still remain the focus of responsibility, they are instructed how to achieve this through the expectations implied by rules of the dominant discourse. These rules identify the 'good' and 'bad' mother and success is measured by a mother's ability to adhere to the standards these rules set (Smart, 1996).

Motherhood is idealised through cultural representations in popular culture, art and childcare or parenting manuals (Marshall, 1991). 'Prescriptions about what 'good mothers' do and how mothers should behave provide a framework for evaluating the behaviour of women as mothers' (Kent, 2000, p.106). Being aware of dominant cultural discourses can draw attention to a mother's behaviour and beliefs and the relationship of these behaviours and beliefs to cultural expectations. What mothers do is not instinctual or innate; rather it is a reflection of the dominant discourse on motherhood. If the discourse on motherhood changes, so to does the way that motherhood is enacted. Roles in society, such as motherhood, are shaped by dominant discourses; they are, therefore, socially constructed.

Assumptions about mothering have been challenged by researchers influenced by social constructionism, particularly in regard to research studies that look at the mother/child relationships (Smith, Cowie, & Blades, 2003). These studies have resulted in individualistic interpretations of socially constructed phenomena, often leading to blame of women for failing to mother their child adequately (Burman,

1994 cited in Smith et al., 2003). Many authors have provided excellent discussions of the history of the social construction of motherhood. (Badinter, 1981; DiQuinzio, 1999; Kaplan, 1992; Phoenix & Woollett, 1991; Smart, 1996). These authors argue that how mothers engage in and consider motherhood does not arise from natural instincts; rather it is the result of the influence of economic, societal and political factors. Tardy (2000) identifies three important themes that arise from these works. First, motherhood has been manipulated for political and economic reasons, both for and against women's rights. Second, in the past 50 years there have been great technological advances, enabling women to choose to reproduce, work or both. Third, greater mobility has resulted in isolation from other family members, reducing the availability of a parenting support system. 'Finally, there is the resulting issue of guilt and blame attached to mothering that can affect all the opportunities and choices women may experience, especially their decisions regarding health care' (Tardy, 2000, p. 438). Importantly, the role of mothers is influenced by historically based constructions of the family, and while mothers may have the opportunities for choice, this choice is often limited by responsibilities society places on mothers as a member of a family.

Research perspectives influenced by social constructionism focus less on the individual and more on the interpersonal, cultural, historical and political contexts in which constructions of childhood and parenting are situated. It was within such a framework that this study aimed to understand the experience of mothers whose children had not been identified with developmental problems until school.

Australian families

When discussing parenting and children, it is important to have an understanding of the demographics of families and the society in which they live. Parenting does not occur in a social vacuum, rather it is influenced by the wider historical, social, political and economic context in a given period of time (Kolar & Soriano, 2000; Lerner, Castellino, Terry, Villarruel, & McKinney, 1995). This discussion will focus on the period 1997-2003, as it is during this period that the mothers in the study raised their young children. Furthermore, while correlations may be drawn between Western countries, each country has it's own idiosyncrasies, and data drawn from a country other than that in which the study is undertaken may not necessarily be appropriate. The following information is drawn from three main sources: three publications by the Australian Institute of Health and Welfare, *Australia's Welfare*

(2001; 2003) and *Australia's Children: Their Health and Wellbeing 2002* (Al-Yaman, Bryant, & Sargeant, 2002)*,* and a report by the Australian Institute of Family Studies*, Australian Family Profiles: Social and Demographic Patterns* (de Vaus & Wolcott, 1997). Both institutions are highly regarded for their significant contributions to compiling information on health and welfare issues in Australia.

Australia's population in 2002 was 19,800,000, of whom 3,700,000 (19%) lived in Queensland and 300,000 (1.52%) lived in North Queensland (Australian Bureau of Statistics, 2002 [ABS]), the region in which the study has been conducted. There were 5,248,000 families of which 2,162,000 (41%) had children under the age of 15 years; 422,000 (20%) of these families with children under 15 years lived in Queensland, and 40,000 (1.85%) lived in North Queensland (ABS, 2002). The ABS describes a family as two or more persons, one of whom is aged 15 years and over, who are related by blood, marriage (registered or de facto), adoption, step or fostered, and who are usually resident in the same household.

Considerable changes in family structure have occurred over the past thirty years, particularly in the last decade. Some of the major changes include: declining fertility rates and an increasing preference for smaller families; increasing numbers of defacto relationships; increasing divorce rates; increasing numbers of one-parent families; increasing labour force participation rates of women of child bearing age and increasing joblessness in families. Marriage is occurring later and childbearing is being delayed, there are also increasing numbers of children born outside of marriage (AIHW, 2003). These changes are not confined to Australia, other Western countries are also experiencing considerable changes to their family structures, including Great Britain and the United States (Family Policy Studies Centre, 1997)

While there is an increase in single-parent families (23% of families), 77% of Australian children live with both natural parents (AIHW, 2003, p. 219). Families are reducing in size; the average family has two children aged 0 –17 years; sole parents have slightly smaller families, with an average of 1.73 children. The number of children in Australia aged 0 – 17 years increased by 5% in the last decade, but they represent a falling proportion of the population. In 1992, this group constituted 26% of the population, compared with 24% in 2002 (AIHW, 2003).

The majority of Australian families are described as 'nuclear families' – a two-generational economic, kinship and living unit made up of parents and their biological or adopted children (Papalia, Olds, & Feldman, 2002). An Australian study identified that nearly two-thirds of Australian families had relatives living within two hour's drive, with rural parents and those from non-English speaking backgrounds the least likely to have relatives close by (Millward, 1992). It is probable in 2005 that an increasing number of families live in close proximity to relatives, particularly as Australians are choosing to move from rural to city dwellings and the Australian immigration policy promotes a family reunion program.

Parenting and socio-economic status

Parenting also takes place in the context of a socio-economic environment. Hoff-Ginsberg and Tardif (1995, p. 161) proposed that the ideas that parents have about parenting, and the ways in which parents perform their parenting functions, differ across socio-economic strata. While the study of socio-economic status in relation to parenting is fraught with challenges due to the sensitivity of the topic, there have been a number of studies undertaken in recent years (Bradley, 1995; Bradley & Corwyn, 2002; Gaziano & O'Leary, 1998; Hoff-Ginsberg & Tardif, 1995). This literature suggests that the effects of socio-economic status on parenting are both profound and pervasive. Parents in different socio-economic strata have different experiences and operate under different external conditions (Hoff-Ginsberg & Tardif, 1995, p. 183). However, while these studies are important in understanding parenting, it is difficult to separate socio-economic circumstances from other influences such as culture, historical factors, education and individual variations of parenting practice. So, while the focus on socio-economic factors is important, socio-economic status must not be considered in isolation from other influences.

From the Australian perspective, a number of studies have found a strong association between family socio-economic status and child health and well-being (Al-Yaman et al., 2002; Burns & Goodnow, 1985; Connell et al., 1989; Howe, 1999; Kolar & Soriano, 2000). This research claims that low family income is highly correlated with poor child health and well-being. Children of low income families (earning less than $25,000 per year) are less likely to be breast-fed, more likely to develop long-term illnesses and less likely to attend preventative and early intervention well-child-care health services (Moon et al., 1998 cited in Al-Yaman et al., 2002, p. 257). Again, while socio-economic status is the focus of these studies,

other influencing factors need to be taken into account when determining the influence on parenting practices.

It is estimated that 25% of Australian children live in families whose income places them at risk of poverty and disadvantage (AIHW, 2002, p. 260). In an effort to support these families at risk, the Australian Commonwealth Government provides a range of assistance to families in need (AIHW, 2002). Financial assistance is offered to families in the form of Family Tax Benefits, maternity allowance, maternity immunisation allowance and child care subsidisation (AIHW, 2002, p. 146). While these family supplements change in form and amount on a regular basis, the government is at least trying to provide for families who need the most support. Whether or not the amount of support is sufficient or not is a moot point – the government is constantly under pressure from lobby groups to increase payments and to provide greater support for parents and their children ("Unionist call for maternity leave pay," 2003). The 2003/2004 annual report by the largest charity in Australia, The Salvation Army, reveals that the gap between rich and poor, is wider than ever, with the wealth concentrated in a decreasing proportion of the population (Dalziel, 2004, p. 6). Requests to charities for help are increasing dramatically, and welfare provision is becoming increasingly difficult to access (Dalziel, 2004). In addition, the problem of children in poverty is growing despite Australia's apparent prosperity (Harding, Lloyd, & Greenwell, 2001). The political ideology now driving Australia is one of 'post-welfare' as the government moves way from the welfare state of the past. The challenge for the government is to adopt policies that provides for families most in need while recognising that all Australian parents and children may, at some point, need assistance to provide their children with the best possible health and educational opportunities.

Parenting and culture
The way we parent and the way we are seen to parent is heavily influenced by the social environment and societal expectations that are closely linked to the cultural context in which a family lives. Bronfenbrenner (1979) argues that the environment in which a child lives has both direct and indirect impacts on what experiences that child has and will have. Bronfenbrenner visualised the environments surrounding children like a series of nested Russian dolls (Bronfenbrenner, 1979). The environment includes, but extends beyond the home, school, neighbourhood and the workplace settings in which people spend their everyday lives.

Closest and of the most immediate impact on a person's development is the 'microsystem' or relational dimension (Harms, 2005), the interpersonal relationship between child and parents, child and peer group, child and school, child and religious community that affect a child's sense of well-being and identity. The strength of the relationships between the various systems, or the extent to which they were mutually reinforcing, isolated from, or antagonistic to each other, Bronfenbrenner referred to as the 'mesosystem', or the social networks (Harms, 2005). The 'exosystem', or broader structural context, refers to the settings that do not involve the developing person as an active participant, but in which events occur that affect, or are affected by, what happens in the setting in which the developing person lives. The provision of local government services, health and welfare services are examples of exosystem influences. Peripheral to this is the 'macrosystem', the overall culture and belief systems in which the other systems are embedded, and includes influences such as values, customs, laws, policies and programmes which implicitly impact on each of the other systems.

Bronfenbrenner (1998) added a final dimension to his ecological model by suggesting that the dimension of time, the 'chronosystem', influences both the individual and the systems in which the individual is embedded. Furthermore, relationships between systems can change and these changes can occur by individuals deliberately selecting, modifying and creating their own settings, or externally imposed by changes in policy, provision of services or changes in cultural values and beliefs.

Bronfenbrenner's *Ecological Model of Development* (1979) has been utilised as a fundamental basis for many research studies (Belsky, Rovine, & Fish, 1989; Cox & Paley, 1997; Denham, 2003; Fenichel, 2002; Howe, 1999; Sidebotham, 2001) and the implementation of family-based policies in Australia and the United Kingdom (Howe, 1999; Kohler & Rigby, 2003; Vimpani, 2003). However, while Bronfenbrenner's systems theory provides a view of the environmental influences on an individual development, it does not take into consideration other potential influences, such as infant temperament, prematurity, serious medical conditions and genetic predisposition. More than just the external environment affects development; it is affected by who the person is, how well that person is and how their genetic predisposition enables them to cope with changing external environments. Complex and evolving biological and social interrelationships all play an important role in how

an individual develops, experiences and perceive the world around them. Furthermore, when viewing Bronfenbrenner's model through the lens of social construction, it is apparent that Bronfenbrenner does not consider the influence of historical, social and cultural environments on how a person *views* their own experiences. The ecological model is very systems focused, based on contextualities that do not take into consideration an individuals own perception of 'reality' of a situation or experience.

Vimpani (2003) claims that the greatest commonality of experience amongst children (and their families) is from the macrosystem and the greatest variability is that which is experienced at the microsystem level. He postulates that changes at the macrosystem level will have more pervasive effects on health and development than changes at the microsystem level. Research undertaken by Sidebotham (2001) supports this suggestion, finding that wider cultural influences impose considerable restrictions on parents and children, including increasing financial demands and pressures on parents, increasing restrictions on children and increasing expectations of parents to provide their children with educational and social opportunities.

A project commissioned by the European Union to develop a set of child health indicators (Kohler & Rigby, 2003) agrees with Vimpani's assessment of environmental influences on child development. In fact, they argue that a child's development is so closely tied to the 'resources and structures within the environment, that developmental indicators could make useful social indicators' (p. 555). A child's development reflects the ability of the society to provide the child with the right conditions for healthy development, rather than the child's development standing in isolation and being considered an 'individual problem'.

Parent expectations and beliefs

Cultural background and the environment in which a parent raises a child has a profound influence on parenting practice. Harkness, Super and Keefer (1992, cited in Harkness & Super, 1995) suggest that:

> Parents actively construct cultural belief systems from personal and publicly shared sources of available cultural knowledge, including reconsideration of their own remembered experiences of their parents as well as contemporary formal an informal sources of cultural knowledge (p. 229).

Culture impacts on how parents raise their children, the emphasis they place on certain aspects of development and the opportunities they provide their children, although why these differences occur is the subject of an ongoing debate. Gergen (1985) argues that how a culture views parenting is socially constructed, the basis for these constructions being the extent to which a particular concept meets the needs of the paid labour force. For example, if economic or cultural conditions call for a reduction of the number of people in the paid work force, then images will be constructed to reinforce the loss of jobs for women by claiming that children are vulnerable and need total care at home (Goodnow & Collins, 1990, p. 77). How a culture, at any given time, defines parenting is therefore greatly influenced by the needs of the society at that time. Furthermore, what parents expect of their children varies with the time and place in which they raise their children. Parental expectations are embedded in the socially constructed boundaries of the society in which they live.

Parental beliefs will, therefore, have a strong impact on how they view their child's development. Belief patterns have been the focus of a number of studies (Booth, 1997; Goodnow, 1995; Goodnow, Cashmore, Cotton, & Knight, 1984; Goodnow & Collins, 1990) that have attempted to identify how parental beliefs are related to their own behaviour and how they impact on a child's development.

Individual influences on parenting

While culture and socio-economic status have some bearing on how parents parent, they are not the only influences. Bradley (1995) asserts that while 'culture and class help to shape and define what parents do and who parents are, the environment parents create for their children does not necessarily reflect these ecological factors' (p. 236).

Parental personality and adjustment are important determinants of how parents parent. 'Research supports the notion that differences in psychological functioning and adjustment are associated with qualitative differences in parenting' (Vondra & Belsky, 1993, p.3). Belsky (1984, p. 84) also claims that the developmental history and personality of the parent shapes parenting indirectly by influencing the broader context in which the parent-child relations exist. The experiences a parent has as a child, the degree of resilience to adverse experiences and the ability to cope with

change and form intimate relationships with others (including their own children) will all impact on an individual's approach to parenting.

How do parents know how to parent?

'Parents are not made at birth but become parents over time' (Neven, 1996, p. 53), yet despite the range and nature of the responsibilities involved, 'parenting is largely a process for which there is no formal or educational qualification' (Kolar & Soriano, 2000, p. 21). Traditionally, mothers have learned how to raise children from other women: a mother, midwives, relatives and friends (Heywood, 2001). Until the late nineteenth century, knowledge on childcare passed down the generations, but, with the rise in scientific knowledge and an increasingly confident medical profession, parenting 'came under an increasing barrage of advice from doctors and others eager to pontificate on child-rearing' (Heywood, 2001, p. 72). Child-rearing manuals began to appear, heavily guided by medical science. *The Care and Feeding of Children,* written by an American Paediatrician, Luther E. Holt in 1894, became exceedingly popular among parents even though it was essentially written as a training manual for nurses (Heywood, 2001, p. 73). Mothers were presented with rules on how to feed, bathe and toilet-train their children; and, in the early twentieth century they started to be given information on baby milestones such as when a child should crawl, walk and talk.

By the mid 1900s, parents, particularly mothers, were inundated with books advising on the best course of action for rearing infants and children. These books were very prescriptive in their advice on how to feed, care and cloth a child. Helen Simpson (1934) wrote in her publication *The Happy Housewife* that the 'health (of a child) is the reward of constant vigilance and the applying of certain principles' (p. 189). For example, Simpson advises parents that babies nearing their first birthday will require three good meals a day at 'eight o'clock, twelve-thirty and five' (p. 192). There is little room for variation of schedules nor the recognition of individuality, and most interestingly, Simpson often refers to the child as 'it'!

The most famous author of child rearing advice in the twentieth century was probably Dr. Benjamin Spock. Spock's publication *The Common Sense Book of Baby and Child Care* (1946) became the biggest seller ever recorded and helped popularise the idea that the mother-child relationship was most important for the healthy emotional development of the child (Sanson & Wise, 2001). Such advice

had considerable repercussions for women for the remainder of the century. Women who worked outside the home were vilified for leaving their child's care to another person.

Today, a number of studies point to the fact that parents still rely heavily on the advice and information from family (Kolar & Soriano, 2000; Redmond, Spoth, & Trudeau, 2002; Sanders et al., 1999). A study undertaken by the Australian Institute of Family Studies from 1995 - 2000, focuses on parents and parenting practices in Australia (Kolar & Soriano, 2000). Parents across three cultural groups (n = 69) were asked, by questionnaire and/or interview, about their parenting practices. How their family of origin influenced parenting values was of particular interest. Interestingly, the study found that a large percentage of parents, across cultures, valued their own parents as parenting models. However, the parenting practices were not accepted unconditionally. Kolar and Soriano found that parents tried to adapt their parents' method of parenting by utilising the characteristics they liked and rejecting or changing those they did not like (pp. 21-22).

While the study is comprehensive, the cultural groups who formed the bulk of the study population were living in a large Metropolitan city where almost all had immediate family or relatives living within an hour's drive away. Although a large percentage of Australia's population is concentrated in just a few large metropolises, this study may not reflect the influences on parenting knowledge in smaller towns or families more isolated from their family-of-origin. It also needs to be noted that while the Australian Institute of Family Studies (AIFS) is highly regarded for its input into family studies, none of its research appears in peer-reviewed journals; rather, the AIFS publishes its research in 'in-house' publications. Nonetheless, it is one of the few sources of research information concerning families in Australia and, as it is highly regarded for its work, it will be relied upon to provide a fairly accurate picture of Australian family life.

While there appears to be a lack of studies of parenting in rural and regional Australia, a number of studies about parents and parenting have been undertaken in Great Britain (National Family & Parenting Institute, 1999 [NFPI]). Although Kolar and Soriano (2000) warn that it is not always appropriate to utilise responses that are framed in a different culture and social environment, it is interesting to note that nearly seven out of ten people (n = 2059, 51% were parents) said that their parents

had the most influence in their approach to parenting (NFPI, 1999). While the population is described as a national representative sample it is not clear where the majority of participants lived in Great Britain. However, it is reasonable to assume that, due to the size of Britain, many families do not live long-distances away from family and relatives. In any case, as in the Australian study, the more isolated parents may not have participated.

Parenting ideas are also influenced by a number of other sources. Parents consider relatives, friends and neighbours as important sources of informal advice and information (Department of Family & Community Services, 2004b; Kolar, 1998; National Family & Parenting Institute, 2001). If family are unable to help then parents may turn to professional advice, particularly if parents are concerned about their child's behaviour (Sanders et al., 1999). Parents, however, are often unclear from which professionals to seek information (Page, 2002). Limited knowledge about what services and resources are available from where, and from whom, restricts parents' access to potential sources of information. The final report of the *Parenting Information Project* (Department of Family & Community Services, 2004a) identified that there was limited awareness among parents (n= 1,913) of available information on early childhood development and the related support services. While it is suggested that participants were selected by stratified randomised sampling, the sample is skewed to lower income groups, with 42% of respondents, and 46% of their partners not engaged in paid employment. This may have been due to a deliberate strategy to focus on non-metropolitan areas where parenting issues were shown, by earlier research, to differ from those in metropolitan areas. Rural areas in Australia have much higher rates of unemployment than urban areas. The study found that parents sought information on health issues mainly from health professionals, intellectual and social development mainly from childcare providers, and emotional development from friends and books. The Internet is not listed as a source of information, leading one to question whether the design of the questions excluded it as a possible answer, especially when it can be noted that other studies (Nettleton, Burrows, O'Malley, & Watt, 2004; Sarkadi & Bremberg, 2005; Williams & Holmes, 2003) have found that the Internet is a popular source of information for parents. Alternatively, it may be related to the high percentage of low-income participants who may have been unable to afford on-line access. Families living in rural areas may also have had limited access to Internet services.

The technological media today offers a boundless source of parenting advice. A quick search on the Internet utilising the 'Google' search engine and the words 'information for parents' returned with 87,000,000 possible web sites – with advice from activities for babies through to coping with navel rings or how to use the information superhighway with your child and how to contact parenting networks around the world. Typing the word 'parenting' into the search facility for Amazon.com and there was a choice of 3,619 books, 1,464 magazines and 548 videos. Even more surprisingly, one of the books was a 1998 edition of Dr Spock's *Commonsense Book of Baby Care*! Talkback radio programmes, television programmes, videos, CD's, lectures, newspaper articles and an endless selection of pamphlets and books are also available to parents. Parry (1989) questioned the effectiveness of the literature and claimed that 'much of what is written is for parents is too academic or wordy' (p. 202). It appears, however, that recent publications have successfully addressed this problem.

Many of today's parenting publications are much more 'user friendly', – employing simple language and colourful presentation with both words and pictures. How many parents actually utilise the media information available is still unclear. The difficulty parents have today is sorting through the enormous amount of information available and trying to determine which is useful and accurate. The more educated parent is most likely to access the information and most likely to sort it successfully (Page, 2002). Page (2002) notes that parents sometimes feel that too much information is available. 'A survey of how parents use the Internet found that the number of websites for parents of babies was likely to make it harder for parents to find the information they were seeking' (p. 11). However, a pilot study of Australian mothers (n = 65) participating in parent chat rooms on the internet, found that while family was still the most important source of parenting information (32%), internet sources were almost as popular (30%) (Williams & Holmes, 2003, unpublished). Strikingly, this study revealed that health professionals were seen as one of the least likely sources of parenting information, along with magazines and friends, with less than 4% of mothers preferring them. This result was not replicated in another study that focused on the Internet use of parents whose children had a chronic illness (Nettleton et al., 2004). These parents (n = 69) were found to draw on a whole range of resources, including relatives, books, magazines and friends, as well as the Internet. Health care professionals were, however, still seen as the most authoritative and reliable source of information. It needs to be noted that the study

was undertaken in collaboration with, and co-sponsored by, the Medical Research Council. More recently, a Swedish study (n= 2499) found that a large group of mothers accessing a popular Swedish parenting web site considered other parent's opinions more valuable than the advice of experts (Sarkadi & Bremberg, 2005), supporting the findings of Williams (2003). However, it may simply be that parents using the web-based sources prefer to use this as their source of health information while parents who visit health professionals, chose not to consult the web.

Many parents want more information on parenting, although the amount and type of information parents' want is variable. One study found that 50% of parents would like more information about bringing up their children (Keep, 2001 cited in Page, 2002) . The most common requests were for advice and support about the range of behaviour that is considered 'normal' at different ages and stages of child development, information about how children learn, and information about schooling. The other 50% of parents said they did not need any information about the stages of development (Page, 2002). It is important to be able to identify which parents would like more information and those who do not. Parents also identified different preferred means of obtaining information. Some prefer face-to-face advice, others like to read brochures and handbooks, while others like to have access to a telephone hotline (Department of Family & Community Services, 2004a). If information is directed towards those who do not wish to receive it, then the information is ineffective and redundant. However, parents who would like to know more need easy access to practical, up-to-date, relevant and useful information. They also like to make informed choices based on credible and culturally appropriate information (Department of Family & Community Services, 2004a).

At this point it is worth noting that regardless of educational, cultural, historical and personal influences, the extent to which parents make a difference to their child's development has come under question. Scarr (1992, cited in Smith et al., 2003) argues that in most circumstances, parents need only provide a basically warm, supportive and nurturant environment for their children to develop to their innate potential. Scarr bases her arguments on the findings that siblings growing up in the same household retain an individuality that is not explained by variations in parenting. While there is no doubt that a child who is deprived of the basic essentials – love, warmth and security – will not thrive, it is remarkable that Scarr considers that a child will be given the opportunity to achieve his/her maximum

potential without the benefit of additional support or opportunities. The foundation for Scarr's argument appears to be one of 'genetic elitism', where genetics is considered the most powerful influence on a child's development.

A study conducted over a 21 year period, the Abecedarian Project in the USA, asserts an opposing view to Scarr (Campbell & Ramey, 1994, 1995; Campbell et al., 2002). This study reported the young adult follow-up of one of the most intensive early childhood education programmes ever provided for children of low-income families (Campbell et al., 2002). They claim that early intervention programmes focused on high quality childcare and education can 'make a dramatic difference' (p. 52) over the long term. The study found that as a result of early intervention programmes the children, from early school years to teens, exhibited improvements in cognitive test scores, years of attendance in school and a reduced likelihood in becoming teen parents. While these results must be interpreted within the ecological context in which the study was undertaken, it certainly places Scarr's approach into serious doubt.

Australian parents search out a multitude of sources when undertaking the complex task of parenting. While many rely on family members for support and advice, the Australian Government provides mothers and their children with a free health service: the Maternal and Child Health Service (MCHS).

Child health services

Child health services in Australia have a short history, and it appears that few infant and child health services were provided for families and children prior to the late 1800s (Mellor, 1990). Child health services were first established in response to the high mortality rates of infants and children, with nurses concentrating on maternal education about infant nutrition and growth (Heywood, 2001). By the mid twentieth century developmental screening and assessment became an integral part of the child health visit, while today child health centres provide much more than the traditional 'weighing-the-baby' service (Sweeney, Jamrozik, & Vimpani, 1989). Antenatal clinics, mobile clinics, toddler consultation clinics, school health assessments and school-based nurses are all part of the service. Information about immunisation, normal development and behaviour and child safety is part of a comprehensive program that takes into consideration not only the needs of the child. Mothers are encouraged to visit these centres with their newborn babies.

Most babies in Australia are born in hospitals (Australian Institute of Health and Welfare, 2004). While in hospital mothers are cared for by midwives and obstetricians, and newborn babies are placed under the care of midwives and paediatricans. Once discharged from hospital, new mothers and babies may be visited by community midwives who check that mother and baby are settling in to their home environment and the mothers are coping with the demands of the new infant (Barnes, Courtney, Pratt, & Walsh, 2003). Mothers are also encouraged to take their babies to a paediatrican for a 'six weekly check-up'. Six-weekly checks are performed to ensure that the baby is physically well, and mothers are given the opportunity to express any concerns. If the child is well, mothers can elect to visit Maternal and Child Health Nurses (MCHNs) who operate from Maternal and Child Health Centres (MCHCs), for on-going well-child checks, immunisations and weighing etc. Maternal and Child Health Centres are funded by state governments, so mothers can attend free of charge. They operate in most Australian townships, although small country towns may only have MCHNs who visit on a weekly or monthly basis. Until recently the consultations with MCHNs were made on an individual basis, but recent changes to the MCHC operation policy has means that most mothers can only attend group sessions. Only mothers and infants who are considered 'at risk' are able to attend individual consultations (Barnes et al., 2003). The definition of 'at risk' is somewhat obscure, but seemingly refers to mothers and children who are considered to have potential social problems that will impact on the later development of the child and the health and well-being of the mother.

Attendance at Maternal and Child Health Centres varies considerably between Australian states. According to the Australian Institute of Health and Welfare (Al-Yaman et al., 2002, p.309), 88.9% of children aged zero to three years visited a baby health clinic in 1995. The proportions were highest in Victoria (97.4%), the Northern Territory (96.5%) and Tasmania (95.1%) where nearly all babies born receive at least one visit by a Maternal Child Health Nurse (MCHN) after hospital discharge. Queensland, at 73.3% had the lowest proportion of children zero to three years of age visiting a health centre. Unlike other states, Queensland did not have a MCHN visit to new mothers and babies after hospital discharge. Interestingly only 56.4% of children in Australia, aged from zero to three years, had regular health checks even though such a large percentage of children were said to have attended baby health clinics. Furthermore, 35.1% of infants between the ages of zero and two months had never visited a baby health clinic, even though this is a time in which

infant health check and parent education is important (Al-Yaman et al., 2002). A more recent Australian study (Goldfeld, Wright, & Oberklaid, 2003) of health service utilisation by first-time parents (n = 173) in Victoria, found that 'approximately 98% of first time parents made some contact with their maternal and child health nurse' (p. 249), however, inconsistency of information given and the limited hours of availability were considered to be problematic for some of the new parents. While this study acknowledges the limitation of its socio-demographic bias, a high proportion of parents had attained a tertiary education and the mean age of mothers was high, it fails to mention that, in Victoria, the MCHN visits all new mothers after discharge from hospital as part of health service provision. It is not made clear how many of the additional visits are voluntarily made by the mother's themselves. However, it is apparent that mothers do not always take advantage of the free service offered by MCHNs.

If a child is sick, mothers usually take their infants along to local doctors, referred to in Australia as General Practitioners (GPs). GPs predominantly operate from private practices charging a fee-for-service, part of which patients can claim from the Australian Healthcare System – Medicare. Free medical clinics are provided in hospitals for sick children or children who need on-going medical care. Mothers can elect to use either the public, free health service, or the private, fee paying health service, although the Australian Government strongly encourages users, through tax disincentives, to 'opt in' to the private system.

In Australia, MCHNs tend to operate separately from GPs with MCHNs attending to well-child checks and developmental assessments and GPs seeing sick children. MCHNs can refer mothers and their infants to doctors if they are concerned about their well-being (Barnes, Courtney, Pratt, & Walsh, 2004). If a GP is uncertain about a child's health problem they may refer a child to a paediatrican. This is very common practice in Australia, as GPs have a general training in a wide variety of health related problems, across all age groups, and, training in the area of early childhood may consequently be somewhat limited. Once a child is referred to a paediatrican they usually remain under their care until the problem is resolved. Paediatricians communicate with GPs about the child's progress, but because of the fragmented nature of the health services, MCHNs are not always privy to the inter-doctor communication. This may impact on the service that MCHNs can then offer the mother and child and may be one reason why mothers do not visit MCHCs,

particularly if they are under the care of a paediatrican. Unfortunately, this may impact on how many mothers are alerted to services available to them through the Maternal and Child Health Centres, or associated services, such as the parenting centres.

Parent support centres are designed to provide extra support to parents with babies and children by means of giving parenting and management advice (Sweeney et al., 1989). Their work is intended to complement that of infant health centres. Parents may be referred to these centres by the MCHN's, the local General Practitioner or by concerned family members. An example of one of these centres, *The Integrated Maternal and Parenting Service* (IMPS) centre, utilises the Positive Parenting Program (PPP) (Sanders, 1999) as a basis for assisting parents to cope with the stress of parenting. However, despite the recent growth in parenting centres, relatively few parents attend the courses they offer (Family Policy Studies Centre, 1997) and not all parents find the services satisfactory to their needs (Hempill & Sanson, 2001). The need to have these centres is a reflection of the changing health and social needs of children and parents in today's society.

Changing health focus

There is little doubt that the health needs of children have changed in the past 100 years, The control or eradication of life threatening diseases along with the implementation of public health measures have been responsible for the enormous decline in infant and child mortality and changed the focus of infant and child health. As Garbarino and Ganzel (2000) state:

> As standards and expectations for the care and life prospects of children have improved, developmental risk has become a growing focal point for research and policy. The focus has shifted from sheer quantitative concern with child survival to qualitative concern with development (p. 91)

Concerns now focus on long-term conditions and disabilities, including lifestyle concerns such as obesity, eating disorders, violence, and learning and behaviour problems. One study reports that between 15% to 20% of the children attending paediatricians in the USA have problems that relate to social interaction and educational needs (Starfield & Newacheck, 1995 cited in Leslie, Sarah, Palfrey, & Behrman, 1998). Oberklaid (1988) refers to this as the 'new morbidity' of child health. Although much of the research on early childhood health and education has been undertaken in the USA, Australian health organisations are aware that these changes are also occurring in Australia (Al-Yaman et al., 2002). Recently, a study

undertaken in Western Australia concluded that of 4,300 children, aged 4-6 years, observed in a metropolitan area, '26% were vulnerable in one or more of the developmental domains and 13% were at high risk of having learning difficulties' (Hart et al., 2003). The focus of early childhood health issues is now very much on social and educational problems that have arisen due to changing societal environments and expectations. However, the efforts are mainly directed at children who are already failing at school, or who have been identified as being 'at risk' due to disruptive social circumstances or a medical history of neurological problems. The children whose developmental problems are mild and have therefore remained undetected will still 'fall through the gaps', even though the development and instigation of childhood development screening assessment tools has been a major focus of health service delivery since the early twentieth century.

Developmental screening and assessment

The study of infant and child developmental stages did not really begin until the early twentieth century. Earlier documentation of infant development was in the form of 'baby diaries', the most famous of these was by Charles Darwin, written in 1877 (Wyly, 1997, p.9). These early studies, although simple and merely observations of the authors' own infants, were nevertheless instrumental in stimulating further study. At the beginning of the twentieth century, the Child Study Movement was founded by G. Stanley Hall, an American psychologist. Hall's studies (1904) of children from infancy to adolescence were the first to methodically attempt to assess and describe the average age at which different developmental behaviours occurred. Following this, the earliest infant assessment tools were developed to document developmental maturation and make long-term predictions about development. These were called 'norm-referenced' tests as they assessed an infant's performance against the performance of a large group of age-equivalent infants (Wyly, 1997, p. 3). In the 1920s Arnold Gesell developed a tool that established normative curves for developmental milestones from infancy to adolescence. Using extensive observations of infants and children for their studies, Gesell identified norms of behaviour in four developmental domains: motor, adaptive, social and language. These were published as the Gesell Developmental Schedules in 1947 (Gesell & Amatruda, 1947). Although, Gesell's work has been criticised for including insufficient experimental work to back up conclusions drawn (Holt, 1991), these developmental schedules are still in use today and many of the more recently published, validated assessment scales 'borrow heavily from their schedule' (Wyly,

1997, p. 11). Similar to the work of Gesell, although less rigidly focused on motor aspects of development, the Bayley Scales of Infant Development were also published. After being revised in 1969 the Bayley Scales became 'one of the best known and most widely used tests of infant development' (Wyly, 1997, p. 11).

Concern over individual differences in intellectual functioning was also evident in the early twentieth century. In 1905, Alfred Binet developed a screening test that focused on attention, comprehension and memory (Binet & Simon, 1973). This test, developed for school-aged children was designed to yield a mental age and identify children who needed remedial education. The test has been revised and standardised and is in regular use today as the Stanford-Binet Intelligence scale (Wyly, 1997).

Assessment tools developed from the 1940s to the 1980s include: the Griffiths Mental Development Scale (Griffiths, 1954) which was similar to Gesell's, but included more social relationship measures; the Uzgiris-Hunt Ordinal Scales of Psychological Development (Uzgiris & Hunt, 1975) measuring infant cognition based on Piaget's theory of sensorimotor intelligence; and, the Brazelton Neonatal Behavioural Assessment Scale (Brazelton, 1973, 1984) measuring newborn responses and reflexes as well as a change in the state of infant behaviours.

Psychologists were also developing an interest in the behaviour of children. Jean Piaget, a Swiss psychologist, was particularly interested in the cognitive development of children (Holt, 1991). Piaget was interested in the cause and effect of every action and response. He wanted to find out what the responses meant to the child and how they helped him to adapt to his environment (Flavell, 1963). Although criticised for using his own three children as the basis for his findings, Piaget's theory of cognitive development has had a major influence on the development of educational programmes in schools for the last thirty years.

Eric Erikson (1902-1994), a student of Sigmund Freud, developed a psychosocial theory of child development. Particularly important in Erikson's theory was his descriptions of the eight stages of psychosocial development in the lifespan, five of which occurred in childhood (Newman & Newman, 2003). Erikson's theory has been criticised for being very linear (Newman & Newman, 2003, p. 41), but, Holt (1991)

remarks that it helps provide a basis for a more comprehensive approach to therapeutic interventions.

Not to be left out of the drive to study children, anthropologists and evolutionary biologists attempted to equate the behaviour of animals to humans. Blurton Jones (1972) emphasised the importance of imprinting for modelling behaviour and theorised that learning occurs most effectively during a 'sensitive period' of development. These studies have led to an understanding of the importance of parent/infant bonding, but have been criticised for suggesting that mothers must always 'be there' for their child, thereby pressuring women to stay home and not participate in the work force.

The recent focus on preventative care in the past twenty years has coincided with the development of a plethora of screening tools. The most recent assessments have attempted to simplify the screening tasks and shorten the time they take to conduct. There are also numerous varieties of screening tools developed for specific tasks. Screening tools developed for clinicians such as doctors, nurses, physiotherapists and occupational therapists focus more intensely on the physical development of the child, although cognitive development is also considered, while assessments utilised by psychologists and educationalists are more heavily geared towards cognitive assessment. However, many of these assessment tools now take into consideration many of aspects of the previously independently developed approaches to assessment. These tools have been developed to incorporate a more comprehensive assessment, not only of the infant's capabilities but also of the infant's family and social environments. Furthermore, parents have been invited to participate in the screening process by being given the opportunity to document concerns.

Although these developmental tools have been developed to more accurately assess an infant and child's developmental status, a recent study suggests that such tools are still failing to detect children with subtle developmental problems (Regalado & Halfon, 2001). Diagnosis of developmental delay and behavioural problems has historically been the responsibility of health care professionals such as paediatricians and maternal and child health care workers, yet fewer than 30% of children with subtle developmental or behavioural disorders are detected by their primary health care provider (Palfrey et al., 1994). Tebruegge (2004) found that 66%

of children, in a UK district, with pervasive developmental disorders were diagnosed before school entry, but studies assessing physicians' effectiveness at identifying developmental problems suggest that only severe, clinically apparent disabilities are likely to be identified (Palfrey et al., 1994; Regalado & Halfon, 2001). Tebruegge (2004) proposed that because symptoms were more noticeable, early detection of childhood autism was more likely than Aspergers Syndrome. It is particularly those children whose developmental problems are subtler who are likely to pass undetected until learning and behavioural problems arise at school as mild delays and deviations are harder to detect.

Many of the available screening techniques are difficult and time consuming to administer (Rosenbaum, 1998). For this reason, a number of simplified screening tests have been developed, but the plethora of available assessments and the difficulty associated with interpreting their results leads many clinicians to resort to a 'wait and see' approach (Glascoe, 2000a), or to rely on 'gut instinct' (personal communication, I. Shellshear, paediatrician, September, 2003). One study, in Australia (Rossiter, 1993), found that paediatricians (n = 140) sometimes used screening and assessment tests inappropriately or relied on their 'experience', while others felt inadequately trained to use the tests confidently. Another study, conducted more recently in the United States (Sices, Feudtner, McLaughlin, Drotar, & Williams, 2003), found that primary care physicians (n= 540) mostly relied on lists of developmental milestones, rather than specific developmental screening tools or parent-completed questionnaires. Their findings also suggested that practitioners were confused about which test to use and when. Drotar (2002) claims that although many new approaches are being used to assess behaviour and emotional status of infants and preschoolers, many of them lack reliability and validity for such clinical use and one might expect that they fail to detect those children with subtle developmental problems.

Commonly heard complaints of parents whose children do show signs of mild delays is that they are told by the health professionals that their children 'will grow out of it' (personal communication, I. Shellshear, paediatrician, October 2003). Health providers may adopt this attitude because some children with mild delays do sometimes 'catch up' because of the irregular nature of child development, but Glascoe (2001) advocates that even children with mild deviations from the statistical 'norm' should be followed up with a more complete assessment. Glascoe argues that over-referral for screening tests is justified because at worst, it is advantageous

to the child. Even if the results are considered 'within the normal developmental limits', the child is still scrutinised closely and more regularly on subsequent visits to the doctor/clinic. Children who are identified with developmental delay receive a diagnosis that may entitle them to access intervention services. This is particularly important as some authors (Hauser-Cram et al., 2001; Meisels & Shonkoff, 2000; Nelson, 2000; Shonkoff & Phillips, 2000) argue that developmental delay may impact on a child's ability to achieve both socially and academically in school.

Learning, behaviour and development

Historically, the relationship between early childhood development and the child's learning processes has been poorly understood. Anecdotal evidence suggests that it is only in the last two decades that many health professionals have recognised that children with learning problems may have a health related problem. Indeed, during this time, the link between developmental delay and later school learning, and behaviour problems, has been placed under increasingly intense scrutiny as researchers look more closely at why more and more children are struggling with the academic and social demands of school. Blumsack (1997), for example, found that a 'sizable portion' of students with learning difficulties in the USA have a history of undetected neurodevelopmental problems. They argue that learning disabilities are a result of deficits in basic physiological processes that are developmentally related to central nervous system dysfunction (p. 288). This is consistent with Levine's (1993) study which found that many of the factors which contribute to school failure occur as a result of subtle deficiencies in neurological development. More recently, neurodevelopmental studies clearly illustrate a link between neurological development and behavioural idiosyncrasies in children (Nelson, 2000; Nelson & Bloom, 1997). Although we must be careful not to misinterpret this as indicating that behavioural problems are linked to neurological defects. Their work only suggests a link, not necessarily implying that each entails the other.

The influential American Academy of Paediatrics Committee on Children with Disabilities (2001a) acknowledges the link between early development and later learning. Based on increasing evidence that 'disparities in what children know and can do are evident well before kindergarten and are predictive of subsequent academic performance' (Shonkoff & Phillips, 2000, p. 386) , the Academy supports the development of well-designed early intervention neurodevelopmental

programmes. These programmes are designed to prevent or minimise the physical, cognitive, emotional and resource limitations placed on young children who are disadvantaged by biological or environmental risk factors (Blackman, 2002). Based on a number of studies undertaken in the past two decades (Campbell et al., 2001; Campbell & Ramey, 1994, 1995; Campbell et al., 2002; Cherkes-Julkowski, 1998; Meisels & Shonkoff, 2000; Ramey & Campbell, 1984; Schraeder, 1993; Schraeder, Heverly, O'Brien, & McEvoy-Shields, 1992), it is now recognised that these programmes can considerably improve the long-term educational and social outcomes of children who would be considered at risk of developing poor educational outcomes. While earlier studies focussed on the efficacy of early intervention programmes for very-low-birth-weight infants considered 'at risk' for developmental delay (Brazelton, 1990; Cherkes-Julkowski, 1998; Schraeder, 1993; Schraeder et al., 1992), more recent studies have focused on the general population of children aged zero to three years, particularly those in lower socio-economic environments (Campbell et al., 2001; Campbell & Ramey, 1994, 1995; Campbell et al., 2002). These studies also reinforce the findings of Doman (1974) and Delacato (1959) who have both long advocated that early intervention programmes for children with both mild and severe forms of brain injury were essential to the development of cognitive and motor skills. However, Currie (2000) argues that the current enthusiasm for intervention relies not on evidence but rather on theoretical arguments. However, Currie fails to present actual evidence to support his stance, relying on theoretical argument that is not supported by research. Furthermore, from an Australian perspective, these studies may not reflect the context in which young Australians are raised and ideas and programmes may not be wholly transferable to this culture. Recognising, however, that early intervention programmes are assisting children to achieve both academically and socially is a consideration too important to overlook.

'What happens during the first months and years of life matters a lot' is a fundamental finding of the seminal report of the *Committee on Integrating the Science of Early Childhood Development* (Shonkoff & Phillips, 2000, p. 384). It matters because undetected and untreated problems can seriously compromise children's life prospects. Furthermore, compensating for missed opportunities, such as failure to detect early difficulties, will require much more extensive intervention later in life. There appears little doubt that the earlier a child is involved in intervention programmes, the lower the likelihood of subsequent academic or social

failure. The American experience, and the research with which it is associated, suggests a significant link between subtle developmental problems and school performance, and implies a rationale for detection and intervention before the child reaches school age.

Scientific evidence points to the first three years of a child's life as a 'critical' period of brain development (Wynder, 1998 cited in Armstrong, Fraser, Dadds, & Morris, 2000), in the sense that this is a period in which the brain is most susceptible to physiological and experiential influences. These years therefore represent an ideal time to apply interventions intended to prevent later development of psychological, behavioural and developmental problems. Kandel and Hawkins (1992) in a study of synaptic pathways suggests that mechanisms of learning 'may be linked to the fine-tuning of connections during late stages of development' that are stimulated by activity (p. 60). Bruer (1998), however, argues that neuroscientific evidence used to justify early intervention has been selective, oversimplified, and misinterpreted. Bruer claims that it is not easy to translate neurological research on rats, kittens and monkeys to human brain development and that critical periods 'are unlikely to depend on highly specific experiences in highly specific social and cultural environments' (p. 390). Bruer cites the work of Shatz (1992), a neurobiologist who observed that 'children must be stimulated through touch, speech and images to fully develop' (p. 35) particularly if these children have previously been grossly neglected. However, Shatz tempers her statement with the comment that there is little proof that enriched environments for young children will enhance development, but later emphasises the importance of experience and stimulation being necessary for modifying and fine-tuning the maturing nervous system. Furthermore, having criticised the misuse of neurological studies, Bruer (1998) goes on to commend the focus on early childhood development and applauds the concern shown for children at risk of school and life failure.

In direct contrast to Bruer's caution, a core finding generated by interdisciplinary research into early childhood development and intervention is:

> that the course of development can be altered in early childhood by effective interventions that change the balance between risk and protection, thereby shifting the odds in favour of more adaptive outcomes (Shonkoff & Phillips, 2000, p. 4).

The implication of this finding is profound and clearly reinforces the view that early identification of children with subtle developmental problems is important. Early

identification allows intervention strategies to be commenced before serious long-term difficulties have had time to develop. Consensus is lacking, however, not only on how such early identification can best be undertaken in respect of individuals, but also on how programmes can be instituted at State and National level.

Detecting children with subtle developmental problems

In this thesis, the phrase 'subtle developmental problems' (SDPs) is used as an umbrella term to represent the mild delays and developmental deviations that are difficult to detect due to their variability in presentation and the variable rate of early childhood development. Typical SDPs include delay in speech development, low muscle tone and clumsiness, a short attention span or difficulty controlling behaviour. Most of the children with SDPs have no observable physical anomalies, and only rarely does birth history or family history contribute to identification (Jones, 1996 cited in Glascoe, 2000a). Furthermore, these children do not present with obvious neurological dysfunction and, if a problem is noticed, the health care provider may conclude that the difficulties will correct themselves (Glascoe, 2000a). Glascoe also suggests that lack of detection may be a result of inaccuracy in screening because children with learning and behavioural difficulties often appear 'normal' until they attend school. The problems may become more apparent as the demands of reading and other academic tasks require increasingly more complex cognitive and behavioural skills and, as a result, it is often teachers who first raise 'professional' concerns about a child's development. Children with SDPs may exhibit learning difficulties, behavioural idiosyncrasies, poor physical skills, or be socially isolated from their peers, and these problems may be physiological and/or psychosocial in origin. However, recent studies suggest that these children do display subtle variations in their performance in developmental tasks and behavioural activity in their pre-school years and that these are often detected by their parents (Glascoe, 2001, 2003; Regalado & Halfon, 2001).

The role of parents

Glascoe is one of a number of researchers to have studied the role of parents in the evaluation of developmental and behavioural problems in pre-school children in the USA. Glascoe's comprehensive series of studies have been conducted over a decade and she insists that parents raise valid concerns in the detection of developmental and behavioural problems from an early age, including subtle developmental problems (Glascoe, 1997, 1998; 1999a; 1999b; 2000a; 2000b; 2001;

2003; Glascoe, MacLean, & Stone, 1991; Rogers et al., 1992). Glascoe's studies are confirmed by Thompson and Thompson (1991) and Young, Davis, Schoen and Parker (1998) who claim that parents are able to raise accurate concerns about their children's development, particularly in regard to behaviour and motor development skills. Glascoe (2000a) further states that parents can recognise problems and raise their concerns regardless of differences in their own educational background and child-rearing experience. Moss (1998) also recognise the importance that primary caregivers play in the detection of developmental problems, particularly in relation to cognitive and emotional problems: 'the people who are usually the first to notice signs and symptoms are immediate carers' (cited in Gillman, Heyman, & Swain, 2000, p.407).

Further studies have reported that parents are able to accurately identify delayed language development (Wetherby, Goldstein, Cleary, Allen, & Kublin, 2003), behaviour (Glascoe, 2003), attention problems (Mulhern, Dworkin, & Bernstein, 1994) and psychosocial problems (Wildman, Stancin, Golden, & Yerkey, 2004). Parents are ostensibly an important source information. Their ability to notice developmental issues is enhanced by their knowledge and experience of the child's history and current situation, and they can interpret their child's cognitive behaviour within the broad framework and context of their own family (Dewey, Crawford, & Kaplan, 2003).

Sometimes, when parents raise concerns with health professionals about their child's development, no action is taken. This problem seemingly arises because of a lack of consensus among health care professionals, and between parents and health care professionals, as to the level of severity at which evaluation and intervention become appropriate (American Academy of Pediatrics Committee on Children with Disabilities, 2001b). This appears to be a dilemma from both viewpoints. Sometimes it is the parents who raise the concerns; at other times it is the professionals. Glaun, Cole and Reddihough (1999), in an Australian study of mother-professional agreement about developmental delay in preschool children, found that there was a 'high prevalence of mismatch between mothers' and professionals' judgements of development'(p. 73), particularly when the child's development was abnormal. They suggest that while mothers recognise and acknowledge the existence of developmental delay they 'tend to underestimate the severity' (p. 73) in the hope that their child 'will grow out of it'. Parents may also be

reluctant to share their concerns regarding their child's development (Glascoe, 1999b). An ethnographic study focusing on the health-related discussions by mothers' attending a play-group (Tardy, 2000) concluded that unless a child is developing normally, mothers appear to be reluctant to talk about their child's development. This reluctance may reflect cultural expectations, including the view that parents should not be overprotective or overanxious, or, as Tardy (2000) suggests, that mothers' directly link their child's developmental skill with their own success as a mother, and so self-worth suffers as a result of their perceived 'failure'. Parents may be reluctant to 'medicalise' their child's problem because of a fear of being identified as a 'poor' mother.

Parental reluctance combined with variations within parental expectations, may therefore result in reduced early detection of children with subtle developmental problems. Most importantly, the type of relationship parents have with health professionals will influence how confidant parents feel in raising their concerns about their child.

The parent/health professional relationship
The relationship between parents and health professionals has been discussed in a large number of studies, particularly those where the child has a previously diagnosed intellectual or physical disability and the parents are actively engaged in a relationship with health services (for example: Adams, Gordon, & Spangler, 1999; Breslau, Staruch, & Mortimer, 1982; Burke, Kauffman, Costello, Wiskin, & Harrison, 1998; Kazak & Marvin, 1984; McCubbin, 1993; Patterson & Garwick, 1994; Ray, 2003; Read, 2000; Stewart, Ritchie, McGrath, Thompson, & Bruce, 1994; Todd & Jones, 2003). Other studies focus on communication in clinical settings, such as those between health professionals and clients (Barry, Stevenson, Britten, Barber, & Bradley, 2001; Charles, Gafni, & Whelan, 1999, 2000; Coulter, Entwistle, & Gilbert, 1999; Gabe, Oluminde, & Bury, 2004; Hilliard, 1981; Korsh, Gozzi, & Francis, 1968; Mishler, 1984; Silverman, 1987) or nurses and clients, particularly conversations between child health nurses and mothers (Arborelius & Bremberg, 2003; Baggens, 2001; Fagerskiold, Timpka, & Ek, 2003; Fagerskiold, Wahlberg, & Ek, 2001; Glaun et al., 1999).

Glascoe (1995) emphasises the importance of parental concerns yet there is little in the literature that retrospectively discusses the experiences of parents who have

had children with subtle developmental and/or behavioural problems. This is in stark contrast to the extensive number of studies that focus on the experience of mothers whose children have a chronic illness or disability. Recently, Malacrida (2003) investigated the relationship between mothers and health professionals in regard to their children's diagnosis of Attention Deficit/Hyperactivity Disorder (ADHD), in both Canada and England. Analysising the mothers' stories through Foucauldian, feminist post-structuralism, Malacrida reported a variety of responses, from both the mothers and professionals, concerning communication and relationships. Some mothers reported positive communication, others negative, between themselves and the health professionals. Importantly, this study draws attention to the fact that most of the children were not identified with ADHD until school age, even though they were exhibiting signs of behavioural problems in the pre-school years. In a UK study, Howlin and Asgharian (1999), compared the diagnostic experiences of 614 parents of children with autism and 156 with Asperger's syndrome, reporting that the average age of parental concern and professional diagnosis to be 18 months and 5.5 years respectively for autism, and 30 months and 11 years respectively for Aspergers Syndrome. While this delay may be in some part due to the caution associated with 'labelling' a child (Gillman et al., 2000; Hacking, 1999), most mothers in Malacrida's study identified that they felt health professionals did not listen to their concerns. This is certainly an area for concern, as parents can provide important information for health professionals. While Malacrida's work highlights a number of important issues in relation to mother-health professional interactions, further exploration of the experience of mothers will provide a greater understanding of why children with subtle developmental problems are not being detected until school age.

Listening to mothers

Asking mothers to recall their experience of having a child with subtle developmental or behavioural problems will assist in developing an understanding of the events that lead up to diagnosis and may provide clues that will aid earlier recognition and diagnosis of problems (Williams & Holmes, 2004). Glascoe and Dworkin (1995) do state, however, that a number of studies identify that tasks in which parents were asked to remember events such as developmental milestones lack reliability and recall should be either avoided, gathered with limited expectations and/or corroborated with medical or other records. Nonetheless this form of inquiry can gather important evidence. Memories are an important and legitimate source of

knowledge and reflect the lived experiences of people (Rice & Ezzy, 2000). Furthermore, Denzin (1989) notes that even though there are ambiguities associated with this form of study, a person's story will be structured according to a number of social influences. Significant events, that Denzin terms 'turning point moments', leave permanent marks on a person's memory and these can be clearly recalled. White (1989) agrees, stating that for most people the events that are remembered effortlessly are those that are personally significant, extraordinary, emotional or unexpected. Therefore, asking parents to recall their experiences is a potentially valuable way of gaining insight into this important problem.

Chapter summary

A number of issues have been raised within the body of this literature review and include:

- The focus on early childhood development has shifted from the nature-nurture argument that either biological determinants or environmental influences have the greatest impact on development to the recognition that it is a combination of these factors that determine developmental outcomes.

- Parenting is conducted within the gaze of the community in which a family lives. How a parent goes about the task of parenting is influenced by their family, the community in which they live and by the cultural, economic and political environments of the time

- Narrowing social tolerance of deviations from the expected societal norms places the children who fail to achieve or behave appropriately in school in an invidious situation, particularly when these children fall within the 'statistically normal' range of medically-based developmental screening assessments.

- Early childhood screening tests, while successfully identifying gross departures from developmental pathways, have failed to detect mild developmental problems that may cause later problems with learning and behaviour.

- Medical intervention for children with learning and developmental problems is a recent phenomenon. It is only in the past twenty years that the link between neurodevelopmental problems to learning/behaviour problems has been made.

- Most of the research in early childhood development has come out of the USA, particularly in the past two decades. While this research may not be

wholly appropriate for the Australian circumstances it provides a useful background from which Australian research and studies can be developed.

- Early diagnosis and intervention programmes have been shown to successfully reduce the likelihood of later academic and social problems in children who are identified 'at risk', either from neurological insults or social environment deprivation.

- Children with subtle developmental problems that are not detected until academic failure or behavioural problems arise in school are excluded from early intervention programmes due to the failure of detection of these subtle variations in the pre-school years. These children are therefore considered statistically normal by health professionals, but socially abnormal by educational and societal standards.

- Parents may be able to detect these subtle variations more effectively than health professionals. Drawing on the experience of parents whose children have passed undetected with their developmental problems until school may provide an opportunity to recognise variations at an early stage and allow the child the opportunity for participation in early intervention programmes.

Chapter 3: Theoretical framework, methodology and method

Introduction

This chapter will describe the theoretical framework, methodology and method chosen to explore the experiences of mothers whose children were not detected with developmental or behavioural problems until school. Social constructionism has been adopted as the theoretical framework because it enables the interpretation of parents' recall while recognising that social, cultural and historical environments influence perceptions and experiences (Burr, 1995; Gergen, 1985). Post-structuralism, underpinned by the epistemological notions of postmodernism, provides the foundation for the exploration and analysis of texts

Methodologically, a life history approach informed the interpretive framework for understanding how people thought and acted and interpreted those thoughts and actions, through the examination of personal stories (Martin, 2002). A synthesis of Norman Denzin's (1989) interpretive biography and Stahl's (1985; 1989) literary folkloristics provided a method of collecting, reading and interpreting life stories. Interpretive biography is a well-known and well used interpretive method (Brettell, 1997; Frank, 1991; Johnstone, 1999; for example: Kleinman, 1988a; Tenni, Smyth, & Boucher, 2003) that focuses on the important role that social, cultural, political and historical environments have in a storyteller's experience. Interpretive biography focuses on personal epiphanies that shape how storytellers interpret their own experiences and make sense of the world.

Literary folkloristics emphasises the importance of the relationship between the personal stories and cultural traditions within a particular social or cultural environment. While apparently used infrequently (for example: Hendricks, 1999) and often only mentioned in 'passing' (for example: Bendix, 2002; Donlon, 1995; Gould, 2002; Kainan, 2002; Pugh, 1998; Ryan, 2002; Sloan, 1999; Swindler, 2000), literary folkloristics offers an opportunity to actively acknowledge my role as both researcher and member of the group under study. The literary folkloristic method adopted in this study utilises multiple literary theories to examine personal stories, particularly

personal epiphanies, and their relationship to cultural traditions within a particular social or cultural environment. Three literary theories, arising from the tenets of semiology, neoMarxism and post-structuralism, have been adopted as they allow for a range of literary interpretations to be made from the stories. An overview of the theoretical framework, methodology and method follows, and is represented in Figure 3.1.

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                    │  Theoretical framework  │
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         ┌───────────────────────┐   ┌───────────────────────┐
         │ Interpretive biography│   │ Literary folkloristics│
         │ Denzin (1989)         │   │ Stahl (1985: 1989)    │
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                     │        Method         │
                     │ A literary folkloristic method │
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         │ Semiotics│  │ neoMarxist literary  │  │ Post-structural literary │
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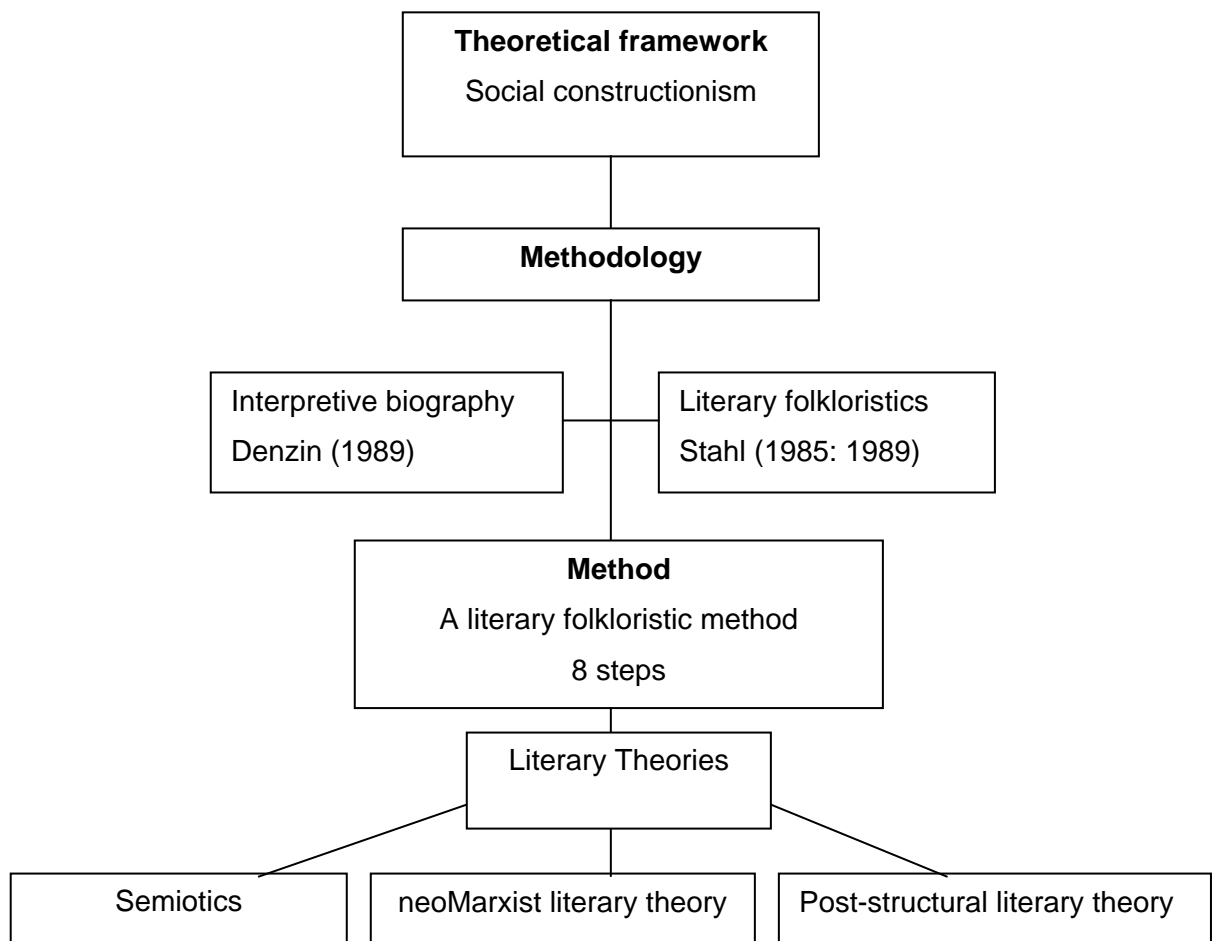
Figure 3.1 Overview of theoretical framework, methodology and method

Theoretical framework: Social constructionism

Recognising the multiple influences on how a parent experiences and recalls a particular period of time, this research was constructed within the broad theoretical framework of social constructionism. Social constructionism arose in a post-modern climate that rejected the positivist and realist emphasis that human beings could only understand the world as it 'really exists' through the search for the absolute

'truth', which was based on objective, scientific evidence (Burr, 1995; Hevern, 2001). Postmodernism also rejected the idea that the world could be understood through the identification of 'grand theories' (Burr, 1995, p. 14) that explain the underlying structures of social life. Instead, postmodernists argued that the multi-faceted society in which people lived no longer supported the 'one-theory-fits-all' approach, but rather recognised that there was a variety of situation-dependent ways of life (Burr, 1995).

Social constructionism is fundamentally concerned with explaining the processes by which people use language to describe, explain or account for the world in which they live (Gergen, 1985). A number of authors writing in the middle to late twentieth century are credited with influencing the development of discussion on social constructionism. Mead (1934, cited in Burr, 1995) postulated that people construct their own and each other's identities through everyday encounters with each other in social interactions. Berger and Luckmann (1971) described how human beings together create and sustain all social phenomena through social practices and, finally, Gergen (1973, cited in Burr, 1995) argued that there was 'no point in looking for once-and-for-all descriptions of people or society as society is continually changing' (p. 11).

Opposing social constructionists (for example Berger & Luckmann, 1971; Burr, 1995; Gergen & Davis, 1985) who argue that a person's 'self' is the interplay of history and social conditioning, Hacking (1999) argues that the term 'social construction' is a non-sequitur. Hacking claims that the self is not a construction of society, rather a product, 'selves have essences…they are not constructs' (p. 15). However, Shweder and Miller (1985) explain that, social constructionists view people as being able to categorise the world the way they do because they have participated in social practices, institutions and forms of language that are relevant to them:

> The 'constructive' part of a social construction theory is the idea that rational, competent and informed observers are, in some sense, free to constitute for themselves different realities and that there are as many realities as there are ways 'it' can be constituted or described. The 'social' part of a social construction theory is the idea that categories are vicariously received, not individually invented, and the way someone divides up the world into categories is, in some sense, tradition bound and is communicated and 'passed on' through symbolic action. (Shweder & Miller, 1985, p. 41)

Social constructionism therefore proposes that the way in which individuals understand and interpret their world is historically and culturally specific and that, depending on experience, each individual is influenced differently (Burr, 1995). The way in which parent's view their experiences is a product of the social processes and interactions in which they are constantly engaged. For example, it has been noted in several research studies that culture appears to influence maternal expectations of development (Harkness & Super, 1995; Harwood, Schoelmerich, Schulze, & Gonzalez, 1999; Joshi & MacLean, 1997; Ninio, 1988; Williams, Soetjiningsih, & Williams, 2000; Williams, Williams, Lopez, & Tayko, 2000). Pachter and Dworkin (1997) also found that parental assessment of a child's development is often based on what they view to be 'normal' or 'abnormal' and Stern (1985) determined that these perceptions are formed well before the infant is born. Furthermore, Glascoe (1999a) suggests that parents' gauge their own child's development by comparing their children to other children rather than being familiar with professional developmental guidelines that identify what is 'normal' or 'abnormal'. As proposed by Bronfenbrenner (1979), an individual's experience, their family and social environments, influence these perceptions and the utilisation of a social constructionist framework enables an appreciation of these influences.

Accordingly, social constructionist's argue that how people interpret facts is socially constructed. People construct their own versions of reality depending on their social and cultural history. Realists would argue that there would be little benefit to be gained in a study that could not clearly identify the facts (Rice & Ezzy, 1999). Gergen (1973, cited in Burr, 1995), however, argues that since society and the people within it are continually changing that 'all we can ever do is try to understand and account for the how the world appears to be at the present time' (p. 11). Moreover, Gergen goes on to say that 'while the accounts of social construction cannot themselves be warranted empirically, if properly executed, such accounts can enable one to escape the confines of the taken for granted' (Gergen & Davis, 1985, p. 14).

Social constructionists focus on language as being a vehicle for and a way of, interpreting peoples' everyday understanding of the world (Burr, 1995). Language is viewed as a form of social action and is the motor force behind social change. Inviting mothers to discuss their experiences enables a reconstruction of the parent's understanding of events to be developed. Placing this information within an

historical, cultural and social framework enables recognition that each mother's experience is unique, as social environments influence experience and a mother's interpretation of events. Life history methodology enables the stories of mothers to be collected and interpreted.

Methodology: Life history

Lives and the experiences of individuals are often represented in stories (Denzin, 1989). In fact, 'we lead our lives as stories, and our identity is constructed both by the stories we tell ourselves and others about ourselves' (Rimmon-Kenan, 2002, p. 11). Life history is a methodology that provides an interpretive framework for understanding the actions and meanings of a person, or group of people, through the examination of narratives, stories or personal accounts (Martin, 2002). The life history approach focuses on the experience of just one, or a few people, creating a 'depth' of material that enables a clear picture of a particular experience or phenomenon to be studied (Miller, 2000). The individual not only has their own history of personal development documented, but it can be seen how the influence of historical events and social change at a societal level can impact on an individual's own life (Miller, 2000). Talking with, and listening to, people brings to the forefront the importance of understanding human subjectivity and individual lives.

Gergen (1998) suggests that within the social constructionist framework, life history accounts are influenced by history, culture and emotions. These influences do not negate the value of the accounts or conversation; rather they provide a framework by which the information may be interpreted. Gathering data via the life history method is an important way of seeking correlations between earlier events and current behaviour. By examining these correlations it may be possible to identify potential relationships (Vasta, 1979 cited in Zigler & Finn-Stevenson, 1986, p.39). These hypothetical relationships can never be tested directly with the participants. The life history approach, however, can serve as a basis for further research with other individuals and it also helps researchers understand determinants of behaviour. Clausen (1998) remarks that studies that look back on experiences also enable us to learn what resources in the community were helpful and how often the formal institutional structures failed to meet or even perceive the needs of the participants.

The mothers were asked to recount their experiences of raising young children whose developmental problems were not diagnosed until school age. Through these accounts, a social constructionist approach focuses on how mothers construct meaning from their experiences. Meaning, rather than 'truth-telling', reflects the influence of wider social processes that determine how a mother interprets, talks about and acts upon particular events. Gergen (1998) also suggests that how a person remembers and recalls an event is socially designated, in other words, the social environment and expectations at the time of recall influences the memory and how it is recalled. This is supported by the most recent studies on memory. Seigel (2001) explains that recounting memory is a social experience that is profoundly influenced by the social interaction at the time of recall. Seigel suggests that while the retelling of memory may not be an exact recounting, it is, more importantly, a powerful form of story telling that integrates 'the self with past, present and future life experiences' (p. 1009). Rimmon-Kenan (2002) agrees, suggesting that 'the act of narration is, at least partly, a response to the needs of the present, as distinct from an attempt at a faithful representation of the past' (p. 15). In other words, remembering is not fixed or absolute, rather, it is 'a re-interpretation of earlier experience, which can never be quite divorced from subsequent experience' (Harden, 2000, p. 511). Ellis and Bochner (2000) propose that 'in the final analysis, the self is indistinguishable from the life story it constructs for itself out of what is inherited, what is experienced and what is desired' (p. 746). Life stories are not separate from life. They are a reflection of past experiences and future desires.

The life history approach enables researchers to delve into the little known everyday world of individuals; in this study, the lives of mothers. While these stories may just be snapshots of a larger social group, they tell of the experience of those whom society claims to understand and know. It is, in fact, likely that we actually know very little and these snapshots can broaden our understanding of life as it is really lived (Denzin, 1989). Utilising mothers recall of significant events that occurred in their child's development and/or behaviour and interpreting this information within a framework that postulates that these narratives are true, relative to culture, social situations and historical perspectives, is relevant and important. Attention is drawn to the discrepancies between mothers' experiences, and their interpretation of them, and their lives as they are generally portrayed or understood to be.

In this study, multiple life histories were collected. This enabled dominant themes to be identified, making it possible to look for commonalities across the mother's experiences and to be able to theorise about general concepts and ideas. This practical approach to collecting and documenting a number of mother's stories gave focus to this study in a number of ways. Firstly, it gave the mothers an opportunity to tell their own story, which in turn, improved coherence and understanding of their own life by tying together the past, present and future. Secondly, collecting and documenting individual life stories provided information about a number of individual experiences and finally, the development of common themes helped me to gain insight into the workings of a wider community (Plummer, 2001). While there exists a number of different forms of life history, Denzin's (1989) interpretive biography, which entails the collection of personal life stories, enables a researcher to conceptualise and represent the life of a person whose experiences do not conform to existing societal perspectives.

Interpretive biography

Interpretive biography, a form of life history methodology is described by Denzin (1989) as the 'use and collection of life documents which describe turning-point moments in individuals' lives' (p. 13) and provided one part of the methodological underpinnings for the data collection and analysis. It is grounded in the social constructionist philosophy that a person's social life has a determinant role in establishing not only what experience an individual will have but how that experience will be interpreted (Hevern, 2001). Social knowledge is also socially constructed and these parents' beliefs, as well as their feelings, all contribute to their interpretations of their experiences.

Interpretive biography is a variant of life history and differs from other forms in a number of ways. Chamberlayne (2000) argue that the difference is that biography accentuates an historical orientation, whereas Cole and Knowles (2001) argue that the key distinction between biographical research methods and life history research is 'in the degree to which understanding of context play out in the search for understanding of individual or collective lives' (p. 22). However, most importantly for this study, interpretive biography differs in the respect that it involves the collection of personal-life accounts that focus on turning point moments, or epiphanies, in a person's life.

Turning points or 'epiphanies', defined by Denzin (1989) as 'interactional moments and experiences which leave a mark on people's lives' (p. 70), are important to this study, as they are incidents that 'stand out' in a mother's mind and enable recall of particular events. These pivotal moments may be gradual, or sudden and are primarily related to inner experiences that result in a change in a person's life (Jolly, 2001). These incidents form the basis of personal stories. They occur in situations where problems have arisen that require a person to reconstruct and reinterpret the experience to develop an understanding of it (Denzin, 1989). This reconstruction occurs within the socially constructed framework of the environment, in which that person resides, and so will be influenced by the cultural and social processes, which surround the experiences.

Cultural and social processes influence the reconstruction of memory and recall, and while it has been suggested that parent's memory not be used to recall events of child development (Neisser, 1982), incidents that stand out to the parents as unusual or different are often easily recalled. These epiphanies are the defining moments in time that shape a mother's subsequent experience. Even if these moments are not identified at exactly the moment they actually occurred, they will be incidents that occurred at some point prior to the child entering school and are therefore significant to this study.

Furthermore, the biographical method enables the researcher to be concerned for the way a specific person perceives and interprets the world around him/herself. This enables the interpretation to 'move toward the subject's perspective rather than the observer's point of view' (Smith, 2000, p. 298). However, as biographical methods rely on verbal and written expressions of meaning it is important to recognise that language can never be taken to be a clear, unambiguous statement of anything, including intention and meaning. A researcher is only able to understand and interpret a story from his/her particular socially constructed experiences, and through the perspective of the chosen ideology. Furthermore, participants are only able to present their stories through their own constructed experiences. As Foucault (1980) explains, 'the subject of self is neither singular nor fixed and power relations that shape the construction of life histories are fluid, unstable, dispersed and mobile' (cited in Cary, 1999, p. 424).

Influence of researcher on the mother's story and how it is interpreted

The influence of the researcher on the participant has been widely discussed in qualitative studies (Creswell, 1998; Huberman & Miles, 2002; Lincoln & Guba, 1985) life history (Cary, 1999; Clausen, 1998; Cole & Knowles, 2001; Denzin, 1989; Faraday & Plummer, 1979; Plummer, 2001), ethnographic studies (Atkinson & Silverman, 1997; Bochner, 2001; Brettell, 1997; Denzin, 1997; Ellis & Bochner, 2000; Holt, 2003; Reed-Danahay, 1997) and literary folkloristic studies (Stahl, 1985, 1989). Ellis and Bochner (2000) argue that this influence is unavoidable as no researcher is devoid of personal experiences and these experiences influence how they collect and interpret data: 'You can't eliminate the influence of the observer on the observed' (p. 747). A writer can no longer presume to be able to present an objective account of another person's experiences (Denzin, 1997, p. xiii), rather, both the storyteller and the listener influence the way the story is created and told. Schutz (1932, cited in Koch, 1996) and Heidegger (1962) both emphasised this co-creation by stating that, as human beings, our meanings are co-developed through the experience of being born human, our background, our collective life experiences and the world in which we live (Byrne, 2001b; Koch, 1995). Gadamer claimed that language is the way in which people share these experiences (Koch, 1996). How a person uses language to tell their story and how another person interprets those words is an intricate combination of personal knowledge, experience and the historical, cultural and social influences of the society in which both the participant and researcher reside. Understanding is also influenced by 'socially constructed discourses of class, race, ethnicity and sexual orientation' (Ellis & Bochner, 1996, p. 26). This does not diminish the value of the study if the researcher acknowledges these influences rather than pretends they do not exist.

Acknowledgement of limitations and influences is not always possible, as they may be subconsciously acquired understandings that are 'collected' through time. How information is interpreted is, therefore, bounded by the limitation of 'knowing what you know'. It is, however, possible for a researcher to acknowledge the limitations of their own interpretation and to recognise that their interpretation is just one of many potential interpretations. Furthermore, Johnstone (1999) suggests that the inclusion of a researcher's experience is a way of making the subjective experiences of others more visible and understandable. The commonality of human experience becomes evident, as researcher's and participant's lives are compared for the purpose of 'building shareable understanding of the life experiences of another' (Denzin, 1989,

p. 28). It is through these shared understandings that an increased appreciation of human experiences is gained. One way that people share their understandings is by telling stories.

Literary folkloristics

According to the social constructionist perspective, people are actively engaged in constructing and understanding their everyday experiences and they do this, not in some esoteric, abstract way, but by telling each other stories. These stories do not present a disconnected point of view, but rather are told from a particular perspective (Abma, 1998), that reflects the story-teller's personal experience, as well as the values and culture of the society in which s/he lives. To understand the perspective from which the story is told, it is necessary for a researcher to engage in a process of in-depth analysis. To this end, the literary folkloristic methodology, in conjunction with interpretive biography, has been adopted in this study.

Contrary to the immediate reaction that folklore studies focus on tales of the unbelievable that are useful only as bedtime stories, literary folkloristics is an interpretive methodology which proposes that literary theory be adopted to examine personal stories and their relationship to cultural traditions, within a particular social or cultural environment (Stahl, 1989). Stahl (1985; 1989), the key proponent of literary folkloristics, utilises the theories of deconstructive criticism, reader-response theory and folkloristic performance to analyse stories (Gould, 2002). Utilising a number of literary theories, the text is critically deconstructed to identify themes, attitudes and allusions that reflect existing societal expectations that influence how a person experiences life and tells their story (Williams & Holmes, 2005).

Important to the analysis of the text is the participation of the listener in the storytelling, and Stahl (1989) proposes that reader-response criticism is an essential element of literary deconstruction. Stahl emphasises the significance of the listener having an 'emic' or 'experience-near' perspective (1989, p. 7). This insider's point of view is an essential requirement of literary folkloristic methodology as the listener is able to hear specific and personally meaningful allusions that would otherwise be obscure to an outsider. To be regarded as an 'insider' Stahl argues that the researcher must share at least one commonality, or 'frame of reference' with the teller's folkgroup. This 'complex interaction between the narrator and the listener situates personal narratives in the context of performance' (Gould, 2002, p. 78). As

one member of the folkgroup tells her story to another there is a fundamental understanding that each mediates the private knowledge of the other.

A folkgroup is defined as '*any group of people whatsoever* who share at least one common factor' (Dundes, 1965, p. 2). Trubshaw (2003c) suggests that instead of thinking about the 'folk' as somehow 'other', folklorists now think that we are all folk:

> In the course of a day we interact with various other groups of people, such as our families, work colleagues, leisure-interest friends. Each of these groups has its own 'lore' and traditions (Trubshaw, 2003c, para. 8).

Bennett agrees (1996), and defines folklore from an academic perspective, as:

> (Lore is) a body of beliefs, activities, ways of making, saying and doing things and interacting with others that are acquired through informal, unofficial channels by the process of socialising in family, occupational, or activity-related groups. The "folk" in the old sense of a group of people distinguishable by class, education or location therefore disappears from the modern equation for it follows that we are all folk…..it follows that 'folklore' can be found anywhere and among any group of people (p. 12).

While this is a seemingly broad definition, which could, no doubt, be used to identify a multitude of different groups, 'mothers' as a folkgroup is unquestionable. Mothers share many experiences, perceptions, pains and rewards, and Western society views them as the (foremost) group who are responsible for raising children. Mothers whose children have developmental problems are part of this group, but share particular experiences associated with their experiences of raising a child with developmental problems. As the listener and interpreter of these mothers' stories, I also share the same experience. My child remained undiagnosed with a developmental problem until school age and I am therefore able to understand some of the folklore that influences how mothers' understand and interpret their experiences.

Linking literary folkloristics to interpretive biography, and hermeneutical philosophy

Stahl's literary folkloristic method (1985; 1989) is a form of interpretive biography. Both literary folkloristics and interpretative biography methodology, actively endorse the importance of the listener perceiving the world through the teller's perspective, although the listener's interpretation is acknowledged as value-laden and so influences the final analysis. Both have their philosophical underpinnings in Heidegger's existential phenomenology, which asserts that nothing can be encountered without reference to a person's background understanding and

experiences (Heidegger, 1962), and Gadamer's notion of prejudice, whereby the researcher brings her own values to the interpretation (Koch, 1996). However, unlike Heideggerian/Gadamerian hermeneutics, neither Denzin, nor Stahl seek to 'validate data analysis' with participants to ensure 'shared understanding' (Fleming, Gaidys, & Robb, 2002; Wiklund, Lindholm, & Lindstrom, 2002). The understanding, from Stahl's perspective, arises from the shared knowledge that exists as a result of the researcher's membership of the folkgroup. This is in keeping with Geanellos's (1998) interpretation of Gadamer's 'fusion of horizons', or shared linguistic, historical and cultural backgrounds, that preclude the need of checking interpretations with research participants.

Like Denzin, Stahl recognises that historical, social and cultural environments influence both the teller and the listener of a story, and it is important to recognise these influences and acknowledge them. However, unlike Denzin, Stahl emphasises that for an interpretation to be 'informed' (1985, p. 54) the interpreter must be part of the folkgroup being studied. Stahl claims that it is only through a 'shared frame of reference' (1985, p. 58; 1989, p. 33) that the significant aspects of the text can be identified and interpreted.

While, both Denzin (1989) and Stahl (1985; 1989) work with biographical material, Denzin utilises a broad range of media; written works, photographs, and film; Stahl focuses exclusively on literary works. These works are taped conversations or stories that are transcribed onto paper. The presence of the listener and the development of a relationship between teller and listener is very important, allowing the listener to share in the life experience of the teller. Stahl (1985) argues that without this shared knowledge, the listener is unable to recognise the important themes and experiences, and interpretation is likely to be less discerning of folkloristic themes.

Stahl (1985) recommends that the listener/interpreter must be knowledgeable in the folkloristic method and that thematic analysis be undertaken using a variety of literary theories. This is in contrast to Denzin (1989) who recommends that any analytical tool that increases the richness of the findings may be utilised, while focusing on 'epiphanies', or turning point moments. Stahl (1985) argues that the use of literary theories provides the reader with a comprehensive approach to

interpretation and enables recognition of the social, political and historical platforms that influence how and why a story is told.

The personal narrative or self-stories

This study draws on the personal narratives, or self stories, that mothers tell. While these two terms are often used interchangeably, Frank (2000) reminds us that people tell stories, they do not tell narratives. The term 'narrative' implies that a structure underpins the story, and although this may be so, a story teller is usually not fully aware of them, instead, she tells a story 'to reaffirm, possibly to create, and possibly to redirect the relationship within which the story is told' (Frank, 2000, p. 354). Both Denzin (1989) and Stahl (1985) agree that stories provide the teller with the opportunity to be heard and provide the listener with the opportunity to engage in a relationship with the teller that promotes understanding. Being able to engage in storytelling is an important part of everyone's existence. Turner (1996) suggests that by storytelling people are able to convert images that are stored in their minds to logical accounts of their experiences. Ricouer argued that people's identities as individuals require them 'to construct a personal narrative which attempts to make sense of the otherwise chaotic nature of existence' (1984, cited in Trubshaw, 2003b, para 90). A sense of belonging to the community arises from sharing these personal stories with others and, as Trubshaw (2003b) explains, is the key function of the lore which bonds folk groups together. This is particularly important to this group of mothers, as many of them have never been given the opportunity to tell their story, often not even to their own families who may live many miles away, and have no understanding of their experiences.

The self-story also gives the listener the opportunity not only to hear what is being said but to 'hear' the nonverbalised folklore – attitudes, values, prejudices and tastes - that is present but hidden within the story (Stahl, 1985). By describing personal experiences the mothers are able to identify a situation that they consider significant, the turning point moment (Denzin, 1989) that signifies a time of change, enlightenment, fear, distress or joy. Expressing such moments in story form encourages the mothers to reflect on their experiences and this, in turn, aids in the establishment of a sense of self and the development of personal values (Gould, 2002). Stahl (1985) contends that the expression of personal values is the hidden agenda in storytelling where the main character of the story and the teller are one in the same. She argues that the most effective way of identifying those hidden values

is to use a literary folkloristic methodology, which enables the covert to be disclosed and discussed.

Explanation of "how to" use Stahl's literary folkloristics

Stahl's (1985) literary folkloristic methodology provides the framework in which the reading of the stories of mothers, whose children were not diagnosed with a developmental difficulty until school, was analysed. While Stahl does outline a number of important considerations a researcher should take into account when conducting a literary folkloristic analysis of text, she does not clearly outline a particular method of analysis; instead she discusses a number of fundamental issues that need to be taken into consideration when undertaking interpretive research. First, the circumstances in which both the researcher and the storyteller find themselves should be identified. This enables me, as the researcher, to acknowledge that the interpretation has been influenced by my personal context and demonstrates shared perspective with, so that the story can be effectively deconstructed. Finally, I must take full responsibility for the interpreted document.

The method that follows therefore represents a combination of elements from Denzin's interpretive biography and Stahl's literary folkloristics. This method adopts Hendricks (1999) proposal that literary folkloristics contains a number of fundamental steps necessary to conduct a literary folkloristic inquiry:

1. Locating the participants within a given social category
2. Identifying the salient themes and experiences in the participants life
3. Connecting the participant's life story to wider social meanings, including communal and private folklore
4. Understanding that the participant's life story reflects a set of meaningful experiences which, when told, create an emotional bond between the teller and the listener
5. Realising that the private, inner meanings of the participant's experiences can never be fully illuminated
6. Interpreting the materials by sharing in the experience of the participant
7. Utilising the interpretive approaches of literary theory and criticism to analyse the life story materials
8. Acknowledging that the researcher creates the document that is interpreted

(adopted from Hendricks, 1999, p. 94).

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These steps will be fully discussed in the method section that follows.

Method: A literary folkloristic method

This is an interpretive, descriptive, exploratory study. A metasynthesis of Denzin's (1989) interpretive biographical perspective and Stahl's (1985) literary folkloristic methodology were used to describe and interpret the experiences of mothers who have raised children whose developmental delay had not been diagnosed until school attendance. The methodological steps taken in this approach, outlined previously, will now be discussed more comprehensively.

Step 1: Locating the participants within a given social category
This step entailed locating mothers, whose children had undetected developmental problems until school age, and gaining access to them.

The literary folkloristic method requires that the material to be interpreted be drawn from a particular social group. In this instance, mothers whose children have not been diagnosed with a developmental difficulty until school age were invited to participate in the study. While the exact number of children identified with developmental delay after school entry is not known in Australia, Glascoe (2000a) claims that more than 30% of children with developmental and/or behavioural problems are not detected prior to school entry. More recently, a comprehensive study is Western Australia revealed that more than 25% of children aged 4-6 years have developmental delays that put them at risk of later learning and behavioural problems (Hart et al., 2003). From this, it can be surmised that the number of parents who have experienced non-diagnosis of their children's developmental and behavioural problems is considerable.

While it is acknowledged that there have been changes in family and parenting roles over recent years, the primary caregiver in the family continues to be the mother (Roe & Morris, 2004; Sanders et al., 1999; Sarantakos, 1996). Twelve mothers, whose children attend, or did attend, local schools in a North Queensland community, self selected for in-depth interviewing. In this study, all but one of the mothers contacted me in the first instance and volunteered their time and information. Their calls were made to me in response to friends talking about the study, a local newspaper article and a radio interview in which I had talked about my

proposed research. I interviewed all the mothers who contacted me and lived in the North Queensland region. Offers from mothers living in other Australian regions, while very welcomed, were declined due to the financial limitations of my study and my desire to conduct face-to-face interviews. In all, 12 mothers told me their stories, but only eight stories were read for the purpose of analysis. Of the four mothers not included in this study, two had children whose developmental problems were diagnosed in pre-school (at the age of 5 years), one had raised her child in an African nation, having recently moved back to Australia in order to obtain special schooling for him, and the fourth mother's child had a number of chronic illnesses which made it difficult to separate out information in relation to developmental problems.

'Life history research rarely involves a random sample of informants' (Goodson & Sikes, 2001, p.24) and self-selection is an appropriate way of selecting participants for an exploratory study (Polit & Hungler, 1995). While non-probability sampling is argued by quantitative researchers to be biased, it is the bias that is important to the study. It is important to acknowledge that all human knowledge and experience that is expressed through verbal accounts is 'essentially biased' (Goodson & Sikes, 2001, p.25). Everyone sees the world through different frames of reference, which develop as a result of their own personal attributes, or experiences of being situated in particular social, historical, geographical, political or religious contexts. This bias also applies to the researcher, as I have discussed previously.

Eight participants represent the usual number of participants in an interpretive biographical study where a small number of participants are interviewed in depth (Russell & Gregory, 2003). Analysis of data is comprehensive and prolonged and time constraints are important to consider in a study that must be completed within a strict time limit. Furthermore, this was an exploratory study and the focus was based on an in-depth appreciation of parent experiences. Rice and Ezzy (1999) support this approach, proposing that qualitative research is not concerned with the size of the sample, rather it is the quality, depth and richness that are important.

Because of the importance of language in the social constructionist framework and literary theory, participants needed to be able to express themselves clearly. Plummer (1983) reinforces the need for participants to be articulate, so that information gathered would be valuable to the study. One of the mothers interviewed

for this study declared English to be her second language, but having lived in Australia for more than 20 years her English was excellent and she was able to talk about her experiences clearly and expressively.

It is important to recognise that there were a number of possible diagnoses within this group of children whose developmental problems were not identified until school age. Attention deficit/hyperactivity disorder (ADD & ADHD), Asperger's syndrome, specific learning disorders, dyslexia, dysgraphia and multiple categories of behavioural problems, are just some of the potential diagnoses (see pp. 115-119 for definitions). Because this study was exploratory in nature, a heterogenous group of the children from a variety of regional areas within North Queensland was sought, rather a homogenous group of children selected from one particular school and with one set of criteria for a particular developmental or behavioural disorder.

Ethical considerations

The James Cook University Human Ethics Committee granted ethical approval for this study. Consideration for the well-being of the participants was of utmost importance. Mothers were informed of the intention of the study by an introductory letter (Appendix A). This letter was designed to clearly outline the aims of the study, the interview process and the requirements of the participants. It was drawn to the mothers' attention that some may feel emotional repercussions as a result of looking back on their past experiences and so counselling service contacts were noted for their use if necessary. To my knowledge, none of the mothers utilised these counselling services after the interview.

Prior to the interview, the mothers read and signed a consent form (Appendix B), which again outlined my responsibilities as a researcher and their right as a participant to stop taping and/or withdraw approval of the use of their story, at any time. All mothers, however, expressed delight at the opportunity to tell their story and were keen to offer further information if required. This response was partially anticipated as many participants in previous life history studies have demonstrated an eagerness to share their stories with others (Armstrong, 1987; Atkinson, 1998; Cole & Knowles, 2001; Hansebo & Kihlgren, 2000; Humphrey, 2003; Miller, 2000).

Telephone follow-up was conducted 2-3 days after the interview to thank the participants and to enquire as to their well-being. No mother indicated any

reluctance for, or ambivalence towards, the utilisation of her story in the study, and none indicated their need for further follow-up or counselling, although one mother later contacted me with a query about her child making the transition from primary school to high school.

Confidentiality

The confidentiality of the participants was protected in several ways. Interviews were conducted in the privacy of the mothers' own home where possible. Names of any place or person that appeared in the transcribed interview or field notes were removed or replaced by pseudonyms. In accordance with National Health and Medical Research Council (NHMRC) guidelines, the interview tapes and transcribed notes are kept in locked cupboards and consent forms and identifying data are locked in a cupboard separately from the interview tapes and transcribed papers. Data will be stored securely for a period of five years. After this time it will be managed in keeping with the James Cook University data storage guidelines. Access to the original documentation was restricted to my supervisor and myself.

Step 2: Identifying the salient theme and experiences in the participant's life

This step entailed a process whereby the mothers' stories were listened to and recorded in a mutually conducive atmosphere.

The mothers participated in semi-structured interviews that provided biographical data for reading and analysis. In keeping with Denzin's (1989) interpretive biographical method, which suggests the researcher begins by obtaining a chronological set of events and experiences that mark particular events in the participant's life, mothers were asked to recount their life experiences as they related to remarkable events such as birth of their child, particular moments that may have raised their concerns about their child, or the availability of community support. For many of the mothers, certain events were unforgettable. These turning point moments, or epiphanies (Denzin, 1989) often formed the basis of what Stahl calls a 'theme'. Stahl (1989) observes that when a storyteller engages in the creation of a personal story, personal values are articulated through themes.

Themes are usually chosen to demonstrate a particular characteristic, behaviour or attitude that the storyteller considers an important representation of self-identity. These themes can be represented in a variety of forms: themes that characterise

the teller as honest, clever, brave, generous or motherly, for example; themes that are humorous and may involve embarrassing situations or incongruent occurrences; or, finally, themes that expose moral lessons, such as unjust situations or how practical problems need to be managed (Stahl, 1989, p. 28). These themes are often closely tied to expected cultural 'norms' and represent particular folkloristic traditions. For example, most of the mothers talked about their close relationship with her child. The theme of 'motherly behaviour' arose as a result of an unforgettable experience where they were made to feel like 'bad mothers'. Telling stories is a way in which mothers expressed these experiences.

Interviews allowed mothers to tell their stories to an interested listener. The interviews conducted in this study were semi-structured in style, with 'prompt' questions utilised only when it was necessary to aid the mother to continue. Some mothers required more 'prompt' questions than others. These questions were carefully phrased to avoid inflicting psychological harm and the participants were given the opportunity to comment at the end of the interview session. These questions were designed to help the participant consider 'turning point' moments in their experiences. Examples of prompt questions included:

- When did you first feel that your child might have been different to other children?
- What differences did you notice?
- What do you believe may have influenced your ability to notice these differences in your child?
- Can you recall what you did or what others did in regard to your concerns?
- How easy was it to access someone who could assist you in regard to your concerns?
- Did you feel that raising concerns with health professionals was successful?
- Do you believe you learned your parenting skills from others or did you learn them as you went along?
- What happened when your child started school?
- Tell me how you found out your child had difficulties at school?
- Were you able to easily access support for your child?
- Do you feel a diagnosis made it easier to access support?
- What other differences did a diagnosis make for you?
- Are you concerned about your child's future?

A pilot interview was undertaken to determine whether the question prompts were appropriate and if the specified interview process generated the desired amount of information and experiences, or whether a shorter or longer time period was required. Most interviews lasted between one and one and a half hours.

Once the material was collected and transcribed by the researcher, the mothers' stories were analysed and themes generated. Thematic analysis was loosely directed by Glaser and Straus's (1967) technique of sorting the information into specific themes, identifying major categories, and re-sorting the data into three major categories. Bronfenbrenner's (1979) ecological model of child development was utilised as a tool to guide category development. Microsystem relationships, between mother, child and the local community, including families, community members, schools and health professionals were considered. Exosystem relationships between the mothers and services such as social services, the health services and educational system were also considered. Finally, macrosystem relationships that take into account the role of culture, beliefs, laws and political and economic policy, helped guide categorical and thematic development. Once the major themes were identified, they were interpreted in respect of larger societal structures, such as cultural issues, ideologies and historical context (Denzin, 1989). The influence of folkloristic traditions was illuminated through the lens of three literary theories (Stahl, 1985): semiotics, neoMarxism and Foucauldian post-structuralism, which are addressed later in this chapter.

Step 3: Connecting the participant's life story to wider social meanings, including communal and private folklore
This step links the mothers' stories to wider cultural influences, drawing attention to the socially constructed nature of the mothers' experiences and how they make sense of those experiences.

Culture, history and the environment all influence the experience of mothers and how they tell their stories. Viewed from the social constructionist perspective, a person's social life plays an important role in establishing not only what experience an individual will have but how that experience will be interpreted and understood (Hevern, 2001). How society perceives the role of mothers is reinforced by actions and language that support folkloristic notions of maternal instinct, caring and the

responsibility for a child's wellbeing. These folkloristic customs are powerful players in how a mother experiences her motherhood and what sense she makes of them.

Stahl (1989, p. 45) proposes that there are two kinds of folklore that influence what people value and believe, one is 'communal' folklore, the other, 'private' folklore. Communal folklore is recognised as being widely shared and is even, sometimes, substantiated through research, whereas, private folklore is exclusively generated and shared by a given group. Trubshaw (2002) describes communal folklore as the activity of 'collective memory' (p. 43), where social function plays a role in the maintenance of certain 'images', values or beliefs. In other words, what a group values and believes is socially constructed. For example, folklore considered important to the function of society, is reproduced through stories, actions and beliefs, by 'drawing upon and simultaneously recreating the underlying assumptions and preconceptions of society' (Trubshaw, 2002, p. 98). Historically, socially constructed communal images of motherhood invoke a picture of the loving mother whose main focus in life was to care for the family. 'Maternal instinct' drove women to have children, as only then, could life be considered fulfilled (Badinter, 1981). Ideologically, motherhood was 'romaticised as self-sacrificing, life giving and forgiving' (Glenn, 1994 cited in Read, 2000, p. 71). This communal lore was reinforced by the research of Bowlby (1951) whose studies into the concept of maternal deprivation had a powerful influence on the concept of mothering. Bowlby argued that children needed their mother for satisfactory emotional development. A mother, who was not continually available for her child, was a poor mother. 'Normal' mothering was said to necessitate a mother to be 'ready, waiting and unhurried', 'attentive to her child's every need' and 'completely and exclusively devoted' (Badinter, 1981, pp. 177-180). This folklore has been reinforced in recent years by the 'professionalisation' of motherhood. Mothers are encouraged, and expected as 'good mothers', to maximize their child's development by actively seeking out information as a professional would (Woollett & Phoenix, 1991). While Woollett and Phoenix (1991) argue that this social construction of motherhood actually runs counter to the reality of motherhood for many mothers, it remains the pervading folklore, in spite of recent feminist attempts to persuade the public otherwise.

Private folklore is the lore that exclusively exists between a specific group of people, such as mothers. Mothering traditionally takes place in the family home. It is conducted in the private world of the family, and it is within this private arena that

most child rearing takes place. An important element of the traditional construction of motherhood is that mothers should ensure that neither their children nor the mothers themselves come to public attention (Wicks, 1987 cited in Phoenix & Woollett, 1991). Mothers who are concerned for the wellbeing of their children must deal with their problems outside of the public eye. Communal lore acknowledges children and accepts them – but only if they are responsible, well behaved and educated appropriately. To this end, the state provides child health clinics, economic support and educational facilities to assist parents in raising children whose behaviours are acceptable to the society in which they are growing up (Phoenix & Woollett, 1991). Mothers who are concerned for their children's health and welfare may find that they have to move out of the 'quiet' protection of the family, and of services provided, to advocate in a more public arena. This often requires negotiating with others who are influenced by a communal folklore that differs from the private folklore of mothers.

Mothers whose children have developmental problems develop a private folklore as a consequence of the familiarity of their experiences. Often, these children do not 'fit' the socially acceptable model of a child, they may not behave appropriately or focus on an academic task in the classroom environment, they may not socialise well or they may not be able to learn as easily as their classmates. Like most mothers, these mothers often go to considerable lengths to provide the best possible life and future for their children. They want them to be healthy, happy and to grow into healthy and happy adults (Read, 2000). To achieve these aims, they often strongly advocate for their children, but while society acknowledges the role mothers play in raising their children, the raising of her voice is denied. For example, a mother whose child has learning difficulties may privately recognise that her child's academic support needs are higher than that of other children and she will request for additional assistance from the school. Communally, the lore surrounding child achievement is that children can learn to read and write in the existing schooling system, and even though this particular child struggles with these tasks, unless the child is tested to be more than two years behind his/her classmates, additional classroom support is often unavailable (Education Queensland, 2005a). This clash between the private folklore of mothers and the communal folklore of society creates an environment in which the voices of mothers strain to be heard. This is particularly apparent in Western society where a mother's concern often remains unheeded unless validated by experts.

Expert opinion is highly valued in the folklore of Western society, particularly the opinion of medical professionals. Habermas refers to the social structure of society as the 'lifeworld', where members of a culture or community share taken-for-granted understandings, convictions and expectations (Outhwaite, 1998). Habermas (1984) argues that there are elements of our social structure that deny individual freedom and growth by imposing unnecessary forms of social control. He suggests that medical professionals 'colonise' the lifeworld by using power to limit access to specialised knowledge and using power-laden communicative techniques to create a situation whereby a patient's questions can be ignored or labelled 'neurotic' (Grbich, 1999, p. 25). For example, mothers who raise questions about their child's development may be considered to be unknowledgeable, irrational and their fears unfounded. However, Habermas (1972) suggests that 'emancipatory knowledge', whereby reflection and awareness can assist people in asserting themselves and taking control of their lives, would create a free and equal environment (Grbich, 1999). In recent years researchers have increasingly listened to mothers, and the publication of mothering stories and perspectives has done much to legitimate their voice. This has

> …allowed the comparison to be drawn between the views of women and those of 'experts', while attention has also be drawn to the gulf that exists between the idealized prescriptions of mothering and the daily experience of many women's lives (Read, 2000, p.81).

Much of the communal folklore about children's developmental delay is underpinned by the notion that the child eventually 'mature' and their problems disappear (Glascoe, 1998, 2000a). In situations where the child has not improved, mothers' responsibility and close proximity to the child have always made, and continue to make her a prime suspect when things go wrong (Woollett & Phoenix, 1991). While recent studies suggest otherwise, the 'mother blame' folklore has been seen as a satisfactory response to an otherwise unexplainable phenomenon. Neither the state, nor the medical profession or educational system wish to accept fault, so blaming the individual is a way of avoiding liability. More recently, child development problems have been blamed on 'broken' families, single mothers, mothers who work, or homosexual mothers (Read, 2000).

Recognising that wider communal folklores influence how society interprets a mother's action that is often different to the private folklore of mothers is an important consideration in this study. Giving mothers the opportunity to voice their

experiences in a non-threatening, sharing environment may help to bridge the gap between what is actually happening and what society acknowledges.

Step 4: Understanding that the participant's life story reflects a set of meaningful experiences which, when told, create an emotional bond between the teller and the listener

Stahl (1985; 1989) suggests that accurate interpretations of a text can only be possible if, in the telling and hearing of the story, the researcher is able to create an emotional bond with the participant. This emotional bond is created prior and during the interview and Stahl (1985; 1989) refers to this as the establishing of intimacy, that is, a security in feeling known. The development of intimacy between the teller and listener 'creates a sense of security for the teller, and allows for an experience to be shared openly' (Stahl, 1989, p. 38).

Mothers who offered to tell their story were all contacted by telephone in the first instance. The conversations that ensued, while intending to be a 'hello, how are you, thank you for contacting me, would you like to meet?' often progressed into an exchange of intimate information about our children and our experiences. Several of the mothers expressed their desire to know more about why I had embarked on such a study. Sharing information created a bond that flowed through into the interviews.

When organising the interviews I was aware of the importance of promoting a secure and non-threatening environment, so the place of interview was selected by the participants, and in all cases, was at the mother's place of residence or at a friend's house where the mother felt comfortable. Enabling mothers to tell their stories in an intimate and comfortable environment facilitated continued relationship building and gave the mothers the opportunity to feel relaxed about recounting their life experiences.

The basis of effective communication, according to Stahl (1989), is shared cultural resources. Shared culture exists when both the teller and the listener recognise that they have similar experiences, or a shared body of knowledge, on which they draw to bring meaning to a story. Intimacy occurs when both the teller and the listener recognise 'that cultural resources have been shared *and* that certain personal facts or ideas have been expressed' (Stahl, 1989, p.42). Intimacy develops as the teller

and the listener enjoy the realisation that the experience is mutually understood. Most importantly in this study, the development of intimacy ensures that the teller does not experience the perception of feeling devalued by the researcher. This is particularly important to these mothers who, at times, have felt devalued by others who have not taken their concerns seriously or felt they have not been listened to (Read, 2000). Needless to say, the mothers were all eager to share their stories, particularly when they understood that I had also had a similar experience.

Step 5: Realising that the private, inner meanings of the participant's experiences can never be fully illuminated

Interpretive biography and literary folkloristics places the listener in a special position that affectively draws the listener into the teller's point of view (Hendricks, 1999). The stories of mothers whose children are not identified with developmental problems until school age portrays a part of the mothers' lives whereby particular circumstances, which present turning point moments in their life trajectory, are related as proof of their experiences. While what one person chooses to tell another person is influenced by both conscious and subconscious desires and motivation, Stahl (1985) contends that literary folkloristics assumes that the hearing of the text is a creative act in which the listener's own store of cultural and personal resources is used to produce meaning. Folklore has a profound influence on how a person tells their story and how the listener interprets that story.

Everyday life is much more deeply interwoven with folklore and folk customs than is commonly supposed (Trubshaw, 2003c). Folklore is not superimposed on a group, rather, it is profoundly entwined in its existence. Bascom (1965) asserts that the essential purpose of folklore is to validate culture, educate people and maintain conformity. Whether people are aware of it or not, folklore has a strong influence on how they see the world, how they interpret actions and how they tell their story. Folkloristic beliefs become acculturated through schooling, social interactions, social rules and other processes and very few adults ever question these implicit beliefs about everyday life (Trubshaw, 2002). Therefore, people's experiences and their meanings are expressed on the basis of existing social and cultural folklore. A mother's experiences can never be fully illuminated because these beliefs are often regarded as 'customary practice', unselfconscious activities that are not thought of as being folklore by the participant, but merely as manifestations of a 'normal' life (Trubshaw, 2002). Mother's may not talk about certain aspects of their experience,

expecting the listener to 'know' about customary behaviour and expectations or experiences. They may also deliberately omit certain experiences from the discussion, believing that these experiences do not reflect customary 'motherly' practice.

How mothers tell their story may also be limited by language. Habermas (1984) sees language as a medium of control, and this is particularly evident in the way mass media is used to regulate what people hear and read (Outhwaite, 1998). This, in turn, influences how people see the world and interpret their experiences within that world. Foucault (1973; 1977) argues that this form of control is powerful, as it limits people's access to knowledge. Knowledge is limited by what our language and culturally associated discourses allow us to see. Language is also time and context bound (Gergen, 2001; Habermas, 1984) and so fully understanding what a person is saying may not be possible for a listener whose understanding comes from a different context. The development of intimacy between the storyteller and listener is important in reducing the contextual gap.

The use of language is an essential element in the interviewing process. While interviewing as a research method has been criticised on a number of grounds, most commonly the inability of both the participants and the researchers to be objective (Creswell, 1998), it is precisely the subjectivity that allows the story to develop its character and uniqueness. Atkinson (1998) argues that 'telling the story implies a certain unique point of view....stories are value laden and value driven' (p. 60). How a person chooses to tell their story is entirely their decision, because that person is the authority on his or her own life. Likewise for the researcher, writing down another person's story is like painting a portrait. No two artists paint the same portrait yet, according to the interpretation of each of the artists, both paintings are faithful portraits of the subject.

Within literary theory the transcription of interview from text to tapes is regarded as communication. The conversion of oral message to written script allows the researcher/listener to purposefully document the storyteller's story. Once converted to transcripts, the researcher is able to 'read' the text and derive meaning from it. Barthes (1972a) contends that a reading of the text consists of actively constructing meaning, rather than passively deciphering it, and this reading produces only one of many possible interpretations. Most importantly, Barthes (1972a) identifies that the

interpretation is that of the reader, not of the author/teller. Accordingly, it must be acknowledged that the inner meanings of the experiences of mothers may never be fully illuminated and that any meaning derived from the text is based on the researcher as reader's interpretation of the text.

Step 6: Interpreting the materials by sharing in the experience of the participant

Being part of the private folklore, establishing intimacy and contributing to the understanding of the mothers' experiences are important aspects of this study. Both Stahl's (1985) and Denzin's (1989) method of biographical analysis emphasise the importance of the researcher being an 'informed reader'.

> The informed reader is one who knows the language used in the story; is able to take the teller's perspective; is willing to take full responsibility for their interpretation of the story; has experience of the issues raised in the story; is conversant with a range of theories which aid interpretation of the story and knows that meaning is created by the reader and that there is not one true meaning for the story (Hendricks, 1999, p. 121).

This approach is also supported by Bronfenbrenner (1979), who attests that a researcher can understand what is happening in a given setting

> …provided the observer has participated in the setting in the roles similar to those undertaken by the participants and is a member of, or has had expensive experience in the subculture in which the setting occurs and from which the participants comes (p. 31).

Recognising that I came to this project as a parent who raised a child with a learning difficulty, I have loosely adapted an autoethnographic approach to the narrative style. Denzin (1989, p.27) refers to this style of writing as 'the incorporation of elements of an author's own life experience into another person's story'. Stahl (1985) sees this as an important way to establish intimacy. This form of writing enables personalised accounts of my own experience to extend understanding of a particular story (Holt, 2003; Reed-Danahay, 1997). Where appropriate, my story has been interwoven with the stories of the mothers. This alerts the reader to those personal experiences of mine that have influenced how I interpret particular parts of the stories. Some stories were so familiar to my own that I was able to include considerable commentary; other stories were so different, that they stand on their own. Ellis and Bochner (2000) argue that interweaving one's own story allows for a greater understanding of another's experiences. However, whereas the focus of their work is the researcher's story, the focus of this study is the mothers' stories. My story is merely a tool for interpreting the experience of others and acknowledging

that I perceive these stories through my own particular lens. It also allows me to acknowledge that I have experienced similar experiences to those of the storytellers and consider myself a legitimate member of their folkgroup.

Step 7: Utilising the interpretive approaches of literary theory and criticism to analyse the life story materials

Both Stahl's (1989) literary folkloristics and Denzin's (1989) interpretive biography emphasise the importance of understanding both the context and 'frames of reference' of the storyteller when interpreting life stories. In this way, both wider cultural influences and an individual's personal experience can be acknowledged and considered in the interpretation. Stahl (1985) emphasises that folklore is best interpreted by combining several different literary approaches. Such a comprehensive analysis enables the reader to recognise the influence of both the wide-ranging communal folklores of the society (the context) and the influence these may have on the personal folklore of the storyteller (the frame of reference). In this study, the following literary approaches were used to read the mothers' stories:

1. Semiotics – in particular, Roland Barthes' use of mythology and attention to signs that are used to construct meaning;

2. NeoMarxist criticism, which regards the social and historical context of the text as fundamental to interpretation; and

3. Foucault's description of power and discourse.

Reading the stories through the lenses of these three theories enabled the development of an interpretation of the mother's experiences. The following section provides an overview of the three literary theories that has provided the theoretical lenses through which the stories of mothers, whose children are not diagnosed with developmental problems until school, were read.

Literary theory

Literary theory is a form of scholarly critique which allows a reader to illuminate the underlying meaning of a given text by critically analysing it in relation to historical, social or political perspectives (Eagleton, 1989; Jefferson & Robey, 1993). The accounts that literary theory provide do not remain focused on the text, but draw links between the reading process and the societal influences and personal experiences of the writer and reader (Traynor, 1999). A framework, or set of principles, guides interpretation of the text, enabling the reader to deconstruct and reconstruct meaning based on a particular position (Harrison, 2001). For example, a

Marxist-orientated reading of a text would reflect a different set of social and political assumptions from a Foucauldian one. Literary theory, therefore, provides a means of identifying different critical opinions and the basis for constructing a rational interpretation of the text. It is a form of inquiry that enables meaning to be found through the interpretation of textual language (Byrne, 2001a).

Modern literary theory arose in the mid twentieth century when the structuralist and post-structuralist critics began to analyse the relationship between words, or groups of words, and the surrounding social, economic or linguistic conditions (Selden, Widdowson, & Brooker, 1997). Prior to this, the major school of literary theory, 'formalism', focused on the internal organisation of a text and the inherent meaning in the formal features of the text (Jefferson & Robey, 1993). The structuralist approach, derived from formalism, emphasised order, structure and rules, but also assumed that the source of meaning in the literary work was neither the writer's nor the reader's experience but arose from the set of relations and rules governing language (Selden et al., 1997). Poststructuralism, on the other hand, was influenced by the climate of postmodernism, which emphasised that 'reality is a plural, and there are multiple positions from which it is possible to view any aspect of reality' (Cheek, 1998, p.20). Meaning was no longer considered as a given, because the world was constantly changing (Eagleton, 1989). Poststructuralists focused on the way language, history and social environments operated to influence meaning in text.

More recently reader-response theory has acknowledged the importance of the reader as the crucial figure in literary theory (Iser, 1979), and the subjectivity of textual analysis, as the reader recreates the literary text in response to his or her own experiences and social background (Rosenblatt, 1995). When analysing literature, a reader is encouraged to consciously reveal, rather than bracket or conceal, their own personal values and views of the world (Cheek, 1998). Literary works are therefore interpreted 'in light of our own concerns' (Eagleton, 1989, p.12). These concerns, used in combination with an assortment of literary theories, enable a reader to critically analyse the text by encouraging an extensive evaluation of the ideas and themes that arise in relation to historical and social influences.

In this study, a poststructural approach to the analysis enabled me to focus on the content and the meanings that arose from the text, particularly in terms of their

social and historical 'situatedness' (Cheek, 2004), rather than adopting a more traditional approach where the component parts of the text are analysed in terms of grammar, composition, stylistic errors and the like. A discussion of the literary theories utilised in this study, semiotics, neoMarxism, and Foucauldian poststructuralism, now follows.

Semiotics: Roland Barthes and mythology

Semiotics, is a term given to the study of signs as they function in human experience and appear in texts (Lavers, 1982). Signs are used by people to communicate and make meaning by selecting elements from a system and combining them according to established rules (Moon, 1992). Ferdinand de Saussure (1857-1913), a Swiss linguist, proposed that the interpretation of language was an important way of developing insights into sign systems which, he argued, were the source of 'meaning' for human existence. Saussure focused on why particular words were used to develop an organised structure of signs and how their meaning depended on the differences with one another (Cobley & Jansz, 1999). Saussure suggested that the system of language (*langue*) is based on rules that are fixed and unalterable, but that the signs, or words themselves, are essentially arbitrary (Klages, 2001b). For example, it is only by social convention that we understand that the word 'pillow' means a soft, cushiony object on which to lay one's head. Saussure proposed that the word could just have easily been 'snorkum', 'blonk' or 'trase'; in other words, the word itself is a random conglomeration of letters. This abstract system of letters and words is governed by rules that, Saussure suggests, just happen to be agreed upon by a group of people. Furthermore, Saussure put forward the view that when we hear the word (*signifier)*, 'pillow', we only know what the word means through *difference* - by what it is not (Cobley & Jansz, 1999). By excluding options, the listener or the reader is able to attach a meaning to the word (*signified*). These signs of language can be combined in many ways to convey many different meanings (Thody & Course, 1997).

Roland Barthes (1913-1980) a French professor of literary semiology, built on the work of Saussure. Barthes saw literature and its structure as the way of knowing about society, particularly in relation to taken-for-granted assumptions imbued within the text. Barthes, unlike Saussure, contends that signs are not arbitrary, rather, they are the response to a particular social context (Culler, 1983). Barthes also claims that people make sense of the world by using words. Feelings, thoughts and ideas

are put into language, both consciously and subconsciously; making words an important way of knowing and understanding the world. An analysis of text therefore enables a relationship to be established between the text, certain cultural beliefs and values.

Barthes (1972a) asserts that the reading of a text consists of 'actively constructing a meaning', since the text can be subjected to multiple interpretations. The text may have different meanings for both the writer and the reader because all readings are subject to the influence of outside forces, such as personal experience and social interactions. This social influence is not restricted to subjective life experiences, but can extend to scientific, 'objective' study in general. Thomas Kuhn (1970) has argued that what emerges as a 'fact' in science, depends upon the frame of reference which the scientific observer brings to the study. Feyerabend (1975) argues that scientists conduct and write up their studies within the conceptual limits of their own particular scientific discourses, which is itself influenced by a particular historical background, society and culture. Even Albert Einstein's theory of relativity acknowledges this social construction of science, as 'the length of something depends on who is measuring it' (Hams, 2003, p. 29). All interpretations differ, and Barthes (1972a) argues that none 'stand apart in the place of truth'. Derrida (1966) earlier makes this point, proposing that the discovery of meaning in text can never be final. Like the layers of an onion, the meaning of text can be peeled again and again. There is no certainty of meaning and no one reality (cited in Selden et al., 1997, p.170-174). Derrida builds on the philosophy of Plato, who postulated that there was only one 'Ideal Realm', wherein dwelt all the ideal forms, and earth was merely an imperfect replica of these ideal forms (Murfin, 1989b). Plato proposed that artistic impressions of worldly events were imperfect copies of already imperfect copies. Deconstructionists adapt this philosophy by suggesting that every repetition repeats with a difference, there are no perfect representations because something is always added or taken away, emphasised or de-emphasised (Murfin, 1989b). This multiplicity of meaning challenges researchers to recognise that it may never be possible to elucidate the inner meanings of experiences of participants. However, Barthes suggests that understanding the underlying social myths may assist in appreciating how text can reflect the social and cultural values that influence an individual's interpretation of their experiences.

Mythology

Myths, for Barthes, are the expression of significant social phenomena that 'goes without saying' (Lavers, 1982, p.104), and he suggested that mythology can be used to illuminate the significance of social activities and happenings of life as they 'appear' in text (Barthes, 1957/1973). Essentially, myths are seen as an important component and manager of social structure (Campbell, 1988), and are widely reinforced by representation in story, language, behaviour and social organisation.

While one could argue that Barthes' focus on mythology was merely a reflection of the academic arena to which he was exposed, it was also an extension of Saussure's analysis that text was a window into the cultural ideals of society. However, the emphasis on mythology, an ancient concept, had also been rejuvenated across a number of academic domains during the period of Barthes' studies. Austrian psychoanalyst, Freud (1950), interpreted myths as substitute gratifications that represent repressed desire; Jung (1949) claimed that myths were a representation of an inherited, collective unconsciousness; Kerényi, (1949) espoused that mythology lay the foundation of the meaningful world (Jung & Kerenyi, 1973, p. 161); and the anthropologist Malinowski (1884-1942) contended that myths were a lived reality that contained uncomplex, practical rules for the members of society (1954, original pub.1926). Malinowski focused on the interconnection between myth and culture, arguing that cultural mythology articulates the boundaries necessary to maintain the social and cultural life of people.

> Myths are not idle tales, but a hard working active force and a pragmatic charter of moral wisdom. Myths reveal a greater and more relevant reality, which determines present life and activities of the society and discloses the motive for ritual and moral actions (p. 79).

In the structural anthropological world, Levi-Strauss (1962, translated 1966, p. 22) understood myths to represent deeply buried primitive thoughts that were constantly changing in the light of new experiences. Unlike Malinowski, Levi-Strauss proposed that myths convey complex abstract thinking (Trubshaw, 2003a) that expresses a culture's understanding of itself as a community and enables articulation of people's roles within that group. Eliade (2003) agrees, and proposes that myths, while reflecting the social order of a culture, also actively construct the social institutions and direct individuals to appropriately supportive roles that ensures smooth the running of a society. Although Eliade has been criticised for tying myths too closely

to religious beliefs (Trubshaw, 2003a), his notion that myths actively impact on societal stability draws attention to the important role they play in everyday life.

Myths are coded messages, 'ideological impositions that create delusions of normality and this is the way it has to be' (Culler, 1983, p. 33). For example, for the French, wine is not just a drink, it is an important part of social interaction and Barthes would argue that in generating mythical meaning, cultures make their own social behaviours appear to be 'facts of nature' (Culler, 1983, p. 34). However, objects can only be suitable for mythical use if they are recognised as part of social usage and produce a 'meaning-effect' (Lavers, 1982, p. 106). Barthes, in his publication *Mythologies* (1973), shows how language, behaviour, fashions, advertisements, toys and wine, amongst other social usages, are all signifiers of deeply embedded social myths. These myths have social importance as they define underlying social values that then, often subconsciously, effect people. People draw on a common culture, and the myths associated with this culture affect how they interpret what is being said or written.

There is, of course, a literature devoted to the myth of motherhood as it appears in a wide variety of cultures around the world, including Aboriginal cultures. Mythologically, the role of motherhood has its origins in the ancient civilizations. From Greek mythology arose the archetypal mother figure - Gaea, mother earth - who wanted all her children whether they were good or bad (Athena, 2003). Mythical goddesses continue to exert a powerful influence on contemporary conceptions and analyses of motherhood. Max Weber identifies that as a society, we imagine people as 'ideal types'- which embody particular characteristics and qualities (cited in Samuel & Thompson, 1990, p.11) and these are often based on historical mythological characters. The myth of the 'ideal' mother is one who is exclusively caring, loving and patient, home-based, self-sacrificing, acting for others, especially for children. Like the Greeks, Jung would describe her as the 'earth mother' archetype (Jung, 1974; Jung & Kerenyi, 1973, p. 157), an older female who cares for and is responsible for the generations to follow. According to Jung (1974), the mother archetype is manifested in the female psyche and can appear as positive or negative in emotions such as joy, fear, despair and anxiety. This archetype unconsciously determines women's behaviour and has a strong emotional component. When a mother deviates from 'good mothering' she may be overcome by a powerful unconscious message, which manifests itself in an overwhelming

anxiety (Hanna, 1996). The Christian mother, Mary, who is, kind, loving and forgiving of sins, also heavily reinforces this notion of the ideal mother figure. More recently, Trubshaw (2003b) argues that myths are reinforced by television drama, cinema productions, computer games and literary fiction. Braverman (1991) suggests that the resulting influence of these powerful myths of motherhood sees women readily accept that motherhood is instinctual and leads them to believe that mothers are the best people to provide care for children

How mothers view their own experiences is also influenced by myths. The stories they tell reflect their own mythological beliefs about motherhood and their expectations and behaviours of both themselves and other members of society. Peneff (1990) describes 'the mythical element in life stories as the pre-established framework within which individuals explain their personal history' (p. 36). Mothers not only tell their story according to 'established storytelling guidelines' but also use language, metaphors and images that are all rooted in the prevailing cultural myths. Recognising the existence and influence of these myths is an important part of any life story interpretation.

It has been postulated that Barthes based his mythological interpretive framework on the political ideology of Marxism (Lavers, 1982). Much of Barthes' writing was undertaken during a period of time when Marxism was seen as the new political and academic light. For the first time, an ideology provided an historical explanation for the laws of the world and the mind. This approach matched well with Barthes ideas of social and historical links to the interpretation of signs and is the second literary approach adopted in this study.

Marxist literary theory
Marxist literary analysis concerns itself with the ideological functions of literary forms and social forces, such as the reproduction of social power (Eagleton, 1976), and 'literature can only be understood within the larger framework of social reality' (Forgacs, 1986, p.167). Marxist literary theory holds that any theory that treats literature in isolation from society and history will not be able to explain what literature really is, nor what it represents. Social history has a profound influence on what and how literature is produced, particularly in relation to class relationships, political and cultural institutions and their relationship to economic production (Forgacs, 1986). Marxist literary theory is, therefore, broader in scope and more

focused than other forms of literary criticism because it endeavours to combine textual analysis with the study of social and historical contexts (Hendricks, 1999).

The early writings of Marx were influenced by the metaphysical, or spiritually based, argument of the eighteenth century German philosopher, Hegel. Hegel proposed that the ultimate 'state of mind' (truth) could only be reached through 'the Absolute Spirit'; a capacity to see things from a universal point of view that was historically driven and socially determined (Redding, 2002). The 'Absolute Spirit' shapes and guides the consciousness of humans to rise above the limitations of nature and institutions to a level of self-consciousness (Turner, 2003). Marx, however, argued that while society needed a platform on which to base its cultural values it need not be of metaphysical origin; rather society could achieve an ultimate 'truth' by the conscious actions of humans themselves. Marx agreed with Hegel's view that only 'contradiction and change' would lead to the perfect society, however, it was not until humans were aware that society was all their own doing, rather than that of a metaphysical being, that they could change anything (McInnes, 1972). To this end, people needed to question the mythological interpretations of society before change could occur.

Later writings of Marx took on a more economic emphasis in relation to societal and class structure. In this period he focused on the influence that the production of material goods, and those who controlled this production, had on societal beliefs and values. He argued that the capitalist economic system was structured around the labour and capital of production and this affected the way people thought and behaved (Kilcullen, 1996). Marx claimed that the production of material life determined the general character of the social, political and spiritual processes of people. In contrast to his earlier writings, Marx now postulated that 'consciousness does not determine life, rather life determines consciousness' (Marx, 1859 cited in Eagleton, 1976, p. 4). Those who control, and profit from, production hold power and have a greater chance of survival than those who are not (Kilcullen, 1996). The ruling class also represses the ideology and interests of the working class for its own benefit. 'The material interests of the dominant social class therefore determines how people see human existence, individual and collective' (Selden et al., 1997, p.89). This dominance often goes unrecognised and is regularly reinforced through literature, art, media and the like. Gramsci (1891-1937) refers to this as 'hegemony', where the ruling class 'co-opt' the working class into their own oppression. Donzelot

(1980) proposes that for Marxists, the family is essential for the reproduction of social (bourgeois) order. Donzelot sees families serving as 'the anchorage point for private property and its function of reproduction of the ruling ideology' (1980, p. xx). Families replicate ideology through compliance with, and support of, family related laws and medical, educative and relationship norms. One proponent of Marx's theory, Lukàcs (cited in McInnes, 1972, p. 50), explains that people often see things as 'natural and given' when in fact they are products of history, of what has gone before, so rather than question actions and text, they accept them as fitting representations of societal values.

With this understanding of Marxist literary theory, literary works reflect both the individual's ideas and experiences, and those of the society in which the author lives. Social reality is not viewed as an indistinct background from which the literature emerges. Rather, social reality is the interplay between particular class relationships and particular political, cultural and social institutions as they are related to the system of economic production (Forgacs, 1986). Culture is therefore inseparable from the historical conditions in which humans create their material lives, the relations of dominance and subordination which govern the social and economic order of a particular phase in human history and which, in some way determine the whole cultural life of society (Seldon, 1989 cited in Hendricks, 1999).

Eagleton (1976; Eagleton & Milne, 1996) suggests that a writer or storyteller can only tell their story in ways prescribed by historically based literary traditions. Eagleton (1996, p. 297) contends that the literary text is a production of ideology whereby the prevailing ideology influences the way language is used to explain and interpret what is happening in reality. Thus, the truth of the text is not about real meaning, but a practice - the practice of its relation to ideology within a particular social and historical context. Because humans write the text, or tell the story, they cannot, unless they set out to do so consciously and deliberately, separate themselves from the ideology of the society in which they live. Social forces, influenced by the ideological imperatives of the time, determine how a story is told, what is written and how it is interpreted. In other words, the production of text gives privilege to existing ideological concepts. To understand text, one needs to understand the base, or societal structure on which it is written – the history, culture and ideology of the given society, because all these things influence how an author writes, or talks, about the world. Marxist literary readings of the mothers' stories

attempt to reveal the ideological assumptions that influence how their stories are told within historical, cultural and economic terms. It is, however, important to recognise that it often is what the storyteller has *not* said that exposes an ideology.

According to Macherey, an advocate of Marxist literary theory, ideology not only pre-exists the text, but is concealed in the text itself (Eagleton, 1976). It is the gaps and silences within the text where ideology can be revealed. Gaps are places in the text where the 'obvious connections' are not written and the reader is expected to apply 'common sense' assumptions (Moon, 1992) which are based on existing historical and cultural values and therefore represent the prevailing ideology. Silences result from these textual gaps, enabling readers to avoid questioning certain cultural values (Moon, 1992), rather it reinforces them as 'the natural way of things'. Macherey (1970, cited in Eagleton, 1976) suggests that ideological disclosure can only truly occur if one examines the silences of the text. Macheray goes on to say that it is the critic's role to identify the meaning of the gaps and silences, by superimposing a theoretical framework, such as Marxism, to tease out the ideological influences on the author (1978, cited in Forgacs, 1986). For example, mothers may be reluctant to say certain things about their experiences. It may be that they fear rejection, blame, punishment or isolation from the community in which they live. Macheray points out that that these fears may arise as a result of a social ideology that determines who can speak when, about what and how (Eagleton, 1976). Only deliberate critical analysis and critical reflection can enable a reader to expose these hidden ideological assumptions, and link them to a specific historical context in which economic, social and political structures drive the production of the text (Moi, 2002). Accordingly, a Marxist analysis is an important means of understanding mothers' stories because this perspective analyses the reach of dominant ideological practices into the social order and the reflection of the order on cultural and social processes.

To sum up, the stories that mothers tell were critically analysed through the lens of a Marxist theoretical framework. The stories were analysed to establish the presence of prevailing ideology and its influence on how the mothers told their story and how they perceived themselves as 'productive' citizens. Recognising the 'gaps and silences', where it was not what the mothers said, but what they did *not* say, allowed ideological assumptions to be exposed. A focus on the language utilised by the mothers also drew attention to socially legitimated ways of expressing their

experiences. By paying close attention to language, not necessarily individual words, but whole paragraphs, was an important way to bring to light hidden assumptions and 'taken-for-granted' values. What mothers saw as 'natural' and 'the right way of doing things' highlighted ideological imperatives, societal values and the folklore, or myths, associated with these values.

Myth and ideology: a comparison

Understanding the difference between myth and ideology helps to demonstrate how the Barthesian post-structuralist approach, which uses myth to explain social phenomenon, differs from a Marxist approach that bases its thesis on the concept of a dominant ideology. Myth and ideology are often used synonymously, along with other terms such as 'ideas' or 'beliefs', yet while these terms may be used in this manner, they mean different things.

Myth is defined variously as 'a traditional story accepted as history; serves to explain the world view of people' (Wordnet 2.0, 2003) or 'a person or thing existing only in the imagination' (Webster's revised Unabridged Dictionary, 1998), or 'a fiction or half-truth, especially one that forms part of an ideology' (The American Heritage Dictionary of the English Language, 2000). The implication from these definitions leads one to suppose that myths are 'not true', their origins are imaginary and their use in society is appealing purely because of their emotional content. Yet Halpern (1961) explains that even though myths are often based on fiction, 'they function to integrate and organise individuals and groups' (p. 8). Myth provides a basis for beliefs that have arisen out of historical experience and this basis provides a group of people with common ways of thinking and behaving. They are unconsciously assimilated into everyday life, providing a 'common-sense' basis to thought and action, and providing people with a sense of security as they go about their day-to-day life. For example, the myth of motherhood provides a distinction between 'acceptable' mothering behaviour and 'unacceptable' mothering behaviour. Mothers feel an internal sense of discomfort when they do not conform to the irrational, inhuman ideal of the 'earth mother' who is patient, kind and always loving.

Philosophers, such as Roland Barthes, who delve into the relation between social action and myth look for connections between how people behave and the historical basis for such behaviour. By explaining action in this way, social behaviour can be attributed to mythological beginnings, often passed from generation to generation

via cultural media. Highlighting the role myths play in determining social behaviour is one way of defining and understanding underlying social values (Barthes, 1973).

Ideology, is defined as 'the science of ideas' (Webster's revised Unabridged Dictionary, 1998) or 'the body of ideas reflecting the social needs and aspirations of an individual, group, class or culture' and as 'a set of doctrines or beliefs that form the basis of a political, economic, or other system' (The American Heritage Dictionary of the English Language, 2000). Like myth, ideology has its origins in history, however, when being described as based on 'scientific ideas' ideology takes on a different meaning to myth. Since the 'The Age of Reason', it has been argued that 'science could reveal truths that transcended mere myths' (Trubshaw, 2003a, p. 162), and in this form ideology takes on a more rational, truthful appearance, yet Gonalez-Perez (n.d.) suggests that it is often the fiction of myth that is used to support ideology, because myth may form the basis for shared meanings and perceptions among groups of people. Gonzalez-Perez (n.d.) goes so far as to say that 'the basis of ideology lies in *a priori* mythic knowledge' (p. 1). Gonzalez-Perez (n.d.) proposes that the function of myth is to unify the group, establish consensus, validate and maintain social order and authorise its moral code. Myth, however, is susceptible to manipulation. It can be stripped of pre-existing context, history and signification, and infused with new conceptual concepts, particularly those useful in promoting the ideologies of the ruling class (Barthes, 1973).

Myth forms the basis of beliefs; ideology uses myth to promote a particular way of thinking and behaving. Ideology enables an individual to rationalise his/her beliefs by making reality intelligible and meaningful (Flood, 1996 cited in Trubshaw, 2003a), although this rationality may actually be based on the identity and thoughts of others. One could argue, however, that ideology does not always depend on myth to reinforce a particular way of thinking. The seemingly rational and scientific bases upon which political and economic arguments are built are also used to support a particular ideological stance.

Ideology is most commonly associated with the philosophy of Karl Marx. Marx argued that most people were 'passive recipients of dominant mistaken beliefs' (Holmes, 1995, p. 306) whereby the members of the ruling class legitimated their power and control so that members of the working class saw life as 'the way it has to be'. Marx saw ideological imposition as an insidious infiltration of bourgeoisie

beliefs and values into the lives of working class people. While this dominant ideology thesis has been challenged (for example see Abercrombie, Hill, & Turner, 1980), the development of a school of thought that considers ideological persuasion to be integral to capitalist societies has promoted a significant critical approach to the study of society.

Critical theorists, such as Horkheimer, Adorno, Marcuse, and more recently, Habermas, focus on the oppressive, powerful nature of ideology and argue that by drawing attention to, and reflecting on, the presence of ideological imposition members of society can act to move society towards a more 'rational' existence. Unlike the uncovering of myths, that aims simply to identify the origins of people's beliefs, disclosing ideology not only promotes a critical approach to analysis but also involves a call to action (Fay, 1987).

Critical social theory

Marxist thought and the literary traditions of critique and literary theory provided the foundation to critical social theory (Fairclough, 1995; DeMarco, Campbell & Wuest, 1993 cited in Powers, 2001). Social theorists such as Horkheimer, Marcuse, Adorno and Habermas, based in The German *Institute for Social Research* founded in 1923, and known as the Frankfurt School, are regarded as the central force behind the development of critical social theory (Crotty, 1998; Morrow & Brown, 1994). Their studies are based on the Marxist notion that historically founded ideologies maintain illusions that cause oppression in the social world, and that emancipation can only arise when one understands and criticises these illusions (Fay, 1987). 'Digging beneath the surface' (Fontana, 2004, p. 95) of prevailing ideas and practices provides a means by which people can alter any distorted self-understandings. Importantly to critical social theory, the emphasis of the research is on action (Fay, 1987). By drawing attention to oppressive situations, critical social theory aims to provide people with tangible ways of bringing about change and in doing so create a more just and fair society. Presently, the philosopher most often associated with critical social theory is Jürgen Habermas (b. 1929).

Habermas

Building on Marx's thoughts and principles, Habermas, a leading philosopher and sociologist of the second generation of the Frankfurt School, developed a new critical social theory that focused on verbal communication as the basis of power,

control and liberation. Habermas' theory of C*ommunicative Action* (1984; 1987) represents a critical synthesis of the leading sociological theories, particularly those of Marx, Weber, Parsons and Hegel (Stickle, n.d.). Like Hegel and Marx, Habermas acknowledges that there is an historical, rational basis to the evolution of humans and he adopts the Marxist ideology and shares the emancipatory aspirations to which it is directed, but he has almost completely eliminated the notions of economics and class struggle from the theory (Mitrovic, 1998). He focuses instead on the causal processes which underlie the systemic distortion of communication and understanding which he sees as constituting fundamental forms of oppression (Holmes, 1992).

Habermas (1984) suggests that language is the principal integrating medium through which individuals convey and renew cultural knowledge in a process of achieving mutual understandings. The processes of knowing and understanding are grounded in the patterns of ordinary language usage that are shared in everyday communication (Stickle, n.d.). Communication also serves as a social integration tool and is the basis on which personal identities are formed (Outhwaite, 1994). However, Habermas sees language as more than just a means of communication and self-formation, it is also a 'medium of domination and power' (Habermas, 1962, cited in Outhwaite, 1994, p. 25). A central element in Habermas' theory of *Communicative Action* (1984; 1987) is the distinction between the genuinely communicative use of language to attain common goals, and success orientated speech which simulates a communicative orientation in order to achieve an ulterior purpose (Outhwaite, 1994).

Habermas' theory of *Communicative Action* proposes that in society today there is a struggle between two types of rationality, which, in turn produces two different types of world (Habermas, 1984). One is the *lifeworld*, a concept Habermas adopts from the works of Edmund Husserl, Alfred Schutz and Max Weber, where value-based rationality informs dialogue and communication. The other is the *system,* an idea that extends the systems theory elaborated by Talcott Parsons, in which purposive rationality guides communication. While no direct definition is given of the system, it can be described as a social system from which the *lifeworld* has become differentiated, or uncoupled (Holmes, 1992).

In the *lifeworld* interactions are symbolic and informed by practical interests, aimed at securing personal identity and shared understandings (Holmes, 1992). Communication is defined by moral considerations and orientated to understanding (Barry et al., 2001). The *system*, on the other hand, represents aspects of society associated with technical interests that are focused on economics and power. In the system, communication is defined by technical considerations and is orientated to success that is measured in terms of money or power. Habermas complains that the success-orientated actions of the system are taking over the value-based, ethically driven actions of the lifeworld through the 'steering media' of money, power and influence. As a result, the system distances itself from the lifeworld while gradually diverting the lifeworld into the system world (Holmes, 1992). While Habermas does not dismiss the importance of the technical rationality of the system, he implies that it should keep to its place. Both the lifeworld and systems have a role to play in modern society, but when institutionalised *systems* infiltrate the shared, ordinary everyday *lifeworld* the likelihood that shared and open communication can occur is reduced (Habermas, 1987).

In the lifeworld, communication is based on the understandings and expectations of a shared culture, where consensus is achieved through the recognition of sincerity, appropriateness and comprehensibility. In contrast, communication in systems is influenced by the systemic constraints imposed by the structure of power and money (Morrow & Brown, 1994). When the systems invade, or *colonise*, the lifeworld it causes a distortion of communication. Thus, communication is manipulated for political and ideological ends, as well as for mass entertainment and profit, rather than for general public interest (Jureidini, Kenny, & Poole, 2003). Habermas is ultimately arguing that this form of communication is exploitative and irrational. Exploitation, in the form of greed and the lust for power, should not triumph over moral considerations that are essential to the functioning of a rational society. This is important to Habermas who assumes that rational discourse will free people from constraining, oppressive processes (Holmes, 1992).

Habermas claims that when the claims of communicative action occur in everyday life they are often not questioned or criticised because they are raised within the arena of an undisputed, shared lifeworld (Deflem, 1996).This unquestioning acceptance occurs because the lifeworld provides a set of cultural values that secures normative standards for the society. By blurring the distinction between

systems oriented communication and lifeworld communication, critical public opinion gets diluted and is no longer a reliable source of judgments. However, Habermas argues that even when the distinction between system and lifeworld communication becomes blurred, individuals can resist the processes of larger institutional-based communication via the medium of an ideal speech interaction (Barry et al., 2001; Morrow & Brown, 1994).

Habermas suggests that an 'ideal speech situation' can occur when all participants have an equal opportunity to speak and equal opportunities to contradict each other (Haralambos, van Krieken, Smith, & Holborn, 1996). Although the ideal speech situation is rare in practice, it can serve as a standard for the critique of systematically distorted communication, particularly in circumstances where one belief system may dominate another (Scambler, 1987). Habermas considers psychoanalysis as a situation in which the ideal speech situation occurs. Here, the relationship between the psychoanalyst and the patient is focused on liberating the patient from the constraints of misconceptions, mistruths or fantasies that would otherwise inhibit truthful, appropriate and sincere communication. By contesting speech claims made by the patient, the psychoanalyst calls upon the patient to defend the truth of the utterances with factual evidence and logical argument. This process represents the ideal speech situation whereby the psychoanalyst and the patient are assumed to be able to reach a rational consensus (Scambler, 1987). While a claim of this nature would be highly controversial because of what occurs in a psychoanalytic encounter and given the primacy of unconscious processes it might be thought difficult to characterise this as a rational process. However, based on these claims by Habermas, and shifting away from the psychoanalyst's couch, it should be possible to employ the ideal speech situation in other health-based professional interactions with patients.

Mishler (1984) and Barry (2001) have drawn on Habermas' concepts and applied them to the world of medicine, where, they argue, the technocratic success-orientated *voice of medicine* can distort communication patterns with patients, who speak in the *voice of the lifeworld*, producing 'dysfunctional consultations' (Barry et al., 2001, p. 500). Mishler's (1984) study (n=25) suggests that in most consultations with patients, doctors use strategic and manipulative methods to maintain control of the dialogue. Medical communication is conducted almost entirely in the voice of medicine and the voice of the lifeworld is suppressed and fragmented. Mishler

(1984) argues that by conducting their consultations in the voice of medicine, doctors 'strip away social contexts of meaning on which a full and adequate understanding of patients and their illnesses depend' (p. 192). This fits with Habermas' ideas about the system rationalization and colonization of the lifeworld. Mishler argues that doctors distort communication in success oriented, purposive rational action in order to maintain control of the direction the consultation takes and the decisions that are made. Barry (2001), however, found that only half of the consultations that they studied (n=35) fitted this format. Consultations where doctors and patients spoke in the voice of medicine (n=11), tended to be straightforward consultations based on single, acute physical concerns. In these consultations, the patients spoke very little. If the consultation was based on chronic physical problems with no easy solutions (n=15), patients were talkative and spoke in the voice of the lifeworld. However, the researchers found that the doctors either immediately suppressed or ignored the patients' talk, and continued to conduct the whole of their communication in the voice of medicine. A consultation where the doctor did not block the voice of the lifeworld tended to occur where the patients had psychological concerns (n=9). In these consultations both the doctors and the patients used the voice of the lifeworld:

> In these consultations the doctors used open-ended questions; active listening without interruption; humor; questions directly concerning the lifeworld and voiced in the natural language of everyday life; and empathetic statements of recognition, acknowledgement and validation of the patients feelings. There was a sense that the patient was being treated as an equal partner with their own expertise to offer in the diagnosis and treatment of psychological problems (Barry et al., 2001, p. 497).

While this last group does not represent half of the study population, as claimed by the researchers, it does at least demonstrate that where the voice of the lifeworld is used by both patients and doctors, the likelihood of mutual understanding is enhanced and consultation outcomes more successful for both parties.

Mishler (1984) concludes that patients and health professionals must establish a domain of shared meanings in order to talk successfully with and understand each other. Importantly, Mishler argues that it is the health professional who must take responsibility for interceding between the voice of medicine and the voice of the lifeworld because of the two parties only the health professional can speak in both voices. This is in notable contrast to Silverman's (1987) Foucauldian analysis of doctor-patient consultations where he suggests the impetus for more control over the encounter must come from the patient.

In this study, the mothers' stories were expressed in lifeworld voices. Mothers' talked about their experiences as real-life events that affected both their children and themselves on a day-to-day basis. Their stories were scattered with humorous tales and tearful reminiscences as they told the story of their experiences in a way that was meaningful to them as mothers. As listener, I endeavoured to respond in a lifeworld voice that created an atmosphere of shared understanding, promoting an emotional bond that helped mothers to feel that someone was listening to, and believing, them. Later, when reading their stories I looked at how mothers interpreted their interactions with health professionals, particularly the form of communication utilised by the mothers and the health professionals. In the present study I had to consider whether mothers used the voice of the lifeworld to express their concerns, whether health professionals responded in the same voice, or whether they, as found by Silverman and Mishler, spoke in the voice of the system that obfuscated meaning?

Critical social theorists provide a theoretical lens, through which the traditional views, behaviours and taken-for-granted beliefs of society can be questioned, criticised and reformulated with the aim of increasing self-understandings that produce social change. Like critical social theorists, Foucault proposes that social transformation can only occur if the underlying social and historical contexts that provide the basis for social action and speech, are exposed. However, while a critical social theory approach aims to 'restructure positivist notions of subjectivity and autonomy, a Foucauldian approach situates subjectivity as an effect of power relations' (Manias & Street, 2000, p. 57).

Post-structuralist literary theory: Foucault's discourse and power
The final literary theory to be utilised in the analysis of the stories is Foucault's theory of discourse and power. Foucault's theory focuses on the how and why different kinds of truth, knowledge, rationality and reason develop within certain cultures (Danaher, Schirato, & Webb, 2000). Foucault offers a technique for exploring how and why people think and act the way they do and how these events can be reflected in text. For Foucault, as for Habermas, one of the most significant forces shaping our experiences is language (Danaher et al., 2000). Foucault suggests that how we understand the world around us is 'mediated through our linguistic constructions' – that language is the tool we use to perceive and make sense of the world (Holmes, 1992, p. 3). He also argues that the concepts of

discourse and power shape how language/literature/text is produced and his approach provides an alternative technique for reading literary works.

Foucault's ideas have their origins in a number of influential theories including those proposed by Kantianism, Marxism, phenomenology, structuralism, and psychoanalytic theory (Dreyfus & Rabinow, 1982). These major intellectual and theoretical ideas influenced his perspective in a number of ways, so a brief overview of their influence follows.

Foucault studied in France at a time when Marxism and phenomenology dominated intellectual life. As a result, Foucault's initial works are heavily influenced by both these schools of thought, particularly the Marxist belief that history is 'driven and resolved by the working class' (Danaher et al., 2000, p. 5). However, he later came to disagree with the belief, advocated by Marxism, that all events could be neatly categorised and evaluated according to economic reasons. Foucault was also profoundly influenced by the work of Friedreich Nietzsche who denied that there is 'one true world' and that the course of history unfolds in a rational way with the gradual development of higher forms of reason (Danaher et al., 2000). Nietzsche postulated that history and the future course of events is unpredictable because people behave in irrational ways that cannot be pre-determined. This behaviour is influenced by the struggle for power by different forces (McHoul & Grace, 1993). Nietzsche suggested that power, rather than historical knowledge, shapes the emergence of truth and knowledge in a culture (Danaher et al., 2000). Foucault's work extends on Nietzsche's supposition of power, developing his understanding of power throughout his writings. Nietzsche also insisted that 'there are no facts, only interpretation' (Kaufman & Hollingdale, 1967, p. 267). Foucault supports this conjecture by adopting a poststructural approach in the development of his theory.

Foucault also supported the structuralist concept, as developed by Ferdinand de Saussure in his *Course of General Linguistics* (1951, cited in Brooker, 2002), that words, events, and ideas only mean something when related to other words, events and ideas (Danaher et al., 2000). According to this perspective, it is not possible to understand the word 'woman' until it is related it to other words, such as 'man, child, or girl'. The same relationship applies to ideas, political events, books and everyday activities (Danaher et al., 2000). Foucault adopts this idea when he explains how the identifying features of a 'discourse' can be made apparent. By using historical

comparison, he shows how the identity of a discourse is revealed only at the site of its competition with others (Rawlinson, 1987).

While Foucault was influenced by the formal, structured method advocated by Saussure, his adoption of a post-structural technique permitted Foucault to read text in a number of different ways. Saussure's theory was based on a rigorous analysis of the text, which sought to explain how the language system (*langue*), such as genre, grammar, syntax, provides a set of rules and relations that influence an individual's speech (*parole*) (Selden et al., 1997). The structuralist approach suggests that language can be used to determine cultural phenomena because *parole* is fixed in specific situations and only changes as the situation does (Cobley & Jansz, 1999). Text is separated from the historical context on the basis that it is the structure of language itself that produces 'reality' (Selden et al., 1997). A poststructuralist approach, on the other hand, argues that all instances of language must be considered within the social and historical context. Derrida (1966, cited in Selden et al., 1997) suggests that the meaning of a word can only be determined by the context in which the word is embedded. The focus of the reading is therefore on the context in which the text is set rather than the linguistic form of the writing. Meanings change as contexts change, contexts change as social and cultural environments change. Foucault takes this one step further, arguing that language is inseparable, not just from social interactions, but also from power. Language is the primary medium for understanding 'how a discourse determines what it is possible to say, what are the criteria of truth, who is allowed to speak with authority and where such speech can be spoken' (Selden et al., 1997, p. 154).

Foucault was further influenced by the phenomenological proposal, in particular the notions espoused by Heidegger (Dreyfus & Rabinow, 1982; Martin, 1988), that social, political and cultural structures influence how people think and speak, but rejected the underlying ontological belief that all meaning was to be found in a person's perception of the 'universal essence' of an object or thing (Danaher et al., 2000). The notion that *structures influence people* was also supported by the psychosexual/psychoanalytical approach of Freud and Lacan who argued that people are only free when they (subconsciously) repress their sexual desires in order to be accepted by society, and so the illusion of freedom is created (Klages, 2001a). While Foucault offered a different interpretation of sexuality, it is apparent in his subsequent work that he did support Freud and Lacan's proposal that society

influences how and what a person thinks and does. Danaher (2000) suggests that Foucault's focus on the role of discourse and power/knowledge developed as a result of his underlying belief that what people could know was always limited by their contexts, and what constituted truth and rationality was not inevitable and changed across history. Foucault (1972) elaborated on these ideas by suggesting that how people act, think and speak can only be understood in terms of the discourse in which they are engaged.

Foucault & discourse

While Foucault has many definitions of 'discourse', in *The Archaeology of Knowledge* (1972) discourse is described as more than just language; rather, it is 'practices' that restrict or permit writing, speaking and thinking. These practices change over time because they are closely aligned with the world view, or *episteme* (Foucault, 1970, pp. 30, 74, 346), in which they operate. A discourse is not immediately definable and the identifying features of a discourse – the concepts, rules and authorities that determine it – can only be revealed by an historical process that enables comparison to be made with competing discourses (Rawlinson, 1987). Identifying historical conditions also makes clear how one way of seeing and thinking and speaking about human conditions is substituted for another (Rawlinson, 1987). Foucault (1972) proposes that society is a conglomeration of discourses and while these are interconnected, each nevertheless contains both written and unwritten rules and regulations that govern how one should behave when engaging in a particular discourse. Foucault (1972) refers to these regulations as 'discursive practices'. Much of Foucault's work seeks to uncover discursive practices to explain the complex relationship between power, language, social institutions and individual subjectivity (Wellard, 1996).

Discursive practices are the kinds of statements associated with particular institutions and their way of establishing order (Brooker, 2002). There are, for example, different discursive practices associated with discourses of motherhood, academia, and health care. These discursive practices provide 'techniques of the self' (Foucault, 1980a) that people use when engaging in a particular discourse. Accordingly, the academic language adopted in this thesis differs from the language used when writing a letter home. People engage in different discourses and learn to follow the rules and regulations that are contained in each. Thus, in the Foucauldian sense, a discourse is whatever limits, or facilitates, writing, speaking and thinking

within a specific historical context (McHoul & Grace, 1993). Foucault (1972) refers to these fundamental characteristics of a discourse as discursive rules.

Foucault (1972) proposes that discursive rules operate to provide a stability and homogeneity that would otherwise not exist. Without rules, the very nature of thought and action would create volatility. Discursive rules create a consistent and stable canvas, and provide a platform for thought and language. According to Foucault (1972), speakers and writers unknowingly construct their linguistic statements to conform to these rules, and so, perpetuate discursive regulations. Foucault proposes that a set of linguistic statements belong to, what he calls, a discursive formation (Gutting, 1989, p.231).

Discursive formation involves four basic elements: the *objects* its statements are about; the *enunciative modality*; the *concepts* in terms of which they have been formulated; and the *themes*, or theoretical viewpoints they develop (Gutting, 1989). The analysis of the discourses encountered in this study is based on the elements of discursive formation, so a more complete discussion ensues.

The first element of discursive formation relates to the construction of *objects* of which statements are about. *Objects* are entities that are considered to be external to the discourse and are viewed as targets for knowledge generation and intervention. *Statements* correspond to the linguistic (written or spoken) representation of those objects. The *objects* are described in the *statements*, and consequently become constructed by the process of the discourse (Powers, 2001). This can be exemplified by the discursive rules that have arisen within the discourse of psychology in relation to normative child development standards:

> Psychology has increasingly provided language in which the concerns of raising children have been phrased, the means of identifying problems and the type of expertise capable of putting them right. (Rose, 1990, p. xi)

Norm-referenced tests, for example, assess an infant's performance against the performance of a large group of age-equivalent infants. Infants (*objects*), whose development does not match the documented developmental norms, are described by *statements* such as 'delayed development', 'low muscle tone', 'visual impairment' and the like.

The second element, the *enunciative modality*, refers to the kinds of cognitive status and authority the statements have (Gutting, 1989). For example, Rose (1990)

suggests that the child development standards, articulated within the discourse of psychology, have had an immense influence on how those caring for children view their responsibilities. There has been a continuous and intensified reflection on the care of children, which has created new desires and expectations, raised fears and anxieties in parents and produced new administrative and reformatory aspirations in professionals (Rose, 1990).

The third element concerns the formation of *concepts* in terms of the articulated discourse, and this is closely related to the final element, the *themes* (theoretical viewpoints) they develop. The *concepts* of early childhood have changed considerably as a result of the psychological discourse on child development. New categories, or what Foucault (1973) would describe as 'deviances', have been created to explain childhood variations from the articulated norms. 'Attention Deficit Disorder', for instance, describes a child whose concentration skills are shown to be outside expected norms for age, and 'Specific Learning Disorder' categorises a child who falls at least two years behind accepted academic norms in school. *Themes,* and variations on the themes, develop around these concepts as a result of intensifying research interest and theoretical commentary. Accordingly, 'Autism' is no longer the only term used to categorise children with specific neurological problems, children can also be categorised as having 'Low Functioning Autism', 'Asperger's Syndrome', or 'Pervasive Developmental Disorder' (American Psychiatric Association, 2000). Varying statements are made about causes, effects, and medical, educational and social treatments. These statements are based on various theoretical viewpoints that arise from the development of scientific knowledge within a particular discourse, in this instance, the medical discourse. Interest in these 'deviances' is enormous in medical and educational discourses today, yet many of these categories did not exist in our thoughts or in our language thirty years ago. Foucault would suggest these changes occur because the authority and status of particular discursive practices within, and between, discourses change.

Foucault (1972) suggests that while these discursive rules direct statements and behaviour within a discourse, discourses are not static entities; rather, rules and regulations that guide how an individual speaks, writes or behaves within a discourse can alter. 'A discursive formation defines a field within which a variety of different, even, conflicting sets of elements can be deployed' (Gutting, 1989, p.232).

In other words, while the unity of a discursive formation is due entirely to the rules that govern the formulation of statements, there can exist within a discourse different ways of defining objects, varying levels of statement authority and a number of diverse theoretical viewpoints (Gutting, 1989). These viewpoints may be complimentary or contradictory, and therefore create an environment in which objects, statements and degrees of authority within a discourse may change.

Foucault draws on history, not to show how history influences discourses of today, but to exemplify how discourses can change (Foucault, 1970; Philp, 1985). For example, the rules and regulations that direct health professionals to judge who is a 'good mother' or a 'bad' mother has changed over the past 50 years. 'Good' mothers in the 1950s were those who positioned their babies on their fronts while sleeping, fed them formula milk and kept them to a strict routine. These same mothers would be considered 'bad' mothers in the mothering discourse of today. Today 'good' mothers sleep their babies on their backs, breast feed them and attend to babies 'on demand'. Foucault suggests that how discourses change is not based on logic or rationality, rather it is based on power and knowledge (Foucault, 1980b).

Foucault & power/knowledge

Typically, power is thought of as a control mechanism that is manipulated by one person, or just a few people, to serve their own purpose and agenda (Bacharach & Lawler, 1981). Foucault, however, sees power operating in a completely different way. He proposes that power is not a thing that is held and used by individuals and groups against others. Rather, 'it is both a complex flow and a set of relations between different groups and areas of society which changes with circumstances and time' (Danaher et al., 2000, p.xiv), that 'establishes positions and ways of behaving that influence people in their everyday lives' (Philp, 1985, p.74). Foucault sees power, not only as negative, working to repress and control people; but also as highly productive. 'Power produces resistance to itself; it produces what we are and what we can do; and it produces how we see ourselves and the world' (Danaher et al., 2000, p.xiv).

Foucault (1977) argues that power is inextricably linked to knowledge. He proposes that power arises through the accumulation of knowledge, particularly scientific knowledge that, in our society, is considered to produce 'the truth' (Foucault, 1980b). The question of truth is central to Foucault's investigation of power, and Foucault proposes that truth is no longer based on epistemological questions, but

rather on the strategies and relations of power within particular social formations (Grossberg, 1985). He argues that scientific knowledge is value-laden and subjective because knowledge generation is shaped by the rules of the discourse in which it arises. The dominant discourse exercises its power by transmitting this knowledge to society through the creation and maintenance of social norms, practices and institutions that reinforce these 'truths'. As a result, 'Foucault challenges the notions which hold that knowledge is objective and value-free', arguing instead that 'knowledge is inextricably bound to power' (Cheek, 1998, p. 22), because 'discourse determines what it is possible to say, what are the criteria for 'truth', who is allowed to speak with authority and where such speech can be spoken' (Eagleton, 1989, p. 154). This is not to say that power is necessarily a bad thing; rather, it can be used to both facilitate and restrain actions and behaviour (Foucault, 1980b).

Foucault (1980b) proposes that power be understood in terms of 'techniques' or 'methods of application' that create the rules through which the power is exercised. Institutions, such as legal, military, health and economic, that rely on these techniques all draw some authority from referral to scientific 'truths' (McHoul & Grace, 1993). Foucault (1977) refers to these institutions as 'disciplines'. Disciplines carefully arrange spatial distribution of individuals, control their activities, organise training to divide novices from experts and generally co-ordinate all its fundamental parts (McHoul & Grace, 1993). In this way the discipline establishes 'disciplinary power' by creating unequal power, whereby one person has the capacity to judge someone else on the basis of knowledge that only the former possesses (Foucault, 1977). However, Foucault (1977) argues that, 'as power becomes more autonomous and more functional, those upon whom it is exercised tend to be strongly individualised' (p. 193). The very power that is aimed at establishing conformity and control, does, in actual fact generate power and provides the individual with the opportunity to take more control. Foucault suggests that this can occur because power is dispersed and without a particular source. As a result, power relations are 'potentially unstable and potentially reversible – I may limit your choice of actions, but your actions may equally limit mine' (Philp, 1985, p. 75).

The rules and criteria of each discourse set up specific places or positions in which people can develop as specific entities with particular associated powers, such as 'doctors', 'mothers', 'nurses'. Power operates to permit or restrict a particular course

of action (Philp, 1985) and can vary within a discourse and between discourses. Some discourses are more powerful than others in certain contexts, and different degrees of power are enjoyed depending on what type of discourse a person is operating in and what kind of credentials that person has in terms of knowledge. For example, motherhood is seen as a discourse over which others' discourses hold power (Smart, 1996). Legal impositions, medical standards and social rules are imposed on mothers in an attempt to compel uniformity and to create standards. These discursive rules can take the form of child protection legislation, which is enforced to ensure that children are protected from "bad" parents; health policy, which insists that all children must be immunized prior to school entry and that babies must sleep on their backs; or educational requirements, which demand that children attend school by the age of six years. Such rules can be seen in Foucauldian terms as measures of good motherhood (Smart, 1996). Success is measured by a mother's ability to adhere to these standards, but because professionals, who operate in a different discourse, set many of these 'norms', Smart (1996) argues it is likely that many mothers will fail. The reason for this is that these rules have been established by 'dominant discourses'.

Dominant discourses

Dominant discourses are more powerful and influential than other discourses and knowledge developed within them is used to establish standards of 'normality' or 'abnormality' (Philp, 1985) which are adopted and reinforced by existing systems of law, education and the media (Brooker, 2002). An example of a dominant discourse, relevant to this study, is the discipline of medicine. Foucault (1973) considers medical discourse to be so powerful that it has taken the place of religion as the most dominant discourse in society. It has risen to a place of dominance over other discourses by establishing a system of concepts and rules for determining the difference between truth and falsity; by determining who has the right to speak about these matters of truth and by influencing political, economic and social agenda's (Rawlinson, 1987). This rise of power does not follow a smooth pathway, but is reflected by on-going struggles between competing discourses. For example, the battleground between the discourse of religion and medicine has been ongoing. The development of 'the pill' and the legalisation of abortion have been promoted by medical sciences as a 'truth' and right for women. Certain religious groups see them as a 'falsehood' and a danger to women and have argued against their availability. The power struggle between the two discourses continues, but lowering

membership in religious groups points to a strengthening of power by the medical discourse. By resisting the 'truth' of one discourse, members of society impact on its degree of dominance over another discourse.

The power of the medical sciences is based on the claims that they are able to reveal the truth about human conditions, and these truths can only be interpreted by experts from within the discourse (Dreyfus & Rabinow, 1982). Rawlinson (1987) suggests that the medical discourse 'embodies, more clearly than any other human science, the intertwining of knowledge and power' (p. 372) by providing an account of numerous specific human conditions, engaging a vast number of skilled and certified personnel and by utilising a complex array of scientific discourses with which to correct, regulate and control the human body. More specifically, it is the science of medicine that constitutes people as *objects of knowledge* that are measured against generalised standards of function (Rawlinson, 1987).

Self-surveillance

Once a dominant discourse is established it can benefit from the conscious and subconscious hegemonic adoption of discursive rules (Foucault, 1977). Individuals unwittingly conform to these rules, thereby promoting the perpetuation of the dominant discourse by ministering to the interests of those in power (Holmes, 1992). For example, a mother deliberately takes her child to the local health professional for a 'check-up'. In Foucauldian terms, the mother is consciously following the rule within the mothering discourse that 'good mother's ask health professionals to check that a child is developing according to medically expected norms'. Unconsciously, the mother who takes her child to a child health professional for advice is reinforcing the dominant medical discourse that the health profession knows 'best', or the social discourse that perpetuates the notion that 'good' mothers take their child to the doctor for regular check-ups. Foucault (1977) would suggest that this mother is reinforcing the discursive rules by self-surveillance, actively trying to 'fit the norms' by reproducing the ideas through obedient behaviour.

Self-surveillance and control

According to Foucault (1977), contemporary society makes use of subtle procedures such as self-surveillance, and surveillance, instigated through the constructed systems of various social institutions, to maintain social control. This control has been described by Donzelot (1980) as a process of self-policing whereby people internalise the cultural expectations of society and engage in self-punishment if they

detect that they are not living or behaving according to dominant cultural expectations. Foucault (1980a) refers to these as 'technologies of the self' whereby individuals engage in a series of techniques that allows them to work on regulating their bodies, thoughts and conduct. At the same time, societal institutions that engage in the process of surveillance judge whether the individual's behaviour is maintaining social rules prescribed by the institution. If surveillance detects inappropriate behaviour then the institution introduces further processes to ensure compliance.

Foucault (1977) and Rose (1990) proposed that in the past the authority that took on the responsibility of maintaining social structure was the social institution of religion. Today, however, institutions such as medicine, the law, the media and the school fulfil this role. By formal and informal means, these institutions create compliance by teaching about and rewarding conformity to standards of thought, morality and behaviour. Rather than being passive recipients of regulation, individuals take on an active role by engaging in self-examination and self-regulation. Dominant discourses, mediated by social institutions educate individuals about their role as responsible autonomous citizens, guaranteeing that the majority will constantly search for ways to improve and understand themselves so they will move closer to achieving the label of normal (Rose, 1990). While people engage in the process of self-examination and self-regulation, they look for guidance from the experts who are holders of knowledge and associated power.

Self-examination is a central component in a strategy of power. For example, medicine, psychology and psychiatry all encourage individuals to find the truth of their mental or physical well-being by making personal disclosures to health professionals (Danaher et al., 2000). This confessional form of discussion creates self-revealing subjects who rely on 'the experts' to help them 'get better' (Powers, 2001). While Foucault suggests that this is a powerful control technique reinforced by the dominant institutions, it can also be used as a technique for resisting oppression and power.

Foucault and life stories
Foucault claims that when people write and speak, they do so within the framework of existing, unspoken rules and constraints. If they do not write, or speak within these constraints, they 'risk being condemned to silence' (Eagleton, 1989, p. 184).

Discourses are the means by which people can consciously or subconsciously, make sense of, and understand themselves, to distinguish right from wrong and true from false (Danaher et al., 2000). However, by regulating and constraining knowledge the existing dominant cultural or political ideas are maintained. When a particular discourse promotes advocacy of new ideas or rules, 'society exercises constraint on 'dangerous' discourse by excluding, dividing, disciplining and rejecting' the ideas or statements (Horrocks & Jevtic, 1999, p. 96). Mothers who speak out about perceived inequalities of a system that excludes children who do not 'fit' mainstream educational requirements, may be seen within the educational discourse as 'dangerous'. These mothers' are voicing opinions that do not fit the existing rules of the discourse and, as a result, are consequently ignored and thus silenced. Discourse analysis enables a researcher to expose these silences.

Ball (1990, cited in Cheek, 1998, p. 85) suggests that Foucault's notion of discourse has enabled the analysis of certain health care practices, by exposing the invisible influences of taken for granted assumptions that shape contemporary health care practices and is therefore a useful analytical tool. The work of Fahy (2002) demonstrates how Foucault's theoretical concepts can be used to highlight the use of disciplinary power in the health profession. Fahy shows how viewing verbal interactions through a Foucauldian lens allows hidden power practices to be revealed and questioned. As Gould (2002) explains, personal stories are a 'mode of knowledge used to acknowledge, articulate and understand existing power relations and to identify areas and strategies of change' (p. 79). Utilising Foucault's concept of discourse, the stories of mothers were examined in relation to the discourses in which they are engaged to identify the elements of discursive formation, the rules which govern the discourse, and to expose the covert power relationships that exist within and between the discourses.

Overview of literary theories

The following figure provides a brief outline of how the previously discussed literary theories concepts and themes were utilised in the reading of the mother's stories.

Semiotic literary theory - Barthes' interpretation of mythology

- Childhood myths - Held by mothers, society and health professionals
- Motherhood myths - Held by mothers, society and health professionals
- Medical myths - Held by mothers, society and health professionals

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NeoMarxist literary theory/Critical social theory
• Ideological imposition
o Productive mother
• Language used
o Expressed experiences
• Gaps & Silences
o 'common sense'
o fear of blame/rejection
• Economic resources & access to professional resources
• Communication between mothers and health professionals
Post-structural literary theory: Foucauldian discourse and power
• Discursive practices & rules
o Motherhood
o Professionals – Health and education
• Discursive formation
o Objects & statements
o Enunciative modality
o Concepts (labels)
• Power/Knowledge

Figure 3.2 Concepts and themes of three literary theories

Step 8: The researcher creates the document that is interpreted

Understanding the views and experiences that a researcher brings to a story enables a reader to place the interpretation within a specific contextual framework, referred to by Stahl as 'frames of reference' (1985; 1989, p. 33) . While the researcher's interpretation is a personal one, it can also be recognised as valid and genuine. Smith (1998) argues that there can never be privileged understandings of information, only our personal interpretations of it:

> The sense I make of the world is not only made, that is, socially and discursively constituted rather than discovered, but what I observe and how I explain it cannot escape the predilections, values and cultural assumptions I bring to it (p. 3).

While the researcher can utilise literary theories to help develop an understanding of the stories, the interpretation will always be from the viewpoint of the reader. To this end, Stahl argues that the researcher must take full responsibility for the interpreted document (1985, p. 53). Fleming, Gaidys and Robb (2002) maintain that this is in keeping with Gadamer's hermeneutical view that the researcher must accept

responsibility for the final interpretation It is with this commitment in mind that I have incorporated, throughout the study, my personal 'frames of reference' and the acknowledgment that the mothers' stories have being interpreted through my personal experiences and contextual frameworks.

Chapter summary

- Social constructionism is the theoretical lens through which the mother's stories were viewed. This made possible the recognition that social, cultural and historical structures influenced individual perceptions and experiences.

- Life history methodology enabled the stories that mothers told, to be captured. An understanding of a mother's life experiences, within the social, cultural and historical structures, was developed from these stories.

- Interpretive biography focused on the 'turning point' moments that stood out in the mothers' lives. Importantly, it enabled me to be concerned for the way mothers' perceived and interpreted that world, and to recognise that, as a listener, I was only able to understand and interpret a story from my own particular socially constructed viewpoint.

- Literary folkloristics provided an interpretive framework that utilised literary theory to examine both the macro and micro-culture. This approach enabled a focus on personal stories of the mothers and their relationship to cultural traditions within their social or cultural environment. Significantly, as listener/reader (researcher) I was an insider in the teller's (mother's) folkgroup.

- The literary folkloristic method utilised in this study represents a combination of elements from Denzin's interpretive biography and Stahl's literary folkloristics. I have adopted Hendricks' (1999) proposal that literary folkloristics contains a number of fundamental steps necessary to conduct a literary folkloristic inquiry.

- The stories were read through the lens of three literary theories. A semiotic reading that a Barthesian approach to mythology; and, a neoMarxist approach focused on text as a social and historical construct. Within the neoMarxist framework a Habermasian analysis, based on the theory of *Communicative Action*, was adopted to enable a focus on the causal processes that lay beneath communication and understanding. Finally, a poststructural approach was adopted, in particular Foucault's notion that text is a site for establishing, reaffirming and testing power. This combination of

theories enabled a comprehensive analysis of the mothers' stories by evaluating the ideas and themes that arose in relation to historical, cultural and social influences.

Chapters 4, 5, 6 Analysis and discussion

Introduction

The purpose of this study was to answer the question: 'What can be learned from the mothers' experiences of their child's development that will contribute to improving the early detection of subtle developmental problems in children?' To assist me in exploring this question I chose a literary folkloristic method based on a metasynthesis of the work by Stahl (1985; 1989) and Denzin (1989). The stories of eight mothers, whose children were not detected with developmental problems until school, were recorded and transcribed so that their stories could be read and analysed. Due to the length of the interview material, the mothers' stories are presented in this thesis in an annotated format to provide the reader with a snapshot of their lives and experiences. A comprehensive inclusion of their interviews was not possible due to the extensive nature of some of the stories, however I envisage that the excerpts utilised throughout the discussion chapters provide an opportunity for a more complete picture to develop.

Following an overview of the mothers' stories, the analysis and discussion takes place. This has been divided into three separate chapters. The first chapter focuses on how, when and why children's development was recognised as different from that of other children. This enabled me to discover the extent to which mothers' were 'aware' of developmental problems with their children prior to school entry and, if so, how, when and why they noticed them. I also draw attention to environmental characteristics associated with the mother's experiences and provide several explanations for why mothers interpret their experiences as they do. The second chapter centres on the relationship between health professionals and mothers, in particular, reasons why mothers and professionals may interpret children's problems differently. The final chapter discusses the role that diagnosis plays in the identification and acknowledgment of early childhood development problems. These three major themes guide the structure of the findings chapters and the chapters are headed accordingly. The literary lenses of Barthes post-structuralist/semiotic accounts of mythologies, neo-Marxism, particularly Habermas' theory of communicative action, and Foucauldian post-structuralism are used to 'read' and analyse the mother's stories in each of the three chapters.

A brief summary of the mother's stories is presented first.

The mothers' stories

Meeting the mothers was the highlight of this study. Their eagerness to tell their stories was obvious right from our first telephone contact. The interviews were conducted at the homes of the mothers, or in the home of their friends, with half of the interviews taking place over 400kms from my university base, but difficulties were minimised by the willingness of the participants to 'fit in' with my travel schedule. Their purpose was altruistic: 'If I can just help one other mother avoid going through what I have gone through, then telling my story will be worthwhile' was a common iteration. On visiting their homes I was always made to feel welcome and, as is the way in country Australia, was plied with endless cups of tea, and in some instances, homemade cake. The mothers' willingness to participate in this study made the interviews more like storytelling sessions. Once they began to tell their story there was no stopping them. I interjected only to clear up points, such as their child's age, or to get clear in my mind when events occurred. My original intention was to intertwine my own stories with those of the mothers, expecting that to be accepted as a member of their folkgroup, I would need to engage in active speaking and listening. Nearly all of the mothers, however, had chatted to me on the telephone prior to the interview and had heard a little about my own experiences. When it came time for the interview, my presence was accepted at face value. Although a few asked me more about my own experiences, it seemed that just my being interested in their stories was enough for them to feel comfortable to be able to tell me about their lives. Some of the story-telling sessions went for an hour; others for nearly two hours.

The mothers' stories form the core of this study but, due to their length, the complete transcripts cannot be included. Several of the mothers' stories were so beautifully told, comprehensive in detail, heart-wrenching and yet inspiring, that it is with regret that I can only include a brief overview. Nevertheless, this should enable the reader to develop a vague understanding of their lives. Excerpts from the transcripts which represented experiences, highlights or turning point moments, are included throughout the chapters. All the names used in this thesis are pseudonyms.

Kimberley's story

Kimberley was a 32-year-old single, unemployed mother living in a large regional city[1]. Kimberley left school in grade nine when she left home to live with her grandmother. She had two children, a son Carl who was 6 years old and a daughter, Jennifer, who was 5 years old. Kimberley had recently moved to the city so that she could access health care for her son. Prior to this she had lived on the outskirts of a small rural township. Kimberley was estranged from her own family and had little to do with her son's father or his family. At the time of the interview, Carl was in his first year at school. For the past five years Kimberley had been expressing concern over her son's behaviour. He had recently been diagnosed with query Aspergers Syndrome[2] and Oppositional Defiance Disorder (ODD)[3]. He was under the care of a local Paediatrician and the Youth Mental Health Service.

Mary's story

Mary was in her early forties, a schoolteacher and administrator with a higher research degree. She was married with two children, a son, Luke, aged 11 years and a daughter, Pippa, aged 9 years. Mary and her family lived in a small rural community about one and a half hour's drive from a larger city. Mary worked in a nearby local school and her husband owned and operated a private company. Mary's son Luke was diagnosed with Asperger's Syndrome in grade one, while the family were living overseas. Mary had been concerned about her son's behaviour since he was a toddler and expressed her concerns to numerous health professionals prior to diagnosis, but it was not until her son threatened to kill himself, at the age of six, that her concerns were heeded.

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[1] A regional city is defined in the *Accessibility/Remoteness Index of Australia* as a major urban centre that has a population of >100,000 people (Commonwealth Department of Health and Aged Care, 2004).

[2] Aspergers Syndrome is defined in the DSM IV (American Psychiatric Association, 1994) as a Pervasive Developmental Order whereby a child displays severe and sustained impairment in social interaction, and the development of restricted, repetitive patterns of behaviour, interest and activities that significantly impair social, occupational or other important areas of functioning (p. 75).

[3] Oppositional Defiance Disorder (ODD) is defined in the DSM IV (1994) as a 'recurrent pattern of negativistic, defiant, disobedient and hostile behaviour toward authority figures that persists at least for 6 months' (p. 91).

Justine's story

Justine, 40, was a single mother who had three sons, Keith, 16 years, Ken, 13 years, and Jack, 7 years old. Justine and her sons lived in a large regional city. Justine worked part-time and drew a single mothers pension. She completed grade ten of schooling but had since earned herself a Carer's Certificate from a Tertiary and Further Education Institution (TAFE). Prior to living in the city, Justine lived in a rural community in another state of Australia. Jack was nearly seven years of age, and in grade two, when he was diagnosed with delayed learning skills and query Attention Deficit Disorder (ADD)[4] although, when he was four years of age a preschool teacher suggested that Justine take him to the local hospital for a developmental assessment. At this time, Justine was not given any information, but the preschool told her that they would be 'keeping an eye' on him. When Justine arrived with her son in the city and he started grade two, the teacher in his new school identified concentration and processing problems. At the time of interview Jack was under the care of a local paediatrician and Youth Mental Health Services who were assessing him and deliberating on his course of treatment.

Melanie's story

Melanie, 41, was recently separated from her husband, and lived in a regional city. She had three children, a son, 20 years, and two daughters, Alice, 12 years and Peta, 6 years. Melanie arrived in Australia from an Eastern European country in the mid nineteen-eighties. She married the son of another immigrant family shortly after her arrival in the country. Melanie completed high school in her home country and a Certificate in Administration at TAFE in Australia. She was preparing to enrol in another Certificate to improve her employment prospects. Since her separation from her husband she had been drawing a single mother's pension. Melanie had close family in the city, relying on her husband's mother for babysitting over the past years. Alice, her daughter, was diagnosed with ADD at the age of 10 years while in her fifth year at school. Melanie had been concerned about her daughter's behaviour since Alice was a very young child, however, these concerns had been dismissed by a number of health professionals. When Alice finished her first year of

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[4] Attention Deficit Disorder is described in the DSM IV (1994) as a 'persistent pattern of inattention that is more frequent and severe than is typically observed in individuals at a comparable level of development' (p. 78). Inattention must be manifest in at least two settings (i.e. home and school). Children with this disorder may fail to complete tasks, perform careless and messy work and have difficulty in sustaining attention in tasks or play activities.

school, her teacher suggested that she repeat the year because she was a 'little' immature. Melanie did not allow her to repeat, but moved Alice to another school. By the time Alice was in grade three, the Child Guidance Officer from Youth and Mental Health Services, assessed Alice as being two to three years behind her peers in academic and emotional development.

Rebecca's story

Rebecca was 44 years old, was married and had two sons, Liam, 16 years and David, 12 years. She and her family lived in a small rural township about an hour's drive from a regional city. Rebecca has lived in this town all her life, completing grade 12 at the local high school. She had had a long association with local organisations and sporting bodies, having been on a number of committees and involved in the day-to-day organisation of the school canteen. She had developed close friendships with a number of other mothers on these committees and has had regular contact with her own, and her husband's, family who all lived close by. David, her second son was diagnosed with Attention Deficit Disorder with Hyperactivity (ADHD)[5], ODD and ADD in his second year at school, when he was seven years old. Rebecca had not been overly concerned about her son's behaviour prior to commencing school. It was not until David's teachers raised concerns about his behaviour in the classroom and the schoolyard that David was assessed by the Youth and Mental Health facility in the nearby regional city. At this assessment, David was found to have an attention span of two seconds. At the time of interview, David was receiving considerable assistance from the learning support teacher at his school.

Alana's story

Alana, 37, was married, with two children, Betsy, aged 11 years and Bonnie aged two. Alana lived with her family in a regional city. They had limited communication with both her own, and her husband's family due to distance, but interactions were positive. Alana had completed a University education and was currently working full-

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[5] Attentions Deficit/Hyperactivity Disorder (ADHD) is described in the DSM IV (1994) as being 'a persistent pattern of inattention and hyperactivity -impulsivity that is more frequent and severe than typically observed in individuals at a comparable level of development' (p. 78). Symptoms must occur in more than one setting and have been persistent for at least 6 months. Children with ADHD display inattentive behaviour similar to ADD, but also show signs of over-activity such as 'always being on the go', fidgety and restlessness, talking excessively and impulsive behaviour.

time. Her husband looked after the youngest daughter at home and he also played a major role in caring for Betsy. When she was 9 years old Betsy was diagnosed with dysgraphia[6], a learning problem that made it difficult for her to spell words and write sentences. Alana first became aware that her daughter had a problem when a teacher in preschool suggested she have Betsy tested for ADD, due to her behavioural problems in the school environment. The doctor did not find any problems and did not recommend any treatments, strategies or follow-up. When Betsy was eight, Alana was so worried by her daughter's behaviour that she took her to see a Developmental Psychologist. Over the next year, Betsy undertook testing and counselling sessions, which led to a diagnosis of dysgraphia. This did not occur until Betsy was 9 years of age and in her fifth year of school.

Maggie's story

Maggie, 39, was the mother of four boys: twin 15 year olds, Matthew who was eight years, and Peter who was six years. Maggie lived with her two youngest sons in the suburb of a large regional city and was separated from her husband who had, in the past, spent many years away from home on work-related trips. She supported her family on temporary part-time work and the supporting mother's pension. The older twin boys lived with her stepmother and stepfather. Maggie had a very positive relationship with her stepparents and they helped her with the younger boys from time to time. Her own family lived a long distance away, but she also maintained a positive relationship with them. Maggie had one really close friend, but had lost a lot of friends because of the behaviour of her youngest child, Peter. Peter was diagnosed with ADHD when he was six years of age and in grade one at school. Maggie had been worried about his behaviour from birth, particularly his aggressive behaviour towards her and his siblings, although she did not raise her concerns with any health professionals until he went to school and the teacher suggested that Maggie take him to a paediatrician for developmental assessment.

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[6] Dysgraphia is a neurological disorder characterised by writing disabilities. Specifically, the disorder causes a person's writing to be distorted or incorrect. In children, the disorder generally emerges when they are first introduced to writing. Children with the disorder may have other learning disabilities, however, they usually have no social or other academic problems (National Institute of Neurological Disorders and Stroke, 2004)

Nerida's story

Nerida, 42, lived on a cattle property about 20 minutes outside of a small rural township. She was married with three children, two girls aged 23 and 17 years and a son, John aged 21. Nerida grew up in a country town and after completing her schooling trained to become a registered nurse, although she has since lived on the property and helped her husband run the farm, while raising the children. John was diagnosed with a chromosomal disorder when he was eight years old. Nerida had been concerned about her son's behaviour since he was an infant. According to Nerida, John screamed for most of his infancy and did not like to be touched. As he grew older his John's behaviour became more and more difficult to manage. Nerida's doctor did not feel that John had a problem, so Nerida pursued other avenues of assessment. Finally, when John was eight years old, in his third year at school and Nerida had been attending a paediatrician's clinic regularly for two and a half years, John was diagnosed with having a double Y chromosome[7], which accounted for John's aggressive behaviour, and by this stage, his exceptional height and physical appearance. Nerida had a little family support from her husband's mother and sister but had no positive relationship with her own family who lived in the nearby town. All of Nerida's friends had left as a result of John's aggressive behaviour.

Below is a tabular overview of the above information so that the range of family types, the age at which the mother first raised concerns about her child's development and the age at which the child was diagnosed with a developmental problem, can be simply viewed. From the mother's stories it was apparent that only one mother (Rebecca) noticed no developmental idiosyncrasies prior to commencing school, two mothers noticed minor social and behavioural problems and the other five noticed a range of developmental or behavioural problems from as early as birth. Seven of the mothers raised their concerns about their children's development with family, and/or health professionals before the child commenced school. When mothers raised their concerns, they experienced a range of responses

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[7] Double Y chromosome occurs in men who inherit one X chromosome and 2 Y chromosomes. Individuals are usually very tall, have an increased risk of learning disabilities and delayed speech and language skills, and may have aggressive tendencies (National Library of Medicine, 2004).

from family, community and health professionals and it is from these experiences a number of themes arose. It is from these three themes that the chapters take their headings.

Table 4.1 Overview of participants and their children.

Mother's name	Marital status	Child	Age of first concern	Age at diagnosis	Diagnosis
Kim	Single	Boy	2 years	6 years	?ADHD
Mary	Married	Boy	2 ½ years	6 years	Asperger's
Justine	Single	Boy	3 years	7 years	ADD
Melanie	Separated	Girl	3 months	9 years	ADD
Rebecca	Married	Boy	6 years	6 years	ADHD, ODD
Alana	Married	Girl	2 years	11 years	Dysgraphia
Maggie	Separated	Boy	Birth	6 years	ADHD
Nerida	Married	Boy	Birth	10 years	Double Y

An important note

Before I continue, I would just like to make an important observation. While I had hoped that I would appear as a fellow mother whose child had a delayed diagnosis, it was apparent from the text that several of the mothers viewed me as an expert. The words the mothers use imply a confession of their feelings, to me, the listener, particularly Maggie:

> ..I always felt guilty because I disliked Peter….that's a horrible thing for a mum to say…but sometimes I just wanted to wring his neck…he created so much drama, so much tension in this family… (Maggie, p. 7, 9-13).

According to Foucault, confession is a power-related technique that supports the dominant discourse through the act of self-surveillance (Powers, 2001, p. 19). Individuals confess personal truths to others whom they view as being more in authority. By revealing these thoughts and feelings, the mothers shared their sense of failure in the hope that I would be able to compare their truths to the normalised truths of mothering and provide an opportunity for understanding and reassurances that 'it's OK to feel like that because these feelings are normal to mothers in these situations'. These mothers were prepared to voice their experiences and risk exposure to criticism purely on the belief that their stories may help another mother sometime in the future. For their trust and respect I thank them.

Chapter 4: Recognising "the problem"

The night Max wore his wolf suit and made mischief of one kind and another
His mother called him "WILD THING!" and Max said "I'LL EAT YOU UP!"
So he was sent to bed without eating anything.
(Sendak, 1963)

Mothers are members of a special folkgroup who share the common task of loving and caring for children. According to much of the literature written about mothers, they are, in Western society, those who bear the primary responsibility for raising and caring for children, and all that entails (Allan, 2004; Hooyman & Gonyea, 1995). They care for their children within an environment that includes family, friends, the local community and activities of the State (Belsky et al., 1989; Bronfenbrenner, 1979; Cox & Paley, 1997). As indicated in the literature review, there are several views on motherhood that attempt to explain why motherhood is enacted the way it is. Some authors suggests that motherhood is biologically determined, with natural instinct playing a major role in driving mothers to be the 'natural' carers of children (Bowlby, 1951; Freud, 1977). Other authors suggest that how motherhood is enacted and perceived is not the result of 'instinct' or the 'natural ways of things', rather it is influenced by historical, cultural and political constructs (Badinter, 1981; Kaplan, 1992; Phoenix & Woollett, 1991; Smart, 1996). In this study, It was important to understand if, and how, these constructs played a role in mothers' perception of themselves as mothers, and how others perceived mothers, particularly in relation to their role as child carers. Drawing attention to the behaviours and beliefs of mother's, and others, highlighted if, and how, dominant cultural discourses impacted on the mother's role in their children's development and how this may have affected the early detection of a child's developmental difficulties.

A semiological/mythological reading

Revisiting main concepts of a mythological reading

Roland Barthes advocated that literature produces the meaning but is not the meaning itself (Selden et al., 1997). Both the writing and the reading of a piece of writing are subject to outside influences and these influences can be identified by interpreting the linguistic messages that occur in text. Linguistic messages may be non-coded or coded (Cobley & Jansz, 1999). The non-coded messages are the

recognisable objects within the text that do not require larger societal conventions for interpretation. The coded messages are the suggestions or underlying assumptions in the text that are derived from the larger sign-system of society. For example, while each individual experience varies from one person to another, each is actually drawing on a common cultural ancestry (Samuel & Thompson, 1990). These common cultural ground rules, or ideologies, are perpetuated through folkloristic traditions or myths. Myths are foundational to the use and interpretation of linguistic messages, providing unspoken, yet culturally understood meaning to text (Barthes, 1973). Because myths are so deeply embedded in everyday thinking people simply fail to notice that they influence their thoughts, words and actions. Trubshaw (2003a) suggests that because myths infiltrate into unconscious thought, they influence what people consider to be 'normal' or the 'way it is'. As people share their understandings, usually unconsciously, through narrative and various media, myths are legitimated, reinforced, acquired, transformed and perhaps even resurrected or created. By looking for the constant factors in a homogeneous group of life stories one is able to discover these shared understandings and the myths that are responsible for them (Peneff, 1990).

A number of myths surfaced from the narratives, which were especially relevant in this study:

- Childhood myths: held by mothers, society and health professionals: how children should look, behave and perform;
- The myths of motherhood held by mothers, society and health professionals: the role of the mother; raising 'normal' children; and, 'good' mothers have 'good' children while 'bad' mothers have 'bad' children;
- Myths of the healer: held by mothers and health professionals (see chapter 5 for further discussion);
- Myths of diagnosis and the miracle cure: held by mothers, society and health professionals (see chapter 6 for further discussion).

Each of these were recurring themes that arose from the semiotic analysis. Discussed below are the myths of childhood and motherhood that influenced the values and beliefs of mothers, other community members and health professionals in determining how mothers went about mothering and how others viewed mothers and children.

The myths of childhood

The myths surrounding children and childhood have changed dramatically over the centuries of human existence. Once regarded as 'little adults', able to work alongside adults as soon as they were physically big enough to do so, children are now regarded as central to family life, and as such, need the nurturing and support of close family members. It was not until the mid eighteenth century that this modern view of childhood emerged, arising in response to the abuse of children in the Industrial Revolution in Europe (Heywood, 2001). Those who wanted the abuse and exploitation to stop developed arguments about children and childhood, which have since formed the bedrock on which the modern Western concept of childhood is founded. Enlightenment thinkers and humanists, those in the Romantic tradition, as well as political radicals, argued that childhood should be a time of growth, wonder, and joy. Rousseau's (1979/1763) publication *Emile* is credited as the first piece of literature that does not depict children's thoughts and actions as dangerous or deficient, rather, he proposed that the original nature of a child was one of innocence (Jackson, 1970; Kennedy, 2000).

While humanists promoted the blamelessness of childhood, the church prevaricated. On the one hand, it agreed that children were innocent and should be treated almost as angels. On the other hand, it exalted parents to see their children as wicked and evil until trained otherwise. American philosopher and puritan, Jonathon Edwards (1703-1758) described children as 'young vipers and (to God) infinitely more hateful than vipers' (Gesell & Ilg, 1943, p. 287). Children were seen as potential sinners and needed discipline and guidance to direct them towards goodness and righteousness. More recently the Christian church has favoured the depiction of children as defenceless innocents, particularly through images of angelic infants resting in the arms of the Virgin Mary. Jung and Kerényi (1973) called this infant figure the archetype of the 'divine' child, where a child's 'apparent insignificance, exposure, abandonment, danger and invincibility signal both the fragility and strength' (Kennedy, 2000, p. 533) of the child.

The modern concept of childhood has also been shaped by psychology and its infiltration into everyday life, especially behaviourism that perceives children as pliable, conditionable organisms that can be manipulated by reward or punishment (Blackman, 2002). Behaviourism has strongly influenced political regimes, such as

the exploitation of children by regimes using indoctrination, 'brainwashing' and the like, and systems of reward and punishment. This psychological approach has also influenced the day-to-day running of government agencies, such as schools (see for example, Phelps, 2002; Reynolds & Gutkin, 1999) and family/child guidance services (Zigler, Taussig, & Black, 1992), and in the home, both informally and formally as part of home therapies that are overseen by a clinical psychologist (Stein & Perrin, 1998).

Psychoanalysis has also been extremely influential in shaping modern understandings of childhood, portraying children as a locus of dangerous impulses (sexual and aggressive) - a battleground between opposing forces whereby the reality principle is in conflict with the pleasure principle (Freud, 1957; Kennedy, 2000). Psychoanalysis has particularly influenced the cultural depictions of childhood in the USA (Kennedy, 2000), where schools, childcare, educational strategies and family and child health services engage in practices that are based on psychoanalytical understandings of children (Cohen, 2002; Farley & Manning, 2002; Kusché, 2002).

While psychoanalytical understandings of children warn of competing forces within a child's psyche, Warner (1995) suggests that the myth of the innocent, vulnerable child remains a powerful image in modern society, particularly the difference between the child and the adult. Consider, for example, Rudyard Kipling's jungle boy, Mowgli, or J.M. Barrie's boy hero, Peter Pan, who 'both reveal the depth of adult investment in a utopian childhood state' (Warner, 1995, p.45). Childhood today is seen as a time of faultless playfulness, a time when young people are to be protected from the harsh realities of the adult world. An exemplary figure in this creation of the modern concept of childhood was Charles Dickens who, in many of his novels, contrasts the behaviour of adults with that of children, where children bring 'important but incommunicable meaning to the adults that surround them' (Kennedy, 2000, p. 534). Dickens also raised sentimentality about the sufferings of children of his era, bringing them to the attention of philanthropists and the medical fraternity in Great Britain (Jackson, 1970).

Yet, not all fairy tales, stories and movies about children project them as 'little angels' who survive and thrive in adverse conditions. Children are also depicted as 'little monsters', who collude, hurt or betray other children or adults. Maurice

Sendak's story for children '*Where the Wild Things Are*' (1963) draws attention to the naughty behaviour of a young boy. Max, the protagonist, is illustrated as 'getting into mischief of one kind and another', so much so that his mother calls him a 'wild thing', and Max replies 'I'll eat you up!' so his mother sends him to bed without his supper. Unlike many fairy tales that portray young children as 'morally pure' (Jones, 2002, p. 105) and as not bearing any responsibility for the problems that arise in the tale, such as changing inappropriate actions, Sendak actually hands responsibility over to the child to do something about his behaviour. We are taken on a journey to a jungle far away where Max meets and tames the wild beasts. Finally he decides that home is where he would like to be and Max journeys back a transformed child. Max is now the 'good' boy, Jones (2002) suggesting that this transformation occurs because this is how society really wants to see children. Warner (1995) proposes that these images of 'little monsters' are designed to remind adults that, rather than children being capable of adult-type behaviour, the adult world can infiltrate the innocent world of children and cause them to become 'bad'. So, even when childhood innocence is constantly challenged by children's own behaviour and adults doubt its existence, the myth continues to grow, as Kimberley revealed:

> ….and basically they said it was my parenting that was causing his behaviour to be like that and that, they were saying my negative vibes…he was picking up on that and responding to that , and I said, well maybe I'm picking up on his negative vibes and I'm responding to him...but they said is doesn't work like that, you're the grown up, you know, you're the adult (Kimberley, p. 4, 48-50, p. 5, 1-5).

Boys will be boys

The negative influence of adults on the innocence of children continues to infiltrate the myth of childhood, however, there is another myth that backgrounds how mothers, others and health professionals interpret the behaviour of boys. A traditional 18th century nursery rhyme draws attention to this myth:

> What are little girls made of?
> Sugar and spice and all things nice
> That's what little girls are made of
> What are little boys made of?
> Snips and snails and puppy dogs tails
> That's what little boys are made of (Anon).

'Boys will be boys' is an oft-quoted phrase that is used to explain the sometimes-amplified physical and verbal behaviour of young boys. While there is little doubt that boys can be loud and physical, there are competing arguments about whether it is socialisation that influences how boys behave (Baumrind & Black, 1967; Carlo, Raffaelli, Laible, & Meyer, 1999; Maccoby & Jacklin, 1980; Tieger, 1980), or whether

there is a biological basis (Collins, Maccoby, Steinberg, Hetherington, & Bornstein, 2000; Siever & Davis, 1991). Regardless of these arguments, the expectation that boys will be more difficult to manage as infants and children has infiltrated communal lore, and may be used as an explanation for a male infant's behaviour. Nerida, who was concerned about her son's behaviour from birth, explains:

> …from birth I realized he was marginally different to my daughter, but being a son I was willing to give him the benefit of the doubt…(Nerida, p.1, 6-7).

While Nerida did seek reassurance from her local doctor about her son's behaviour, her belief that boys behave differently from girls prompted Nerida to accept the doctor's response to her concerns:

> …you're not going to have another child like your elder one, because *she* was a text-book baby…(Nerida, p. 3, 26-28).

Nerida's son's fractious behaviour was excused on the basis that he was a boy. It is possible that boys are not identified with developmental difficulties early in infancy because of the mythical notions about boyhood. Myth backgrounds the expectation that boys will be louder, rowdier and more difficult to manage as infants and children. As a result, when mothers complained that their son's behaviour was difficult to manage, their concerns were marginalised. Mythical notions of childhood were further exaggerated when television commercials, programmes and magazines included images of angelic children whose 'perfect' physical appearance reflected, not only innocence, but also a deep-rooted belief that good-looking children were free from developmental problems.

Children who look OK are OK

The stories of Kimberley, Mary, Nerida and Alana, drew attention to the societal myths that influenced how members of a society differentiate between children who were considered healthy and those who were not. These myths were so pervasive, that mothers found it difficult to receive acknowledgement that their children had a difficulty or problem that needed assistance in one way or another, particularly when those children looked 'OK'.

The children who had learning difficulties or behavioural problems looked just like any other children. There were no physical markers that pointed to a disability. The photographs shown to me by several of the mothers demonstrated this point clearly as many children looked almost angelic with beautiful smiles and arresting eyes. However, the 'hidden disability' (Curtis, 2002) of learning or behavioural problems

comes at a price. Not only were the children's problems not detected early, but the mothers struggled to find a sympathetic ear when they raised concerns about their child's development. Mary felt that because her son was such a good-looking child, other members of the community did not understand that he could have a problem:

> And I think that anything that is neurological…and neurological in the sense that it is the behaviour or the mannerisms that are the problem , nobody wants to know….see, if I could trot him out everyday with a great big bandage around his head….our life would be much simpler, because it would be "oh, this child's got a problem"…(Mary, p. 15, 17-23).

Mary was not imagining her sense of isolation and the disbelief that the community held in regard to her son's behavioural problems. David Hay, Professor of Psychology at Curtin University in Western Australia undertook a study that looked at parental stress in parents with children who had obvious physical disabilities (cerebral palsy) and compared them to parents with children who had ADHD. He found that:

> There was much more stress in parents with ADHD because society doesn't like it. You're a bad parent, that's been the standard explanation of ADHD. (If) You've a child with an obvious physical disability you get sympathy, (if) you have a child with ADHD, you get criticism (Australian Broadcasting Commission, 2005, para. 32).

Stone (1995, p. 413) argued that the tendency 'to focus on visible disabilities and ignore the prevalence of invisible disability' was a result of the 'myth of bodily perfection' that invades the Western culture today. The myth of beauty and attractiveness being associated with health and well-being is a pervasive myth that circulates throughout all age groups in society. This myth is reinforced through social activities such as baby competitions, where mothers take their children along to be judged against other infants and children of the same age. By judging children on their physical attractiveness, these competitions reinforce the relevance of physical attraction to well-being, especially when the winner is given the title of 'Bonniest Baby'. While the judgment may be made on physical appearance alone, the word 'bonny' implies that the child is of good health.

Such competitions have been around in the USA since the early 1900s as a natural consequence of the popularity of eugenics. 'Better baby' programmes and 'best baby' competitions were especially common. Stern (2002, p. 68) says: 'During the height of maternal and infant reform, from about 1910 to 1930, better baby contests were all the rage in many countries across the globe'. These better baby competitions, run by maternal and child health workers and doctors, saw over 62,000 babies assessed on the basis of 'developmental norms', setting out to

dismiss judgments based on beauty and weight, but unfortunately continued to reinforce the myth of the bonny baby by basing the winner's attributes on physical 'norms'. While these 'norms' were based on medically developed scales of childhood development, such as height, weight and the infants' progression through developmental milestones, children were still judged in the light of physical well-being. It was not always physical appearance that was judged however; in some cases the child's pedigree was also a consideration, although the two were thought to go hand-in-hand as good genes were considered more likely to produce a 'good' appearance. This view was supported by theories of mental illness and criminality, such as Cesare Lombroso's 1911 work *Criminal Man* (Rafter, 2001), which claimed to link degenerate behaviour to (biologically inherited) physical characteristics.

Through baby and child competitions, the myth that the physically attractive child does not have a problem, either behavioural, academic or socially, is replicated and adopted by members of society as being 'the way it is'. As Alana said:

> …see lots of people don't realise….it takes 2 or 3 days, because then she talks non-stop….then they know…..she's lucky because she has other positive….you know she's very friendly, even looks good, you know, and she's very artistic…(Alana, p. 13, 37-41).

Beautiful looking babies may conceal a problem, that (initially) only mothers notice. Even though the children in this study all 'looked normal', most mothers noted in their stories that their children displayed varying developmental idiosyncrasies in their early years, and some of the mothers expressed concern about these developmental variants.

Mothers concerns were often based on what they considered to be inappropriate behaviours for an infant or child. Nerida remarked that her infant son:

> wouldn't suckle properly……he always screamed, he seemed to have colic a lot as a baby, he was a frustrating child, you couldn't comfort him, he would not allow us to cuddle him, always pushed away …(Nerida, p. 1, 8, 13-16).

Mary, noted that her son, at about the age of 18 months:

> … started to show signs of obsessive behaviour, for example, couldn't bear to have a lid off a jar or a door open or a draw open and would run behind you slamming things, shouting "lid on, door shut, lid on, door shut!", and of course everybody said…"Oh, isn't it cute"…now, I thought "No, this is a little odd"…(Mary, p. 1, 45-46, p. 2, 1-4).

Kimberley was worried about her son's behaviour in his second year:

> …he would want to be on you but you couldn't kiss him and your couldn't hold him, he would be fine to crawl on you, sit on you or touch you, want to

be picked up but you couldn't show him any kind of affection, he would push away from it…so, basically from then, I knew that that wasn't right…it wasn't normal…(Kimberley, p. 3, 19-25).

These concerns arose in response to a mother's notion about 'what a child should be like', the benchmark often set by the cultural, or folkloristic adoption of the mythical ideals of childhood.

Myths and folkloristic knowledge

Mythical ideals often form the basis for cultural, or folkloristic, knowledge about childhood. Attached to these mythical notions is the essentialist assumption that all children should behave the same, and that there exist fundamental qualities that are common to all. For example, most people believe that children will follow a common developmental trajectory. While 'individual differences' are accepted as a measure of human distinctiveness, most mothers have some ideas about what they consider 'acceptable' differences. While they may not be able to articulate sound, scientifically grounded rationale for these beliefs, they nevertheless hold these folkloristic beliefs that provide them with a benchmark on which to base their interpretation of a child's development. When children exhibit behaviours that mothers 'feel' do not fit 'acceptable' differences, they become concerned about their child.

Mother's raised their concerns about their children's development at different times. Nerida noticed that her son's behaviour was 'different' from birth, Melanie worried about her daughter's behaviour in her first year of life, and both Kimberley and Mary began to worry about their boys' development when they were just two years old. Alana's daughter was three years of age and in kindergarten, both Justine and Rebecca's sons were four years old and in preschool, and Maggie was worried about her son's behaviour from an early infancy, but relied on family for assistance until teachers confirmed her concerns when her son reached school.

When asked how she 'knew' that her son's behaviour and development was not 'normal', Kimberley referred to her experiences as a teenager, living in a large household of children. Her babysitting experience led her to question her own son's development, as she noticed that his behaviour was unlike any of the children she had ever looked after:

Jane   How did you know that do you think?
Kimberley   Umm...because my mum's the oldest out of ten kids and I
                had a lot to do with her sisters kids..

Jane	when you were growing up?
Kimberly	yeh…I used to baby sit them a lot, all the time…
Jane	So you knew from that experience that Carl's behaviour wasn't normal?
Kimberly	yeh, it wasn't like anything else I'd ever seen, he was very withdrawn, very negative…um…abusive, you know...yeh, and just cry and cry and cry for no apparent reason (Kimberley, p. 3, 26-37).

Several of the other mothers compared their child's development to that of his or her siblings. Nerida compared her children, and noticed the extreme differences in development:

Jane	Right…and your older child was how much older than him?
Nerida	Two years…two years, two weeks older….
Jane	So, compared to the older child, his behaviour was quite different….
Nerida	Yes, chalk and cheese, day and night….mm…(Nerida, p. 2, 16-21).

Maggie compared her son's development with that of his two older siblings and also with other children:

> …he [had] trouble making friends, because if he was in, like a little group, at playgroup, that sort of stuff and he wanted something, well, then he would do what ever he had to do to get that toy…if that meant hitting someone over the head, or fighting them or…you know…more so that what the other children ever did, so, it was an extreme difference there…um….(Maggie, p. 2, 1-8).

Maggie also drew on her knowledge of 'normal development', based on personal experience, two older children, advice from her mother-in-law, pre-school teachers and a comprehensive library of books, to list a host of issues she considered her son exhibited as developmental deviations from normal:

> ….yeh, so, I'll just run through these ones…..(referring to a list she has prepared prior to the interview)…..hard to get to sleep, used to keep waking up all the time….grew out of the daytime sleep (early)….(poor) fine motor skills…you know, holding the pencil, colouring in…that sort of stuff…um…still can't do up shoe laces…and he's in grade two….you know,…couldn't draw anything that resembled anything until he was at least 5 and a half….(Maggie, p. 3, 5-12).

Interactions with family and friends enabled mothers to develop a personal concept of normal child development, and to identify if their child displayed a deviation from these expected norms. Folkloristic notions, based on the essentialist view that children's characteristics are, on the whole, similar, appeared to play an important role in informing a mother's interpretation of her child's development. While these folkloristic notions may be socially constructed (Marshall, 1991; Tardy, 2000), with the mothers' values and beliefs being based on cultural belief systems of the day

(Goodnow, 1995; Goodnow & Collins, 1990; Harkness & Super, 1995), the mother's concerns were very real and important to them.

When mothers drew attention to their concerns, however, it was difficult for other members of society to 'see' that a child may have a difficulty, especially when the difficulty lay in the sphere of behaviour or learning where there was no obvious physical manifestation. The manifestation of the problem was often so subtle that it was only 'visible' to the parents (Glascoe, 2001, 2003; Regalado & Halfon, 2001). Based on Stone's (1995) argument that it is 'invisible disabilities' (p. 417) that tend to be forgotten, it can be suggested that because early childhood developmental concerns remained invisible to the community or health care workers, they were likely to be dismissed as inconsequential. Coupled with the communal belief, based on mythical ideals of motherhood, that mothers were responsible for their child's emotional, social and cognitive development, mothers may have been reluctant to seek assistance, fearing that they were to blame.

The myths of motherhood

The myths of motherhood extend back to ancient civilizations. Across many cultures the 'Great Mother' was manifested as both the giver of life and nurturer of the young.

> The Great Mother is the creatrix of life, the bearer of being, the origin of the gods themselves: she gives birth to heroes, fosters the growth of life and destroys life's enemies (Eliot, 1976, p. 67).

Gaea, the Greek earth goddess was revered as the 'fruitful power sustaining universal life' (Eliot, 1976, p. 68), while in India, the Mother goddesses, of whom there were many, came to represent all aspects of creation - birth, life, death and supreme wisdom. In Middle Eastern cultures, the Great Mothers were symbols of fertility, as was the Divine Mother of the Aztecs, and the Celtic Mother Goddesses, the Chinese Mother Earth, the Norse goddess Freyja and the Egyptian goddess Qodshu (Eliot, 1976).

The existence of the earth mother is such a powerful myth that it has infiltrated society in various forms throughout the centuries. In fact, Jung (1974) suggests that the same myths are presented in different forms in different societies because they are archetypal myths that exist in the collective unconscious of all humans, regardless of race, culture or beliefs. 'In other words, myths precede any type of culture, even the most primitive, though they are expressed differently according to

different cultural styles' (Eliade, 2003, p. 16). Even in modern society today, where technology is seen as the new 'god', the ancient mothering myth still inveigles its way into the psyche of mothers and other members of the community. Every society has its own motherhood mythology 'complete with rituals, beliefs, expectations, norms, and symbols' (Thurer, 1994, p. xv). The myth of motherhood today portrays the ideal mother figure as caring, loving, patient, ever suffering and always willing to act for others, especially children (Badinter, 1981). While this myth may be based on an irrational, unobtainable goal, many mothers feel compelled to replicate the myth of the 'ideal mother'.

Raising & loving children: The responsibility of mothers

Although the role of raising children, in Western society, has been relegated to the children's parents, it is often the mother who takes primary responsibility for her child's day-to-day care (Goward, 2002). Myth forms the basis of communal folklore that reinforces this socially constructed view of who should raise children. The myth of the 'good mother' is actively reinvented as 'each age or society redefines mothers in its own terms, according to its own mythology' (Thurer, 1994, p. xv). In current motherhood mythology, children are seen as perfectible, and it is the mother's responsibility to ensure this perfect being is sculptured accordingly. Good mothers are those who perform the task effortlessly with unending love (Swigart, 1991). The narratives of the mothers showed how potent the myths of motherhood are today and how they are replicated in their action and speech.

Several of the texts drew attention to the expectations of the mothers in relation to their role. When Kimberley approached her mother for help, her mother said: 'I've raised my children, these are your children, and it's your job to raise them' (Kimberley, p. 13, 6-7), and even though Kimberley would benefit from the assistance of others, she adopted this same folklore herself, saying: 'I became a mum to be a mum, so I don't want to have to pay for someone else to raise him…' (Kimberley, p. 11, 39-41). At times, Kimberley struggled to care for her son, yet she remained adamant about her responsibility as a mother, replicating the mythical preconceptions of a previous generation of women:

> I'd like to be like my grandmother…she would give all her time up for her
> kids, which is why I have done the same… (Kimberley, p. 12, 5-6, 7-8).

Mary's narrative shared the same fervour and while Mary incorporated full-time work into her schedule, she was adamant that her mothering responsibilities were

extremely important: 'I'm a fulltime mum, the minute I drive up the driveway…' (Mary, p. 13, 7-8). More importantly Mary believed that she was responsible for her son's wellbeing: 'we were committed to do the absolute best we could for him….' (Mary, p. 14, 8-9). Perhaps Mary's and Kimberley's resolute stances are a reflection of their keen concern for their children, but it is also likely that both mothers have been powerfully influenced by the dominant social myth that mothers are primarily responsible for the care of their children. In a society that places such liability on mothers, the responsibility comes at a price, namely that other mothers and members of the community will be critical of a mother's ability to fulfil her role as a competent mother. Swigart (1991) argues that the myth of the good mother makes it appear that mothering is a sole endeavour, when in actual fact it is a 'collective responsibility' (p. 8). The myth hides the complexity of child rearing and the need for support mechanisms to be available for mothers raising children.

The myth that mothers are the primary carers for children was pervasive and strongly reflected in the narratives, particularly in Rebecca's story that focused heavily on her role as a loving mother. Rebecca was so concerned that she would not be seen as a good mother, the 'good mother' theme superseded any other theme in her story. Rebecca's transcript reveals that she helped her son with his reading and homework, was a leading member of the school Parent & Citizen's Association, worked in the tuckshop, took her son to cricket every Saturday and played an active role in her son's school life:

> …as I said to my mother a while back, I would be willing as a parent to go in and teach any child how to do their times tables, or reading, spelling, anything…having known what David's gone through…(Rebecca, p. 19, 24-27).

Furthermore, Rebecca emphasised that teachers should pay more heed to mothers, especially when it comes to managing a child's behaviour, because 'that's what mothers are better at…you understand him more, you live with him everyday…' (Rebecca, p. 10, 44-45).

The transcripts disclose that the mothers understood, and acknowledged, their responsibilities in observance with the mythically based, communal folklore of mothering. Melanie explained that loving and caring for her child was sometimes a difficult thing to do, but she saw it as her responsibility as a mother:

> …how can I explain this to you…you can't go to the wall, you have to try to work it out, if you want something for your kid and you know it's hard to get, you have to try and go a different way, learn to……(Melanie, p. 5, 6-9).

Melanie, who, like all the other mothers had worked hard to get help for her child Alice, and planned to continue doing so:

> ….you know why, because she is my daughter and I would do anything for her….I felt that when people say…and they told me not many parents would do that….maybe they had tried to help, but they either give up or they think they are not going anywhere….but I always felt I had to push a bit more…I took me a few years..4, 5 years…you know, but I felt that I would get there…I don't know….and we're nearly there, I hope, nearly there…..(Melanie, p. 13, 17-25).

The mothers' commentary on their mothering behaviour reflects the dominant (Western) cultural folklore that mothers should always love their children and take responsibility for their well-being, education and socialisation skills (Dally, 1982; Phoenix, Woollett, & Lloyd, 1991). The use of terminology, such as 'I became a mum to be a mum', 'I'm absolutely determined' and 'I would do anything for her' reflects the intensity of the mothers feelings of their roles, suggesting that they willingly participate in the dominant folklore that encourages and expects mothers to focus their energies on their child in order to maximise his/her potential, even to the cost of their own personal development (Woollett & Phoenix, 1991). By articulating these thoughts, the mothers, unconsciously set out to demonstrate a particular characteristic they considered important to their self-identity. This self-identity is built on the foundations of a myth that identifies what thoughts and behaviour 'make' a good mother and what do not. By focusing on the theme of good mothering in their stories, the mothers were able to personally reaffirm that they were 'good mothers', even though, they often felt at odds with the collective myth.

At odds with the collective myth

The narratives drew attention to the existence of a personal folklore of alternative mothering behaviours. While the mothers expressed their continued commitment to their child's well-being, their stories suggest that many of the mothers in this study struggled, at times, to even *like* their children. These feelings stood out in the mind of the mothers as they considered them as inappropriate feelings for mothers to have. Parker (1995) refers to these feelings as 'maternal ambivalence' (p. 1), where feelings of love and hate for their children are constant companions. These mixed feelings created a gnawing sense of guilt because the mother's personal experience contradicted mythical ideals and community expectations of 'how mothers should feel'. This was particularly so for mothers whose children had major behavioural

problems. Maggie, for example, struggled with the clash of her perceptions of how a loving mother should act, and how she really felt:

> …..I always felt guilty because I disliked Peter….that's a horrible thing for a mum to say…but sometimes I just wanted wring his neck….he created so much drama, so much tension in this family…he didn't know the boundaries…..(Maggie, p. 7, 9-14).

Maggie's expression of guilt and anxiety over her feelings revealed that she acknowledged the communal folklore of motherly love. 'Hatred of one's child goes against every ideal of the good mother' (Singh, 2004, p.1199). However, Maggie, while revealing such intimate feelings, also drew attention to a subtle rule that, while not reflecting communal myths, exists in the private folklore of mothers. By speaking of her dislike, Maggie acknowledged that it's 'OK' to feel like this under certain circumstances, particularly when a child's behaviour created an enormous amount of tension in the family. In these situations, feelings of dislike were understandable and acceptable. However, it was only with the security of knowing that I too was a mother of a child with developmental problems that Maggie felt 'safe enough' to express her innermost thoughts and feelings about her child. It was unlikely that Maggie would have expressed her feelings so openly if she thought that I had not experienced the same feelings. Parker (1995, p. 4) suggests that mothers:

> …look to other mothers to find 'absolution' for maternal emotions which the dominant cultural representations of motherhood render unacceptable, and which mothers themselves experience as both painful and unforgivable.

Like Maggie, Kimberley also struggled to come to terms with her feelings about her son, which did not reflect what she considered to be the communal folklore of a 'good' mother. She was, however, able to recognise that her feelings would be unacceptable to the communal rules of how mothers should feel about their children, and used that conflict to access help:

> …..but yeh, but that's the feeling I had.. (I) really did want to kill him just so I didn't have to deal with it anymore...…..really did…and quite easily could of done it….and that's why I rang child welfare, you know...'cos I said look "I'm feeling like this…". The thought of doing it actually was exciting me because I'd had enough, I just…yeh…I was just like that, I wanted to choke him….I didn't know what I was going to do but, the thought of him having gone out of my life so I didn't have to deal with it was overbearing…it was horrible…(Kimberley p. 17, 47-50; p. 18, 1-5).

Here, Kimberley's use of the words 'it was horrible' clearly implies that Kimberly understood the communal rules of mothering. It was important for her to make clear to me, the listener, that she was appalled by her own feelings, yet her action showed that by drawing on her knowledge of what was socially acceptable behaviour of a mother, and what was not, Kimberley was able to attract attention of those

authorities she thought would best be able to help her. While this may have been an unconscious 'motivation of action' (Giddens, 1984), Kimberley manipulated the mythical, communal folklore to gain access to assistance for herself and her son. Unfortunately for many of the mothers, the overwhelming influence of the mythical qualities of a 'good' mother meant that many felt to blame for their child's behaviour.

Self blame

Several of the mothers struggled with feelings of self-blame, especially when their children did not behave or respond appropriately, either at home or in social situations. Melanie, for example, felt that she had failed as a mother because she had not persisted in getting help for her daughter (p. 10, 20). Kimberley, who, under doctor's advice, had her son vaccinated with the Triple Antigen at an age when her 6-week premature son was 12 weeks old, blamed herself for allowing her son to have the vaccination so early:

Kimberley	well, it's always in the back of your mind…well OK, if I didn't immunise him until he was 12 weeks old would things be different? If I'd waited until he should have been six weeks old, from his date that he should have been born…you know I always blame myself for that because I just didn't know
Jane	and you were encouraged to get him vaccinated at the age, 4 weeks?
Kimberley	Yeh, yeh…. absolutely
Jane	Why do you think you blame yourself then?
Kimberley	Because I took him there to get the needle…yeh...yeh…I just wonder if I'd let it go a little bit longer…yeh…would things have been different..
Jane	You were just following the advice of others…
Kimberley	Yeh...the doctors… (Kimberley, p. 14, 4-23).

Nerida's narrative also conveyed a strong message about how Nerida saw her roles and responsibilities as a mother. Her story entails descriptions of endless medical visits, overwhelming concern for her child's wellbeing, and of a confidence rocked by repeated rejection of her concerns:

I knew I was trying to do everything that I could do for him…..you know, it undermines you at the end of the day, you do start thinking.. "am I a proper mother…am I a caring mother?" (Nerida, p. 4, 8-12).

Mothers' expressions of self blame have been replicated in many studies, particularly when mothers were caring for children with developmental or cognitive disabilities (Carpenter, 1999; Malacrida, 2003; Rogers, 2005; Singh, 2004; Todd & Jones, 2003). Singh's (2004) research found that mothers' blamed themselves because they felt inadequate and unable to help their child control behavioural problems associated with ADHD. Furthermore, mothers felt responsible for family

problems that arose as a result of the tensions that occurred between other family members, and school or social problems that the child may have (Rogers, 2005). These feelings of blame were strongest prior to diagnosis when the child was often seen by others as 'out of control' and needing more effective mothering (Singh, 2004).

Mothers had these feelings of blame because they idealised what a 'good' mother did and what a 'bad' mother did. 'Good' mothers were responsible for their child's wellbeing, connected emotionally with their children and controlled their behaviour. These ideals were supported through the communal folklore of mothering and were replicated and reinforced by institutions, such as medicine.

Myth and health professionals

It is not only mothers and general community members who were influenced by the mythical notions of childhood and motherhood. Van Dijk (1998) suggests that *all* members of a culture share general, cultural knowledge:

> …cultural knowledge, or cultural common-ground may be defined as the (fuzzy) set of those beliefs that are shared by (virtually) all competent members of a culture, and that are held to be true by those members by similarly shared criteria of truth (p. 37).

Even though aspects of cultural knowledge are based on mythical beliefs, it is likely to affect all members of society, regardless of whether the belief is a 'truth or a falsehood' (van Dijk, 1998, p. 130). Health professionals usually experience childhood, adolescence and the transition to adulthood in the same cultural environment as the mothers and their children who approach them for advice and, as a result, are influenced by the same societal myths. Several of the mothers noted that because their children looked 'perfect', the health professionals they visited disregarded their concerns about their development. Alana, noted that her daughter's physical attractiveness belied her behavioural problems and it was on this attractiveness that health professionals based their interpretation:

> …and that's what people….like nurses and doctors, they would never think there was a problem…(Alana, p. 44-45).

Kimberley, Mary and Justine also remarked on the physical good looks of their children, and all had difficulty accessing support from their local health professionals. In contrast, when physical problems were apparent, attention towards the child was absolute. When Mary's son was 4 months old, the child health nurse 'became very alarmed at the rate his head was growing' (Mary, p. 1, 28). Mary was

referred to a paediatrician who ordered an immediate ultrasound scan to exclude hydrocephalus (the build up of fluid in the brain). Once the child was found to 'just have a big head' (Mary, p.1, 32), the child was dismissed as healthy. This was in direct contrast to Mary's later experiences with health professionals when she was concerned about her three year old son's behaviour, particularly his poor sleeping pattern and his obsessive behaviour when he ran around the room 'slamming things and shouting lid on, door shut, lid on, door shut' (Mary, p. 2, 2-3). Mary commented that the paediatrician she took her son to see did not agree with her concerns and concluded that her son did not have a problem (Mary, p. 2, 8-10).

When anomalies in physical development did not manifest themselves overtly, medical opinion appeared to favour explanations that linked the child's developmental idiosyncrasies to the folkloristic belief that the behaviour of the child was directly linked to the quality of the mothering. Furthermore, the child was viewed as vulnerable to the vagaries of poor mothering, rather than as being an active participant in the mother-child interaction, replicating the myth of the defencelessness of children.

Kimberley's story also revealed a reliance on mythical explanations for her child's developmental idiosyncrasies. Kimberley raised concerns about her son's behaviour from the age of two years. At the age of four years, Kimberley was advised to place her child in foster care for a month, and then to take him to full-day child care for a month (Kimberley p. 4, 45-46). While this may have been a well-intentioned opportunity for Kimberley to have some time away from her child, her narrative implied that she considered it as punishment for not being a suitable mother:

> …and basically they said it was my parenting that was causing his behaviour to be like that…' (Kimberley p. 4, 48-49).

Other myths also influenced how health professionals interpreted a mother's concern for her child's development. Nerida was concerned about her son's fine motor development at the age of six because he 'couldn't write properly' (Nerida, p.1, 30) and took him along to the local doctor. Nerida was told that 'boys were just slow learners and developers and not to overly worry' (Nerida, p.1 32-33). While Nerida had repeatedly visited her local doctor with concerns about her son's social, emotional and behavioural development over the proceeding five years, the additional manifestation of learning difficulties were apparently not enough cause for medical concern. This interpretation not only replicated the mythical belief that

physical symptoms are needed to obviate a problem but also highlighted another communal myth that proposes that boys are developmentally slower than girls, 'catching up' later in life. While there are certainly variations in developmental progress between children, Nerida's son exhibited a cluster of developmental idiosyncrasies from a very early age:

> I used to present to them and say "look there is something wrong with him, I can't pinpoint it…he screams, he's not doing this…like the milestones….he's not crawling"…um, even when he was tiny…there was just this field around him…he just wanted to be by himself…there were times that he needed you, but he didn't appear to sort of want you in a loving way or anything like that, it was just, "get it over and done with"….like, if his nappy was wet, he would cry a little bit, you'd change his pants and put him down, and that was it….he didn't want to be cuddled, he didn't want to snuggle in to you…..things like that….(Nerida, p. 3, 3-15).

When asked what the doctors would say to her when she raised her concerns, Nerida replied that she was told that nothing was wrong with her child and to go home (Nerida, p. 3, 24-26).

Mythical notions of childhood and mothering appeared to continue to provide the basis for decisions about Nerida's son's behaviour and developmental concerns, and even though the myth of boys being developmentally slower than girls has been discounted by a large body of research over the past fifty years (see Papalia et al., 2002), it continued to provide the basis for decisions about Nerida's son development.

It is likely that professionals unwittingly perpetuated communal myths about mothers and children. Similarly to other members of the society, these myths are so ingrained in the basic values of the health professionals, that health professionals are not fully cognisant of their affect on their beliefs and medical interpretations. Even though health professionals are trained to recognise and consider other, more rational explanations or causes for a child's idiosyncratic development, myths still influence how they view mothers and their children. Unfortunately mythical beliefs take on an authority status when replicated by trained professionals and, as a result, they continue to influence both the values and beliefs of the general public and individual members of professional bodies. As a result, mothers left health clinics feeling even more responsible for their children's problems, as Mary said:

> …..umm, well, for along time I actually did stand back and think, no, I've got the problem, I must just …I'm reading things into this situation that I shouldn't be reading…and perhaps I am…I have expectations that are unreasonable…(Mary, p. 6, 41-45).

Exonerating the self

Even when health professionals seemingly supported the notion of 'bad' mothers, and mothers appeared to blame themselves for their child's developmental difficulties, there also existed a contradictory, but co-existing discourse, whereby mothers reassured themselves of their ability as a 'good' mother.

Knowing that she had two healthy, happy girls allayed Nerida's thoughts of being a 'bad mother', even though family, friends and health professionals appeared to blame her for her son's difficult behaviour:

> Nerida …we've got two perfect daughters….so I know it cannot be parenting, because the girls have been reared in the same family…..and all the way through John has had more attention….always had more attention than the girls…..
>
> Jane Imagine if you just had one child…who was like John, you would think that you…
>
> Nerida …you'd blame yourself….you would, because there are still times when I do think…if I'd done that, would it have worked out differently?...but, when you start to think clearer and sit down and you become more rational, well you think "I couldn't of done anything different, because I know that if I ignored him…I'm certain people would come along and say "well, he's your child...do something!"……even though, I was do something, I was still being told "do something else"……(Nerida, p. 16, 7-11, 27-38).

The mother's narratives highlighted the presence of a strong personal folklore that provided a response to the critical communal folklore of blame. By comparing the behaviour of their children to each other, mothers were able to reassure themselves that they were not responsible for their child's problems and they were able to draw strength from these personal affirmations. However, these declarations often came years after initial concerns about their children were raised and the intervening years were replete with feelings of self-doubt.

The myths of childhood and motherhood strongly influenced how mothers, others and health professionals viewed the experiences of mothers who were concerned about their children's development. These myths became even more influential when they were adopted as the foundation for political and cultural ideology. Myths that provided the basis for ideology paved the way for widely accepted 'assumptions' to be concretised into coherent philosophies and political action.

A Marxist/critical theory reading

Revisiting critical theory

Critical social scientists argue that what mothers experience and how they relate these experiences to others is primarily a reflection of dominant ideologies that regulate social behaviour (Fay, 1987). As discussed in the methodology chapter, ideology can be defined as 'a set of beliefs and goals of a social or political group that explain or justify the group's decisions and behaviour' (History Central, 2000, para 1). When ideology is designated as 'dominant', it most commonly refers to the Marxist notion that the beliefs and values promoted by a given ideology reflect or serve the interests of the dominant class in society (Abercrombie et al., 1980). Importantly for this study, the dominant ideology of motherhood was used to emphasise that there existed one major set of ideas about motherhood, and it was against this set of ideals that mothers' actions were measured. This dominant ideology of motherhood was concisely summarised by Anne Oakley in the 1970s as the belief that 'all women need to be mothers, that all mothers need their children and that all children need their mothers' (Oakley, 1974, p. 186).

An ideological analysis of the mothers' stories enabled questions to be raised about the ideas and beliefs about the nature and role of mothers in society and how they were reproduced in both communal and private folklore. The mothers' stories were examined to determine the extent to which the narrative reflected cultural hegemonies, dominant ideologies and the interests of the powerful. By drawing attention to these ideological impositions, I expose how these mothers developed self-misunderstandings that led to dissatisfaction and a social crisis for the group.

The ideology of mothering

How mothers are perceived by society is influenced by the imposition of socially and historically constructed ideological notions of motherhood (Phoenix & Woollett, 1991). How mothers and other members of Western society perceive motherhood has been the topic of a number of research studies in the past (Badinter, 1981; Braverman, 1991; DiQuinzio, 1999; Johnstone & Swanson, 2003; Kleinberg, 1999; Moore, 1996; Phoenix et al., 1991; Smart, 1996; Tardy, 2000; Williams & Cooper, 2004), and the clear message from all of these studies is that mothers today are deeply affected by a cultural ideology that portrays mothers as the 'natural' person to carry the primary responsibility for raising children. This ideological imposition carries into the 21st century; even though social policy, economic improvement and

technological advances in recent years have changed the way mothers may go about their daily activities of mothering (Smart, 1996). It is important to determine whether the mothers who told their stories had been influenced by a dominant 'mothering' ideology, and if so, whose interests are served by this hegemonic adoption of ideological driven values and beliefs of motherhood.

'Whatever it takes'

The conviction with which mothers emphasised their dedication to their children and their determination to help them 'what ever it takes', was a theme that arose repetitively throughout all the mothers' stories. Kimberley stated that she had not had a night off *(as a mother)* in six years, as her son sleeps in, and wets, her bed every night, and she allowed this to continue even though 'I hate being a mother after 7 o'clock…(by then) I've had enough…yeh' (Kimberley, p. 15, 43-44).

Mary's narrative also reinforced her commitment to motherhood. She emphasised the number of people she took her son to see, and while seemingly brushing aside the expense of all these visits and tests, her statement strongly reiterated her role as a mother:

> I'd spent thousands and thousands of dollars…not that that's an issue…but, going from pillar to post having aural assessments, eye assessments, this assessment, that assessment, you know, every possible assessment [ ]…as you can see (she shows me two very large folders full of papers and reports)..that's……all that is all his…everything filed in order of…(Mary, p. 6, 4-8; 10-13).

Mary's narrative strongly reflected ideological notions of motherhood, and parenthood, where parents, particularly mothers, are those naturally responsible for their child's well being:

> …but we firmly believe he's where he is at, he's made the progress he has because of us…I do believe that….that 90% of it is because we were committed to do the absolute best we could for him…..irrespective of what the problem was…(Mary, p. 14, 5-9).

Maggie's story focused on her ability as a mother to manage her difficult child. She told how she attended parenting courses, read books, took him along to sporting activities to redirect his attention and activity, and followed the advice of her son's teachers and paediatrician.

The high ideals and values that are attached to mothers were replicated in all of the mother's stories in this study. These expressed ideals and standards reproduce the culturally defined norms that are driven by the dominant ideology of motherhood in

today's society. Yet, the emphasis with which these mothers referred to their mothering ability may seem excessive to those who are not mothers. Perhaps this was because these mothers needed to counteract and compensate for having children who did not fit the societal expectations of 'the perfect child'. All of the mothers' narratives overcompensated, overcommitted, over-emphasised and overstated their commitment to good motherhood. Their statements that implied a fierce loyalty to their children may be, in part, the outcome of ego defence. Mothers needed to assure others, and reaffirm to themselves, that they were good mothers (Parker, 1995). Choi, Henshaw, Baker and Tree (2005) found that when mothers are fearful that they will be seen as a failing to be a 'good' mother they will work even harder at their mothering 'performance' (p.177). The fear of failure carries with it a huge burden of guilt and drives mothers to mother more intensively.

Their fear of failure and subsequent increased drive to perform 'better' implies that there is little resistance to the capitalist ideology of motherhood that Donzelot (1980) would argue places families, and mothers in particular, as those responsible for the upbringing of an effective commodity - the child. Children who follow societal rules, and can be educated to become efficient workers are what the capitalist state needs to perpetuate wealth for the bourgeoisie (Donzelot, 1980). By adopting and defending such a powerful commitment to their children, the mothers' narratives located them firmly within ideologically dominant ways of thinking and behaving.

Nestling beside the dominant ideological notions of the role of mothers is the role of fathers. Accordingly, a father's role is to provide a child with financial security while a mother is required to provide the care essential for a child's emotional, social and academic success (Donzelot, 1980).

The role of fathers
All of the mothers' emphasised a great commitment to their child's upbringing, replicating the primary ideological concept of the role of the mother. In direct contrast, in several of the stories the role of fathers was barely mentioned. Rebecca's transcript did not refer to the father of her child, even though he was living with the family, and Maggie only talked about her son's father when contrasting her own child rearing style directly with his. While not wishing to venture into the enormous amount of literature that discusses how dominant ideology encourages men and women to enact their roles in different ways, I acknowledge

that ideological notions of masculinity and fatherhood influenced how men responded to their children and interpreted their role as fathers. What is important to note was that these stories identified that the roles mothers were playing, as primary caregivers of their children, were those that follow dominant notions of mothering. Most mothers took on the direct responsibility for their children's development, while fathers were placed somewhere in the background. Two of the mothers did, however, talk about the active role fathers played in the care and responsibility of the children.

Alana stated that her husband had been actively involved in the raising of their daughter. Alana explained that her husband stayed at home to raise their children while she went to work, explaining that her husband had undertaken most of the child rearing:

> …so she did all those sort of active things, mostly with my husband because he had the time...um…(Alana, p. 2, 9-10).

Throughout her narrative, Alana referred to 'we', rather than 'I' when talking about her experiences, confirming the active role that her husband played in the upbringing of Betsy, their daughter. Mary also referred to her husband's role in raising their son, although through the majority of her narrative, Mary referred to 'I' when discussing assessments, tests and doctors visits. Later in the narrative Mary began to use 'we', talking about the collaborative nature of her and her husband's role in raising their children. Mary's husband changed his business practice so that he could assist in the child rearing and attend all the doctors' appointments with his son:

> ….my husband works part-time now because it's just not manageable, and he does his consultancy from home…so that he can take them to school and pick them up because the routine is so important…(Mary, p. 13, 13-16).

While both of these mothers shared the responsibility of their children's upbringing with their husbands, both Alana and Mary still appear to enact the capitalist driven ideology of motherhood. Because these mothers have grown up in a society so focused on the roles and expectations of mothers, it is hard for them to consider any other alternative way of mothering. This is particularly apparent in Mary's comment:

> ….and I mean, she's (*Mary's daughter*) close to her dad and he talks to her a lot….I suppose in a sense I'm rather resentful of that as well, because I feel that I wasn't able to have established a bonding that I wanted, and she wanted, because it was sabotaged so frequently…(Mary, p. 17, 30-34).

Mary regretted being unable to spend time with her daughter and develop a close relationship with her, and as a result felt guilty that she had 'failed' to be a good

mother. Mary felt torn between her responsibilities as a mother to a child who needed additional support, and her other child whom, she felt, was 'growing up without her'. Mothers often find that they are pulled in two directions at once, especially when they try to act in accordance with ideological notions of the 'good' mother.

Mothers as a 'pushmi-pullyu' (Competing messages of motherhood)

Hugh Lofting (1920) wrote a series of children's books about the travels of Doctor Dolittle, a man who could talk to the animals. In his stories the doctor was introduced to a strange African animal, the 'pushmi-pullyu'. Pushmi-pullyus were animals who had not tail, but a head at each end. While able to work together at times (it could eat while talking), sometimes the pushmi-pullyu was pulled in two directions at once. At times mothers feel like Dr. Dolittle's pushmi-pullyu two-headed animal. On one hand, the dominant capitalist ideology of motherhood lauds the commitment of mothers who stay at home and their ability to conduct child rearing on their own (Donzelot, 1980). Accordingly, mothers who stay at home are fulfilling an important role for the future of the nation. They are raising children to be productive citizens in the most economically viable format. On the other hand, 'the natural ability of mothers is undermined because they are made dependent upon expert advice for the most simple of mothering decisions' (Johnstone & Swanson, 2003). Mothers are caught up in the ideological notion that they are inherently capable of looking after their own children, yet they need to ask for the assistance of experts at every turn. Often, when advice is sought, mothers receive little additional help or support, so they are back in the position from which they first started out. Mothers end up not knowing which way to turn, feeling pushed and pulled in every direction, but going nowhere fast.

This pullmi-pushyu pattern of mothering serves the interest of the governing people, as mothers, while accepting assistance from experts, also feel reluctant to draw additional attention to their children's problems due to their self-perceived inadequacies as an ineffective mother. While these notions merely reflect prevailing ideology, they limit a mother's ability to seek assistance. Kimberley did not seek professional advice until her son was two years of age (p. 1, 43), even though she had been concerned about his behaviour for over 12 months. Justine was concerned about her son's socialisation skills, but only discussed her concerns with a friend (Justine, p. 2, 3-4). It was not until her son was four years old that Justine

sought professional assistance, on the advice of her son's pre-school teacher. Maggie noticed that her child behaved differently from as early as pregnancy, yet did not seek professional advice until her son was in his first year of school. She managed her child with the assistance of her family by:

> ….just passing him around…because he was such a handful…you couldn't sit, you couldn't stand, he wanted to do the opposite all the time….this was at ten months…(Maggie, p. 1, 39-42).

Even though all of these mothers felt that their child had a problem, they often managed their concerns within the microsystem (Bronfenbrenner, 1979) of family and friends. This was consistent with the findings of Choi (2005) who found that mothers had mixed feelings about asking for help because they didn't want to be seen as bad mothers.

Yet, while these mothers fulfilled their ideological inspired role as independent mothers, they were also burdened with a sense of guilt, especially when they considered that their child might have long-term difficulties. When Kimberley did finally request assistance from a professional, her concerns were dismissed as being the result of 'a bad day' (Kimberley, p. 1, 47). Furthermore, this particular professional interpretation 'went on for 2 years' (Kimberley, p. 1, 48). The response prompted Kimberley to question her ability as a mother, interpreting the expert advice as a more accurate explanation of her son's behaviour, than her own. The doctor's assessment of Kimberley's needs differed remarkably from Kimberley's, yet it took her two years to seek another opinion. Kimberley's hesitation was a reflection of the mother as a 'pushmi-pullyu'. Mothers were pushed into seeking advice concerning their child's development, yet were pulled into believing that their child's problem was their own responsibility. Parker (1995) refers to mothers as being 'torn in two' (p. 1).

Mothers are 'torn in two' when they experienced conflict between the 'prescribed rules' of mothering and their own instinctual feelings about their child. This conflict left them feeling confused about their role as mothers, leaving them 'powerlessly powerful' (Parker, 1995, p. 199). Even though mothers were 'accorded overwhelming responsibility for their child's development, their authority was circumscribed, subjected, as they are, to the critical gaze of a network of structures' (Parker, 1995, p. 200). This was perhaps the result of living in 'a society that simultaneously idealizes and devalues the mother' (Swigart, 1991, p. 6). This was

particularly so for single mothers who, Parker (1992, p. 217) suggests, are singled out for blame more than any other group of parents in Western society.

You can't do it on your own – single motherhood

Some mothers fell outside of the dominant notion of 'good' mothers, purely through social circumstance. 'The family' as an ideological concept influences policy and shapes public opinion about a range of social issues (Kent, 2000), including single parenthood. According to the dominant capitalist perspective, children need both mothers and fathers to help them become compliant and productive citizens (Donzelot, 1980). Single mother families are demarcated as 'dysfunctional families', due the absence of a father provider, and accordingly dysfunctional families are more likely to produce 'deviant' children. Single mothers have, in recent years been singled out as the root cause of rising unemployment, increasing juvenile crime rates, teenage homelessness and mounting social security costs (Bank, Forgatch, Patterson, & Fetrow, 1993). For example, research undertaken by Bank et al. (1993) suggested that single parenthood was associated with less effective parenting, arguing that discipline was inconsistent, which in turn was associated with boys maladjustment. Hanna's (1996) doctoral study of teenage mothers contradicted Banks, finding that some single teenage mothers to be excessively altruistic and careful in bringing up their babies. Other studies (Bradley & Corwyn, 2002; Conger et al., 1992; Hoff-Ginsberg & Tardif, 1995; Yeung, Linver, & Brooks-Gunn, 2002) advocated that it was the economic distress that arose in low, single income families that was associated with adjustment and behavioural problems in children, however, single parents still received considerable negative attention in regard to their parenting skills. This is reinforced by current Liberal government policy that demands single mothers (by reduction of their support pension) return to the workforce once their children are six years of age (Australian Government, 2005), the implication being that State dependent single mothers are a burden on the public purse. Similar policies are in place in the USA (Meyer & Rosenbaum, 2000). One mother, Kimberley, felt that as a single mother she was constantly blamed for her child's behaviour. When asked if she felt that being single had made a difference in her doctor's response when she raised concerns about her child's behaviour, she replied:

> Yeh, I think so, absolutely…because their exact words to me, my doctors <u>exact</u> words to me were "It's hard being a mother, it's even harder being a single mother, but what makes it more difficult is you've got two small children, you're having a bad day, get over it"…and I'll never ever forget those words for as long as I live (*laughs).* (Kimberley, p. 7, 38-44).

While this perception of single mothers as 'poor' mothers has been widely reported (Bank et al., 1993; Becker, 1987; Garey & Arendell, 1999) the ideological focus that identifies single mothers as 'poor' mothers was not replicated by Kimberley's lived reality. While 'others', may have seen her as a 'poor mother', Kimberley believed that she had managed her family well, particularly given the difficult behaviour of her son. When asked if she blamed herself for her son's behaviour Kimberley replied, 'No, because I didn't ask to be a single mother' (Kimberley, p. 12, 21). By stressing that her single status was not her choice, Kimberley's statement replicates findings from other studies that identify that even though many single mothers are engaged in a large amount of child rearing work, they do so 'in conditions not of their own making' (Garey & Arendell, 1999, p. 6).

Even though single mothers did not feel responsible for their single status, they still questioned their ability to mother their children. Melanie was concerned that her single mother status had left her unable to care for her child appropriately. Melanie explained that she worked and studied as her daughter grew up and, as a result her daughter was left in the care of her grandmother. Melanie replicated the dominant hegemonic ideology of motherhood, stating that she felt guilty that while she 'had a feeling' (Melanie, p. 9, 13) about her daughter's behaviour, she was unable to spend more time with her and notice more. She also regretted not having had more time to pursue assistance for her daughter from teachers and health professionals.

While not feeling responsible for their single status, the mothers felt responsible for their children's problems, the lack of resources and time to do anything about it. Justine, for example, wondered if she had been in a relationship where household chores could have been shared, she might have had more time with her child:

> ..and I know he (Jack) does need that little bit of extra attention…you try and do it, but you get pulled in a lot of different directions and being a mother and household and…so…(Justine, p. 13, 47-49).

Single mothers who had no opportunity to share chores and childcare felt the pushmi-pullyu of motherhood even more strongly than mothers who had direct support from their partners.

Contrary to Bank 's (1993) proposal that single mothers are 'poor' mothers, it was apparent from the narratives that all the mothers without permanent partners cared for their children with as much dedication and fervour as those mothers with partners. However, the single mothers may have been poor in financial situations,

lacking the financial resources to seek help outside of the public health and education system.

Access to resources

While the capitalist ideology focuses on the actions and behaviour of the mothers, in actuality, some authors argue that restricted access to resources is likely to be a key limiting factor in the early detection of children with developmental problems (Ray, 2003; Roe & Morris, 2004). Indeed, mothers who lived in small rural communities had very limited access to health advice and support services. Kimberley lived in a very small rural township where health advice was limited to one local doctor. Her limited financial resources restricted her ability to travel to a larger regional centre 200km away, so she relied totally on the advice of her local GP. She was further isolated by her personal lack of knowledge, 'being a first time mum' (Kimberley, p. 3, 46) and lack of family support. Kimberley was so concerned about her son's behaviour that she repeatedly visited her local GP, even though, every time she went, he advised her that 'nothing was wrong' with her son, and that it was more likely that she was not coping as a single mother. Kimberley's access to services was severely restricted by her financial limitations, and as a result she was unable to seek advice from other potentially supportive services.

For the mothers' in this study, however, access to financial resources was no guarantee that a child's problem would be detected early. Both Nerida (p. 6, 43-44) and Mary (p. 6, 3-4) spent thousand's of dollars on tests and assessments in the preschool years, and yet both had children whose problems were not clearly identified until they were 8 and 6 (respectively) years of age. Donzelot (1980) argued that this lack of professional support occurred because all mothers, regardless of financial security, are required to conduct their mothering within the confines of home and within the restrictions of what resources are already provided for mothers and children by the State. Seeking assistance and acknowledgment of a child's problem in the preschool years costs the people in power more, and when a child is so young, there is little medium or long-term financial reward for the government. Mothers are expected to conduct the 'business of child rearing' within the limitation of existing services. Mothers who require additional State resources in managing their child become marginalised in a society that values efficient productivity over welfare. Hugman (1998) argues that the State is able to control access to services by regulating how health professionals practice and distinguish between those who are in 'need' and those who are not.

The regulation of practice and assessment of 'need'

Hugman (1998, p.115) suggests that health professionals are at constant odds in regard to aligning their notions of 'caring' and their socially contextualised judgements about individuals seeking their advice and assistance. Because most health professionals in Australia are trained and educated by the State, the context in which they make judgements about an individual's 'need' is coloured by the state regulation of practice. The establishment and development of developmental assessment schedules, for example, not only limits individual discretion by the practitioner, but also restricts the number of people who could be considered 'in need'.

The concept of 'need' has long been debated, however, important to this discussion is the neoMarxist cultural critique that links needs theory to politics. Marx, Maslow, Marcuse, Fromm and Adorno have dominated the development of needs theory (see Fitzgerald, 1977b), essentially arguing that 'expressed or perceived needs…are shaped by dominant political ideologies and social practices' (Holmes & Warelow, 1997, p. 436). Marx distinguished between 'true' and 'false' needs, suggesting that true needs were objective 'real' needs, whereas false needs were artificially created needs, or desires (Fitzgerald, 1977b). False needs become so important that they displace true needs (Springborg, 1977). Marcuse elaborated on Marx's definitions, arguing that true needs were those vital ones such as food, clothing and housing, whereas false needs are 'those which are superimposed upon an individual by particular social interests' (Marcuse, 1964, p. 4-5). Satisfaction of need is not determined individually, rather it involves 'standards of priority' (Marcuse, 1964, p. 6) established by those in power. Through the development of a needs criteria, needs no longer remain 'simple matters of fact', but 'involve value judgements' (Fitzgerald, 1977a, p. 196; 204). When the political State determines health care services based on needs, the priority given to certain needs will be drawn from a capitalist ideology that, neoMarxists argue, denies workers their needs, in favour of political economy (Macpherson, 1977).

Following on from the neoMarxist arguments and based on Bradshaw's (Bradshaw, 1972)(1972) concept of need, Smith (1980) suggested that 'need' is not an objective fact, rather it is based on subjective interpretation of professionals who are influenced by ideological values inherent in the dominant capitalist state. Bradshaw identified four different concepts of need: 'felt need'; 'expressed need', where explicit

statements are made concerning a lack of something; 'normative need', where judgements of need are made by professionals; and 'comparative need', where comparisons are made between individuals and groups. In order to gain assistance, a professional must assess individuals who consider themselves 'in need'. This professional in turn, compares the need of the individual against the needs of others. Professional assessment of need may therefore not match expressed need. Hugman (1998) proposes that the problem arises in assessing 'need' because the State gives power to certain groups to determine what 'needs' are, and this might not match what needs really exist. This gap is exaggerated in a neoliberal State, where there is ideological opposition to State support of individuals, the State preferring the 'natural' dependency relations of the family. This is particularly so in Australia, where health and social welfare policy and legislation is 'constructed around ideas of the family, and the way in which health and welfare are seen to either buttress or undermine that institution' (Hugman, 1998, p. 14). Health professionals are usually trained and work in government-operated organisations, and Hugman argues that members of the caring professions, such as nurses and doctors, while serving the interest of their clientele, also serve the interests of the State. The State, therefore, influences how caring is practiced and perceived, and how need is determined.

Asking for assistance was, therefore, problematic for these mothers. Mothers who felt and expressed a need for assistance with their children may not have had their concerns ratified by a professional. Professionals may have judged the mother's need to be something that could be dealt with by the family, rather than as a problem that required the intervention and support of State run services. Kimberley felt that her son's problem was one that required professional assistance, and when it took over two years to be considered as a mother with a child 'in need' of assistance, Kimberly took a remarkable form of action:

> I rang child welfare up and said "if someone doesn't come and get this kid right now, I'll give him to you tomorrow in a body bag" because I'd had enough….absolutely had enough…(Kimberley, p. 2, 1-5).

According to Kimberley, the social welfare's response to her plea was:

> Oh, we'll come and see you tomorrow…and I said "well that will be too late, I need someone here, like <u>now</u>" (Kimberley, p. 2, 7-9).

Kimberley expressed her need in the strongest terms possible, yet the professional interpretation of her 'need' did not match Kimberley's. Hugman (1998) would suggest that professionals misunderstand the felt and expressed needs of

individuals because ideological notions of a neoliberal government infiltrate into the organisation of health and social welfare, divorcing professional perceptions of need from those who need the services.

Kimberley's experience replicates the findings of Ray's study (2003) of special-needs parents. Ray found that mothers often had to beg, end up in tears on the phone or 'threaten to relinquish custody of their child' (p. 289) before getting support. Mothers commented that they 'were made to feel guilty' when they asked for help:

> If you are asking for these services that were designed for children like your child, you are somehow not quite as good as the person who does it ALL ALONE. NEVER ASKS. PAYS FOR IT ALL. And ISN'T A DRAIN ON THE TAX SYSTEM. You are not quite as good. You are a normal parent, and these other guys are saints (Ray, 2003, p. 289).

Similarly, in a recent Australian study, Roe and Morris (2004) found that women were portrayed as responsible for failures in their children, while also being criticised for their dependence on the public purse when they needed assistance.

Other mothers found that they had to wait months or years for access to resources. Melanie's daughter Alice, for example, was referred to the local hospital for assessment. Alice was finally seen by an occupational therapist 10 months later (Melanie, p.4, 23-26). Hugman argues that the reality of social welfare in Western neoliberal societies is that there is a limitation of resources relative to perceived need. In a neoliberal State, health professionals become the 'rationers and gate-keepers' (Hugman, 1998, p. 157), deciding who can access the state provided resources and who cannot. Even though two of the mothers were able to afford to pay for assessments and tests, they were only able to access free government resources, such as classroom assistance or early childhood intervention programmes on the approval of a health professional. It was the health professionals, particularly medical practitioners, who held the power to determine who was eligible and who was not. While it could be argued that most health professionals do not deliberately set out to deny mothers and children access to resources, the realisation that resources are severely limited would encourage them to select only the individuals they considered the most 'in need'. Just as Carpenter (1999), Malacrida (2003) and Rogers (2005) found in their studies of mothers whose children had ADD and ADHD, the children in this study were less likely than physically disabled children and their families to fall into the category of 'in need'.

Subtle developmental problems in young children, while noticed by mothers, remained invisible (Stone, 1995) to public health services that define 'need' according to State rules and regulations. By making 'blanket denunciations' (Holmes & Warelow, 1997, p. 467) about who is 'in need' and who is not, it is likely that children whose need is not physically explicit, will be overlooked.

When the state supports and promotes the rhetoric that early childhood is a critical period for development and developmental problems in early years increases the risk of future social, emotional and academic problems, it creates a felt 'need' in mothers whose children are exhibiting early developmental problems. While these felt needs are, in the Marxist sense, 'false' needs, having been imposed by the political and social structures, the mothers are caught up in the ideological manifestation of the 'developmentally correct' child. When children do not typify this type of child, mothers seek help from health professionals. The desires of the mothers to have these problems addressed, however, create a need that is then not met by the very society that advocates the need for improvement. As Holmes and Warelow (1997) suggest, 'the felt needs generated by consumer capitalism are continuously reconstructed so as to be always beyond reach' (p.465), or as Adorno and Horkheimer remark,' it perpetually cheats its consumers of what it perpetually promises' (Adorno & Horkheimer, 1944, p. 139). Not surprisingly, mothers felt dissatisfied with a health service that did not meet with their perceived need, as Kimberley expressed:

> (*I felt*) very neglected…like, the government provides this system for people
> who need help, but when you put your hand up and say you want help, well
> they say, oh yeh, we'll be there tomorrow…(Kimberley, p. 2, 20-23).

Mothers were left to cope with their children in the privacy of their own home, rather than with the support of the public institutions that mothers had understood to be in place to assist them.

The home as 'lifeworld'

The expectation that effective child rearing takes place in the privacy of the home, sits interestingly alongside the observation that the home is increasingly a 'lifeworld', colonised by 'systems' (Habermas, 1987). A family's private place is being more and more regulated by governmental systems, such as childcare, physical and mental health, police and justice systems. Poster (1978) suggests that families are increasingly isolated from the community as homes become a place of retreat from the working world. These nuclear families have reduced contact with extended

family and community members. However, the intensification of recognition of a child's needs creates a new form of oppression where women are increasingly dependent upon advice from others. When families and community are no longer actively engaged in support, professionals employed by governmental institutions are used to fill the breech. State employees such as nurses, doctors, psychologists and developmental specialists prescribe strategies for mothers to follow. Child welfare policies further emphasise these strategies that shape mothering behaviour towards State approved ways (Carpenter, 1999). Mothers actively adopt the strategies as they strive to fulfil their roles as 'good' mothers. In Foucauldian terms, surveillance by the state now extends not only into the home, but through various self-surveillance techniques, mothers are co-opted into that process.

A Foucauldian reading

Revisiting main concepts of a Foucauldian reading

Discourse is the most important concept in Foucault's (1972) work and it is centrally concerned with language. In his work on discourse Foucault discusses discursive practices that provide valuable insight into the role of ideology, social control and the rules that govern language, how people think and how people behave. Foucault (1972) defines discursive practice as:

> A body of anonymous, historical rules, always determined in the space and time that have defined a given period, and for a given social, economic, geographical, or linguistic area, the conditions of operation of the enunciative function (p. 117).

The stories of Kimberley, Mary, Justine, Melanie, Rebecca, Alana, Maggie and Nerida provided an opportunity to understand the hidden practices and rules that impacted on their experience as mothers of children who had developmental or behavioural difficulties that remained undetected, except by their mothers, until school age. Reading their stories through a Foucauldian lens enabled themes to be identified and discussed in relation to the discourse of childhood development and motherhood, as expressed in the text by the mothers themselves.

As discussed earlier, in Western society today, the task of raising children is considered the responsibility of parents, and more specifically, mothers. To help parents with this undertaking, the community offers 'advice', usually through statements that offer 'the best way' of raising a child. This advice is gathered from friends, family, health centres, educational bodies, community-based organisations and sometimes, complete strangers. The advice may include information on the

'best way to': breast feed, introduce solid food, get your baby to sleep; play with your child; manage behaviour; educate your child; socialise with other children; bond with your baby; and the list goes on. Most importantly, this information highlights to parents the negative implication of a child's development going awry. These statements about early childhood development have become so powerful that how a child develops, whether physically, socially or behaviourally, becomes an important concern to parents (Rose, 1990). Parents become anxious about developmental idiosyncrasies in their own children and seek advice and support in regard to these concerns (Malacrida, 2003; Todd & Jones, 2003). But is this 'advice', as suggested by Foucault (1977), merely a normalising strategy that has been implemented by powerful groups within society to regulate how mothers go about the task of mothering? Furthermore, when wider societal groups adopt the recommended strategies of 'knowledgeable group' are they engaging in self-regulation and surveillance (Foucault, 1977; Rose, 1990) that reinforces the 'truthfulness' of this advice and the consequent actions? These are particularly important questions when one considers what mothers understand 'normal' to mean (in their children) will play an important role in what advice and assistance they seek from others as part of caring for their children.

What's normal?

The development of children is a long studied phenomenon, intensively investigated over the past one hundred years by specialists in the field of human sciences, namely psychologists, anthropologists, evolutionary biologists, behaviouralists, physiotherapists, occupational therapists, educationalists, and medical doctors. These groups have attempted to identify and define childhood 'norms' against which children's development can be compared (Aylward, 1997). These 'norms' include measures of gross and fine motor skills, socialisation skills, emotional responses, and physical development such as weight and height, behaviour and academic ability. Children whose development does not match the 'expected norms' can be identified and treated accordingly (Aylward, 1997; Brazelton, 1990; Rosenbaum, 1998). There is little doubt that this scientifically supported knowledge of human development has heavily influenced the communal folklore that surrounds child development. Expectations that children behave in certain ways, achieve certain milestones at certain ages and develop according to a specific pathway have gradually infiltrated, through books, magazines, newspapers, television and the Internet into the every-day understanding of 'how children should be'. When children

do not develop according to these 'norms', mothers and other members of society become concerned.

It could be seen in the transcripts that nearly all of the mothers 'noticed' that their children somehow were not reflecting the expected developmental norms. At the beginning of the interviews, mothers were asked if they would like to tell the story of their experiences raising a child whose developmental problems were not identified until school age. To begin their stories, several of the mothers chose to go back to the time when they first noticed that their child was not developing or behaving in a way that they considered 'normal'. The developmental variations in their child may have been in just one, or a few areas of the child's development, or they may have been in a number. The age of the child at which the mothers 'noticed something was different' also varied, from as early as pregnancy to as late as grade one at school, when the child was 6 years of age.

Two of the mothers said they felt something was different about their child's behaviour as early as pregnancy. Maggie noted how her third child was very demanding, even *in utero*, and his sleep patterns as a baby were unusual:

> The very first thing I noticed was when I was pregnant…it went right back that far…he was just…if anyone….like the other boys come to jump on my lap to give me a cuddle or anything like that it would just be "bash, bash, bash….." like, and it was just….against my stomach, as if to say, get off, she's mine…and it has been like that ever since….from the moment he was born, he has always been very possessive, which was a strange thing…you know…(Maggie, p. 1, 9-18).

Maggie went on to mention her son's increasing difficulties in regard to disciplinary problems, aggressive behaviour, clinginess, inability to sit down for short periods, disorganisation, forgetfulness, impulsivity and poor memory (Maggie, p. 2, 1-52). 'It was like someone had wound him up, and you have a little toy that twirls around until it slows down' (Maggie, p. 1, 49-51).

Like Maggie, Mary reported that her son's behaviour was disconcerting from a very early age. Mary explained how her first born child, a son, Luke was so active in her womb that he broke one of her ribs about 6 weeks before he was born:

> Well, he was a caesarean birth…he had quite a big head…um…and he'd actually overshot the pelvis….and he'd been very active in the womb to the extent that he actually broke my rib about 6 weeks before he was born…so, he was caesarean born….and one of the things…he was an emergency….even though the obstetrician said one of the amazing things

about it was when he pulled him out he was wide open-eyed, and like "here I am"….. (Mary, p. 1, 12-20).

While unconcerned at the time, Mary later expressed concern about Luke's 'odd' behaviour that, while initially 'cute' (Mary, p. 1, 40) persisted into his third year of life. She recounted how Luke continually flapped his hands, became obsessive about shutting draws or doors and was difficult to rouse after a nap (Mary, p. 1, 42-46, p. 2, 1-8).

Several of the mothers noticed that their child's development was not how they expected it to be in the first year of life. Kimberley lived for a time with her grandmother, helping her raise a large number of children. When her own son was just a year old, she became concerned about his behaviour:

Jane	When did you first realise that he was different? That this wasn't acceptable behaviour?
Kimberley	Probably from when he was at that age where most babies laugh and smile and want to cuddle you and he didn't
Jane	about one?
Kimberley	Yeh… (Kimberley, p. 13, 13-19).

Melanie also grew concerned about her daughter's development at a very young age:

I noticed from an early stage….she was born small, not to small, 2,980 grams but, all through to maybe three years old she was very petite one, tiny one, and she cried lots…that's the something I remember clearly…her crying...they told me she had colic, or whatever, but…and even when I would hug her she would always cry, you would have to carry her around to calm her….(Melanie, p. 1, 11-16).

These mothers all had infants who, from the beginning, had been difficult to hold and comfort, or whose demeanour differed from that of other siblings. When their children grew older and started socialising with other children they also noticed that their children played or interacted differently. Melanie noticed that her young daughter, when she was four years old and attending day-care, behaved quite differently from other children:

...and I think when Alice started preschool, that's when real problems…and I noticed…and I started seeing there was…at preschool she would cry…um, when something happened she would run away…like would scream, she didn't like anyone touching her…(Melanie, p. 2, 19-23).

Nerida's concerns escalated when her young son John was in preschool and he nearly killed himself, twice, once by hanging, when she reasoned that he 'probably didn't hold a concept of what death was' (Nerida, p. 1, 19) and the second time by electrocution (Nerida, p. 1, 24), when she became concerned that he 'knew no danger' (Nerida, p. 1, 25). John also had problems at school:

> ….then when he got to grade one, he was very much a bully…couldn't write
> properly, seemed to have poor motor control…(Nerida, p. 1, 28-30).

Not all mothers, however, had experiences of children whose development they considered different or unusual. Rebecca noted that she had no concerns over her son's development until the teachers in her son's pre-school raised concerns about his behaviour. In order to understand what influences these mothers to consider their children's behaviour to be a cause for concern, one needs to consider the normalising strategies that exist in society today.

Normalising strategies of society

Foucault (1977) suggests that normality is a human value against which people are continually judged. People are judged in terms of their mental ability, their emotional state, behaviour and physical appearance. Institutions, such as the medical, psychological and educational disciplines, establish a range of normative values that are used to ascertain what human behaviour is considered 'normal' and what is not. People are assessed and diagnosed according to this normalising set of assumptions. Members of society accept the set of standards and values associated with normality because these standards are represented, through scientific knowledge, as beneficial to society (McNay, 1994). Foucault (1977) refers to this normalising strategy of human science as 'bio-power'. 'Bio-power takes as its target the biological processes of the collective social body' (McNay, 1994, p. 116) and attempts to normalise the population by introducing a series of interventions and supervisory regulations that are concerned with governing all aspects of life, including sex, birth, death, family life, general health, life expectancy and so on (McHoul & Grace, 1993). These life processes become 'normalised' by the action of the population in two ways. Firstly, social agents, such as health professionals, are disciplined through educational institutions that reinforce the normalising strategies of human social science. These social agents are responsible for 'disseminating truth-producing discourses in a manner that ensures understanding and compliance' (Powers, 2001, p. 22). Secondly, Foucault suggests that individuals want to be accepted as part of the 'normal' population, and rather than be considered as outsiders, work on themselves in order to meet and comply with the models normalised by their culture (Foucault, 1988). In this way, the population replicates and reinforces the power of the dominant human science discourse by self-surveillance and self-regulation.

By providing mothers, and other members of society, with a set of instructions about how they should identify normality, social agents encourage mothers, and others, to self-regulate behaviour and seek out assistance when abnormality is detected (Powers, 2001). To assist in their job of raising a 'normal' child, mothers in this study acquired information about child development from a number of different sources, including taking their child along to health professionals either for 'well child checks', or when the child required immunisations, or was sick.

Child health nurses and medical doctors

Because the instructions on how to raise children keep changing, parents often need to seek advice from those outside their immediate social circle who are considered more 'up-to-date' in child development and health, for example, maternal and child health nurses. Foucault (1977) suggests this is part of the 'normalising strategy' endorsed by a discursive body (the medical discourse) wishing to regulate and control both group and individual behaviour.

While the mothers were encouraged to attend health services for health and development advice about their children (Department of Family & Community Services, 2004a), it was notable that in this study only two of the mothers regularly attended mother and baby clinics for 'well child checks' in their child's first year. Until her second son, Jack, was about 2 years of age, Justine utilised the services of the local mother and baby clinic. At the clinic Jack was weighed and measured but Justine's concerns about her son were never a topic of conversation. After Jack turned 2 years of age, Justine stopped going to the clinic and only visited the local general practitioner when her son was sick and for his immunisations. Mary went along for a few months with her son Luke until the child health nurse became 'alarmed at the rate his head was growing and insisted that we return to the paediatrician' (Mary, p. 1, 27-29). Mary did not return to the health clinic, choosing instead for her son to be monitored by her local doctor and paediatrician. Other mothers did not attend infant health clinics for 'well child checks' but utilised the services of the local doctors when the child was unwell or required immunisation.

As previous studies have suggested (Al-Yaman et al., 2002; Family Policy Studies Centre, 1997; Goldfeld et al., 2003), while child health nurses are trained to provide mothers with support and advice in early childhood development, most of the mothers chose not to, or did not access their services. This reluctance to attend health clinics and parenting centres may be explained by the parents' fear of

surveillance. Drawing on the notion of disciplinary power as advocated by Foucault, Peckover (2002) argued that the mothers in her study, while on one hand, welcomed health visitors' advice and interest in their family, on the other hand were concerned about later repercussions if the health nurse found out anything that identified them as 'inadequate mothers' (p. 374). While Machen (1996) refuted the suggestion that surveillance is part of the health visitors role, Peckover (2002) argued that parents perceive it as taking place. This may be one explanation as to why mothers in this study were reluctant to seek assistance from child health nurses. However, if fear of surveillance discouraged mothers from attending child health clinics, why then did mothers place themselves under even greater medical scrutiny by revisiting general practitioners and medical specialists?

As noted earlier, when one of the nurses did raise concerns about a child and referred the mother on to a medical doctor, the mother preferred to remain under his care, rather than return to the child health nurse's regular surveillance. It is apparent that mothers were less reluctant to seek the regular advice of doctors. Discursive statements about who is best able to assist in matters of early child development emanating from the medical discourse appears to hold far greater authority than those circulated about child health nurses. Mothers deliberately chose medical expertise over nurse expertise, even when the mothers themselves did not necessarily agree with the doctor's assessment of her child (see chapter 5).

Carpenter (1999) suggests that mothers voluntarily place themselves under the care and authority of a medical expert to prove that they are responsible mothers who are doing everything possible to help their children. By placing themselves under the umbrella of medical care, the mothers protect themselves from further criticism as 'bad' mothers, showing to society that they are seeking appropriate assistance for their child. By seeking medical advice, mothers not only remain under surveillance from the medical profession but also engage in self-surveillance, replicating existing discursive rules on child development and mothering behaviours, and a doctor's position as knowledgeable expert.

Some mothers did, however, choose to avoid surveillance from health professionals until the child attended school, preferring to rely on support from their own family members and others. Maggie (p. 5, 4-5) had only spoken to her mother-in-law about her child's behavioural idiosyncrasies until he attended pre-school and Rebecca

only took her son along for immunisations. However, surveillance of their mothering did not necessarily abate, in fact, the surveillance from the local community often resulted in harsh criticism of the mother's ability to raise a 'normal' child.

Family & community

It is not only mothers that were influenced by the normalising strategies of the biomedical science discourse; it also influences the wider community. The transcripts draw attention to the responses of family and community who 'noticed' that 'something was different' about a child's development and either directly (voiced their concerns) or indirectly (behaved negatively toward the mother) made their concern known. In their stories, mothers tended to talk about being 'supported' or 'unsupported' in their concerns for their children.

Alana's daughter, Betsy used to have 'really long tantrums and screaming fits' (Alana, p. 1, 19-20) from the age of about 2 years. Living close to her mother enabled Alana to confide her concerns to her; in fact, it was Alana's mother, a nurse who recommended allergy testing at a nearby clinic, where Betsy was diagnosed with food allergies. While Betsy has since been diagnosed with a significant learning problem, the surveillance of her grandmother contributed to her initial assessment and treatment by an allergist.

Not all mothers were fortunate to have had positive responses to their children's problems. In fact, several of the mothers' transcripts revealed how people from local communities let the mothers know that their children were not developing according to 'societal standards'. This was particularly so if the child exhibited behavioural problems in a public space. Many of the mothers felt scrutinised by a community that judged their children to be less than perfect or abnormal. The pressure of the opinion and actions of others was strongly felt by a number of mothers, and represented turning point moments (Denzin, 1989) in the mothers' experiences that they found hard to forget. Nerida found that when she took her young screaming son shopping:

> …more times than not, in town, I would be approached by elderly women…I suppose I was in my twenties, they probably would have been in their sixties….but, they'd come up to you and say "If he was my child, I would…..", you know, "If he was my child, I'd be doing this….", "why don't you flog him?", "why don't you shut him up?'…….you know, that sort of stuff……it irritated other shoppers as well……..yeh…(Nerida, p. 3, 44-46, p. 4, 1-6).

Dropping her child off at school was just as stressful:

> Nerida   I hated pulling up at the school gates, because you'd have 4 or 5 mothers taping on your car the window…..
>
> Jane   Saying something?
>
> Nerida   Ah ha, always derogatory, always "please control your child".." If he was my child…", "Why don't you discipline him, why don't you flog him, why don't you do this? Why do you send him to school at all if he's going to upset the class…." (Nerida, p. 5, 18-26).

Nerida felt that other mothers and community members blamed her for her son's behaviour, and it was 'a big relief' when the school bus service started, 'because I didn't have to front….every day, twice a day to the school gates….' (Nerida, p. 5, 30-31).

Rather than finding support from the community, many of the mothers found themselves isolated. Kimberley, whose son, Carl had difficulty controlling his aggressive outbursts, found that her friends just no longer came to visit:

> I've lost a lot of friends, yep. .all my friends that I had in that town, I lost every single one of them because of Carl….because they wouldn't come over any more and they didn't want him to go to their house….so it was a case of…they just dwindled out of my life…yeh...it was a case, of ring them up, say what are you doing today, would you like to come over for a cup of coffee, and they'd ask "have you got Carl today?" (*small laugh*) and it used to hurt so much…(Kimberley, p. 11, 29-38).

Mary found that others accepted her child's behavioural idiosyncrasies when he was an infant, but as he grew older her friends stopped coming to visit and her child suffered from social isolation:

> Oh yes……people were very understanding when he was little it was cute…..you know… and he was such an engaging child…but you see the older you get, it's not cute anymore….you actually become an object of ridicule…..not invited to parties…we've had that situation where he's been the only child in the class not invited…and he's just devastated, and of course ……and on one occasion, I thought "this is really not on"…so I rang the mother and I said who I was and she said "yes", "I'm sure there's been an oversight"….and there was dead silence, and she said "*No, is was quite deliberate*" (*laughs)…*I was quite taken aback….and I said but why?...and she said because he's strange, he's odd…..and I said, he's not odd, he does have some odd or peculiar mannerisms…and I said I was quite happy to come with him for the whole time of 2 hours…sit under a tree, or under a bush or hide in the car or whatever, and she said "*No, I don't want that, that sort of thing here*"….and I said "well, thank-you very much"…and then he said, am I going, am I going? And I had to say no, and I had to explain that some people have a great difficulty understanding him…and then he cries….you know, it's really heartbreaking…(Mary, p. 15, 36-42; p. 16, 1-17).

By responding to the children and their mothers in these ways, other members of a community revealed that they had particular developmental expectations and behaviours in mind. It may be, as suggested by Donzelot (1980) that these

communally adopted developmental expectations were influenced by the widely circulated, medically sanctioned, rules about 'normal' child development. The general community adopts these rules and practices as 'their own' and, in so doing so, ratifies and legitimates the medically sanctioned rationale that identifies what is normal and what is not. Jenkins (2000) argues that the process of group identification and the subsequent definition of acceptable social practice occurs as a result of the power/knowledge categorising discourses such as social policy, official classification, healing and medicine, and science. Formal, legal authority is likely to be enhanced by the informal practices of the social group.

Conversely, it could be proposed that these standards were culturally constructed and medicine merely acted as a mirror, adding scientific authority to what was already a social norm. Jackson (1970, p. 765) suggests that medicine has been 'far to obsessed with physical disability and illness' to be concerned with educational and social interpretations of a child's developmental problems. If this is the case, it could be argued that medicine has not set the social and educational expectations for childhood and merely responds to societal pressure to do so. However, by adding its scientific voice to the cry for 'normality', children with developmental idiosyncrasies are likely to continue to be regarded as 'different' and remain as outsiders.

Society and 'difference'

The normalising strategies of a social group are designed to ensure the continuation of a functional and stable society (Donzelot, 1980; Foucault, 1977; Rose, 1990). To manage irregularities, or variances in behaviour, society puts into place its own rules about how to deal with 'difference'. Moore (1994) refers to the significance of difference on identity, sameness and the need to belong and be part of a social group within society. The position of a person within a social group depends on the degree of sameness that the person has with the dominant group and the way in which the dominant group treats differences. In this study it is apparent that the 'identification of difference' occurred through surveillance (Carpenter, 1999, p. 115), whereby mothers and their children were judged by community members as not being 'normal'. Children whose behaviour did not match the expected 'norms' of society were not only identified, often verbally to their mothers, they were consequently isolated. Not only were others critical of the developmental behaviours they considered different from the 'acceptable norms', they also implied that the

mother was to blame. These findings replicated those of Carpenter (1999), Malacrida (2003), Neophytou and Webber (2005) and Rogers (2005) who found that mothers of children with behavioural problems felt criticised and isolated by their communities. Community members distanced themselves from responsibility, leaving the mothers to cope alone. Facial gestures, verbal abuse and exclusion from social activities all reinforced the mothers' nagging feelings of inadequacy and poor mothering skills, because mothers themselves were constantly worried that they were doing something wrong.

Society and stigma

How mothers go about the task of parenting is greatly influenced by the expectations of the community in which they live (Goodnow & Collins, 1990). Parenting is a public performance carried out under the eyes of other family members, children, friends, health professionals and government authorities such as Maternal and Child Health Services, 'all of whom feel the right to judge and, with varying degrees of openness, to comment' (Goodnow & Collins, 1990, p. 109). Mothers are constantly scrutinised as they are perpetually under the 'gaze' of the community and feel pressured to perform accordingly. In this study, mothers, whose children did not comply with expected societal standards, were considered socially irresponsible and often felt stigmatised by the community in which they lived.

Stigmatisation is a socially constructed phenomenon, whereby people who look or behave differently from other social or cultural group members are identified and isolated by the group (Goffman, 1963). Stigmatised people are regarded as different, flawed and 'somehow less human' (Dovidio, Major, & Crocker, 2000, p. 3), as could be seen in Mary's story when another mother says to her: 'No, I don't want that, that sort of thing here…'.(Mary, p. 16, 12-13) 'That sort of thing' referred to Mary's son, whom had taken on a less than human form in the eyes of the other mother.

Goffman (1963) proposed that the defining feature of 'difference' is not static; what is accepted as 'normal' in one place and time may not be accepted in another. Children with behavioural manifestations of 'difference' were not identified as problematic 50 years ago, yet, today certain forms of behaviour are considered indicative of a disorder that is unacceptable to the social group. Stigma most notably falls on the person whom others consider as different, however it can also affect

supporting families, such as the mothers of children with developmental problems (Friedson, 1970). As a result, mothers whose children did not behave in public spaces were discredited as 'good' mothers, and consequently 'disqualified from full social acceptance' (Goffman, 1963, p. 1). Children were no longer invited to parties; childhood friends did not come over to play and other mothers avoided coffee mornings. Furthermore, mothers withdrew from the community because feelings of humiliation arose when their children did not manage their bodies in a socially acceptable manner (Street, 2001), particularly in public spaces where the 'deviance' became visible to others (Goffman, 1963, p. 48).

Link and Phelan (2001) described five components of stigma: labelling, stereotyping, separation, status loss and discrimination. They argued that stigma exists when people distinguish and label human differences and that dominant cultural beliefs link labelled people to undesirable characteristics, or negative stereotypes. Stereotyping separates the labelled people into distinct categories, which 'accomplish some degree of separation of "us" and "them"' (p. 367). Foucault (1973) suggested that the 'them and us' principle is concerned with establishing a value structure which judges who is good and in favour, and who is bad and out of favour. Labelled, or bad and out of favour, people experience loss of status and discrimination that leads to unequal outcomes. Most importantly for Link and Phelan (2001), stigma can only be effective if the person, or group, being stigmatised is less powerful than the group who identify the differences. Social, economic or political power all give weight to claims of 'difference'.

Based on Link and Phelan's proposal, stigmatisation can only be effective if a more powerful group labels a person as 'different'. However, several of the mothers in this study felt a keen sense of separation, status loss and discrimination even though the stigmatising group were not those who are normally understood to carry powerful positions in society. Several of the mothers perceived intense stigmatisation by other mothers dropping their children off at school, mothers with children the same age, community members in the local supermarket or family members who were not usually associated with power and position that would give weight and credibility to their claims. However, while such individuals were not necessarily powerful in their own right, their existed a notional power vested in the social discourse of mothering and child development. The social discourse draws on the discourse of more powerful institutions, such as the discourse of medicine, psychiatry and psychology,

which support notions of difference in child development and behaviour. Mothers and their children came under constant scrutiny, being caught by a gaze which was 'always receptive to the deviant' (Foucault, 1976, p. 89). The gaze of the community afforded a mechanism of surveillance that monitored and controlled social deviance at a grass-roots level. By stigmatising those whose behaviour did not conform to accepted social standards, the community group functioned as agents of social control (Goffman, 1963, p. 139) for more powerful institutions. In this way, mothers were literally forced to seek assistance from those considered 'experts' in child health and development.

Goffman (1963) identified that stigmatised people often seek support from a small group of people, most notably family members, other members of the same stigmatised group and health professionals. Most of the mothers in this study sought support and advice from doctors, yet, not all received the support they anticipated. Nerida noted that when she took her screaming infant to the doctor, he remarked: 'You're neurotic, there's nothing wrong with your healthy child…' (Nerida, p. 3, 24-25). Mary was also told her three year old son was healthy; it was she who had the problem because she was 'anxious and frustrated' (Mary, p. 2, 14). Kimberley was told that she was just 'having a bad day' (Kimberley, p. 7, 43).

The adoption of stigmatising attitudes by health professionals carried particularly powerful repercussions for the mothers, as health professionals are understood by the general community to have high status, technical knowledge and the power to alleviate pain and suffering (Whitehead, Mason, Carlisle, & Watkins, 2001). When health professionals not only failed to provide support but engaged in actions that reinforced the stigmatising behaviour of the general social group, mothers were further isolated from the community. The medical gaze (Foucault, 1973) not only exacerbated stigmatisation, but validated the community action that marginalised those who are different (Whitehead et al., 2001). Mothers were isolated from both community groups and those they understood to be 'supportive' professionals. The words of Nerida intoned the feelings of these mothers: 'Oh no, where do I go, what do I do…who do I tell? (Nerida, p. 3, 29-30). For several of these mothers, it was not until the children began school that they found a supportive professional and assistance for their children.

Teachers

Once children commenced formal schooling they were faced with more complex social, academic and behavioural tasks. Often, it was not until these demands arose that people, other than the mother, noticed a child's developmental difficulty (Glascoe, 2000a). For some mothers, this was the first time that anyone else had suggested that their child might have a developmental problem.

Justine noticed that her son Jack had not developed good socialisation skills before commencing pre-school at the age of four. She had only discussed her concerns with a friend. Several months into pre-school, a teacher suggested he be 'checked out at the hospital' (Justine, p. 2, 9), and while Justine remarked that the teacher 'didn't really say exactly what' (Justine, p. 2, 22) the concerns were in regard to Jack, Justine had begun to notice that 'he wasn't up with the other kids' (Justine, p. 2, 24), particularly in jigsaw puzzle skills. Like Justine, Alana was also advised by a pre-school teacher to seek medical advice for her daughter Betsy:

> …when she started formal kindergarten, she was… probably about a month in, her teacher spoke to us and said she thought she had attention deficit disorder…which, you know, we'd all heard about and we were horrified about, and um, we didn't think it was that bad… anyway we went to a GP, that was the first time…particularly to address that problem..(Alana, p. 2, 29-33).

One of the other mothers noted that, looking back, she felt that the teachers in her child's early school years might have noticed that the child's development was not 'on track'. However, they did not directly raise their concerns with her:

> ….and then after almost 3 months, 4 months one of the ladies said "Ah, we think Alice ..could be…" they were asking me questions, they were thinking because of the language…you know, with what language I talk…and actually, she was doing …not study, but similar…she wanted to ask me some questions about Alice…and I think she must of noticed something different…you know, but no-one mentioned anything..(Melanie, p. 2, 12-18).

Maggie did not raise her concerns with a professional person about her child's development until Peter was in preschool. By this time:

> …I knew then that there was something wrong, because he wasn't sitting in with the classroom, like the structure that the teacher had set up, he would be wandering off playing cars because that's what he wanted to do…nobody could get him to stop…so, the class was here, Peter was off doing whatever he wanted to do all the time… (Maggie, p. 4, 30-36).

Yet, when she raised her concerns to Peter's preschool teacher:
> …..and I said to her a couple of times "do you think there's anything wrong with him?" and she said, "no", she said "he's adorable, but he's a handful, but he's a lovely little boy"…she said "he's very intelligent…"..um, and I didn't see the intelligence…I seen all the naughty stuff, because I'd had it for…you know….(Maggie, p. 4, 43-49).

In contrast, Maggie, received a very direct, positive approach from her son's grade one teacher:

> ….grade one…the teacher that he got…I thought "oh, no", because I had heard from other people that she used to keep a lot of boys down…and um, I thought…I know we're going to have problems here…..she was absolutely fantastic….she was an angel….she was just amazing….she said to me after a couple of months…..well, she had said to me right from the start that she was having a few different problems with Peter…um…we set up meeting, that sort of stuff…and talked back and forth…and it got to about , um, I think it was April and she said…"would you mind taking him to a paediatrician?"…she said "because he's got a lot of behavioural problems" and she said "I'd like to see, what the paediatrician says and what we can do about it" (Maggie, p. 6, 18-34).

Maggie felt that Peter's teacher's depth of knowledge and long history of teaching was integral in his problems being picked up and attended to so quickly once school commenced.

In stark contrast to the mothers who had raised concerns about their children's development prior to attending school, Rebecca noted that she only became aware of her second son's behavioural idiosyncrasies when a teacher drew her attention to them in grade one at school:

Rebecca	I was told at the preschool, at the preschool, they thought he was blind…ok, losing his sight…then it was hearing….um…then it was something else…
Jane	By whom? Who told you this?
Rebecca	The preschool teacher, the preschool teacher wanted him tested for all these things….it would be one thing one week, then another thing the next…(Rebecca, p. 14, 19-25).
Jane	Had you had any of these problems with him at home?…before school? before school started, as in when he was younger?
Rebecca	Not as I was noticing (Rebecca, p. 2, 20-23).

The difference between the teachers' approaches to the mothers is note-worthy. One of the pre-school teachers used the label 'attention deficit disorder' to draw pointed attention to her child's behavioural problems in preschool. Another pre-school teacher focused on 'health problems' such as eye tests and hearing assessments when she wanted to draw attention to her concerns about a child's behaviour. A day-care centre teacher questioned a mother about her child's behaviour, but did not suggest any further action or assessment, leaving the mother to 'fill-in-the-gaps'. In contrast, a primary school teacher approached one of the mother's very directly about her son's problems and without pre-empting a diagnosis, suggested a paediatric assessment.

All these teachers noticed 'something different' about a child's development, but how they approached the mothers varied considerably. Within the educational discourse, there exist discursive rules that relate to the responsibilities of teachers in regard to concerns about a child's educational development. Education Queensland's Code of Practice (Education Queensland, 2002b) clearly states in its introductory statement that teachers have a responsibility to attain optimum learning outcomes for students, but gives no specific directions on how this should be achieved, particularly in relation to the process of early identification of children with social or academic problems. While the Code of Conduct does note that parents must be included in any discussion or intervention the school undertakes in regard to their children, the teachers are left to interpret how they can best approach parents when they are concerned about a child. Such vague rules are likely to mean that only the confident and competent teachers actively recruit parents into the classroom and address concerns.

Conflicting discourses

Teachers may also be caught *between* competing professional discourses, as could be seen in Alana's story where a kindergarten teacher first alerted Alana to her daughter's behavioural problems, suggesting that she have her assessed for Attention Deficit Disorder (ADD). When Alana took her daughter Betsy to a general practitioner:

> …he immediately, in that first consultation, did a couple of tests with her and was able to tell us that she was able to focus on tasks and that she could answer simple questions and she didn't seem to have this deficit of attention, so he dismissed that label and said 'that's just her, it's her personality', …(p. 2, 38-46) I think I remember vaguely in him making the comment, you know that some teachers had been using it as a buzz word lately and that some teachers tended to put too many kids in that basket…(Alana, p. 7, 1-3).

Rebecca's story also revealed conflict between the teaching and medical discourse. While Rebecca was not personally concerned about her son's development or behaviour in the pre-school years, on the advice of her son's pre-school teacher, she revisited the child health nurse on a number of occasions:

Rebecca	The preschool teacher, the preschool teacher wanted him tested for all these things….it would be one thing one week, then another thing the next…what is the place up at the hospital?
Jane	Maternal and child health?
Rebecca	yes, I was forever going there…and , I knew the lady at the time who was the sister in charge there and she'd say "oh, back again?" um…"no, there's nothing wrong with his

	hearing, there's nothing wrong with his sight, there's nothing wrong with this"…she'd check him out as in head wise…like measured his head, height, everything, when he was at preschool...nothing wrong with him…
Jane	Did she do a developmental assessment…do you know…she would have got you to say when did he start to walk, when did he talk and all that sort of thing?
Rebecca	yes, yes, yes, she went and did that…she had his eyes tested…yeh…
Jane	..and nothing….
Rebecca	…nothing, nothing wrong, nothing wrong at all (Rebecca, p. 13, 50-53; p. 14, 1-18).

The inconsistency *between* different professional discourses is notable. While the teachers are concerned about the children's development, the doctor and child health nurse were not. The terminology used by the doctor suggests the existence of territorial imperative, whereby individuals protect entitlement to territories they consider 'theirs' (Ardry, 1967). By negating the teacher's concern the doctor validates his own position as 'the expert' in medical problems. Being derogatory about the teacher's use of the term 'ADD', by suggesting that the teacher used it as a 'buzz word', the doctor protects the medical discourse from intrusion by other professionals, questioning the right of teachers to diagnose a child with a medical problem. Rebecca's experience with the nurse, while more implicit, replicates this territorial imperative. When the assessments the nurse undertakes do not indicate the presence of developmental problems, rather than considering that the teacher may have legitimate concerns, the nurse appears to discount them. Barsch (1969) suggests that one of the biggest hindrances to assisting children with developmental problems is the presence of territorial imperative. Instead of professionals working together, and with parents, to protect children, they work to protect their own discourse.

These interactions highlight the dominance of the medical discourse and the discursive rules contained within. Reliance on the medically established screening tools by the nurse, or on 'a couple of tests' by the doctor excluded observation and concern by other parties. This is particularly problematic for children when the medical assessments do not concur with the social or educational expectations. A child who has not been diagnosed with a medical problem, yet fails to learn to read and write at school, or behaves inappropriately in a social environment, is caught between two levels of expectation. This same child falls within the 'statistical norms' of the medical assessment, yet falls outside of the expectations of 'societal norms'. While not advocating that all children need to be diagnosed with a specific medical

problem, it is apparent from these transcripts that it was difficult to obtain assistance for these children without some form of medical recognition (see chapter six for further discussion).

There also existed a contradiction of opinion *within* a discourse. The following excerpt drew attention to how two doctors held entirely different opinions in relation to a child's behaviour. Mary was prompted by the day care teacher to seek medical assistance for her son, and in contrast to the opinion of one paediatrician, the general practitioner agreed with Mary and the teacher's concern:

> …..so I immediately went and took him to the GP who looked at him in absolute amazement and said "you've never thought of having this child assessed?", and I said "Of course I have"…and he said, "well, he must see a (*another*) paediatrician soon….today, tomorrow"…(Mary, p. 2, 20-25).

The contradictory statements made by different health professionals reflect the competing enunciative modalities of childhood development within the medical discourse. Members of the medical profession adopt different theoretical viewpoints and, as a result, interpret a child's development differently. While Foucault (1972) suggests that the constant flux of discursive statements creates the opportunity for change, it is this very instability that creates confusion in the mind of parents already concerned about their child's development. While parents may be familiar with some of the discursive statements circulating about child development, through the media, Internet and books, they may find it confusing when professionals contradict each other. This confusion is exaggerated because of the parents' expectation that they are dealing with the 'experts' - those who should 'know'. This expectation exposes the presence of the dominant discourse of science and its claim that there are single, absolute truths in respect of all phenomena, including the human world of feelings and experiences. Positivistic realism lies behind the expectations of certainty and the power to eliminate doubt. Of course, scientists and medics of today are likely not to subscribe to such a view, however, parents, as general members of the community, may still be influenced by its tenets.

Chapter summary

Semiotic reading

The folkloric myth of motherhood strongly influenced how mothers act, speak and feel; yet the transcripts revealed that mothers were constantly engaging in a personal battle between these mythical expectations of motherhood and their actual life experiences. The collective societal myth of loving, caring mothers was not

always congruent with personal experience and mothers were often at odds with their feelings towards their child and the communal demands placed on them to love their child at all times. Due to the powerful influence of the motherhood myth, mothers were highly sensitised to their perceived inabilities in fulfilling their mothering role in a way that met the expectations of society. Self blame, feeling of failure and of 'doing something wrong' were spoken about, or strongly implied, in all of the mother's stories, and while many of them have, over time, convinced themselves that they are not to blame for their child's problems, these feelings of inadequacy and incompetence remained as question marks in their minds. These feelings were exacerbated by collective myths that highlighted the innocence and faultlessness of children and the responsibility of adults in protecting children from failure.

Marxist reading

Mothers who were concerned about the development of their children in the early years of life were like most other mothers in Western society today. Their belief in their fundamental role as nurturer and protector of their children reflected the dominant ideology of motherhood. Unfortunately for these mothers, however, it was no easy task to comply with the ideological imposition that mothers conduct the raising of young children in the privacy of their homes and without additional support, especially when mothers were concerned about their child's development or behaviour. This was particularly so for single mothers. Mothers who were concerned about their child's development sought assistance from those the State considered best able to help them, however, more often than not, these mothers and their children did not fall into a State-identified category of 'need'. This created a social crisis for the group, as they felt that they needed assistance for their child who did not meet the ideological manifestations of the well-developed child, yet assistance always seemed to be just out of reach. Mothers are the 'pushmi-pullyu's' of the capitalist society, where competing demands and ideologically driven imperatives create a situation in which mothers find themselves pushed and pulled in many directions, yet unable to gain any ground in their concerns for their children.

Foucauldian reading

Definitions of 'normal' childhood development arose from medical and psychological sanctioned discursive statements. These statements were subconsciously adopted by mothers and other community members as truthful representations of how

children should be. When children did not conform to these standards, mothers, and others, become concerned about their child's development. Community members sometimes stigmatised mothers and their children, particularly if the child's behaviour in public spaces did not conform to societal stereotypes of the 'normal child'. As a result, most mothers sought support and assistance from those members of society whom they considered most knowledgeable on matters of early childhood development - the medical profession. Mothers engaged in self-surveillance in an attempt to 'normalise' their children so that they would 'fit' into society. Unfortunately, health professionals sometimes reinforced the stigmatisation experienced by the mothers from the community.

Teachers at school were often the first professionals to acknowledge a mother's concern about her child. However, raising concerns appears to have been done in an ad-hoc way. Some teachers were direct in their concerns; others appeared to be less so. Competing discourses may have impacted on how and when teachers raised their concerns. When teachers suggested particular problems, medical professionals sometimes subjugated their concerns, particularly if medical assessments did not concur with teacher concerns. Conflicting discursive statements within the medical discourse may also have delayed a child's access to assistance and often left a mother confused and unsure of how she could best help her child.

Chapter 5: Getting help. The dialogue between mothers and health professionals

And when he came to the place where the Wild Things are
They roared their terrible roars and gnashed their terrible teeth and rolled their
terrible eyes and showed their terrible claws
Til Max said "BE STILL!"
And tamed them with a magic trick
Of staring into their yellow eyes without blinking once
And they were frightened and called him the most wild thing of all
(Sendak, 1963)

In light of their concerns about their children's development, the mothers sought advice from a variety of health professionals. Their interactions were extremely varied, and while several of the mothers found that their concerns were taken into consideration during the consultation, others felt that their concerns and opinions counted for little. Expectations of the service also varied between mothers, and between mothers and health professionals. Mothers experienced a 'mixed bag' of responses from health professionals, and it is apparent from the transcripts that a number of issues affected what a mother felt about her interactions with health professionals and how this affected the outcomes for her child.

The following chapter reflects on how the 'myth of the healer' influences the interactions between mothers and health professionals; how gaps in communication affect meaning and mutual understanding; and how the concept of 'expert' knowledge is harnessed by health professionals to justify decisions, even when it is apparent that decision-making may be based on a less than scientific rationale.

The type and amount of interaction the mothers had with health professionals was often influenced by where the mothers lived and the availability of services in the area. The following table provides an overview of the mothers and their children, where they lived and how often they engaged with health services.

Table 5.1 The mothers, their children, places of residence and visits to health professionals.

Mother	Child	Location	Engagement with services
Kimberley	Carl	Small rural township, moved to regional city when Carl was 4 years of age	Regular visits to local doctor from when Carl was 2 years old. When moved to regional city, visited paediatrician
Mary	Luke	Moved between a number of small rural townships. One year overseas when Luke 6 years old	Many visits to local doctor and paediatricians from time Luke was 3 years old. Also many visits to occupational therapists, optometrists and child mental health services
Justine	Jack	Regional city	Occasional visits to maternal and child health nurse and local doctor for immunisations and sickness
Melanie	Alice	Regional city	From birth, regularly visited maternal and child health nurse and local doctor
Rebecca	David	Small rural township	Did not visit health professionals except for vaccinations and illness
Alana	Betsy	Regional city	Only visited local doctor for vaccinations and illness. Used 'alternative' therapy services occasionally
Maggie	Peter	Regional city	Only visited local doctor for vaccinations and illness
Nerida	John	Rural property, 5 km from small rural township	Many visits to local doctor from birth. Later, many visits to paediatricians, occupational therapists and child health mental services.

A semiological/mythological reading

The myth of the healer

In Western society today, there can be little doubt about the formal authority that biomedicine holds (Thorne, 1993). Accompanying this authority is the communal belief that health professionals are special members of society who are able to heal the sick (better than anyone else). It is likely that societal preconceived notions of 'the healer' derive from the ancient mythical Greco-Roman stories of figures who healed the sick and saved others from the torments of the mind. Ancient myths tell of gods and goddesses who instructed people in the secrets of medicine and healing. As a result, medical knowledge and skill were associated with divine power, and healers were considered to be associated with the gods (Eliot, 1976). In Greek mythology Apollo, the son of Leto and Zeus, ruler of all gods, was associated with prophecy and medicine and was immortalised as the chief god of healing in the Olympic Parthenon (*Encyclopaedia Britannica*, 1984). Aesculapius, Apollo's son, was the most important among Greek gods and heroes to be associated with health and curing disease. Aesculapius was taught the art of healing by the half man-half horse Centaur, Chiron, although Aesculapius is said to have discovered life-giving properties of herbs when one snake he killed was restored to life by another snake carrying life-giving herbs (Bulfinch, 1947). The myth tells of Aesculapius' later ability to restore life to the dead but, unfortunately for Aesculapius, Hades, the ruler of the dead, complained to Zeus that he feared Aesculapius would make all men immortal (making Hades redundant), and so Zeus killed Aesculapius with a thunder bolt (Smith, 1870). The Greeks called Aesculapius the 'Physician', 'The Desired One', 'the Health Giver' and the 'Universal Remedy' (Cornwall, 1995) in recognition of his healing abilities, and the many temples built in his honour were believed to have healing powers. These temples, called Asclepions, were places where priest and priestess healers tended the sick for over 1,000 years, and have been compared to modern hospitals (Smith, 1870).

Serpents are associated with the healing powers of Aesculapius, and the ancient symbol of Aesculapius is a knotted staff around which a snake is coiled. Today, most medical associations around the world have adopted the coiled single snake and staff as their symbol, however, a similar staff, the caduceus, is often mistakenly used to represent the profession of medicine (*Encyclopaedia Britannica*, 1984). The caduceus (Latin) or kerykeion (Greek) staff, however, is not that associated with Aesculapius, rather it was the staff carried by Hermes, who was referred to as the

'Guide of Souls', as it was his duty to 'lead the souls of the dead to the underworld' (Nichols, 1995, para. 4); an unfortunate association for a profession that promotes its purpose as the healing, and saving of, lives.

Sarbin and Mancuso (1995) suggest that contemporary medical doctors derive their authority from these historical images of the healer. They propose that Aesculapian authority provides doctors with three different types of control. Firstly, the general public regards doctors as having specialised knowledge and skills. Second, doctors are perceived to have moral authority because they are dedicated to performing acts that ease suffering and save lives. Finally, the public confers upon doctors' priestly authority, a form of control derived from the mysteries and rituals historically associated with the healing professions.

Legend also tells that Hippocrates studied the knowledge and practices of Aesculapius, translating what were oral traditions and knowledge into written form. By 500 B.C. Hippocrates had catalogued and written about many methods of scientific treatment, with many of the subspecialty categories he identified still used today (Keegan, 1994). Hippocrates is widely acknowledged as the father of Western medicine because he symbolised the change of the practice of medicine from the mystical/mythological to the use of natural/logical principles (Taylor, 1922). Unlike previous healers who based their practices on a combination of practical, mythological, symbolic and spiritual healing, Hippocrates taught that disease is a natural process and symptoms are the reaction of the body (*Encyclopaedia Britannica,* 1984).

Following on from work of Hippocrates, Western biomedical medicine claims to follow a scientific, positivistic and rationalistic approach to healing, yet there still exists within society a less rational explanation about the role of doctors. Katz (1984, cited in Lupton, 1994, p. 106) suggests that medicine is still regarded as a mystical force to which 'patient's happily abrogate responsibility *(of their illness)* because of an unconsciously held belief that physicians are miracle workers':

> Medicine, after all, was born in magic and religion, and the doctor-priest-magician-parent unity that persists in patients' unconsciousness cannot be broken (Katz, 1984 cited in Lupton, 1994, p. 106).

Such powerful beliefs continue to link modern medicine with mythically defined ideals, even if on an unconscious level.

But why in this modern, technologically driven, scientifically rational society do notions of doctors as healers and miracle workers still exist? Whyte, van der Geest and Hardon (2002) suggest that doctors are the only members of society given the power to distribute medicines. Medicines are seen as tokens of healing and hope as they have the powers to transform bodies and bring 'hope to people in distress' (Whyte et al., 2002, p. 5). In primitive societies, medicines were seen as 'magic potions', and it could be argued today, that most members of society still view medicine as magic, as most do not know the action of drug, merely, 'that it works'. Furthermore, those with the power of distribution and allocation of medicines are revered as knowledgeable experts who are able to heal the sick. Malinowski's (1948, p. 75) comment that:

> Magic is the quality of the thing, or rather the relation between man and the thing…..it implies the performing magician quite as much as the thing to be charmed and the means of charming…

might still apply, since the doctor (magician) is the only person permitted by law to distribute medicine (magic potion). An illustration of this can be seen when Maggie's paediatrician suggested that she trial medication for her son. Twelve months later, Maggie stated, 'I am so glad that I did, because it has helped him amazingly' (p. 7, 49-50). While Maggie did not understand the actual mechanism of the drug, she believed it to be effective and the reason for her child's improved learning ability at school (p. 8, 1-4), his behaviour, and his ability to sleep more soundly at night (p. 14, 49-52). For Maggie, Ritalin® had literally become 'the magic potion'.

It is not only because of their right to distribute medicine that the image of doctors as miracle workers persists. Thorne (1993) suggests that Westerners reside in a world where members have been indoctrinated to believe that the biomedical health system is necessary for social order and the only way to improve quality of life now and into the future (p. 1932). As such, neither health professionals themselves, nor community members question or challenge the underlying assumptions and principles surrounding biomedicine or the power associated with the practice of medicine. The belief in the ability of doctors to help their children was prevalent throughout many of the mothers' stories. Several of the mothers told how they repeatedly visited their doctors for assistance, these findings replicating those of Rodger and Mandich (2005) and Ahern (2000) who found that parents consulted between three and six professionals before receiving a meaningful diagnosis or recognition of their child's motor development difficulties. Kimberley (p. 1, 48) revealed that she visited her local doctor constantly over a two-year period, while

Melanie (p. 2, 1-4) regularly took her daughter along to a paediatrician for three years. Both mothers were worried about their children's behavioural development. Nerida (p. 1, 11) talked about 'going to a succession of doctors' over an eight-year period, and Mary's story demonstrated how she continually visited her local GP and paediatrician over a four year period with concerns about her son's behaviour. These visits continued, despite the fact that all mothers were repeatedly informed that there was nothing wrong with their children and little was offered in the form of assistance. Yet, the mothers continued to believe that the health professionals were the people who would be able to assist them with their children's problems. Furthermore, this belief continued even though many of the mothers left the health professional consultations feeling 'blamed' for their children's problems.

Medicine or myth?

Medicine separates itself out from other forms of healing by advocating the superiority of knowledge that is based on objective, rational, scientific truths. From these readings it can be surmised that when child development issues, particularly in relation to 'normality' are under consideration, there are two types of judgements. One is based on the 'common sense' judgement of the mother, often attributed to 'gut instinct' or intuition. The other is the objective, clinical judgement based on the use of reliable, scientifically validated tests that are advocated by the institutional discourse of medicine or psychology as the way to find 'the truth'.

When mothers were concerned about their child's development, they sought assistance from those they understood to be the expert healers. Mothers' judgements of their children's development, while, on one hand appeared to be influenced by the medically controlled information surrounding child development that has infiltrated the communal folklore of 'what's normal', were also influenced by their practical experience. Comments such as '…for some reason, I wasn't sure what it is, but I just felt that something…(*was wrong*) (Melanie), or 'I felt there was something wrong with him' (Nerida), and 'there is something wrong with my child' (Kimberley), leads one to propose that these mothers were able to recognise subtle developmental problems due to intuition. However, a mother's 'intuition', rather than knowledge gained through sanctioned educational channels, is given little credibility by a medical profession that considers intuition as little more than 'hocus pocus'. This 'common sense' approach to knowledge is considered 'unreflected, untheoretical and unscientific, based on….everyday observation or experiences'

(van Dijk, 1998, p.104), and therefore less credible than scientific knowledge. Interestingly however, while discrediting the mothers' 'instinct' and common sense, some health professionals also appear to rely on instinctive judgements.

The mothers who did detect developmental idiosyncrasies when the children were in their pre-school years raised their concerns with health professionals. But several of the mothers revealed that even though they were concerned, the health professional was not. Often, what *is not* said in the transcript reveals just as much information as what is said and in these transcripts only one mother actually commented on the health professional's use of screening tools when assessing a child in the pre-school years. Justine's first visit to the occupational therapist when her son was four years old involved a fairly comprehensive cognitive assessment (Justine, p. 2, 31-42) but other mothers told about tick sheets or 'a couple of tests' (Alana, p. 2, 39) or physical checkups that involved weighing and measuring (Melanie, p. 2, 49-50). One mother implied that the doctor did not even look at her son's development, but rather she was blamed for 'having a bad day' (Kimberley, p. 1, 47-48).

Even though the biomedical model of healing postulates that it is its scientific rationale that separates it out from other forms of healing as a superior type of knowledge, there is a discrepancy between rhetoric and practice. While there are a multitude of 'scientifically developed' medically based early childhood development screening tools available for use, some of the health professionals appeared to rely on 'gut instinct'. This was just as Shellshear (2003) had observed occurring in some paediatric practices. 'Gut instinct', it could be argued, is a form of knowledge that has been influenced by the myths, or communal folklore, that circulate in society. Assuming that there is an advantage in utilising standardised objective tests, rather than subjective opinion, it is notable that the health professionals still elected to use non-scientific judgements. While van Dijk (1998) would suggest that 'common sense' knowledge is likely to be a simplified version of scholarly knowledge, because of the infiltration of medical knowledge through education and the media, the use of intuitive knowledge by a medical professional does not reflect the fundamental basis of the biomedical approach to healing. So, even though it is argued that professional medical opinion is based on the authority of the scientifically supported rationale on child development 'norms', not all health professionals use the specifically developed measurements scales, but rather rely on subjective assessments.

While Glascoe (2000a) suggests that practitioners avoid the use of assessment tools due to their complexity and the time-consuming nature of the process, these transcripts also revealed that some health professionals believed their interpretation of the problem was only based on knowledge the institution of medicine regards as a 'justified true belief' (van Dijk, 1998), even when they did not use scientifically supported assessments. As such, it is likely that they considered their subjective interpretation to be more accurate than the subjective opinion of the mother, whose knowledge was regarded as merely an uninformed guess. I would argue, however, that these medical decisions are also subjective, with personal values and beliefs infiltrating the doctor's interpretation of the clinical situation. These findings support those of McKinlay, Potter and Feldman (1996) who, in their study of physicians decisions about patient illnesses and treatments, concluded that decision-making was not entirely based on objective assessment. McKinlay et al. (1996) found that characteristics of the patient, such as age and gender, experiences of the doctor and features of the practice setting 'significantly affected decisions that they made' (p. 769). Although, in contrast to McKinlay et al. (1996), who noted that doctors used both objective-based assessments and subjective knowledge, some of the mothers in this study revealed that doctors appeared to make decisions based purely on subjective judgement, or 'gut instinct'.

Myth and evidence-based practice

While the use of 'gut instinct' by some of the practitioners may be a reflection of their disillusionment with current developmental assessments, it may also reflect resistance to the implementation of 'evidence-based practice' (EBP). EBP is a form of clinical decision-making that attempts to place the practice of medicine on a sound scientific footing by systematically reviewing scientific evidence of alternative forms of diagnosis or treatment (The Joanna Briggs Institute, 2005). Opponents of EPB argue that basing their decision-making on scientific evidence alone does not allow them to utilise their own 'clinical judgment', claiming that personal input is an important part of their effectiveness as a practitioner (Williams & Garner, 2002). Some practitioners resist change to EBP and continue to base their practice on 'clinical judgement', even when it has been shown that emotional bias affects such types of decision-making (Dernevick, 2004). While the profession of medicine claims to be scientifically based, in actual fact, some of its practitioners appear to consider themselves blessed with special powers that enable them to 'heal' the sick without

the guidance of scientifically based knowledge. In doing so, doctors show how they share the communal myths that exist in relation to health, medicine and doctors.

The healer and self-belief

Marteau and Johnstone (1990) propose that when health professionals make judgements that are not based on scientifically validated evidence, their own personal beliefs about health and illness affect how they view health and illness in their clients. These subjective beliefs influence decisions even if a health professional is considered an 'expert' in his/her particular field of work, particularly if the 'expert' believes that the problem the patient presents is one over which the patient has some form of control (Marteau & Johnstone, 1990; Weiner, 1979). It is apparent, from the mother's stories, that some health professionals hold a personal belief, based on mythically derived communal folklore, that mothers are responsible for, and are able to control the development/behaviour of their children. As Kimberley says:

> I think a mother's instinct on her own children should be looked into, and ruled out if it's not apparent or whatever, but he didn't even look into it, he didn't even assess me, he didn't even assess my son… (Kimberley, p. 7, 47-50).

While some doctors may believe that mothers are at fault, Schopler (1985) also suggests that a general lack of knowledge and the inability to treat and cure the child may lead doctors to feel guilty about their own failure. Rather than admit these feelings, blame is directed toward parents, who, as 'scapegoats' (Schopler, 1985, p. 236) reduce a doctor's feelings of confusion and inadequacy as a 'healer'.

Kimberley's story also implied that, to her knowledge, the doctor did not conduct any form of assessment; basing his interpretation purely on 'clinical judgement', and holding that judgment to be 'more correct' than Kimberley's. Not only did this doctor consider his judgement superior to Kimberley's, but he also showed a strong belief in his own ability to heal. Mary expressed similar responses from doctors when she raised concern about her son's growing behavioural idiosyncrasies:

> …I'd been going to the same paediatrician who had told me basically that I had the problem, that I knew very little about parenting, he was the paediatrician, and he knew what was best….(Mary, p. 2, 8-11).

It is hardly surprising that medical professionals idealise their own ability, particularly when media articles regularly proclaim the brilliance of medical science and the doctors who wield the tools of the trade. The myth of the miracle worker and medical

hero is alive and well in Western media, and it would be difficult for mothers or health professionals to ignore their message. Myths are regularly replicated on television and in newspaper and magazine articles. Shows such as ER, All Saints (Australian emergency room drama), Chicago Hope, House and endless others, constantly present the viewer with images of medical heroes. On these shows, viewers are inspired by the brilliance of the medical teams as they save lives time and again. Yet, even though many doctors are aware that these representations often do not replicate real life at all; because 'medicine is often about failing to save lives, getting it wrong and messy situations' (Hope, 2005, p. 3); it is hard to ignore their message.

Ivan Illich (1976) has written extensively about the iatrogenic affects of medical intervention since the early 1970s, yet, few mistakes are aired in public, and only occasionally are they incorporated into media representations of medical practice. Even when contrary articles draw attention to the increasing numbers of medical 'mistakes' in Australian hospitals the myth of the healer survives, often because media articles are written to reassure citizens that this occurrence was exceptional and does not reflect actual medical practice, such as the following commentary on a doctor who has been reported as being associated with the death of over 50 patients in the past 2 years:

> "Care should be taken in interpreting death rate data because the unnamed surgeon highlighted in the review might handle only extremely ill or high-risk patients. He may well be our best surgeon in WA, who gets all the hard cases and when everyone can't do anything they send (patients) to him and unfortunately there is a high mortality rate," Dr Fong told ABC radio. (Australian Associated Press, 2005, para. 3).

Like the myth of childhood, the myth of healers remains mostly untarnished by reports that point to the existence of 'less than ideal' behaviours. Campbell (1988) argues that members of society need to believe in myths, because they provide a stable core of explanations about everyday life, which promote societal permanency and constancy. Even when actions and behaviours fail to match up to mythic ideals, people are inclined to disregard the aberrations as merely 'hiccups', the myths providing a form of security against change. A powerful example of this can be found in the experience of the medical establishment in Great Britain after the exposure of the murderous doctor, Harold Shipman. Shipman was perhaps the most prolific serial killer of all time, killing at least 215 patients during 30 years of medical practice (Baker, 2004), yet, after the public exposé of his murders, an inquiry found that public faith in doctors remained 'virtually unchanged' (Baker, 2004, p. 304).

When individual members of a society lose faith in the healing ability of individual practitioners, they still maintain a belief in the healing ability of other medical professionals. In this study, however, it was found that two of the mothers did resist seeking advice from 'mainstream' health services for several years because of personal dissatisfaction with practitioners.

Avoiding orthodox medicine

Rebecca lived in a small country town and my impression on first reading her interview transcript was that she had avoided contact with 'mainstream' health professionals, unless for immunisations or illness. Later comments revealed that Rebecca suspected the 'expertise' of the health professionals, particularly as she felt misguided by the advice given to her by nurses over her first son's infant feeding formula:

> ….because I had so much trouble with Michael, like, as a first baby, he had constipation because he had trouble with milk, like S26 didn't agree with him, and it wasn't until …a cousin of mine came along and she'd by this time she was on her second kid and she said to me, "have you ever thought about changing the milk?" ….no……so we changed the milk, overnight he was a different kid…. you know, having gone through all the problems I had with Michael just in the first few months, that I found out with Michael, I had no worries bringing up a second child…so I didn't worry about going…the only time I went was to get him his needles, get him weighed, things like that…(Rebecca, p. 16, 12-15, 22-32).

This caution towards accessing advice from nurses and doctors was based on previously perceived, unsatisfactory experiences with particular health professionals, and while one health professional does not represent all health professionals, a mother who felt that the 'representative of the system' had failed to deliver, avoided future contact. While unspoken, Rebecca may also have felt that she was judged on her choices of care for her son, the health professionals identifying these choices as unsatisfactory or inappropriate, this was particularly reinforced by her statement:

> …with the first one I went through a lot of pain trying to feed B, and when the second one came along, the same thing happened again, and I just said "forget about it, let's go to the bottle…", there was a lot of disappointment with the nurses and sisters at the hospital, but I didn't care, it was my choice (Rebecca, p. 15, 24-29).

While Rebecca exhibited certain bravado in this statement, the fact that she then avoided contact with health professionals implied that she was uncomfortable with the professional criticism of her mothering choices. Alana also avoided contact with mainstream health specialists, choosing to seek the advice of a naturopath:

I also had a cousin who'd been through the general health system with her children, her child, her first daughter was a similar age and she had found it not very satisfying, so we decided to go this way…(Alana, p. 1, 42-45).

Few alternative choices existed for either of these mothers. Rebecca and her family lived in a small country town where the only service was a local GP and Maternal and Child Health Centre. If Rebecca had wanted to attend alternative services, she would need to have driven 100 kilometres south to a larger regional city. Alana was able to access a naturopath because she lived in a regional city where a limited range of alternative services was available. Both mothers continued to avoid contact with mainstream health professionals until their children attended school and were found, by teachers, to struggle with social (Rebecca's son, David) or academic (Alana's daughter, Betsy) demands. Referrals from the schools were to Child Mental Health (David) and a psychologist (Betsy), both mainstream health services. At this point in their child's life, mothers were given little option if their children were to receive assistance in school (see Chapter 6).

Most of the mothers, however, continued to place their faith in medical practitioners even though they were not always satisfied with the doctor's opinions. Ineffective communication between the mothers and the practitioners affected how doctors' interpreted a mother's concerns, what the mothers took the doctor's interpretation to mean and what assistance was offered for the mother and the child.

A Marxist reading

Habermas' theory of communicative action (1984), which focuses on verbal communication as the basis for power and control, will provide the framework for this reading of the mother-professional dialogue. Habermas proposes that in society there is a struggle between two types of knowledge. The first type is value-based knowledge which exists in the 'lifeworld' where speech is informed by everyday events and life-grounded experiences. Communication in the lifeworld is orientated towards understanding. The second type is focused knowledge, which exists in 'the system', where speech has a purpose that is orientated towards success. Habermas suggests that a person using system-based knowledge may sometimes use deception, manipulation or distorted communication to achieve this success. When reading the mothers' stories I looked for instances where there may be a gap between the lifeworld-based communication of the mothers and the system-based communication of the health professionals.

Habermas is committed to a more rational world where communication is not constrained by oppressive processes (Holmes, 1992), raising concerns about the infiltration of the rational system into the rationality of the lifeworld. He argues that the success-orientated interests of the system, which values power and economic success, can subsume the lifeworld values of personal experience and shared understanding. When this occurs, the possibility of shared, open communication is reduced and rational discourse cannot take place.

Communicative action can only occur when power differentials are set aside and participants in the interaction commit to a shared rationality that permits an equal opportunity to speak, question and contradict. Habermas (1984) suggests that when communication is based on working toward mutual agreement, the ideal speech situation can be attained. When this form of communication occurs, all parties engaged in the conversation feel satisfied that they have been able to express their concerns or ideas, that the other party has listened, and a rational debate about the concerns and ideas has resulted in a mutually satisfying outcome. It is clear from the mothers' accounts that not all interactions were of this kind. Most notable in the mothers' stories is the expressed frustration that their concerns were unheard by many of the health professionals they visited, a clue that in many instances mutual agreement, and therefore satisfaction with the outcome of the consultation, was diminished.

Intuitive versus objective knowledge
The knowledge that mothers bring with them to a health clinic or doctor's surgery is based on their own experience and 'intuitive' knowledge that is build up over preceding generations (Gadamer, 1975 cited in Ray, 1993). Gadamer suggests this stock of knowledge forms the basis of understanding in the 'lifeworld', where speakers can engage in a dialogue of shared understanding and norms, without actually having to verbalise them. Lowe (1995), in her study of educational and health professional interactions with parents of children with developmental disabilities, found that the contributions of most parents emanated from experiential or intuitive knowledge. Mothers came to a meetings with professionals bearing a stock of lifeworld experiences, and in this particular instance, their focus was on the wellbeing of their child. The mothers' concerns all arose from their experiences in the lifeworld, and it was in the voice of these lifeworld experiences they communicated with the health professional. Yet, the stories revealed that despite the

mothers' concerns, the health professionals often held a different perspective about the child's development and well-being.

Kimberley started visiting her local doctor with her son Carl when he was about 2 years old, worried that his behaviour was not normal:

> I started to go to my doctor and said there is something wrong with this child. He's not normal, he's not happy, he never laughs, he can't go away from me. He basically told me 'you're having bad day, get over it'…and that went on for 2 years (p. 1, 44-48).

Melanie raised her concerns with her daughter's paediatrician when Alice was three:

> …but they kept reassuring me… 'Oh, nothing is wrong, she's so happy' (Melanie, p. 2, 2-3).

Alana, on the advice of her daughter's pre-school teacher, who thought Betsy may have ADD, took her child along to see her local GP:

> ...he immediately in that first consultation did a couple of tests with her and was able to tell us that she was able to focus on tasks and that she could answer simply questions and she didn't seem to have this deficit of attention, so he dismissed that label and said 'that's just her, it's her personality'.(Alana, p. 2, 38-43).

These excerpts of transcript highlight the mismatch between mothers' concerns and the conclusions of the health professionals whose advice they sought. Schön (1983) suggests that professionals use technical rationality to guide their decision making and also to communicate those decisions to their clients. Schön (1983) describes technical rationality as the dominant view of knowledge in most professional institutions and held by many practitioners, whereby professional activity consists of applying scientific, research-based knowledge and techniques to solve given problems of practice. Technical rationality forms the basis of knowledge and practice within the medical discourse and is considered a superior form of knowledge to the commonsense, lifeworld opinion of the parent. In fact, Stainton Rogers (1991) suggests that health professionals frequently think that 'lay health beliefs are at best watered down versions of proper professional medical knowledge (i.e. no more than old wives tales)' (p. 3). In these excerpts, it can be seen how the lifeworld concerns of the mothers were not validated by the technical rationality of the health professionals.

'Nothing is wrong'

When mothers bought their lifeworld-based concerns about their child to the clinic, only to hear that 'there is nothing wrong with your child', a mismatch between the lifeworld based expectations of the mothers and the scientifically based practice of health professionals, occurs. There is no doubt that both the mother and the health

professional held a genuine concern for the well-being of the child, and the communication gap may best be explained in terms of the mothers' and health professionals' expectations of the consultation.

Mothers arrived at the health clinic with certain expectations (Davis, Day, & Bidmead, 2002), based on previous experiences of attending health clinics and a belief that the problems they were encountering with their children were soluble. Mothers therefore expected:

1. A consultation with a professional who had expertise in health matters, particularly child health.
2. Their concerns about their child would be listened to and taken seriously.
3. The health professional would be able to identify 'what was wrong', and
4. The attending health professional would 'do something' to fix the problem.

Health professionals, on the other hand, have different expectations of the consultation. They are trained in particular areas of knowledge and are likely to see themselves as experts and, as a result:

> They tend assume that they will be able to make sense of people's problems, and will have expertise to formulate solutions to them, so that the problem can be removed entirely, or at least ameliorated considerably (Davis et al., 2002, p. 48).

Therefore, when a mother brings a child to a health clinic the practitioner expects:

1. To listen to the mother's concerns.
2. To examine the child and determine developmental growth/behaviour against known scientifically developed 'norms'.
3. Identify if any signs or symptoms on examination match with known developmental aberrations.
4. Offer a diagnosis and treatment.

So, while both mothers and the health professionals anticipated a solution to a problem, what they focused on as 'meaningful' information differed considerably. Mothers expected their concerns to be understood as sufficient validation of their child's problems, yet health professionals focused their interpretation on specific signs and symptoms exhibited by the child.

Health professionals are trained in the technically and scientifically based biomedical model of health care, so the perspectives of health professionals are biased towards a system that values success-orientated actions and outcomes

(Mishler, 1981). From the health professional's perspective, if the child displayed no particular signs and symptoms to which a diagnosis could be legitimately attached, there was no medically legitimate problem. By saying *there is nothing wrong with your child* the health professional may actually mean: 'according to codified knowledge of medical disorders, I cannot apply a medical diagnosis or suggest a treatment'. However, from the mother's lifeworld perspective, this *was* something wrong with her child, this was why she had made the effort to seek advice.

The mother, whose interpretation was based in the lifeworld, often took *there is nothing wrong with your child* to mean, 'you are causing your child's behaviour', or 'there is something wrong with you', particularly when the health professional attached a sentence focusing on the mother, to the utterance. Mary revealed how the paediatrician had implied that while her son did not have a problem, his behaviour was linked to her parenting:

> …and he said that one of the problems with children like my son was that they took on, or absorbed the anxieties or frustrations of the mother…(Mary, p. 2, 13-15).

The meaning attached to the phrase *there is nothing wrong with your child* differed between the two parties, producing a misunderstanding that prevented the mother and the health professional reaching a mutually satisfying agreement. The doctor fulfilled a pragmatic, functional role and the mother played an emotional, dependent role, limiting the possibility of reaching a common goal. While there was a mismatch of understanding, there could be no rational discussion because an ideal speech situation could only occur when both parties had matching expectations of their role, purpose of the encounter, and could engage in a rational debate based on a clearly communicated understanding of the problem (Habermas, 1984).

When a health professional did diagnose a child's problem, the mothers were more satisfied with the outcome. The expectation of the mother that the health professional would 'do something' to solve the problem had been met, as the health professional had been able to apply scientific criteria to successfully identify a diagnosis. Unfortunately for many of the mothers in this study, this process of diagnosis, treatment and validation of their concerns took many years, even when mothers repeatedly sought support from health professionals. One of the reasons this validation took so long was that children, when in the health clinic setting, did not show obvious manifestations of the concerns that a mother was raising.

Acting by proxy

The mothers in this study took their children to health clinics because they were concerned about their child's wellbeing, yet, often what the mother said occurred at home, and how the child presented in the clinic, did not match. After explaining to me that her infant son had a high-pitched scream that went on for hours, Nerida elucidated why she felt that her son was not diagnosed with a problem in infancy:

> Jane It just fascinates me that for all those early years everybody said he was all OK….did he cry when you were in the doctors surgery….did he do his carry on?
> Nerida No…..rarely did he do that….you see, you know how they….(Nerida, p. 14, 7-12).

Here, Nerida expected me to understand, as a mother of a child, that infants change their behaviour in a new situation. While she explained to the doctor how her son cried constantly, did not like being handled and was temperamental with feeds, her son lay quietly in her arms. Melanie also tried to explain how her daughter's behaviour differed between home and the health clinic:

> ….and she was...when they would check her and everything, she was always happy…(Melanie p. 2, 3-4).

At home, Melanie's daughter was fractious and anxious, yet in a health clinic, she was happy and co-operative. Brown (1969), in his study of children with intellectual disabilities, suggested that when children are in unfamiliar environments they will behave differently. Nerida's son did not cry, nor resist handling, and Melanie's daughter was well behaved in the medical clinic. There existed a difference between what the mother was saying happened at home, in her lifeworld, and how the child behaved in the systemised clinic environment. In the clinic, the settled baby looked, for all intents and purposes, 'normal' on examination. The subjective, lifeworld experiences of the mother, therefore, did not reflect what the health professional was seeing from an objectified viewpoint. Because medicine objectifies the patient, deliberately turning the person into an object and rejecting the lifeworld perspective for a systems one, the child was assessed 'as seen' instead of in terms of the lifeworld context on which a mother based her experience. It is apparent from the transcripts that health professionals not only systematised communication, but the patient as well. This transformation of patients to 'objects' appeared to be exacerbated when mothers had to communicate on behalf of their children and their experiences were embedded in the context of the lifeworld.

'What is said' versus ' what is heard'

Mishler (1984) suggests that a diagnosis is 'critically dependent on what physicians ask and what they *want to hear'* (my emphasis) (p. 11). Because health professionals are trained in the biomedical model of health care, what health professionals *want to hear* are particular physiological problems that they can use to diagnose a particular problem and recommend treatment accordingly.

When a mother went to the clinic complaining of a number of 'non-specific' problems with her child, the health professional transformed the practical contextually based problems into decontextualised technical ones, because this reflected the way that s/he had been trained to think and communicate. The transformation from subjective lifeworld experiences to objective decontextualised signs and symptoms may have resulted in a misinterpretation of the problem. Mishler (1984) infers that by reconstructing the lifeworld into a technical system of purposive-rational action, the health professional actually excludes the form of communication that is essential for understanding what is happening in the mother's world. By decontextualising the mother's concerns, and applying technical standards, the health professional is able to *hear* specific scientific constructs (signs and symptoms) that isolate the cause of the problem. What health professionals do not want to hear are contextually based problems that confuse the scientifically based diagnostic pathway. Mothers, on the other hand, can only communicate their concerns in terms of their lifeworld experiences with their child, although Nerida tried to do so when she suggested to her doctor that her son might have a chromosomal anomaly:

> I had a bit of nursing knowledge and I wondered if he had a fragile X chromosome…so I approached the paediatrician about that and he more or less told me "No, you're silly, go home"…so, which we did…(Nerida, p. 2, 10-14).

The above transcription from Nerida draws attention to the health professional's response to a mother's attempt to communicate in a more technical voice. The mother's concerns were no more likely to be listened to when she raised the possibility of a genetic disorder; in fact, the doctor's response implied that only he held the right to use technical language associated with medical diagnosis. Mary also reported a similar response to her suggestion that her son Luke may be autistic:

> … his general behaviour didn't change at all…and his obsessive nature became really quite disturbing…so back I went, again and again, and again…um, I had a feeling that he may have been autistic…*(the*

paediatrician said) "No way, absolutely, no way"…he was not autistic…he is probably nearly 4 at this stage…no way…..(Mary, p. 3, 28-30, 34-37).

While this may not be the deliberate intention of a health professional, rather, a reflection of the way medical professionals are trained, it is, I would argue, the responsibility of health professionals to actively include mothers' lifeworld experiences, and their attempts to communicate in a more technical voice, in the process of working out 'what's going on'. While Prior (2003) argues that, over the past twenty years there has been a considerable shift to more open and accountable communication between health professionals and clients, I would argue that sometimes inclusive action is only a superficial attempt at reconciling lifeworld experience with purposive action. Prior (2003) exposes the essence of this superficiality when she suggests 'experience on it's own is rarely sufficient to understand the technical complexities of disease causation' (p. 53), and while most patients would agree that they had little technical knowledge, such a statement arms 'experts' with the justification for minimising the importance of 'lay' knowledge. The exclusion of client knowledge becomes particularly apparent when health professionals communicate in a way that limits choice.

Communication that limits choice

Habermas (1984) suggests that limiting choice, by not suggesting alternative treatments or ideas, is a communication tool that may be used by professionals to manipulate another person's decision. Kimberley, for example, discussed the opportunity a paediatrician gave her to choose treatment for her son:

> ..he (*the specialist*) gave me a list of medications, and I was to chose one that I thought would suit him best…(Kimberley, p. 6, 4-6).

While this offer appeared to be an attempt to engage Kimberley in shared decision-making about her son's treatment, it was actually a choice that severely restricted her options. When she refused to treat her son Carl with any of the prescribed medication, the doctor made no further suggestions about alternative treatments, in fact, he no longer wanted to treat her son:

> ….we'd moved up to T. (*the regional city*), especially to keep seeing this doctor up here, who then refused to treat us, so…that was the end of that (Kimberley, p. 8, 24-27).

Kimberly based her choice on her lifeworld experiences. Most notably, recently published newspaper and women's magazines articles had drawn her attention to the issue of over-medication of children with behavioural problems. The risk to Carl's development caused Kimberley to question the doctor's opinion: 'I spoke to him

about the possibilities of the damage the drugs do to a developing brain' (Kimberley, p. 6, 9-11). This expressed her concern about lifeworld issues, her child's future development and prospects as a young man. The doctor replied: '…there's no research been done to…um..justify what the side effects are…'. (Kimberley, p. 6, 11-12). Here, the doctor brings the conservation back to the voice of the system, and calls up scientific-technical rationality as the base for recommending a drug-based treatment. Freidson (1986) suggests that use of 'formal knowledge' (p. 3), justifies and legitimates domination over those who are unfamiliar with specialised knowledge:

> People are not allowed to choose among a variety of alternatives because the issue is presented as a technical one that involves the necessary use of the 'one' best method (p. 8).

According to these transcripts, there is conflict between how each participant in the conversation views themselves and how they view others. Graham and Oakley (1981, cited in Scambler, 1987) note that health professionals see themselves as well-educated practitioners, informed by a scientific knowledge base that is superior to the ad hoc basis of a mothers' knowledge. Whereas mothers see themselves as possessing knowledge and expertise about their own children and their lives that make a valuable contribution to the care and development of that child. The transcripts revealed that mothers also viewed health professionals as knowledgeable experts, because they actively sought out their assistance when they were concerned about their child's development. When a health professional did not incorporate the voice of the mother in rational dialogue, the mothers became despondent, frustrated, and angry. Nerida, after being told that there was nothing wrong with her child said she 'left the hospital thinking, oh no, where do I go, what do I do?' (p. 3, 29) and she would just go home 'and struggle, struggle like anything' (Nerida, p. 3, 31-33). She even tried to 'pinpoint' (Nerida, p. 1, 13) the problem so that she could communicate her child's symptoms in a more systematic way. Mary got angry, even though she was an articulate professional herself, she still felt unheard. Her transcript revealed the frustration that she had experienced, and which she knew other mothers had experienced, when communicating with professionals who focused on system-based problems rather than contextual issues:

> …so, yeh, I guess I'm very angry, I am angry…I'm still very angry…I'm angry because the whole situation transpires and it took <u>so</u> long and <u>so</u> many attempts…I'm angry there are so many other women…I know there are, I've spoken to them…who go through the same thing, and because they don't have the knowledge I have, they don't have the ability to articulate the problem as clearly and as strongly as I can, that it is so hard for them…..(Mary, p. 14, 15-23).

Mary's anger reflected continuing frustration in regard to communication issues. Notably, her frustrations mirrored the feelings that arose from nearly all of the transcripts in this study. Regardless of their age, number of children, marital status, economic status, geographic location or level of education, the mother's repeatedly drew attention to misunderstandings that occurred between themselves and many of the health professionals from whom they sought assistance.

These across-the-board communication issues may be related to the fact that doctors characterise patients according to their capacity for processing information (Mathews, 1983). However, unlike previous studies that suggest these characterisations are largely based on the patient's social class and level of education (Pendleton & Bochner, 1980), in this instance, the 'patients' are characterised as 'mothers'. Some health professionals consider 'mothers' as incapable of understanding not only their children but also medical explanations, and communication is consequently compromised. As a consequence, this characterisation limits the amount of information that professionals accept from, and pass on to mothers.

Limiting information

Habermas(1984) suggests that in a discussion, the professional who is focused on achieving a technical-rational outcome may choose to withhold information from a client in order to maintain a certain level of control. After Justine had her son Jack assessed for learning difficulties, the report from the hospital was sent directly to his pre-school. Justine does not know what the report said, only that the pre-school would 'monitor and try to bring his skills up to a certain level' (Justine, p. 3, 47-49). Previous research into doctor-patient communication suggests that withholding information enables a doctor to preserve control over the doctor-patient relationship by controlling the patient's level of uncertainty (Mathews, 1983), and while it is apparent that Justine remained uncertain about her child's problems, the fact that the letter was sent from expert to expert also implies that it was believed that the mother 'would not understand'.

It can be seen from the transcripts that health professionals control information, yet Davis (2002) claims that in a health professional/parent interaction it is the parents that can, and do, choose to limit the amount of information they divulge. Indeed, Davis suggests that parents are actually the ones in control of the entire consultation

because 'they can choose to seek help or not; they can choose what information they give; and they control what action to take' (Davis et al., 2002, p.18).

All of the mothers in this study actively sought assistance and advice about their children's development or behaviour at some point. While it is not explicitly stated in the transcripts what information the mothers gave the health professionals, it is likely that their conversation was based on lifeworld experiences and on responses to questions raised by health professionals. Barry et al. (2001), in their qualitative study into general practice consultations, found that even though patients had particular concerns prior to the consultation, they did not voice them during the consultation. Barry et al. postulated that patients do not voice their thoughts, feelings, or specific concerns when they attend a consultation because they are concerned about what information is deemed appropriate and about wasting the health professional's time. So, rather than choosing what information to give, it is likely that the mothers felt restricted by the technical focus of the medical encounter and communication was limited accordingly.

Furthermore, if mothers really do control the consultation, why then did they leave consultations with health professionals feeling so de-valued and powerless? Lupton (1994) argues that while a client can choose to limit communication, there is a limit on how much they can challenge a health professional's authority. These mothers had limited access to alternative advice, and, as a result, this reliance constrained how they acted in the clinical consultation. Furthermore, the unspoken restrictions imposed by their notion of the 'good' patient, and the 'good' mother limited their responses and created a feeling of powerlessness.

Timely treatment

Understanding that a breakdown in communication between the lifeworld based voice of the mothers and the systems based voice of the health professionals, may help explain why many of these mothers experienced such a long gap between their first expression of concern and the final confirmation of a problem.

Nerida noted that it took eight years for someone to finally identify her son's chromosomal anomaly (Nerida, p. 2, 24), even though she had been persistently pursuing advice from the moment he was born. Mary, who actively pursued health advice and support for her son from the time he was three years old remarked that:

> …well, he manifests just about every criteria on the Asperger's tick sheet…and it took just over 6 years, it could even be seven for his situation to be finally taken seriously….(Mary, p. 1, 5-8).

Melanie was frustrated with the time it took for her daughter Alice to finally receive confirmation that she had a problem. Melanie first raised her concerns when Alice was three years old; Alice was 11 years old when she finally received a diagnosis.

> …..it took us one year again, I think she was grade 6 when we finally…and we did a test…she got a report, she asked me about her behaviour at home, at school, got a report and everything, and when we all thought that she is not moving and we decided, she said "Yes, I agree, she's ADD"…(Melanie, p. 5, 35-40).

Kimberly sought advice and support from health professionals from the time her son Carl was two years old:

> Jane   So, basically it's taken 6 years for you to get into some sort of system that's providing support..
> Kim   Yeh..it's taken me 6 years to find a doctor who believes that it's not my parenting…as well…mm..
> Jane   ..it's too long isn't it..
> Kim   Yeh, too long…way too long…(Kimberley, p. 15, 46-50; p. 15, 1-2).

Alana, on the other hand, was very satisfied with the speed at which her daughter Betsy's problem was identified. Betsy was eight at the time she went to see a child psychologist, and while the testing process was lengthy, she was identified with a problem fairly quickly and intervention strategies were put in place. However, Alana wondered if Betsy's problems would have been identified earlier stage had the doctor Betsy attended visited in pre-school suggested follow-up surveillance checks. While mothers voiced their concerns about lack of early identification, many did not openly voice their feelings about the health professionals who did not listen to their lifeworld concerns.

Professional power

The language throughout several of the mothers' narratives reflected feelings of frustration, particularly those mothers who did not know what to do about their children when professionals did not acknowledge their lifeworld concern. While mothers were effusive in their praise for professionals who did acknowledge their concerns, there existed, in contrast, a resounding silence about those who did not.

Most mothers enthusiastically endorsed professionals who supported them: 'He *(the doctor)* was brilliant…' (Kimberley, p. 4, 21); 'the sessions with (*the psychologist*) were extremely satisfying…wonderful lady…understanding, empathetic' (Alana, p. 5,

7, 8); 'she (*the teacher*) was just amazing…' (Maggie, p. 6, 23); 'they (*Child and Mental Health Services*) were very good, they were very good' (Rebecca, p. 4, 6-7). In contrast the mothers rarely verbalised directly their feelings about unsatisfactory consultations and services. Any criticism that was made of the professionals was presented in carefully constructed terms, alluding to their feelings through the use of particular words, rather than direct criticism.

Justine, for example notes that the local Maternal and Child Health Service was 'non, very non' (Justine, p. 5, 22). While 'non' sounds like a fairly neutral word, it can be better understood in terms of Justine's later comments that, as a single mother of three boys, she felt very unsupported by health professionals, particularly when they were young (Justine, p.6, 27-35). The Australian habit of understatement sees Justine euphemistically adopting the word 'non' when it is likely that she means 'dreadful'.

Nerida, while praising her son's schoolteachers, does not refer directly to her attitude toward health professionals at all, yet frustration flows throughout her entire narrative. Nerida also adopts a euphemistic approach to understatement when referring to the time she had requested a chromosomal test for her son. On describing this occasion, Nerida used the word 'begrudgingly' (Nerida, p. 2, 17) to describe the doctor's attitude to her request, as 'he threw it across the desk at me' (Nerida, p. 2, 18). Nerida was very careful in her choice of words, masking her obvious distress at the doctor's response.

Mary, a well-spoken, confident mother described one of her consultations with a gastroenterologist:

> ….the gastrointestinal …whatever he was, who looked at him...and he said.. "you know, well, these things happen"…and while he said that to me he was actually on the phone to his wife who wanted him to bring home a dozen eggs…I remember these things….and I thought, "well, thank you very much, you've obviously taken that seriously….". (Mary, p. 10, 12-18).

The 'dozen eggs' are symbolic of Mary's outrage at the doctor's apparent lack of concern. For Mary, her son's problems were central in her life, yet here was a doctor who did not consider his illness to be anything special. A 'dozen eggs' represented the mundane, every-dayness of life and Mary's take home message was that her son was no more important to the doctor than other parts of his daily routine. To Mary, the 'dozen eggs' became representative of what she considered to be the uncaring attitude of the health professional.

Careful as they were to avoid direct criticism of health professionals, both Nerida and Mary were still able to make known their concerns about lack of medical attention and poor quality of care. Direct criticism was deliberately avoided, as Mary revealed when she admitted to keeping a comprehensive journal from very early on in her son's life. Mary commented that she would be very reluctant to share her journal with me, saying that it 'named names'. Why did Mary, who was so outspoken about her experiences, want to protect the very professionals she felt had ignored her son's needs? Both Mary and Nerida are highly intelligent women, yet there existed a reluctance to criticise those who had failed to supply a service they needed for their child. Perhaps their voices were muted by the fear of rejection and retaliation. Both Mary and Nerida lived in small country communities where there was little choice in health care. There were a handful of local doctors, at the most, and the only Child Health and Mental Service was operated out of the nearby major city. Both Mary and Nerida relied on these services to assist them in the management of their children and could not afford to express their concerns because of the risk of being marginalised. Indeed, Mary's narrative indicated that her occasional outspokenness had already led to isolation from medical professionals:

> I make a fuss…and I do…I'm not popular, but I don't care any more….and when I get….oh, my husband does it….but, we know that the perception is…. "she's a difficult mother, so he deals with it"…(Mary, p. 22, 15-19).

Shared communication

From this study it is apparent that not all health professionals communicated in a voice that alienated mothers from the conversation. One mother found that health professionals who were more likely to listen to her were mothers themselves, and have similar aged children:

> …I found female GPs, particular those much the same age as I am, or in that bracket and those with children, are very, very supportive…(Mary, p. 12, 40-42).

Having experienced a comparable lifeworld to the mothers, these health professionals were able to relate and communicate with mothers more effectively. The voice of the lifeworld was meaningful to both the mother and the health professional and became an important part of the interview equation. While Silverman (1987) argues that it is the responsibility of the client to actively challenge the technical-based value system of the health professionals, Mishler (1984) argues that it is the responsibility of the health professional to actively engage with the client through conversation based in the lifeworld. It is apparent from these transcripts,

that when engaging with mothers whose concerns extend to their children, health professionals must take a lead in addressing communication strategies that recognise and value their lifeworld experience. By taking into consideration and conversing through lifeworld-based values, health professionals are more likely to encourage mothers to actively engage in the conversation about their child. Reaching a common understanding is a matter of finding something that works interactively without use of power and without breaking off communication. This does not mean that a completely identical common understanding will always be reached; it is a matter of resolving communication breakdown without use of force or a collapse in coordinated interaction. Working towards a mutual understanding with mothers will lead them to feel more respected, involved and heard. As Mary noted:

> Well, I'm firmly convinced that …relating to parents, and in the vast majority of cases, the mothers who do the consultation, the mother's who do the hands on nursing with sick children, I think it's imperative that this becomes part of their training….imperative…and I mean, a component of their program that is taken very seriously, not just…and "oh yes, and by the way if you get an hysterical mother….." …I demanded to see a file on him once, in Victoria…part of the letter from the paediatrician to another specialist was quote "mum tends to lose it" unquote….I'm very offended by that……you know…..I mean if I spoke to parents in my capacity the way I've been spoken to, I wouldn't have a job…..I think it has to be mandatory that the parent, in particular the mother, is listened to and taken seriously, and not diminished, because most of the people I know that have been through this …and I know a fair few….you are at your absolute wit's end…..and to be patronized or dismissed or, as I've had at various times…. "oh, not you again!"…..you know, it's not on….I don't believe it's a professional approach …(Mary, p. 12, 9-31).

A Foucauldian reading

The major concern for all of the mothers in this study was the expectation that the health professionals would take their worries seriously. While there is an expectation among mothers, teachers, health professionals and the general public, that mothers take their children to a professional person for advice and support in relation to early childhood development, problems arose when they failed to live up to mothers' expectations. Furthermore, some mothers expressed concern over the responses received about their own role and responsibility. Some noted that when they persisted in obtaining assistance or advice from a professional person, they felt patronised, dismissed or labelled as poor mothers.

Foucault suggests that knowledge is one of the defining characteristics of power. In modern society, scientific knowledge is highly regarded, and those professions that

base their knowledge on scientific truths are most likely to hold power. In this section I will discuss how the rules and practices emanating from the discourse of medicine create an environment where power is exercised over mothers, even though the decisions made by some health professionals are not always based on scientifically validated knowledge.

Mother blame

In Western society, many community members hold health professionals in high regard. Unlike used car salesmen and lawyers, doctors and nurses enjoy a high status as trustworthy citizens and people on whom other members of society can rely to provide expert advice and assistance. This regard has been established over the past 100 years as the medical discourse and associated health professions have consolidated their central place in society. For this reason, mothers feel confident that when they seek medical assistance they will receive expert advice and care, yet several of the narratives revealed that mothers were not always satisfied with the responses they received from the health professionals.

The mothers' stories revealed that they often felt as if they were being blamed for their child's behaviour or developmental problem. Most often the accusations of poor parenting were made to mothers whose children displayed aggressive or non-compliant behaviour. Several of the mothers repeatedly visited their local health professional or sought advice from a number of different health professionals in order to be heard or to find someone who 'believed', rather than blamed them.

Nerida, for example, was concerned about the behaviour of her son, Carl, from the moment he was born. Because he always screamed, did not like being touched and his motor milestones were very delayed (Nerida, p. 2, 37-40), she took him to a succession of doctors for assistance (Nerida, p. 1, 11-12), but her concerns were rebuffed:

> …You're neurotic, there's nothing wrong with your healthy child…be thankful that he's healthy….um, go home…you're not going to have another child like your elder one (Nerida, p. 3, 24-27).

By the time Carl reached grade one, at the age of five, he was very aggressive, the class bully, he could not write properly and seemed to have poor motor control (Nerida, p. 1, 28-30). But, on visiting her local doctor, his response replicated earlier ones, telling her that she was 'a neurotic mother…' (Nerida, p. 1, 30).

Mary, who had taken her son along to numerous health professionals because she was concerned about his obsessive behaviour, referred to a number of occasions where she was made to feel, not only overanxious and neurotic, but the cause of her child's problem. One visit to a certain paediatrician resulted in the following:

> …and he said that one of the problems with children like my son was that they took on, or absorbed the anxieties or frustrations of the mother…and I quote, without any exaggeration, he said women like you quote "come out of the freezer to conceive" unquote…(Mary, p. 2, 12-17).

Mary also found that doctors were willing to place her child in respite care so that she could have 'a rest ' (Mary, p. 2, 30), the implication, as Mary saw it, was that poor mothering was the problem, not her child's behaviour.

According to Rawlinson (1987), Foucault argues that the medical discourse objectifies people, based on generalised standards of function. Mothers, who repeatedly express concern in relation to their child's development, a concern that is not validated by health professionals, are objectified as deviant. They are then labelled in order to define the 'type' of deviant mother: refrigerator mothers, neurotic mothers, single mothers, overanxious mothers, overachieving mothers or poorly mothered mothers. The enunciative modality of these labels, and the statements made about them has been extremely powerful in past decades, reinforced by knowledge based on 'scientific research'. Psychologists, such as Sigmund Freud (1856-1939) suggested that an abnormal psychosexual relationship between children and their mothers would create deviant children (Najman, Bor, Andersen, O'Callaghan, & Williams, 2000), Kanner (1949), coined the term 'refrigerator mothers' to describe the mother whose apparently, cold, obsessive personality was responsible for her autistic child's behaviour, and Bowlby (1951), emphasised that the absence of a warm, loving mother would create mental health problems in her child. Studies undertaken in the 1950s, 60s and 70s frequently attributed children's autistic characteristics to the personality and behaviour of the parents, as Cantwell et al. (1978) discovered when reviewing literature from this period:

> Numerous pejorative epithets have been applied to the parents of autistic children. They have been described as cold, undemonstrative, formal. Introverted and obsessive…The parents have also been considered overprotective, symbiotic, indecisive, lacking dominance and showing 'perplexity' or psychic 'paralysis' (p. 273-274).

In a study of clinical psychology journals published in the 1970s and 1980s, Caplan (1998) found that:

> Mothers were blamed for seventy-two different kinds of problems in their offspring, ranging from bed-wetting to schizophrenia, from inability to deal

with color blindness to aggressive behaviour, from learning problems to "homicidal transsexualism" (p. 135).

Netley et al. (1975), for example, argued that their research found that while a child with autism may have neurological problems, the degree to which the autistic tendencies manifest themselves relates to characteristics of the parents. Another study by Ward (1990) proposed that mothers of autistic children were found to have experienced significantly more family discord and to have had significantly more diagnosed psychiatric problems than mothers of normal children.

One theory that was commonly adopted to explain the cause of behavioural problems focuses on parenting style. Baumrind's Model (Baumrind, 1967, 1971) inspired a large body of research over the proceeding twenty years which claimed to have identified a strong association between parenting style and child behaviour, proposing that either very relaxed parenting (*permissive*) or very strict parenting (*authoritarian*) can result in problem behaviour. Even though Baumrind (1967) adds a cautionary note that warns of the problem of distinguishing 'cause and effect':

> It does not follow from these results that either parental control or nurturance bears a positive linear relationship to competence in preschool children…the directions of cause-effect relationships were inferred only from the successful predictions of those relationships (p. 83).

Over the past 10 years, however, research has moved away from social explanations of behavioural problems and mental illness. Attention has instead focused on biological causes, particularly since the advent of brain scanning technology, such as magnetic resonance imaging (MRI), and the increasing accuracy of genetic material analysis. Scientific research today often tends to centre on a biological/neurological basis for autism (Dawson, Carver et al., 2002; Dawson, Webb et al., 2002; Johnson, Halit, Grice, & Karmiloff-Smith, 2002; Trottier, Srivastava, & Walker, 1999), ADHD (Hadders-Algra, 2004; Whitmore, Hart, & Willems, 1999), behavioural problems and learning difficulties (Brown & Minns, 1999; Diamond, 2000; Wassenberg et al., 2005; Whitmore et al., 1999).

The move away from social explanations of child behaviour and development has been supported by a large study of Australian families (n= 5296) that found patterns of child-rearing and troublesome child behaviour are not correlated, nor could more than 52% of preschool children who had troublesome behaviour be shown to have risk factors related to maternal social and economic characteristics, maternal lifestyle or maternal and child physical health (Najman et al., 2000). Other studies

today tend to focus on the factors that influence parenting, rather than focusing on how parenting causes child development problems. These studies look to how wider environmental factors affect how a parent goes about the task of parenting. The Australian Department of Family & Community Services (Department of Family & Community Services, 2004b), for example, has recently undertaken a comprehensive literature review into the factors that influence parenting. While intended as a tool to assist in the development of support programmes for parents, it confirms that the parents continue to carry the responsibility for their child's development; however, it does not 'blame' parents for their children's problems, nor does it pathologise parent-child relationships. While focusing on 'how to educate parents', however, little is said in the report about the need for professional education, nor of the importance of listening to parental concerns in relation to their child.

While the research focus has changed to neurobiological explanations of child development and behaviour, and broader inquiry into environmental effects on parenting, the powerful statements of a historically developed medical discourse that pathologised parenting still appear to impact on how some health professionals approach child development problems, particularly behavioural ones. McDonnell (1998) argues that these past statements are resistant to change because children with behavioural-based developmental problems look so normal and are usually of good health that they do not fit any pattern of illness that health professionals are used to looking for. In addition, McDonnell (1998) proposes that a 'trickle-down' (p. 225) effect, to teachers, social workers, general practitioners and others, continues to occur over time, even though the findings have been questioned by more recent research. I would also suggest that some medical practitioners are slow to change their perceptions of mothers when past research may have supported their own personal views of how 'good' and 'bad' mothering affects the behaviour and development of children.

As Foucault identified, individuals operating within a discourse also bring other beliefs and values from other discourses. Health professionals are likely to bring to their practice pre-existing values and beliefs about the role of mothers, and when these values and beliefs are supported by research, even when the research is no longer considered 'the truth', they find it difficult to change their opinions and ideas. As a result, several of the mothers in this study found themselves blamed for their

children's problems. Kimberley, for example, felt that her son, Carl, was sent to foster care because of the health professional's perception that she was not a 'good' mother:

> He(*Carl)* went to foster care for a month and then he went to day care every day for a month as well after that, while I went on anti-depressants…and basically they said it was my parenting that was causing his behaviour to be like that and that, they were saying my negative vibes…he was picking up on that and responding to that , and I said, well maybe I'm picking up on his negative vibes and I'm responding to him…but they said is doesn't work like that, you're the grown up, you know, you're the adult" and I said well, in that case, I've got two children, why am I only having this trouble with one if I am such a bad parent? You know why?...and they're both the same, I treat them both the same…exactly the same…and they couldn't answer that….it just led back to 'you're the one making him like this through your antics', yeh, which didn't do a lot for my self-esteem (laughs) (Kimberley, p. 4, 45-50; p. 5, 1-12).

Regardless that findings of more recent research no longer implicate mothers as the 'primary causal factor' in child development problems, the 'conceptualisation of the family as a dangerous and neglectful place continues to hold sway' (Malacrida, 2002, p.377) and individual practitioners operating within the medical discourse continue to embrace research findings that implicate parents as the cause of their children's behavioural difficulties. I have suggested that deeply rooted, long-held beliefs, which arise from a practitioner's engagement with other social discourses, influence what rules and practices they embrace when operating within the medical discourse. Even when the discursive rules change within the medical discourse, the individual's values and beliefs continue to influence the decisions they make and the course of action that is adopted.

Irrespective of the blame they shouldered, mothers persisted in approaching medical practitioners for support. Like many members of the general public, who have been exposed to the powerful enunciative modality of the value of scientific truths in medical matters, mothers continued to regard health professionals as knowledgeable, responsible and truthful in their actions as practitioners and so continued to seek out their 'expert' advice and assistance.

Expert reliance on scientifically validated data

Several of the narratives pointed to feelings of dissatisfaction and frustration at health professional responses to mother's concerns. Nerida's narrative implied that she felt that the delayed diagnosis of her son's problem occurred because her doctor did not believe her concerns were anything more than a sign of her own over-anxiety. Nerida had repeatedly visited her local doctor expressing her deep concern

over her son's behaviour and after a series of assessments, with no particular outcome other than 'he *may* have ADHD' (Nerida, p. 2, 6) Nerida, who had conducted some research of her own, suggested to her doctor that her son may have a chromosomal problem:

> …I was still concerned about the chromosomal type things so I went back to him and on the third occasion I refused to leave his office until he actually wrote the blood test out for me…..very begrudgingly it was done….threw it across the desk at me with "well, you know this is going to cost you a lot of money"…(Nerida, p. 2, 12-20).

While the doctor did eventually concede and order the blood test, his attitude suggested to Nerida that he believed she did not know what she was talking about. Interestingly, when the blood results came back 10 days later they showed that John had a double Y chromosome, which causes aggressive behaviour, amongst other problems. By now, John was eight years old (Nerida, p. 2, 20-25). How the doctor responded to the results is unknown, as Nerida did not refer to this in her story.

Mary found the disbelief in her concerns over her son, Luke, particularly exasperating, especially as she had spent a lot of time and money on having tests done to try and find out why his behaviour was so problematic. When many of these tests showed no major irregularities, it fuelled her doctor's belief that it was Mary who had the problem, not Luke:

> ..they felt there was an attention problem….that while there were minor aberrations at times, nothing, nothing presented itself as indicating that it needed further investigation… So, once they had made their conclusions…..and, of course send it off to the paediatrician… it gave the paediatrician fuel to say you're anxious, you're neurotic…(Mary, p. 6, 21-24, 31, 37-38).

Neither Nerida's nor Mary's concerns were validated by the health professionals they visited. While the mother's believed that their children had a problem, the various tests and assessments, in Mary's case, did not support her claims, supporting the doctor's interpretation that there were no problems with her child. It was not until Nerida's son received a diagnosis, based on a blood test, that Nerida received acknowledgement that her son had a medical problem. It is likely that the medically developed discursive statements about how medical problems should be determined, informed the doctor's beliefs about how specific situations should be interpreted. These informing beliefs provided doctors with their own knowledge, their own attitudes, their own frames of reference and their own worldview of the subject matter, reinforcing the attitude that one particular set of beliefs and values is superior to others. In this instance, these beliefs value the objective data from the assessments over the subjective concerns of mothers.

To understand what was happening here, Foucault proposes that one must look to the wider historical and social environment in which the story is told (Murfin, 1989a). This is important when considering the rise and influence of the biomedical model of healthcare, particularly in relation to early childhood development. In Australia, nearly all health professionals are educated through the tertiary education system, be it Technical And Further Education (TAFE) Colleges or Universities. The courses offered are based on the bio-medical model of health care which focuses on the treatment of disease and illness and the biological functions of the body (Grbich, 1999). The information students learn about the human body is presented in precise medical terminology, based on scientifically produced medical knowledge, through textbooks, training manuals and official policy discourse. For example, both the psychological and medical discourse incorporate discursive statements about child development norms that inform other health science professions such as nursing, occupational therapy, physiotherapy, and education, how to recognise, assess and treat developmental problems. Health professionals are trained to accept these statements as representing 'the truth' about child development because they arise from scientifically based research conducted within the wider health sciences discourse. Furthermore, these 'truths' are considered to be more truthful than other forms of knowledge, such as the knowledge a mother may have accrued over her years of raising children, or the knowledge that is gained through communal folklore.

The shift away from acknowledging the role of other forms of truth is exemplified by the comparison of an original medical text and its newly updated edited version. Mary Sheridan's highly regarded and utilised text: *From birth to five years: Children's developmental progress* (Sheridan, 1988) contains the information:

> The earliest indications of deviant development usually depend upon: *Mother's suspicions (emphasis in original text)* that her child is not seeing, hearing, moving his limbs of taking notice like other children of his age. NB: She is usually right (p. 16).

The text has since been revised by editors Frost and Sharma (Sheridan, 1997), and notably, the comment on listening to parents early suspicions is removed to final pages of the book (p.43), and there is no longer any emphasis placed on their likelihood to be right. Mary's story appears to support this changing emphasis:

> I'd been going to the same paediatrician who had told me basically that I had the problem, that I knew very little about parenting, he was the paediatrician, and he knew what was best….(Mary, p. 2, 8-11).

Medical discourse therefore reaffirms the superiority of a technical knowledge over the intuitive, subjective reasoning drawn from the parents' experiences. This creates unequal power relations, since those operating outside the medical discourse will not be considered knowledgeable. As outsiders, mothers have little influence over assertions of the medical profession. While it could be argued that Nerida was able to exert a certain amount of power over her local practitioner by demanding the blood tests for her son, it needs to be remembered that it had taken eight years of concern and frustration before she was able to assert herself. While today's rhetoric insists that patients are to be actively included in the decision processes relating to their health, the discourse of health professionals still embodies beliefs and practices that support and reproduce their own power.

Validation of mothers' concerns

Not all of the mothers expressed concern about their relationship with health professionals, although it is notable that most of the positive responses came once the child was in school. This period also corresponded with recognition of the child's problem by other professionals, such as a teachers and occupational therapists. Maggie, whose six year old son, was in grade one at school, attended a paediatrician's practice, supported by her mother-in-law and several pages of documentation from the school:

> …I went to the paediatrician, I took my mother-in-law with me…um…we both had to fill out a form….or I had to do it, but I asked if she could do one too…about Peter and his behaviour and stuff, the teacher had written a three page letter as to all the different stuff that she had noticed since the start of the year, and those things combined was what gave us the outcome… (Maggie, p. 6, 35-42).

It was not until John's teachers verified Nerida's concerns, through letters to the doctors that her worries were taken seriously. By this time, John was eight years old, and even though he is now a young adult, Nerida expressed frustration that her opinion counted for little and that, without the paperwork from the school, her concerns were not taken as valid:

> Nerida … his teachers wrote letters to the specialists and everything for me …when he was about eight/nine/ten…they actually volunteered to do that because I would say "John is going to the paediatrician in so many days"…they actually asked "would you like us to write something for you, so you've got verification from the education side of things that all is not well"
>
> Jane   Did that help you having those letters with you?
>
> Nerida I felt like I should have been believed when I was saying these things…I felt, well here's the information, here's my…these are my witnesses…their not here in person, but it's here on paper…that I'm not the only one seeing this behaviour…. (Nerida, p. 7, 4-17).

Kimberley needed a comprehensive report from the day-care centre, which her son attended for a month to validate Kimberley's claim that her son displayed major behavioural problems:

> ….that was the whole point of getting it done…for them to …because my word wasn't good enough…because of my "mental state"…(*gives a small laugh*) (Kimberley, p. 7, 25-27).

From these transcripts it appears that mothers are regarded as the 'least expert' in matters involving their own children and, even if mothers have been raising concerns about their children for many years, it is not until 'educated' professionals raise their own concerns that doctors take them seriously. Yet, such a lowly regard for mother's expertise about their children is bizarrely combined with the notion that they are considered the most responsible for their children's welfare and for any problems that arise.

The medical discourse of children's developmental problems, particularly those involving emotions and behaviour is strongly linked to the scientific knowledge of the psychiatric profession and this information is disseminated to health professionals through the publication of the *Diagnostic and Statistical Manual IV* (*DSM IV*) (American Psychiatric Association, 1994). Mothers who raised concerns about their children's development prior to school attendance were more likely to experience greater difficulty in having their concerns validated by a health professional. Children, whose mothers did not seek advice until after the child started school were more likely to be assessed comprehensively, diagnosed and treated more promptly, this was particularly so if teachers sent supporting documentation. This discrepancy, particularly in relation to ADHD, may be explained by the requirement in the *DSM IV* that implicitly discredits mothers as sources of reliable information about their children. The *DSM IV* requires that parent concerns cannot be taken in isolation from other people's opinions and any concerns must be supported by the professional opinion of teachers or others. The child's problems must extend across multiple social situations, including school, home or clinic (American Psychiatric Association, 1994).

While it may be appropriate to collate information from a number of sources, mothers who raise concerns while their children still spend the majority of their time at home are left without expert assistance until their child reaches school age. Furthermore, the notation in the criteria which states that ADHD may occur in situations 'where there is a history of child abuse or neglect' (American Psychiatric

Association, 1994, p. 81), places the mothers under scrutiny for the 'role' they have played in their child's behavioural problem. While it needs to be acknowledged that health professionals must seek out all possible causes of a child's problem, mothers should not be deliberately harassed or be made to feel guilty. Doctors need to pursue several avenues of inquiry so that mothers do not feel that the finger is solely pointing at their own inadequacies and failures. Unfortunately, some mother's in this study felt that they were exclusively blamed for their children's problems. This was particularly so for mother's who found themselves the focus of 'treatment', or being 'advised' to attend parenting classes, to 'sort themselves out', while no interventions were offered for their children.

The Positive Parenting Program

The enunciative modality of the medical discourse surrounding parenting practices is so powerful that educating a parent in 'proper parenting practices' is considered to be a primary course of action when a mother alerts health professionals to a child's behavioural problem. In Australia, the *Triple P-Positive Parenting Program* (Sanders, 1999; Sanders, Markie-Dadds, Tully, & Bor, 2000) is considered a superior parent training tool for parents whose children display behavioural problems (Department of Family & Community Services, 2004b) even though recent research shows that it may not suit all families or all situations (Hempill & Sanson, 2001). The conflicting discourse can be seen clearly in a paper by Galboda-Liyanage et al. (2003), who suggest that parenting programmes are beneficial to some parents, 'behaviourally disturbed or "difficult" children may discourage parents from engaging with them in harmonious joint activities' (p. 1046), and the success of these programmes is therefore limited. Kimberley tells how she was exasperated by continual efforts of health workers to improve her parenting skills, rather than her son's behaviour. It was strongly implicated that her son's bad behaviour was a result of her poor parenting and Kimberley explained that she was encouraged to undertake Triple-P on *three* occasions:

> Yeh, and then I had to do a positive parenting course. "Go and do positive parenting and everything will be OK" and it just escalated the problem…..so it didn't work… the positive parenting, that was all that was thrown at me, and I've actually done that three times (*laughs)*…..because they said it was worth going back because I might of missed it and because of the mental state I was in when I first did it, I probably didn't pick it all up and I probably didn't enforce it the way it should have been enforced, so I went back and did it again.. and I just did it here at the beginning of the year…and in the end I just laughed and walked out …(*laughs*).. because it was just not working…I just thought, no this is just not right. (Kimberley, p. 2, 38-39, 43-48).

It maybe – in the drive to improve child outcomes - that such a strong parental focus has pushed to the background the importance of the child's characteristics on developing relationships. Bronfenbrenner (1979), for example, emphasised that the development of a child is influenced, not just by environmental stimulants, but also by nature, in other words, what the child brings to the relationship that is driven by genetic determination. Sameroff and Fiese's (2000) theory of 'transactional regulation' proposes that a dynamic relationship exists between children and their environment, and that a child's development has 'multiple contributors at multiple levels' (p. 135). Most recently, an Australian study has found that 'the *recipe book* approaches in parenting programmes, promoting *the right way* to parent, may miss the mark for many children' (Hempill & Sanson, 2001, p.47). For some families, parenting classes may be of assistance, but there are also some families where this approach is not successful, and the emphasis on parenting skills merely reinforces a parent's sense of failure and guilt. While the mothers in this study repeatedly stated their commitment and responsibility as parents to assist their children, and several engaged in parenting education classes that were designed to help them 'manage' their difficult children, they still felt that they were blamed for there children's problems. This was particularly so when they were repeatedly encouraged to attend parenting classes, while little intervention was provided for the child.

While recent research points to a growing link between a biological and/or neurological basis to children's developmental problems, weakening the argument that mothers are solely to blame for their children's problems, nearly all the mother's in this study felt blamed. Mary was seen as an overachieving mother who 'came out of the refrigerator to conceive' (Mary, p. 2, 12-17), Melanie was an overanxious mother, Alana was seen as an overachiever whose expectations of her child were too great, Kimberley was considered a poor parent as a result of her single-mother status and Nerida, a neurotic mother accused of wanting 'another text-book baby' like her first (Nerida, p. 3, 28). While mothers will all bring different personalities into their relationship with their children and these will have some impact on the developing child (Luster & Okagaki, 1993a; Vondra & Belsky, 1993), focusing on the personality traits of a mother will affect how a health professional regards a child's problems. From this study, it appears that when a mother's personality was considered a primary cause for a child's problem, the mother's felt that they are being blamed, and other possible causes were not taken into consideration. Although all of the mothers in this study were the first to admit responsibility for their

children's well being, they did not appreciate being blamed, either overtly or covertly, for their children's developmental problems. This was especially so when they had followed the medically defined enunciative modality in regard to child development that encouraged mothers to 'seek medical advice when concerned'.

In light of these findings, health professionals must take greater care when presenting alternative methods of helping mothers help their children. Attending to a parent's concerns will be hampered if mothers feel blamed for their child's problems. This creates a barrier in the provision of health services. When mothers feel blamed, often because the focus of intervention is on their own behaviour, rather than on the behaviour of their child, they feel that their children are effectively excluded from early assessment and appropriate intervention services. Furthermore, mothers become frustrated by a 'system' that gives them little opportunity to voice their own concerns free from retribution. Fortunately for most mothers, they have since been able to find health professionals that are supportive and understanding.

Supportive health professionals

Mothers saw themselves as fortunate when they encountered supportive and understanding health professionals. Several expressed relief at finding health professionals who listened to what they had to say, and who involved them in the day-to-day decision making required for their child's treatment or on-going assessment.

Having spent the previous six years trying to find a health professional whom she felt would listen to her and believe that her son Luke was in need of help, Mary expressed relief at finally finding a doctor whom she felt actually listened to her and her husband's concerns:

> ….then this child psychiatrist…very good…actually had a full consultation with my husband and I, using a tape recorder, and said he would do give his reports to various people, but wouldn't do it until I had a hard copy of it and I could make my comments, because it had be something with me….well, …AT LAST!...(Mary, p. 11, 1-5)

While Mary felt more satisfied with her son's doctor, Low (1995) suggests that even when parents are given the opportunity to actively engage in decision-making processes with professionals, they are still restricted to a supporting role. This occurs because of the unquestioned acceptance of participants' positions, which gives ultimate authority to professionals. While decision-making is seemingly

interactive, parental interests are overruled by the superior discourses of professionals. This is evident by the strategic use of language. For example, even though Mary was asked to comment on the consultation before it was made available to other health professionals, the psychiatrist was still the one who decided what the *appropriate* course of action was to be. He selected and organised the appropriate mental health, medications and follow-up appointments (Mary, p. 11, 6-29). So, collaboration was only an illusion, constructed by the medical doctor in order to encourage parent compliance with the decisions he made. Maggie's paediatrician, for example, suggested that Maggie consider the use of medication for her son Peter:

> Well, first of all it was just, she told me to think about whether to medicate him or not…um…she said, like she read through the teacher's letter, she said "probably, reading this…and with the problems you're having at home…*it would be better to actually medicate him*…." She said, "but that decision is entirely yours"….because of the classroom situation and because he wasn't learning at all, I did chose to actually medicate him…and I am glad I did. (Maggie, p. 7, 25-34).

The paediatrician appeared to be giving Maggie the choice, but her words, *it would be better to actually medicate him*, came attached to a powerful claim to expertise. Here, there exists a tension between the rhetoric of user-driven services in health care, where 'patient empowerment' (Segal, 1998, p. 31) is an important consideration, and the need of the doctor to impart her expertise. Doctors are also constrained by legal responsibilities. If the child is not medicated and his behaviour becomes so extreme that he causes a major incident, such as damaging school property, or hurting himself or others, the mother may hold the doctor responsible for not recommending medication. Not all mothers, however, took the advice of their doctors.

Challenging the advice

Foucault suggests that power is not only restrictive, it also produces resistance to itself (Philp, 1985). While all the stories in this study demonstrate the use of power by the 'knowledgeable experts', there are also a number of examples in which the mothers refused to go along with expert opinion and followed their own path of resistance. By doing so, they felt more in control of their situation and therefore more powerful, although some felt that refusing to accede to medical advice left them with few options.

In the case of Kimberley, who preferred no medication, and faced rejection by her doctor, Foucault would suggest that the doctor was using the power of 'knowledgeable medical discourse' to manoeuvre Kimberley into using the drug. Instead, she resisted by speaking to a naturopath about natural alternatives. Stepping outside mainstream medical discourse allowed her to regain control of her situation and provided her with an alternative treatment for her son. She felt that she was now making the decisions, rather than having someone else making them for her:

> I spoke to a naturopath who suggested that I find a natural alternative and I found a company in America that deals with natural medicines and I ended up getting stuff through them ,which helped, but it's too expensive…to keep going…(*laughs*)..but it got me through the nightmare of that black day, you know, when it's really dark and hard and it was just impossible…and it really worked...yeh…so that's what I turned to, until I was able to compose myself and then take control of the situation again.(Kimberley, p. 6, 23-31)

By way of further illustration, by the time Nerida's son was eight, she had visited a variety of health professionals for advice and support, including medical doctors, an optometrist, an occupational therapist and a paediatrician. Even though she was accused of being 'a neurotic mother' (Nerida, p. 1, 31) she persisted in the face of adversity, rejecting this as a mistaken opinion. As noted earlier, Nerida actively resisted that doctor's opinion by insisting her son have a blood test. McLaren (1985) suggests that this deliberate and systematic approach to questioning existing power structures is one way of subverting normative codes of the dominant social order.

Other mothers used more passive means. Mary, for example, had been told by a number of health professionals that her child did not have a problem, so she pursued multiple assessments for her son, without the support of medical professionals (Mary, p. 6, 3-8).

Silverman (1987) in his study of communication between medical professionals and patients, suggests that in issues of the family, some parents were 'far from being passive recipients' of expert's versions of what is best for their child. Parents choose to compromise communicative compliance by challenging professionals' judgements or suggestions, particularly when their child was not improving, or the professional was perceived as being less than expert. However, in her study of communication between parents, education and health professionals, Low (1995) found that professionals were generally advantageously positioned through the status position they occupied, their access to authorised knowledge within their field of expertise

and their experience with and familiarity with the subject matter. These factors impacted on the interactions between the parents and the professionals, and limited the amount of parent involvement and ability to question decisions. Even though Mary is a highly educated mother with a supportive family and the financial means to seek other opinions, and was able to access a number of resources, when it came to health professionals, she felt that she did not have the opportunity to engage as an equal. Her relationships with health professionals are now very strained and very limited:

> Mary: I suppose that the upshot of it is I have a little to do with the medicos now as possible….I learned from an early stage that I'm a woman, I'm intelligent, I'm small and polite…and it mitigates against me….my husband is several years older than I am, he's six foot two, he's distinguished looking , he has a quiet presence and he does the vast majority….
> Jane …and do you find he gets somewhere…he doesn't get the condescending….?
> Mary: Oh, no, no, no, no, ……I suppose is what happens is I'm very intimidated, I'm very intimidated…(Mary, p. 11, 40-46; p. 12, 1-5).

While Mary did not regret her persistence, she felt that because she constantly challenged the advice she received, she was personally blamed, intensively scrutinised and demonised. However, Mary recognised that resistance was an important role for her to play in her own child's well being:

> Mary …but I said, you've got to fight it…. [ ]
> Jane So you feel parents really have to fight for the rights of their children...
> Mary They do have to fight… (Mary, p. 15, 12-15).

Chapter summary

Semiotic reading

Several mothers repeatedly visited their local health professional for advice about their child's development and continued to do so even though they were often told that there was nothing wrong with their children. Some mothers did choose to avoid contact with health professionals, particularly if they had experienced, or known of someone who had experienced, a negative interaction. Nevertheless, belief in the power of the healer is still potent; so potent in fact that healers believe in their own potency. While discrediting other forms of healing as merely 'hocus pocus', or unscientifically-supported intuition, the medical profession sometimes utilises mythically driven interpretations and explanations as to why things are the way they are, despite their dismissal of mothers 'evidence' as unscientific. Medical doctors do not always judge children's development by utilising the evidence-based child development assessment tools, and often seem to use gut instinct based on their

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own personal values and beliefs. While they may argue, that their 'instinct' is grounded in an accumulated scientific knowledge base, it is an expression of personal values and beliefs accumulated from their own cultural experiences growing up in a society that is continually reproducing mythical ideals about children, mothers and healers. The findings from this study are consistent with a strong and enduring belief in the myth of the healer, which appears to be as strong today as it has been for centuries.

Marxist reading

Habermas suggests that the best form of communication is one that works toward a shared understanding, where all parties are considered equal members in the discussion. This form of conversation requires power differentials to be set aside and for all parties to have equal opportunity to talk, listen and be heard. In this study, when health professionals communicated in a technical-rational voice it was likely to dominate the conversation, while mothers, who spoke with the lifeworld voice of experience, were likely to have been felt unheard. The differing expectations between mothers and health professionals exaggerated this gap in communication, particularly when a health professional said 'nothing is wrong with your child' and a mother felt that there was. This was exacerbated when mothers brought their children into the clinic and they did not display the behaviour mothers had been concerned about. As a result, many mothers left the clinic feeling as if their concerns about their children were unheard and questioning their ability to effectively mother their own child. These feelings were aggravated when mothers were 'left out of the loop' of conversations between health professionals. Professional power is such that few mothers questioned this exclusion, and they were loath to criticise those health professionals they felt had treated them unfairly. Mothers felt much more satisfied with conversations with those health professionals who appeared to treat them as equals and whom they felt regarded their concerns as important.

Foucauldian reading

The experience of mothers engaging with health professionals was extremely varied. Most notable was the mother's reliance on medical doctors for almost all the advice sought about their child's perceived difficulties, even when mothers regularly felt blamed for their child's problems. The discursive statements emanating from past medical research reinforced that mothers were to blame for their children's

problems, and while current research has discredited them, their enunciative modality remains potent. This was particularly so when these historical statements replicated and reinforced the socially derived beliefs and values that health practitioners bought to their own medical practice. Mothers who lived in rural communities, who had little choice about whom they could take their child to see, along with limited alternative support, were most affected by these practices.

The discourse of medicine values scientifically validated data over the personal concerns of mothers, yet several of the health professionals did not utilise the assessment tools available to them, instead relying on their own subjective judgements. Mothers often found themselves the focus of the medical gaze, and were subsequently treated accordingly, some being advised to attend parent training programmes. Mothers, while happy to admit responsibility for their children's well-being, felt blamed by health professionals, particularly when they saw themselves as the focus of treatment while their children received no assistance. This feeling of blame was exacerbated when their concerns about their children were not heeded until other professionals acknowledged and validated them. Validation of a mother's concerns often did not occur until the child reached school age, and teachers raised their concerns about the child. Reliance on the discursive statements and rules that arise from the *DSM IV* (APA, 1994) severely limited the likelihood that a mother was able to obtain pre-school acknowledgment that her child had a problem. While some mothers did challenge the advice of the health professionals, engaging in active resistance, it was because they were 'at their wit's end' and could see few alternative options. Questioning medical advice, however, often left mothers even more powerless, particularly in future interactions with medical practitioners.

Chapter 6: Diagnosis

… Max stepped into his private boat and waved good-bye
And sailed back over a year
And in and out of weeks and through a day
And into the night of his very own room
Where he found his supper waiting for him
And it was still hot.
(Sendak, 1963)

What is diagnosis?

Diagnosis was a central theme in many of the mothers' stories, and this chapter focuses on why and how diagnosis became an integral part of mothers' experiences with health professionals, teachers and educational systems.

For most people, the word diagnosis is closely associated with the practice of medicine, and images arise of white-coated people with stethoscopes around their necks. However diagnosis is not limited to the domain of medicine. The word diagnosis means 'to distinguish', and it involves the process of deliberate choice or discrimination, 'the process where we say that *this* - whatever it may represent - is an example of *that*' (King, 1967, p. 154). Car mechanics, engineers, scientists, and general community members diagnose when they are trying to work out whether a particular problem, or thing, fits into a particular category. According to Cooper (1995), the term diagnosis implies:

> …the identification of a process underlying the immediate obvious symptoms and behaviour, and so carries (according to current knowledge) implications about possible causes (p. 4).

Within the domain of medicine, Gillman et al. (2000) define diagnosis as 'a system of analysis of people's lives (that is) based on specialist knowledge and the expertise of professionals' (p. 389). From the orthodox medical perspective, diagnosis is fundamental in determining which treatment pathway is selected by the doctor. Diagnosis puts into order the unordered (Balint, 1957), providing the doctor with a way of categorising problems within a medical framework (Brown, 1995). Trainee doctors are encouraged to hone their diagnostic skills, and doctors who are good diagnosticians are highly regarded by medical colleagues. Publications, such as the *International Statistical Classification of Diseases and Related Health Problems: 10th Revision [ICD-10]* (World Health Organization, 2003), have been

developed to assist medical practitioners to classify diseases and other health problems.

The American Psychiatric Association (APA) has also produced a classification manual for mental illness disorder. This manual (*DSM-I*) was first published in 1952 with the primary aim of collecting statistical data for enhancing research into the diagnosis and treatment of mental health problems (Warelow & Holmes, 1999). In order to claim medical rebates from the Australian government health scheme, Medicare, psychiatrists need to designate an item number from the *DSM-IV TR*, to categorise each individual's disorder. This type of reporting is not replicated in general medical practices where doctors do not need to specifically state a client's physiological illness in order to claim medical rebates. Reporting of designated item numbers is a means of collecting statistical data for research purposes. However, insurance companies, and other regulatory bodies not directly involved in health care provision or research, also use diagnosis for a number of purposes. Queensland Education, for example, utilises the *DSM-IV TR* categories to determine whether school students qualify for additional classroom assistance.

According to Kleinman (1988b) the basis on which a diagnosis is made differs between general medical and psychiatric practices. General medical diagnoses are usually based on specific disease processes that leave a trail of associated signs and symptoms that can usually be categorised. In comparison, the signs of psychiatric disorders are more difficult to interpret because they relate more to complaints about behaviour and emotions that have no definable cause or 'underlying physiological process' (Kleinman, 1998b, p. 8). Mental health issues are far more idiosyncratic than physiological disease processes, and, as a result there are usually different constellations of problems for different people. For example, children with Asperger's Syndrome usually have difficulty with social relationships, but not all have problems with learning academic tasks. Psychiatrists, while diagnosing the child's symptoms into a particular category, tailor responses to each individual's set of problems, although some argue that these responses are increasingly biophysically orientated as drug therapy replaces 'talking' as the preferred method of treatment (Williams, 2003).

Health professionals practising outside the domain of the medical profession are not generally considered, by medical professionals, to be eligible to diagnose. Nurses,

occupational therapists and psychologists, for example, are expected to identify signs that indicate the possibility of a problem, and then to refer clients onto medical practitioners, or psychiatrists for diagnosis and treatment. From the perspective of mothers, however, when these professionals use labels to identify their children's problems, they are diagnosing. This is not surprising since most members of the Australian public consider diagnosis as an integral part of any health consultation, expecting, and usually experiencing, one form of diagnosis or another whenever they attend a health professional. This suggests that the mothers' do not perceive diagnosis to be the prerogative of the medical profession. Or, at least, that they fail to differentiate health disciplines vigorously enough to realize that psychologists, occupational therapists and nurses have different roles to doctors.

The social construction of diagnosis

Medical labels and diagnoses are accepted as being rational and neutral because they have been scientifically discovered and interpreted by professionals working within the medical discourse. Gillman et al. (2000) suggest, however, that diagnoses are not objective facts, but are just ideas constructed and defined by professionals. A 'diagnosis' is not value-free and objective, rather, it is a social construction that reflects the medical and social attitudes of a particular society in a specific era (Hacking, 1999). An example of the culturally constructed notion of diagnosis can be seen in the case of ADHD. Malacrida (2003) in her comparative study of ADHD in Canada and the United Kingdom (UK), found that the ADHD label is used much less frequently and far more cautiously in the UK than Canada. Malacrida notes that the competing arguments about the 'existence' of ADHD affect how many children are diagnosed with ADHD and when that diagnosis occurs. King (1967) suggests that this variability in diagnosis occurs because 'the diagnosis that doctors actually make and the diagnostic framework they actually use 'will depend on circumstances' (p. 156). As a medical practitioner, King highlights how diagnosis is socially constructed by noting that diagnostic categories are selected depending on 'the *use* we have in mind' (p. 156). Malacrida (2003) proposes that ADHD is only diagnosed once children attend school and difficulties arise in the classroom, even though mothers had raised concerns about their children's behaviour in the years leading up to school. Doctors could only 'see' a 'use' for the diagnosis once the children were actively engaged in educational pursuits, even though mothers felt that their children needed access to early intervention programmes, or treatment, well before school started.

Sociologists, and others, have written extensively on the socially constructed nature of diagnosis (Brown, 1995; DeFelice, 2005; Gergen, 1996; Gillman et al., 2000; Harley, 1999; Kleinman, 1988b; Lupton, 1994; McLaughlin, 2005; Molloy & Vasil, 2002; Rosenberg, 2002; Schmitz, Filipone, & Edelman, 2003; Turner, 1995; Williams, 2003). Many of these writers suggest that diagnoses are socially constructed because they do not occur purely as a result of new scientific discoveries. Rather, a combination of elements combine to influence the development of new diagnoses, including advocacy by community groups, health-related organisations, political lobby groups, pharmaceutical companies, academic researchers, health clinicians, and school eductors (Conrad & Potter, 2000). As a result, medical diagnosis has extended into areas historically considered non-medical, such as social and educational arenas. This 'domain expansion' (Best, 1990) into areas not traditionally associated with medicine can be seen in the increasing categorisation of learning and behaviour problems listed in the *DSM-IV*.

The diagnoses applied to some of the children in this study included: attention deficit disorder (with or without hyperactivity) (Carl, Jack, Alice, David, Peter), oppositional defiance disorder (David); Asperger's syndrome (Luke) and dysgraphia (Betsy), a learning problem. The principal psychiatric manual, the *DSM IV* (American Psychiatric Association, 1994) lists these disorders and identifies specific behaviours for each. John was diagnosed with an XYY chromosomal abnormality.

While the XYY chromosomal abnormality is a specific pathological disorder, the other diagnoses are recent additions to the psychiatric discourse from which medicine draws when requiring information and diagnoses relating to mental health issues. It is notable that in the *DSM II* (American Psychiatric Association, 1968) these disorders are not clearly distinguished, rather behaviours are generalised as: 'hyperkinetic reaction of childhood (or adolescence)' (308.0) and 'unsocialised aggressive reaction of childhood (or adolescence)' (308.4). Only a passing mention is made of children with learning problems. By 1980, the diagnostic categories in the *DSM III* (American Psychiatric Association, 1980) are more comprehensive, covering 'specific developmental disorders' that include: developmental reading disorder, developmental arithmetic disorder and developmental articulation disorder, and behavioural disorders such as attention deficit hyperactivity disorder, conduct disorder which includes a sub-category of oppositional disorder.

The *DSM IV* (American Psychiatric Association, 1994) expands the diagnoses of learning disorders to include dysgraphia and dyslexia, amongst others and includes a new category of autism, 'Asperger's syndrome'. Diagnostic criteria for many of the categories are elaborated, for example, there are four more symptoms added to the category of ADHD, which itself is divided into three broad categories instead of the previously defined one; yet the criteria are more rigidly specified.

The refining of diagnoses closely mirrors the changing social emphasis on childhood behaviour and learning as being fundamental to later success in an adult world. Children who do not achieve social or academic success are considered to have a problem that reverberates into the future. The 'civilizing process' (Elias, 1982), whereby society strives for constant improvement, drives societal change and the *Diagnostic and Statistical Manual's* increasing size and categorisation of behavioural and learning problems reflect that change. Identifying 'problems' medically allows for intervention and amelioration of the potential long term 'side effects'. As a result, diagnosis forms an integral part of a child's journey to recognition of his or her problem and assistance with that problem.

While the increasing categorisation of children's learning and behavioural 'is the product of collective action' (Conrad & Potter, 2000, p. 560), the diagnoses are legitimated through the domain of medicine and psychiatry, which objectifies and pathologises them as biological conditions or mental illnesses. New language is generated to define, describe and explain newly generated modes of thinking, such as the medical 'discoveries' of specific learning or behavioural problems. By creating a language that describe a particular set of symptoms or behaviours, 'experts' are able to disseminate to the wider public and into the communal folklore - through health professionals, classrooms, popular magazines, television and the like - new terms that become adopted as 'real' (Gergen, 1996).

The recognition that diagnosis is socially constructed backgrounds the discussion in this chapter. It does not focus on whether these children need a diagnosis or not, but rather looks at the nature of the purposes which diagnosis serve. Does the concept of a mental disorder, such as Asperger's syndrome, attention deficit disorder, oppositional defiance disorder or dysgraphia, have any value to these children, or do these categories serve other social or political ends?

A semiological/mythological reading

Semiotic overview

Through a semiotic lens, the act of diagnosis can be considered as primarily concerned with meaning (Harley, 1999), and that the label attached to a diagnosis as having a symbolic function which fulfils the need of both the patient and the practitioner. Roland Barthes (1973) would suggest that diagnosis is a semiotic act that signifies a bundle of deeply embedded social myths about social roles, authority and power. Understanding the myths that background the act of diagnosis helps to tease out underlying social values that affect people what people do and why.

When considering diagnosis as a process, Kleinman (1988b) suggests that diagnosis is a form of pattern recognition, 'in which the patient's experienced symptoms are reinterpreted as signs of particular disease state' (p. 8). Turner proposes that this was particularly so prior to pre-modern medicine when 'the body was a virtual forest of symbols which could be read and interpreted by a literate medical practitioner' (Turner, 1991, p. 266).

Otswald (1968) proposes that diagnostic processes bear certain resemblances to language processes, where 'symptoms and signs are perceived facts, and whoever renders a diagnosis interprets these according to diseases concepts' (p. 105). Barthes assigns symptoms to the category of a signifier, whereby symptoms are elevated to the status of a sign only when they enter the context of clinical discourse and become medical language: 'le symptôme, ce serait le réel apparent ou l'apparent réel' (Barthes, 1972b, p. 38). Here Barthes proposes that the doctor sees what is really happening inside the patient as it becomes visible through symptoms, while the patient doesn't really understand what s/he's got, but knows that something is not right. The symptoms are translated into signs 'through the organising consciousness of the physician' (Sebeok, 1994, p. 47). Martínez-Hernáez (2000) suggests that signs are more highly valued than symptoms in a medical interpretation because they provide 'real' clues about 'what's going on', whereas symptoms are influenced by the subjective concerns of the patient :

> …signs are understood to be objective evidence of disease which can be perceived by a professional, while symptoms, on the other hand, are viewed as more ambiguous and uncertain because they originate in the perception and expression of the patient's themselves (p. 4).

In this study, the concerns of mothers' can be regarded as symptoms, whereby mothers are only able to express their perceptions of a their child's problems. While

doctors can translate these signifiers into signs, the meaning they extrapolate from them may not necessarily be the same as the meaning mothers attach to them. Martínez-Hernáez argues that this occurs because symptoms reflect 'local worlds of meaning' (p. 2), that are affected by cultural, social and political-economic considerations.

Determination of the meaning of illness signs is the primary function of a medical professional, and in the framework of the biomedical models, through which Western medicine operates, signs are 'regarded as empirically classifiable given sufficient information and the necessary technology to generate and evaluate the information' (Staiano, 1979, p. 108). Yet, Staiano proposes that symptoms represent more than just signs of an illness or disease, they are, in fact a cultural act that communicates 'subjectively perceived states in culturally approved modalities (p. 111). This is the view of a number of leading figures in anthropology, including Kleinman (1981; 1988b; 1988c), and Szasz (1974), who argue that how signs of illness, and mental disorders are interpreted, defined and categorised by doctors and psychiatrists varies according to the time and place in which the illness, or disorder arises.

Burnum (1993) proposes that the contexts in which signs appear 'shape the meaning of the sign and in some cases may change it altogether' (p. 942). Patients describe their 'illness' in a language that reflects cultural expectations and codes, particularly in terms of existing illness categories, and according to expectations associated with specific roles. Medical professionals are also affected by this social construct, interpreting symptoms through a medical code that centres on translating symptoms to signs, disease classification and diagnosis. The cultural and social environment also impact upon how the doctor interprets symptoms, and as a result, not all doctors, when faced with the same signs and sign systems will see the same event and provide the same diagnosis. This occurs, according to Burnum (1993), because the meaning of the sign has to be inferred, and inferences are subjective interpretations that 'are circumscribed by the experience and bias of the clinician' (p. 939).

Harley (1999) suggests that illness and healing is a social construction that 'requires a plausible practitioner who can deploy a credible system in a successful negotiation that brings order to the patient's experience' (p. 434). This is because 'culturally

specific beliefs and social structures create local realities which define and determine health and illness' (p. 434). Because illness signs and diagnosis do not sit separately from social structures, Staiano (1979) proposes` that patients, medical professionals and political systems can potentially exploit medical signs for personal benefit, or communal ends. The signs of illness may be utilised by the patient to manipulate and control such things as eligibility for remuneration, health or educational assistance, or sick leave. Members of the medical profession may define an even broader range of signs as indicative of illness, thus creating an ever-increasing proliferation of named disorders, which attract research funding, and increase control over the lives of others. Finally, State systems may utilise signs to serve communal interests or state interests (Szasz, 1974), such as the allocation of resources to specific illnesses, or the development of educational assessment procedures that require specific medical diagnoses for educational assistance. Szasz (1974) argues that people diagnosed with mental disorders are particularly vulnerable to State control because patients can be detained against their will purely on the basis of a culturally determined interpretation of a set of signs. Semiotic analyses help to uncover the connections between political, religious, or economic social constructions, the redevelopment of medical beliefs, and the success or failure of healing (Harley, 1999, p. 435).

Mothers are driven to seek a diagnosis for their children for a number of reasons. Without a diagnosis the mothers feel unable to access assistance for their children, cannot free themselves of the shackles of blame and feel they cannot develop a satisfactory understanding of their child's problem. The following discussion draws attention to the multiplicity of meanings of the act of diagnosis in the social, medical and educational world with which the mothers and their children engage.

Diagnosis as illness
Understanding why diagnosis was a major theme in the mothers' stories is important to this study. Barthes suggestion that language is a signifier of deeply embedded social myths means that 'diagnosis' is not a simple word representing a singular act, but is a word that signifies a complex body of social meanings.

Diagnosis may, on the surface, appear to be about clarification of an illness or health problem, Crowe (2000) suggesting that most people want an explanation for

abnormal behaviour. Williams (2003) proposes that the naming of an illness is important to people because:

> Naming what is wrong gives one a sense of power over it. Knowing the word is knowing the nature of the disease; it brings it into being, gives it form, and gives the knowledge used to combat it. It also brings a sense of membership, belonging to a group of people with the same disorder: the patient is no longer alone (p. 4).

As Maggie articulates: 'I know what the problem is now so that's made it a lot easier' (p. 13, 2-3). Diagnosis provides an explanation for an illness, and gives a sense of 'knowing' that enables people to pursue treatment, or 'a cure'. With this understanding, it is apparent that the most fundamental semiotic function of diagnosis is it signals that, whatever its characteristics may be, whatever hope it holds, the child's problem is an illness.

The semiotic function of 'illness' has been discussed variously by a number of philosophers, including Boorse (1975), Engelhardt (1981), Sedgwick (1982) Armstrong (1995), and Turner (1996). Engelhardt (1981) views illness as the consequence of a disease process, whereby 'certain phenomena are analysed for the purpose of diagnosis, prognosis and therapy' (p. 44). Boorse (1975) interprets illness to mean that 'a person is seriously incapacitated and that illness is therefore undesirable for its bearer; a title to special treatment; and a valid excuse for normally criticisable behaviour' (p. 61). He argues that the motivation for the condition needs no explanation and that the connection between the illness and personal responsibility for it, is diminished. Locker (1981) proposes that the illness-ascription is therefore a social act that confers a certain status to an individual that frees them from certain responsibilities.

While the proposals of Engelhardt (1981) and Boorse (1975) do not reflect on the social construction of the signification of illness, Sedgwick (1982) argues that illnesses only exist by virtue of their socially constructed nature. Turner (1996) suggests that the significance attached to illnesses arises as a result of the impact of cultural values on medical judgement and interpretation. This cultural influence can be seen in the shift of the meaning of illness from Boorse's time to today. Today, the borders between health and illness are less well defined, Armstrong (1995) arguing that a person can be healthy and ill at the same time. These people, Armstrong (1995) suggests, are those who are identified as 'at risk' (p. 400). From this perspective, a diagnosis can signify a potential illness, pointing to increased

concerns about future health and well-being. The adoption of the terms such as Asperger's syndrome, ADHD or learning disorders, while signifying a mental disorder, may also signify that children are 'at risk' for learning, behaviour and social problems in their formative years. This is exemplified in Rebecca's comment that her son was 'a healthy child' (p. 14, 42), yet she felt that his teacher identified him as unhealthy because his behavioural problems affected his ability to socially engage and successfully learn in the classroom.

When the children in this study were 'diagnosed', the mothers read this sign in a number of different ways. Mothers expressed relief at a diagnosis as it signified that their child had a legitimate illness that required special treatment, and that neither the child nor the mothers could be held responsible for the illness. Diagnosis was especially meaningful for mothers as it enabled them to excuse their child's problems as an illness and to pass the responsibility of treatment over to the medical profession. But the mothers did not regard their children as 'sick', the diagnosis signifying that their child had a 'healthy illness' that placed them at risk of social and academic problems for which they required assistance.

Diagnosis as validation

Diagnosis was particularly important to these mothers who often felt unbelieved and blamed for their children's problems. A diagnosis signified that the child suffered from a legitimate illness and validated the mothers long-held concerns about their children. This legitimation enabled mothers to strategically re-enter a society from which they, and their children had previously felt excluded.

A diagnosis signified to mothers that doctors believed them. Finding health professionals who would listen to them, and believe that their child had a problem, was tremendously reassuring for all of the mothers. Health professionals saying 'yes, I do believe you, now what can I do to help you and your child?' made mothers feel their concerns were valid and legitimate. Kimberley's story exemplified this argument. After struggling for six years to have her concerns about her child confirmed, Kimberley's son Carl was currently under the care of a local paediatrician whom, while suggesting that Carl may have Asperger's Syndrome, 'wants to rule out any other sort of things first' (Kimberley, p. 11, 2), he had organised support for Kimberley and had put into place an assessment program for Carl. Kimberley now felt believed. Her relief at finding a doctor who listened to her concerns was

palpable, and as she said 'it's taken 6 years to find a doctor who believes that it's not my parenting [ ]….too long, way too long…'(Kimberley, p. 15, 48-49; p. 16, 2). In a follow-up telephone conversation with Kimberley she added: 'Now I feel that it can only get better from here…now we have someone who believes me and will help me…' (Kimberley, 10/8/3).

The legitimation of symptoms as a medical problem was extremely important to these mothers as it pointed to the existence of a genuine illness. Validation by a doctor legitimised the child's problems and enabled the mothers to gain meaning 'in the face of polysemous uncertainties' (Holmes, 1996, p. 115). For most of the mothers in this study diagnosis signified the confirmation of long-held concerns, and this had a number of positive outcomes. The mothers felt they could rely on the doctor to help them treat and manage their children's problems, and help them access support services. Most importantly, mothers were less likely to blame themselves for their child's problems, and they were less likely to perceive themselves as failures.

Diagnosis as exoneration of blame

It was not until diagnosis that most mothers felt able to dismiss accumulated feelings of blame and guilt. Diagnosis appeared to relieve the anxiety that many of the mothers experienced as a result of the uncertainly surrounding their children's difficulties. Once their child was diagnosed with a 'medical problem', most of the mothers expressed feelings of relief. The stories of Alana and Nerida exemplify the importance attached to this meaning of diagnosis. Alana talked about her relief at her daughter being diagnosed with a learning problem, dysgraphia:

> Jane   How did you feel about the tag or the label?
> Alana   I was glad.
> Jane   Why do you think?
> Alana   Because, it kind of gave us an excuse…you know…which was an excuse for her behaviour, we were able to…well, not everything was attributable to her having this learning difficulty, it kind of excused a lot of her frustrations and I could, you know, and I felt, kind of relieved I suppose that it was something that you could seemingly fix and if you gave it the right attention then that was a good thing, so she wasn't, you know a paranoid schizophrenic or…you know…a horrible…not a horrible...but you know….other clinical things...that we weren't bad parents…yeh...all that…so yeh, all that, so I guess it kind of gave us an excuse for some of her behaviour and we were fairly relieved, although I was…that we could, move on…you know we had this direction…so it was...a good time… (Alana, p. 5, 34-50)

After eight years of concern, Nerida's son's diagnosis of a double Y chromosome came as a huge relief. Nerida felt a huge burden lift from her, even though she understood there was no cure for her son's problem, just knowing that 'there is something actually there' (p. 14, 36) was important to Nerida:

> Jane   What difference did having a diagnosis make to you?
> Nerida I left the doctors surgery elated….the doctor…the specialist, when he gave me the diagnosis said "you're not crying"…I said "no, I feel like a weight has just come off my shoulders", and he said "why?", and I said "Because I now know there's a reason, it's not just me"…..I just felt I was walking on air, it was unreal…and he just thought I should have been in tears, but for eight years I've wondered if there was something wrong with him and now I had confirmation that there was a cause for this… and it wasn't the family or the home situation…….(Nerida, p. 4, 41-46; p. 5, 1-7).

The transcripts draw attention to the keen sense of relief that mothers experienced once children were diagnosed. Why are these mothers so pleased to have their children diagnosed, even though the diagnoses may have forecast long-term problems and challenges for both the child and his/her parents? What are the mechanisms surrounding this response to diagnosis?

From a semiotic perspective, diagnosis signifies that these children have a legitimate illness for which they require support and assistance, while mothers are exonerated of the blame they felt so acutely for so many years. Nerida's expression 'walking on air' refers to how the diagnosis signifies vindication of personal fault and the legitimation of her concerns.

Until diagnosis, it is obvious from the transcripts that many of the mothers felt that they may have been responsible for their child's condition. Diagnosis signifies exoneration from blame, because the problem is no longer directly linked to a mother's relationship with her child. Traditionally, 'the problem' becomes a medical condition, and once defined as such removes blame from both the mother and the child. A diagnosis signifies that a 'patient' is able to enter into the realm of medicine, relieving both the patient and other carers of responsibility, and locating accountability with the health professional.

Historically, there is a strong link between disease and individual responsibility. Up until the mid to late 1800s, lay theories of illness placed responsibility for illness at the feet of the person who was sick. Religion played an influential role in the development and replication of these theories; encouraging people to believe that vice and sinfulness caused people to become sick. The germ theory of illness

accepted by society in the 1870s and 1880s as an alternative hypothesis, separated illness from moral judgements. No longer did 'bad' people become sick. Sick people were those whose misfortune it was to become infected by a disease-causing germ, something outside of their control. Based on this organic theory of illness, once an individual is diagnosed with an illness, moral judgements are suspended, because medicine, an objective, scientifically based approach to healthcare, does not blame, or judge people for their illnesses, rather, the cause is attributed to a biological-based pathology. Individuals who require the services of the organisation feel comfortable in the knowledge that they will not be blamed for their illness, and so continue to utilise their services.

This scientific, detached value-neutrality is, however, a frail, socially constructed quality. Under the right conditions, medicine can abandon this quite easily. Several of the mothers in this study, for example, found that they continued to feel blamed by health professionals, for their children's behavioural problems, even after diagnosis. Boorse (1975) suggests that non-responsibility for an illness seems to break down in modern interpretations of mental disorders. The meaning attached to mental disorders differs from the meaning attached to illness of other body parts, because, Boorse argues, some people have difficulty distinguishing between 'mind and character' (p. 66) and interpret action of the mind to signify a conscious action, and 'therefore beyond all hope of excuse' (p. 66). Mothers of children diagnosed with mental disorders such as Asperger's syndrome, attention deficit disorder or oppositional defiance disorder did not always find that diagnosis signified exoneration from blame. Mary, for example still felt blamed for her child's aggressive tendencies even after he had been diagnosed with Asperger's syndrome. When her son had experienced a particularly difficult behavioural episode and was admitted to hospital, Mary was directly accused of causing her son's problem. On one occasion, while Mary was visiting her son, he lost control. The nurse in the mental health facility turned to Mary and said 'Well, this is what some parents are responsible for...' (Mary, p. 9, 46). While the nurse later apologised, her passing comment to Mary remained ingrained in Mary's memory, and draws attention to the network of complex and sometimes fragile meanings attached to 'diagnosis'.

Diagnosis as hope

Luhrmann (2000) suggests that diagnosis is important to people because it signifies hope for a treatment and cure. The desire for a 'cure' is embedded deeply in the

human psyche. From the beginning of humankind, people have sought out 'cures' for a range of human ills. Depending on the time and place, cures were sought from either the natural or the supernatural worlds, hunting the wilds or appealing to gods, and sometimes a combination of both. In Western society today, communal folklore about illness, treatment and cure is primarily based on the bio-medical model of health care, which, over the past 150 years has established itself as the preferred approach for the treatment and cure of illness. Today, diagnosis forms an integral part of the bio-medical approach and most members of the public anticipate a diagnosis whenever they consult a doctor. Diagnosis has become integrally linked to the promise of a cure. This promise is reinforced by media articles, which regularly headline the 'discovery' of new cures for a multitude of illnesses. Hence, there is a communal expectation that once a diagnosis is made, treatment and cure 'naturally' follow, as Mary clearly articulated:

> Jane   ....did the diagnosis enable you to then go out and look for answers?
> Mary   Yes, ...
> Jane   OK....and did you actively pursue that?
> Mary   Actively, actively.....and at one stage, and this was like a really extreme reaction on my part...I mean, I think...I often wonder now how I didn't lose it totally at that time....but, you know, I started to investigate via the web all these really exotic locations like Mexico and countries in South America where you live on tomato juice for a week and all that sort of stuff and alternative therapies.... (Mary, p. 13, 29-39).

Belief in the efficacy of 'diagnosis' and 'cure' is powerful, and has been harnessed by religion and medicine in both traditional and modern societies. Malinowski (1948) suggested that these beliefs are based on a fundamental human need for hope. In traditional societies, 'magic', often taking the form of one sort of religion or another, embodied hope, whereas in modern society, it is science and medicine. According to Greek mythology, Pandora, the first mortal woman shaped by the gods, opened a jar given to her bridegroom, and allowed to escape, 'all the unwanted ills of man' (Eliot, 1976, p. 73). In the bottom of the jar, however, remained hope, and it this hope that provides human beings with the fortitude to face the problems all the 'unwanted ills' bring (Bulfinch, 1947). The theme of hope appears repeatedly throughout history; Alexandra Pope's famous poem *An essay on man* (1733) begins with 'Hope springs eternal in the human breast', and is oft repeated in media headlines, human interest stories and the like. Common sayings such as 'never give up hope' and 'all you can do is hope' both reflect the importance role hope plays in contemporary society. Health professionals also hope that a diagnosis will provide them with the opportunity to offer the parents a cure, as Rapin (2002) states:

> The responsibility of physicians who investigate children with developmental delays is to determine whether there is a diagnosable condition responsible for the problem. Lurking behind this question is the unvoiced hope that a pill, a dietary change, or a surgical treatment will cure, or at least ameliorate, the problem (p. 54).

Sitting alongside hope is the belief that modern medicine will provide a cure. While past societies placed their faith in religious powers and the promise of the afterlife, the promotion of medicine in modern society as scientifically rigorous, and therefore the most appropriate route to treatment and cure, has created a confidence that 'medicine will deliver'. Ekeland (1997) suggests that medicines, such as pills, represent the condensing of hope and belief into relief and healing. 'In the hands of the good doctor the pill is not just chemistry but sacrament as well' (Ekeland, 1997, p. 82). This suggests that tablets, injections and other medical treatments are all rich in semiotic value.

However, if modern medicine fails to find a diagnosis, or, having found one then cannot cure, then people hunt for the miracle cure in other places. Thus, an Australian study of parents whose children had been diagnosed with ADHD (Sinha & Efron, 2005) showed that a large number of children are exposed to both complementary and alternative medicine, as well as 'conventional' drug therapy, such as Ritalin®. While 58% of the parents reported that many of the treatments did not work, they continued to search out new treatments and potential cures. When modern medicine fails to deliver, 'hope never entirely leaves us' (Bulfinch, 1947, p. 17) and parents continue to search for a cure. This outcome was replicated in the stories of the mothers in this study. While some mothers chose to adopt conventional drug treatment for their children, others chose unorthodox medicine. Once a diagnosis was made nearly all of the mothers searched out as much information as they could find, seeking potential treatments and cures through information in books, the World Wide Web and from other parents. Justine, having refused to medicate her son with Ritalin® tried a number of alternative therapies:

> I took him to a naturopath…and um, sought out kinesiology exercises…ok?…ok, this is where I tried this, he was on…um…some things with his nails…some zinc, magnesium, some brain things...because he was a really bad fingernail chewer, so he was on naturopathic things to help his body…(Justine, p. 11, 37-38).

Likewise, Kimberley, sought assistance and advice from a naturopath and she also sourced medicines through the Internet:

> I spoke to a naturopath who suggested that I find a natural alternative and I found a company in America that deals with natural medicines and I ended

up getting stuff through them ,which helped, but it's too expensive...to keep going…(Kimberley, p. 6, 23-28).

For Kimberley, however, the hunt for the miracle cure came with a hefty price tag, and one she could little afford, and while she continued to pursue assistance for her child, her hope for a 'cure' had to be reconciled against her limited resources. The rainbow of hope also lost its shine when replaced by the pragmatic realisation that the miracle cure may not exist, as Mary explained:

…..but I very quickly realised I could go on chasing that rainbow forever, and it wasn't going to do him any good and it certainly wasn't going to do me any good….(Mary, p. 13, 40-43).

Yet, the mothers never gave up hope. They hoped that their child would be able to actively engage in society in the future and while not 'cured' would keep safe and well. Kimberley feared for her son's future, but continued to hope that the treatment he was receiving would help him avoid a difficult adulthood:

Jane	Do every worry about what he's going to be like when he's an adult?
Kimberley	I think he'll be in jail.
Jane	How do you feel about that?
Kimberley	I can only support him because I know what he's like…I would hate for him to go down that road, but I've prepared myself for it because, I know what he's like now, he's just 'seek and destroy' anything and everything… so, yes...it's very worrying…definitely…but we'll have to face that when we get to it, but I'm hoping that we don't ever get there, but the possibility is very high…I think… (Kimberley, p. 18, 48-50; p. 19, 1-5, 13-16).

Kimberley's hope was closely associated with her belief that her son's problem had been identified and that he would be able to access support and intervention services over the coming years.

Diagnosis as support

Associated with the myth of the miracle cure, was the belief that diagnosis signified an illness, entitling the child to access societal support services. Yet, even though parents may have actively sought diagnosis in the belief that it would legitimate requests for support services, assistance was not guaranteed. Gillman et al. (2000) found that even though parents believed that a diagnosis would benefit their child, in actual fact, services were scant and inadequate and the child was stigmatised. In their study, Gillman et al. identified many parents who sought a diagnosis for their child 'with the strong belief that it would lead to an improved lifestyle and increased social support' (p. 406). However, the study found that many participants were substantially worse off as a direct result of receiving a diagnosis. They became

members of a devalued group, which 'brings forth prejudicial and discriminatory attitudes' in some people (p. 406).

From a semiotic perspective, it is apparent that there are multiple meanings attached to a sign. While mothers believed that diagnosis signified an illness that entitled their child to assistance, other members of the community read the diagnostic sign differently. Children were not viewed as ill, but 'different'. Melanie's experience was consistent with these findings, noting that it took some time for family members and friends to support her and her child. While she commented that diagnosis was important as it verified her concerns, understanding and support from others did not come easily:

> ….but I think it was more that no one believed…I felt that I didn't have the support, even my own family….like my own sister….it's so hard, they all support me, but it took them a long time for them…..and I had to give them *(information)* to read…and I had to get them to see, and eventually they did….but, even now I have the support of my family and a few friends at all, but I feel still alone…you know, I have good support at school and all, but still it's so hard…sometimes…(Melanie, p. 7, 26-34).

Having expected a more positive response from family and friends, most mothers expressed disappointment that support remained limited. Kimberley, a single mother with little family support looked to community services for support. She strongly believed that her son's diagnosis would make a difference to access of community resources both for herself and her son:

Jane	Do you think it would have been easier for Carl if that doctor you saw when he was three had actually given him a diagnosis then?
Kimberley	Yeh, yeh, because I could of put strategies into place for <u>me</u> to help me as a mother to deal with it, rather than just fly solo and basically drown…yeh, because there's only so much you can do without knowing what you're doing….and that's what made it hard…
Jane	Do you think it would of given you access to more resources?
Kimberley	Yeh, and support groups maybe...yep. .most certainly…
Jane	And are you accessing support groups now?
Kimberley	Um...yeh…we're in the process….
Jane	Ok, ok…are there support groups where you live?
Kimberley	That's what the doctor's trying to do now, he's trying to find out about what's available there for me...yes… (Kimberley, p. 15, 27-45).

Yet, the reality is different from Kimberley's expectations:

Kimberley	He went to the child youth and mental health clinic here, which he is still going to now.
Jane	How often does he go there?

Kimberley   Every available appointment that we can fit him into…um…about once every six weeks I suppose it is… (Kimberley, p. 9, 33-35, 39-41).

Kimberley went on to explain that: '…one half an hour to an hour session every six weeks is not enough I don't think…' (Kimberley, p. 10, 9-10). Kimberley felt that her son needed intensive intervention, yet his access to services was extremely restricted. There existed a large discrepancy between anticipated assistance and the assistance that was actually provided. Yet, from Kimberley's perspective, this was still much more support for her son than when her concerns about his behaviour remain unheeded.

Community support remained limited for some families even though the mothers read the diagnostic sign as the legitimation of their children's problems. Some mothers found that they still had to 'prove' to others that their child did have a legitimate illness that required special consideration. Furthermore, some also experienced limited professional support, even after diagnosis. Mary noted that the school, which her son attended when he was first diagnosed, paid no attention to his diagnosis, and no additional support was received during the year, he spent there:

…the school he was at was not supportive of it, unfortunately…he was bullied terribly...and the school principal was not, I think…he was of the belief that children like my son, and I suppose any others along the spectrum, all they really needed was a good kick up the backside….or, it's probably a bit of bad parenting…or combination of both…so he really did have a very difficult year there….with a teacher who categorically refused to accommodate his needs (Mary, p. 7, 29-37).

Mary's experience replicates Ray's (2003) study of parents whose children had chronic health conditions, finding that children who 'looked normal' and did not require technological intervention, such as oxygen therapy, found it much more challenging to access services and educational assistance. However, the school Mary's son was currently attending was much more supportive:

He has excellent support, he has outstanding support in this particular public system…..in this particular area…I don't believe that it's a unilateral thing in then public system either…I think it's the luck of the draw…(Mary, p. 8, 8-12).

The contrasting views by teachers are reflective of the competing meanings associated with diagnosis, particularly in the area of behavioural and learning difficulties. On one hand, children with diagnosed behavioural or learning difficulties are not considered to have a medical illness that excuses them of personal responsibility, teachers therefore viewed these children as being 'malingerers'. On the other hand, some teachers were highly supportive of children with learning

difficulties and attempted to provide educational strategies for them. These varying responses are illustrative of the polysemous nature of signs. Signs can be read differently by different people (Barthes, 1972a), creating the potential of multiple meanings. Some teachers read the diagnostic signifier as a sign that the child needed educational assistance; others read the sign as a 'cop out', where the child's problem had been medicalised merely to excuse poor behaviour or laziness.

It is apparent from this discussion that diagnosis is not a value-neutral word, having many myths and expectations bound up in both the diagnostic act and label. As a result, mothers often noted that a diagnosis did not lead to the treatment, cure or support they expected, and that teachers and health professionals did not always attach the same meaning to the diagnosis that they did.

A Marxist reading

Marxist overview

From a Marxist perspective, diagnosis is a demonstration of expertise and the legitimation of a professional's claim to authority. Power resides with professionals who can define a problem and determine the solutions (Freeman, 1988). Because doctors control much of the diagnostic 'rights' they may be accused of utilising diagnosis as a tool for gaining and maintaining power. This is particularly apparent in the recent increase in the number of children's diagnoses, especially in the category of learning and behavioural disabilities (Brown, 1995). Being the only group of professionals that hold the authority to conduct appropriate tests and determine the diagnosis, medical professionals place themselves in positions of power that, some would argue, ultimately ensure reproduction of social inequalities and control of others (Freeman, 1988). Signs and symptoms must be translated into technical language, preferably one that is not understood by others. Diagnosis therefore becomes a tool that demonstrates expertise and legitimates the medical professionals' claim to authority. Members of the general public engage in hegemony by demanding diagnoses for their problems, and so reinforce the doctor's authority and role.

While Prior (2003) would suggest that in recent years there has been an increasing focus on patient-centred decision making and a recognition of the importance of shared decision making in medical consultations, it is apparent from the previous chapter that sensitivity to patient viewpoints is still very limited in some medical

practices. Looking at diagnosis as a process, rather than as an event, it is possible to scrutinise the power distortions that enter into the doctor/client dialogue. From a Habermasian perspective, what should actually happen in a doctor/client relationship is that both the doctor and the mother relinquish power differentials, in order to create an opportunity to engage in an ideal speech situation. The process of diagnosis should be one that is characterised by reason, unencumbered by previous power relationships, myths, stigma or biases.

Diagnosis is also utilised as an expression of power when access to resources is tied to specific medical diagnoses. Habermas (1984) would argue that this kind of medical imperialism is an example of how the rationality of the system colonises the everyday activities of the lifeworld, particularly when the resources are not those normally associated with the provision of health care (Scambler, 1987). In this chapter, the educational assessment process of 'ascertainment' will be discussed in relation to medical diagnosis and access to educational resources and support.

The problematic nature and meaning of diagnosis arises in the context of the narratives. On one hand the mothers see diagnosis as a means of exonerating them of blame and as a way of gaining both educational and financial assistance for their child. On the other hand, the blame does not evaporate and anticipated assistance does not always eventuate, yet mothers all felt relief once their child was diagnosed. When children are labelled with particular behavioural or learning problems, does the diagnosis serve the needs of the child, the mother or the profession that develops and applies the label? To answer these questions from a Marxist perspective, one needs to look at what is happening in the wider historical and social environment.

Why is diagnosis important? Whose interests are being served?
Societal expectations of literacy and behaviour have been enormously influential in driving forward medical involvement in the assessment and diagnosis of educational and social problems. Medical encroachment into the lifeworld of mothers, children, their families and educational institutions that they attend is increasingly apparent as behavioural and educational problems become more frequently scientised, technicised, and rationalised by the medical approach to what were previously considered social problems. As a result, children with behavioural and learning problems are increasingly diagnosed as having medical problems. Consider, for

example, the enormous numbers of Western children who have been diagnosed with Attention Deficit Disorder (either ADD or ADHD) in the past decade. These children are characterised as having short attention spans, unable to sit still in a classroom and often behaving more aggressively than their peers. Today, many are treated with drugs and are under the care of a paediatrician. Twenty years ago, this 'problem' was unheard of, yet it is now the most commonly diagnosed neurobehavioural disorder in American children (Fewell & Deutscher, 2002; Zito et al., 2000), while Australian children are also being diagnosed in increasing numbers (Australian Broadcasting Commission, 2005; Rogers, 2002).

Drawing on Parson's (1951) notion of the 'sick role' and the labelling of 'deviances', diagnosis provides the route through which the medical profession can identify and separate out those individuals who are deemed to be ill and needing medical treatment. While it can be argued that diagnosis is necessary to assist an individual's access to appropriate and timely treatment and therefore fulfils an important social function, it can also be argued that diagnosis serves the interests of the health profession itself. Some of the mothers in this study actively sought diagnosis for their child's problem. Nerida repeatedly visited her local general practitioner and paediatrician, and was not satisfied until her son's diagnosis was 'the right one'; Mary sought assessment after assessment, looking for an explanation for her son's behaviour and Melanie kept taking her daughter to the paediatrician for check-ups. By seeking a diagnosis, mothers become part of a feedback loop that reinforces the need for a diagnosis and the involvement of medical professionals in problems that, historically, have not been within the medical domain of practice. This increasing reliance on diagnosis augments the power and control exercised by the health profession over the assessment, labelling and treatment of behavioural or learning problems, where, in the past, families and their teachers have managed these issues. The mothers', as members of a society that upholds notions of them as dependent upon others for advice in parenting, are driven to seek advice from those society considers 'experts'. This is particularly so in recent times as 'childcare has become redefined as an area for professional expertise and intervention' (Kent, 2000, p.108). As more mothers seek professional intervention for child-related learning and behavioural problems, the greater the involvement and power of health professionals. Their power increases further when medical diagnoses are adopted as essential for access to resources such as educational assistance social welfare. As discussed in chapter four, doctors become

the legitimate gatekeepers to resources as a result of government delegation. Diagnosis becomes the tool by which the medical profession controls who can and who cannot access, often scarce, resources, and thus a strong expression of its power. Ultimate control, however, rests with the government who can chose whether or not to maintain existing power structures.

The power and control exercised by the health professions also increase as knowledge and language develop within the profession to explain particular 'problems'. The privileged knowledge and the specialist language of the doctors set 'experts' apart from the general public, and even though, epistemologically, the diagnostic term is merely a shorthand name for a list of signs, diagnosis is a function unique to a doctor. Furthermore, only a doctor has access to the technology and associated tests, the results of these tests and the knowledge to interpret the results. The specialised knowledge required to interpret these signs impresses the lay person, and so the general public are drawn to seek the expertise of the health profession when confronted with a health problem. Even though the children in this study did not display disease-based 'health' problems, the mothers were drawn to, or were recommended by others, to seek a diagnosis from health professionals.

The effects of labelling

Within the medical discourse, diagnosis and labelling are usually regarded as helpful, as patients can be identified and treated for diseases that may have otherwise had fatal consequences. In other circumstances, however, diagnosis may be regarded as unhelpful due to the negative connotations of the label, such as schizophrenia, HIV and AIDS (Gillman et al., 2000). One of the mothers, commented, for example, that her daughter's diagnosis was not one with a negative label attached to it: '….so she wasn't, you know a paranoid schizophrenic or…you know…a horrible…not a horrible...but you know….other clinical things….' (Alana, p. 5, 44-45).

Furthermore, labelling a child with a learning or behavioural problem focuses attention on the individual, rather than on the social or structural context (Ho, 2004). Hacking (1999) argues that classifications can change how other people view that person, because many of the labels that have emerged in the past identify deviances. 'These classifications identify who is troubling or in trouble …and identify the kinds of people to be or not to be' (Hacking, 1999, p. 131). Becker (1966) refers

a 'master status', whereby individuals who are labelled with unusual, mysterious, extreme or outrageous labels become seen, and see themselves, as the label. In his work, Goffman (1963) pursued the negative effect that 'labelling' has on people, arguing that people are constrained by the commonly shared and socialised views of other people and to this end he suggested that people try to avoid labels that portray them in a negative light. Becker (1966) concurs with Goffman, suggesting that the socially produced values associated with labels marginalises people and isolates them even further from the commonly shared norms of society. If what these authors say is correct, why then do some mothers appear to actively seek a diagnosis and 'label' for their child? The following exemplar draws attention to this phenomenon.

A recent visit by a child psychologist, Bob Rogers, to Townsville, illustrates the importance of a diagnosis to a parent. Dr Rogers argues that ADHD is not a diagnosable disorder (Rogers, 2002), and claims that the children with ADHD are merely being 'labelled' for the benefit of the drug companies which make billions of dollars from the sale of the drugs used to 'treat' ADHD. He suggests that parents need to learn how to 'manage their children differently' and advocates a behaviouralist approach to the 'problem'. The parent members of the local ADHD support group were up in arms, and protested loudly, bearing placards and banners at the meeting which expressed their belief in the right of their children to be identified as 'different'. As one mother particularly emphasised a diagnosis of ADHD exonerated the parents from blame. No diagnosis implied a parenting cause, particularly when behavioural management strategies were suggested as the appropriate intervention (this implied that parents were not doing a good enough behavioural management job in the first place). As a parent, I can understand their anxiety, particularly as no diagnosis often meant no help from family, the community or schools and no recognition that their children are indeed 'different' and need additional services, particularly once the child attended school.

There is little doubt that diagnosis provided mothers with an enormous sense of relief, enabling them to acknowledged that their children were 'different' and needing assistance in learning skills or behavioural management. Gramsci, however, argues that by hegemonically adopting the rules of the dominant medical system (Abercrombie et al., 1980), mothers and their children fall prey to ever-expanding control over their lives. Mothers have been subverted by the system of medicine

because it has invaded the lifeworld so completely that mothers have no choice but to accept it. The access to formal support, and even informal sympathy or understanding, now depends entirely on accepting the medico-technical perspective. The lifeworld of mothers is consumed by the technological world of medicine, and, as a result, diagnosis becomes a route through which the system of medicine is able to control parents. Doctors control both the medical diagnosis and the parent's responses and choices.

Diagnosis is the crossover between technical systems and lifeworld. Colonisation of the lifeworld occurs through the hegemonic adoption of diagnosis and, as Habermas complains, the needs of the lifeworld become secondary to the success-orientated focus of the system (Holmes, 1992). Just as Rogers (2002) argues, the big winners in this invasion of the lifeworld are the pharmaceutical companies who make massive profits from the sale of drugs, and medical professionals who continue to diagnose and prescribe on-going treatment. Furthermore, medical power is legitimated through the use of technical language that becomes a 'taken for granted' part of the lifeworld. In this way, trust and belief in the doctor, and diagnosis, is consolidated.

Diagnosis also provides the access route for the extension of medical power into other institutions. In Queensland state schools, overseen by Education Queensland, children cannot receive additional classroom assistance without a medical diagnosis.

Diagnosis and teachers

It was often not until the child first attended school that their problems were formally investigated. In most instances, the child's classroom teacher was the first professional to suggest that the mother take the child to a medical practitioner for an assessment. This finding is consistent with other studies, such as Malacrida (2003) and Carpenter (1999), who found that this was the situation for most of the children who were later diagnosed as having ADHD. Breeding (n.d.) notes that 'the most common point of entry for a child into psychiatry is during the transition from the preschool life into the early elementary experience ' (para. 14). This transition to school was obviously a difficult one for the children and their mothers, and was highly influenced by the attitudes of the mothers, the teachers and other professionals as well as the policies and practices of the educational environment

(Newman, 1995). To receive classroom assistance children were required to have a medical diagnosis, and as a result, teachers referred children to general practitioners, or paediatricians for assessment and diagnosis when they were concerned about children's ability to function, socially or academically, in the classroom.

According to Education Queensland (2005b), to be eligible for classroom assistance, a student must have 'a verified diagnosis in autistic spectrum disorder, hearing impairment, intellectual impairment, physical impairment, speech-language impairment, vision impairment or a combination of these' (p. 1). A medical specialist must complete the verification report, and this person must identify himself or herself as a paediatrician, neurologist, psychiatrist, ophthalmologist or geneticist (Education Queensland, 2005d). There is only provision for psychological reports verifying that a child has an intellectual impairment, and a speech pathologist is able to verify speech and language associated problems. While a narrow range of professions are associated with verification, medical professionals are required to diagnose and verify the majority of disorders. Requiring a medical diagnosis of the child's problems implies that the educational institution in Queensland is primarily medical in nature, even though it is teachers that identify the problem and make the referrals, and the interventions are likely to be educational in their orientation. The medical profession maintains a very powerful position within the educational discourse as far as these children are concerned.

Diagnosis and access to educational resources

Diagnosis, while only being one factor used to determine a child's eligibility for classroom assistance, appears to be the key factor. A number of the mothers found that unless their children were diagnosed with categorically defined medical problems, they could not receive any additional classroom assistance for their child. A teacher, for example, suggested to Kimberley that she have her son diagnosed so the school could get additional teacher aid time for him. Without a diagnosis Carl would receive no extra help in the classroom (Kimberley, p. 10, 36-38). The power associated with the diagnosis and associated label enabled a child to potentially access classroom assistance. Maggie found that once her son was diagnosed with ADHD, he was given extra support in the classroom:

> What does the school do? Last year they had a lady come in and work in the classroom, it was two to three days a week, and she took Peter and a couple of other kids who had learning problems out and they basically

> played games and it just helped them learn some of the stuff they had to learn, even though the other kids in the class learned it very quickly, well they would play games and that sort of stuff, just to really….(Maggie, p. 8, 18-26).

It was not until Melanie's daughter was diagnosed that she received additional classroom support. Before diagnosis, Melanie commented:

| Jane | So she spent a whole year at that new school… |
| Melanie | A whole year and didn't improve…and didn't receive any help because they didn't know how to help her, she wouldn't listen…and we still didn't know it was Attention Deficit Disorder…(Melanie, p. 4, 8-10). |

Since her daughter had been diagnosed with Attention Deficit Disorder, Melanie had been able to apply for government money in the form of Youth Assistance and the school has attempted to provide some teacher aid support, although being a small private school it has been unable to afford much and Melanie still felt that adequate educational support for her daughter was lacking. Nerida found that she was able to access far more support from the educational system. Her son's behaviour was so unmanageable at times that the Education Department suggested that they run an individual education program for him and this was instigated through the School of Distance Education (Nerida, p. 8, 33-37). John's problem behaviour was removed from the classroom, and he was (unsuccessfully) schooled at home.

Not all parents and their children, however, were so successful in obtaining support for their children in school. The complexity of the application process for educational assistance in Queensland, referred to as '*Ascertainment*' often discourages parents from completing the document. The process is further complicated by the inclusion of strict medical criteria that children must fulfil.

Diagnosis and 'ascertainment'

Diagnosis is an important part of the educational procedure of *Ascertainment* in the Queensland education program. Until January 2005, ascertainment was the process used by schools to recommend the level of specialist educational support needed by students with disabilities. The process consisted of classifying students with disabilities who needed specialist educational support, identifying the level of support required and appropriate educational programmes which could support this need (Murphy & Haughton, 2004). A student who had an ascertained Level 5 or 6 disability received an allocated amount of extra Teacher Aide hours per week (Diocesan Education Services, 2004). The process for gaining ascertainment was

complex and required information to be gathered from parents, specialists, teachers and Education Queensland representatives. Unfortunately this process was extensive and paper intensive, and many parents gave up, as Mary explained:

> ….in order to be ascertained, you <u>must have</u> a paediatric assessment, a GP's letter is useless, you must have all the paper work , and you must answer a hundred and one absolutely ridiculous questions….you know…that you can't answer…like "describe his dreams"….well..I don't know…..you know…it's bizarre…that was one of them (Mary, p. 15, 1-7).

The ascertainment process was certainly complex, as identified by the Education Queensland *Ascertainment Policy and Revised Procedures Manual* (Education Queensland, 2002a). The process involved a Principal Education Officer, a case manager, support teachers, therapists, medical specialists, a state-wide representative, managers of specialist staff, and parents. If the child was considered to require a high level of additional specialist support, an Education Services Manager was also involved in the ascertainment process. 'Data' about the child's condition was mostly required from medical specialists, although speech pathology, and psychology reports were included in some instances. Comprehensive forms requiring specific information and a definitive diagnosis, were sent for completion. To ensure that the child's case was legitimate, this 'data' was then compared against Education Queensland's specific disability criteria. According to the *Ascertainment Policy and Revised Procedures Manual* (Education Queensland, 2002a) this criteria was based on the *DSM-IV Text Revision (TR) 2000* (American Psychiatric Association, 2000) definitions of Pervasive Developmental Disorders, and impairments of intellect. Interestingly, while requiring medical specialists to assess a child and complete a form that required a Yes/No answer about the presence of a child's diagnosis, the Education Department employee was further required to verify the report against the *DSM-IV TR* criteria to make sure that this diagnosis 'met with Education Queensland criteria' (Education Queensland, 2002a, p.13).

For the parents, the process was complex and bewildering and one from which many withdrew. One wonders whether such a multifarious and time consuming process sits well with the Education Queensland Code of Conduct (Education Queensland, 2002b) which advocates that the central feature of their work is to attain optimum learning outcomes for their students.

From a critical Marxist interpretation, there is evidence here to suggest that mothers struggle to access resources and assistance for their children because the government and the medical profession collude to protect the power and status of medicine. In return, medicine protects the government from having to provide the help that teachers, mothers and their children need. Even if mothers and teachers successfully complete the complex paperwork, children may still be considered ineligible for classroom assistance unless a medical specialist confirms a particular *DSM-IV* diagnosis. The systematised, complexity of the process is constructed for the benefit of those in power rather than there to provide help. The state government departments, and in particular, the school system, use diagnostic categories to ration finite resources (Ray, 2003). As Mary said: '…the system mitigates against us all the time..it does' (Mary, p. 19, 29-30), making it difficult for parents to gain assistance for their child.

By adopting the *DSM-IV TR* as a diagnostic tool, against which a child's development is measured and compared, Education Queensland overlooks the fact that the *DSM* was produced with the primary purpose of assisting research in the area of mental illness, rather than for the purpose of diagnosis (Warelow & Holmes, 1999). Furthermore, the *DSM-IV* has been criticised for neglecting a patient's own accounts of their situation (Tucker, 1998), and the social and cultural context in which experiences occur (Crowe, 2000), concentrating instead on ascertaining the symptoms associated with particular illnesses that demarcate a person as mentally disordered (Tucker, 1998). An introductory statement in the *DSM-IV* appears to support this criticism, warning that 'a DSM-IV diagnosis by itself should in no way constitute the full spectrum of knowledge' (Pincus & McQueen, 2002, p. 9). In addition, Warelow and Holmes (1999) argue that the *DSM-IV:*

> Creates new 'catch all' categories, and effectively dissolves the distinctions between mentally ill and the mentally healthy, thereby serving as a medium for psychiatric expansion (p. 168).

Warelow and Holmes go on to warn of the *DSM-IV's* latent potential as a licence for unbridled classification and categorisation of many more people as mentally disordered, particularly in behaviour that was once considered 'healthy' and 'normal' (p. 168). By adopting the *DSM-IV TR* as a diagnostic tool for identifying children who need additional educational assistance, the psychiatric discourse extends its legitimate authority of social control over a group of individuals once considered 'normal'.

By utilising the *DSM-IV TR* as the definitive tool for categorising children, the educational domain fails to acknowledge that there are other reasons for a child's need of educational assistance. Children may need additional educational support as a result of missed opportunities, cultural barriers, or the presence of subtle developmental problems that affect learning readiness. In addition, requiring that the medical specialist tick a Yes/No box that asks whether a child has a specific developmental problem, binds both the educational sector and the medical authority to a reductionist-style assessment of a child's capabilities. If the specialist ticks 'No' then children, who may have other disabling circumstances such as social or cultural limitations which impact on their emotional and/or academic achievement at school, are excluded from educational assistance. No wonder Skellern (2004; Skellern, Schulter, & McDowell, 2005) and Rafalovich (2005) found that medical practitioners use their clinical discretion, treating the *DSM-IV* simply as a diagnostic umbrella rather than as a categorical imperative, when diagnosing a child's problem. By ticking 'Yes', Skellern suggests that the doctors attempt to protect the children from the harm that may result from the lack of educational intervention. Medical specialists are aware of the constraints under which they operate when acting on behalf of government systems, and being members of the powerful medical profession, doctors represent some of the few individuals who can chose not to collude with governmental control. If doctors are so concerned, however, about the categorisation of learning and behavioural problems as mental disorders for educational purposes, this act of defiance is meaningless. Children are still categorically labelled, doctor's still maintain control over diagnosis and access to resources, and functional disabilities are overlooked as primary indicators of a child's educational problem.

Focusing on diagnostic imperatives rather than functional problems is likely to create a problem for children, such as those in this study, as research has shown that children with developmental difficulties usually have different clusters of problems, which create a range of varying disabilities (Bellis, 2002). For example, the child with ADHD may or may not have learning difficulties, may be good at mathematics, but poor at English, may or may not be able to socialise with classmates, may or may not be able to participate in sporting activities, and may or may not have poor balance. Focusing on the diagnosis, rather than the resultant disabilities means that many children do not receive adequate support or intervention for the resulting functional problems. Crowe (2000) warns that by rigidly adopting the psychiatric

mental health criteria, educators not only limit themselves to a role dependent on medical endorsement, but they also fail to explore other possibilities for those whom they teach. This is particularly important counsel for those responsible for the education of these children as they are more than likely to have a highly varied range of functional problems that require a highly varied set of interventions (Bellis, 2002).

In January 2005, Education Queensland replaced the process of ascertainment with the '*Educational Adjustment Program' (EAP)* (Education Queensland, 2005b). The new process remains time consuming and extensive, although medical input is slightly reduced, as children are not required to have their medical diagnosis revalidated every two years. Nevertheless, a medical diagnosis still remains the most essential component of the assessment (Education Queensland, 2005e). This is in stark contrast to new assessment procedures in place in other Australian states where functional assessments have replaced the need for a medical diagnosis (Skellern, McDowell, & Schulter, 2005). The EAP process continues to exclude all but the most high need students, with many students who have learning or behavioural related difficulties still disqualified from government funding. Even if a child is assessed by the learning support teacher as requiring extensive learning intervention, without a medical diagnosis that places the child within a specific *DSM IV* category, these children and their schools receive no additional governmental support (personal communication, K. Metcalfe-Smith, learning support teacher, Townsville Grammar School, September 2005). Metcalfe-Smith noted that of the 55 children whom she had assessed as requiring considerable learning support, only 6 children were 'ascertained or EAP'd' and considered eligible for assistance in the classroom. Children who are considered to have special needs by their parents or teachers are disadvantaged by not having a label that distinguishes them clearly from 'normal' students. 'In a climate of resource constraints, distance from the norm has become valued' (Allan, 1996). The replacement EAP process in Queensland Education continues to exclude most children from additional classroom assistance.

There is little doubt that by adopting the strict medically based diagnostic criteria, rather than functional assessment, which measures a child's actual ability, the government limits how many children are eligible for resources and saves considerably on financial expenditure. Furthermore, the medical system continues to encroach into both the social and educational lifeworld of the children and their

families as diagnosis becomes the tool by which educational difficulties are measured and resource allocation is determined.

Foucault would agree with the Marxist view that diagnosis can be interpreted as a form of medical control whereby an individual's access to services is permissible on the strength of a diagnosis. Some Foucauldian sociologists would argue that by defining who is sick, and who is not, the medical discourse regulates and controls the health of people and their access to resources, placing them in a subordinate position from which it is difficult to extricate themselves (Lupton, 1997). Lupton (1997), however, argues that Foucault did not specify that medical professionals deliberately set out to control others, rather the medical discourse is hegemonically adopted by lay people in their search to improve their health status, and in this way power increases as a result of collusive action.

A Foucauldian reading

Foucauldian overview

Through the lens of Foucauldian post-structural theory, diagnosis can be viewed as a form of classification that acts as a powerful agent of social control. Diagnosis can be seen as a way of controlling dangerous bodies and minds that would otherwise threaten social order. Through the process of diagnosis, individuals are characterised, classified and placed in hierarchies in relation to one another through the process of observation and surveillance (Foucault, 1977). Labelling and categorising a person according to his or her symptoms, creates both social and moral order, as responsibilities are shifted from one group to another (Williams, 2003). Those who are considered 'deviant' are placed under the control of a socially legitimated profession that maintains a program of surveillance, correction, regulation and control for the 'good' of society. Diagnosis is a system for disciplining the mind and body, and so-called treatments are an effort to control so called 'dangerous and subversive behaviours'. Health professionals, in particular, act as agents of social control, as they are often those who instigate and promulgate the need for diagnosis, although individuals, institutional bodies and communities also engage in self-surveillance, adopting and replicating the discursive practices of the controlling discourse.

The following discussion focuses on how mothers' hegemonically adopted the dominant medical discourse's emphasis on diagnosis, engaging in a form of self-

surveillance whereby they actively adopted the diagnosis given to their children. Even though mothers sought acknowledgement of their concerns for their child prior to school age, a diagnosis became particularly important once the child was interacting with other children, parents and teachers. Mothers saw diagnosis as the route to accessing both health and educational services, although in the child's pre-school years children were unlikely to be diagnosed with a particular problem.

Competing discursive constructions of diagnosis and labelling

When seeking acknowledgment of their child's problem, mothers were often faced with contradictory practices, finding that the discursive rules and practices that surround behavioural problems and learning problems are rife with conflicting messages. On one hand, certain rules within the medical and psychological discourses advocate the identification and labelling of children who sit outside standardised norms, while other, more recently defined rules and practices point towards the deleterious effects of labelling (Hacking, 1999). The impact of these competing discourses directly affected the experiences one mother had when she took her child along to see a health professional. Kimberley took her son to a paediatrician when her son was three years of age. The specialist was prepared to treat Carl with medication, but did not want to apply a label to his behavioural problem:

Jane	He saw you for three months, but he wouldn't put a diagnosis on Carl?
Kimberley	Not really, because of his age.
Jane	He said it was too early to tell if anything was… ?
Kimberley	Yep. .but he wanted to medicate him anyway.. (Kimberley, p. 5, 49-50; 6, 1-5)

By engaging in the discourse on the negative effects of labelling some medical practitioners actively avoided diagnosing and labelling children with a medical problem. This is particularly apparent in the pre-school years when the application of a label may have been deemed to have long-term implications for that child's social, academic and emotional future. By delaying diagnosis until school however, dominant discourses collude to limit pre-school diagnosis because this limits the amount of resources that need to be provided and leaves mothers to absorb the disorder caused by the child, in her own home. Children are excluded from the intervention services that may help to ameliorate their problems.

Social control requirements increase as the breadth of a child's social world increases and the disorder s/he causes becomes more of a threat to social systems,

and as a result, once a child attends school health professionals are not so reticent to label a child with a particular diagnosis. This is particularly so if the child is referred by school teachers who are concerned about a child's ability to control their behaviour in the social environment of the classroom, or unable to cope with the academic demands. Maggie, whose son, Peter, was referred to a paediatrician by his first year school teacher, revealed how he was diagnosed with a behavioural disorder on his first visit to a medical specialist:

> When the paediatrician told me he had ADHD, I laughed….I thought, OK, she's just putting him in a category… (Maggie, p. 7, 1-2).

Maggie's comment that the term ADHD is just a 'category', reveals that she is aware of the categorising behaviour associated with the medical discourse. By laughing at the diagnosis she exposed her scepticism about the use of the term to categorise her son's behaviour. Maggie's doctor, however, suggested that she read a book that used non-medical language to explain ADHD. In this way, the doctor justified the use of this diagnostic term in relation to Maggie's son's behaviour and placed Maggie under pressure to treat her son's condition:

> ….and she suggested that I…..that book by Dr Christopher Green…the ADHD book….so I went out and actually bought that copy and after reading it I could of sworn that Dr Christopher Green had written basically about Peter…..(Maggie, p. 7, 3-7).

By referring children to medical practitioners for a diagnosis, the educational discourse promotes and supports the role that medical diagnosis and treatment plays in the classroom. Maggie's doctor recommended treatment with Ritalin® and Maggie agreed, and while she did not refer to her son's teacher's response to the diagnosis and treatment she notes his improved well-being by commenting on his academic ability:

> I am so glad that I have, because it's helped him amazingly…he's learning now….yep…because in grade one he sat on level one reader right through until he got diagnosed….and then after he was diagnosed and first went on medication, he went up two levels pretty much within a couple of weeks….(Maggie, p. 7, 49-52; p. 8, 1-3).

Competing arguments about the likely causes and treatments of learning and behaviour problems have exacerbated the problem of where they fit 'in the scheme of things'. Learning and behaviour problems have moved variously between theology; where they were considered to be suffering from Divine visitation, then punished for the sins of their father; medicine; where genetics, biochemistry and neurobiology are thought to be the causes; sociology; where children are seen as the victims of poverty, the environment and discrimination; and psychology; where they have a learned deficit which can be corrected. This is particularly significant, as

many children with learning difficulties require long-term intervention, yet conflicting viewpoints create confusion about the best course of action. While the disability advocacy movement has played an influential role in attempting to move learning difficulties out of the medical arena, advocating that people with disability are not 'sick', medical validation is still a primary consideration in the educational assessment process (Barnes, Mercer, & Shakespeare, 1999).

Diagnosis and disability

Much of the discussion surrounding the social construction of diagnosis focuses on the concept of disability. In his overview of disability studies, Shakespeare (2005) notes the effect that academic studies in disability studies have played in the development of changing social models of disability and flow-on affect into political policies that acknowledge the rights of those who have disabilities. It is implied that disability is no longer a word that comes attached with past meanings whereby those who had disabilities were seen as having an illness that made them different from other members of society, and were likely to 'suffer' long-term problems. Yet, if the word *disability* is no longer imbued with negative meaning, then it is surprising that not one mother in this study referred to her child as disabled.

In the mothers' narratives, mothers' never refer to their children as having a *disability*, nor is there any indication in their stories that doctors referred to children as disabled. In contrast, throughout their narrative, mothers freely used the diagnostic term given to their child. This is really interesting, as a medical diagnosis implies a biological cause for their child's problem, but, it does not necessarily lead to a particular path of intervention or treatment, especially for a diagnosis of ADHD/ADD, conduct disorder, Asperger's Syndrome and other behaviourally based disorders. Rather than focussing on the disability that arises as a result of the child's mental health problem, or physiological cause in the case of John, mothers, doctors and educational policy all focus on the probable cause. Categorically identifying a problem implies that the problem has a specific cause, effect and treatment. Disability, on the other hand, comes imbued with the meaning that the child has a long-term problem that is unlikely to be solved. Shakespeare (2005) points to similar research findings which found that people were often unwilling to be identified as disabled, concluding that the changing social models of disability had not impacted on the dominant values of society. Sanderson (2001) argues that moving mental health disorders into the general model of disability, would be beneficial for those

normally labelled with mental illnesses. While this would improve focus on functional outcomes, and reduce the focus on psychiatric-specific treatments, reluctance by mothers' to refer to their children as disabled limits this argument. Until there is a change to the social meanings of disability, backgrounded by the myth of the long-term hopelessness of being disabled, disability theory and policy, and the good intentions that accompany them will have little impact.

In direct contrast to the mothers' avoidance of the term 'disability', educational discourse adopts it as the descriptor for children who are identified as requiring additional classroom support. The Education Queensland ascertainment document (Education Queensland, 2002a) directly refers to 'students with disabilities' (p.1). In direct contrast, however, to the suggestion by Sanderson that the adoption of a disability model will train focus on functional problems and outcomes rather than medically based treatments, the ascertainment procedure demands a medical diagnosis for access to support services, even though the diagnosis may not accurately reflect the functional needs of the child.

Diagnosis and the educational discourse
It could be argued from a Foucauldian perspective that the educational discourse adopts medical diagnosis as a control mechanism, regulating the population of children who pass through its doorways. Because the medical discourse is accepted by the majority of the population as rendering the 'truth' in regard to health and well-being, it is adopted by the institution of education as an unquestionable provision in determining who warrants educational assistance. Educational institutions have increasingly adopted this form of control in an effort to monitor and manage school populations so that they are able to produce competent children. Tyler (1997) suggests that elements that go to make up definitions of a 'competent child' are not contingent upon competence, but rather are a reflection of institutional objectives. Teachers are required to operate a classroom in which children are expected to achieve certain learning and behavioural objectives. When a child arrives in school and cannot perform according to institutional requirements, teachers use their power to find a way of reducing classroom disorder, or improving a child's learning outcomes. Diagnosis and treatment by a doctor is a socially legitimate form of control. By adopting discursive rules and practices of medicine, educational institutions can justify resource allocation and the incorporation of their own discursive rules required to manage and control these children. While the medical

diagnosis may not necessarily reveal the 'inner workings of a child's mind' (Tyler, 1997, p. 91), which would normally be important for understanding how and why children attain educational competence, Tyler notes that the adoption of medical diagnosis is about 'techniques of governing child populations' (p. 91).

Surveillance of pupils who are identified as those who have special needs enables professionals to show concern for the children's welfare, yet it also 'constructs them as objects of power and knowledge' (Allan, 1996, p. 222). Diagnosis and the accompanying label 'imposes a principle of compulsory visibility' (Allan, 1996, p. 223) whereby the child is objectified, categorised and compared against others. Educational interventions are then put into place in an attempt to correct the deviations from the norm. Surveillance is on going as the child's needs are regularly reassessed and modified accordingly.

Yet, while the educational discourse adopted the medical model of diagnosis, the mothers' transcripts reveal that other social discourses were not so supportive of a medical interpretation of a child's behaviour, and rejected diagnosis and treatment as being inappropriate. Maggie found that other parents' attitudes did not reflect those of her doctor or teacher, not approving of the use of the label 'ADHD' or the use of medication:

> It met a lot of resistance for other people….yeh….people used to…like, they knew that I'd been sent off to a paediatrician and that sort of stuff, and some mum's would come up and say "well, what happened?", you know and I'd say…well, we've found out the Peter has ADHD…" and it's like "ahh"…and it's just the facial reactions and the way people reacted, and when you talk to some people about it, when I explain that I had decided to medicate him, I then felt that I had to back up my reasons….because people were saying "oh well, that's really strong medication…and.." yeh…so that was hard….(Maggie, p. 7, 35-46).

Diagnosis and resistance

Not all members of society were readily willing to accept a medical diagnosis and subsequent treatment as the appropriate course of action. Maggie found herself caught between the competing discourses surrounding diagnosis and labelling, especially in early childhood development, a reflection of the resistance to certain forms of medical intrusion into the social discourse. The medical professional, in this instance, advocated a particular diagnosis and treatment, and members of the community rejected it as inappropriate, and even 'dangerous'. Foucault (1982) identifies that individuals who live in the free world and 'who are faced with a field of

possibilities' (p. 790) will respond in different ways, because they are free to question and contest power.

The field of possibilities can be seen operating in the discourse surrounding categorisation of ADHD and the use of Ritalin®. Over the past twenty years, the discussions about ADHD and Ritalin® have taken a number of paths. These discussions have been played out in the public arena, particularly in the media, and many parents are aware of the ongoing contradictions and conflicts about the use of Ritalin® within the medical discourse. Schmitz, Filipone and Edelman (2003) draw attention to the role the media has played in the consolidation of the categorisation of ADHD, from 1988-1997, as a mental health problem that needs medical treatment. Schmitz et al. (2003) argue that media representations often produce conflicting social representations of the problem, drawing on different interpretations and explanations from a variety of different sources. In this way, parents are exposed to a range of explanations about what ADHD is, what causes ADHD and how ADHD is best treated. Initially hailed as a safe and successful way of helping children concentrate in the classroom (Serfontein, 1990), Ritalin® was presented as 'the answer' to behavioural problems and concentration difficulties in the classroom. However, in the mid to late 1990's, questions were being raised about long-term side-effects, the effectiveness of the drug when used in isolation from other behavioural and social interventions and the growing number of young children (particularly boys) who have been prescribed the medication (Gliksman, 2000; Zito et al., 2000). As a result, community perceptions of Ritalin® do not always match those of treating practitioners.

Most recently however, the media emphasis is firmly focused on the brain imaging technology and the suggestion that ADHD is a physical illness, which can be successfully treated with the use of stimulant drugs. With the assistance of the media, the medical discourse consolidates its control over the treatment of ADHD. Parents, however, are still influenced by the differing social representations of ADHD, and so health professionals and parents may hold contradictory understandings about causal foundations for the way a child behaves and the suitability of different treatment options.

While Foucault would suggest that these conflicts bring change to discursive practices within a discourse, it can be seen here that they also create anxiety and

conflict for those people who are not part of the changing dialogue, but who are torn between contradictory statements. Justine, while deciding not to go ahead and give her son Ritalin® still, 4 years later, feels that she may have made the wrong choice:

> ok...this is where I feel a bit bad, because maybe I should of even just tried it …I was scared of side effects, the lack…of the amount of time kids have been on them as opposed to what they come out you know like…does it fix them? And I didn't think that it did…does it rot their teeth? Because I know speed (the street drug) people have rotten teeth and manky skin…you know…and what it might do to his heart…you know…I didn't know, you know…I didn't know what these drugs do…so I was scared. (Justine, p. 12, 18-28).

I understand how Justine felt. As a mother of a child with learning and attention difficulties I also had the opportunity to give my son Ritalin®. In fact, the medical doctor told me that if I did not give my son the medication he would 'end up sweeping the streets'. I refused. This was in the mid 1990s when newspaper reports and magazine articles highlighted the growing concerns in regard to the potential side effects of Ritalin® (Schmitz et al., 2003). Ten years later I felt guilty that I had made the wrong choice and had missed an opportunity to help my son achieve more successfully at school. At the age of 21, and having difficulty finding a job, I actually suggested to him that he try Ritalin®. His paediatrician agreed to prescribe the drug. The Ritalin® helped him to focus more clearly on specific tasks but also gave him coloured nightmares, increased anxiety and incessant insomnia. He stopped using the drug after 4 weeks. My initial reluctance, as was Justine's, was based on fear, a fear that was supported by conflicting discursive statements about the ADD diagnosis and associated drug treatment. As mothers, we were caught up in competing discourses and competing discursive statements within discourses. On one hand the drugs were advocated as 'miracle' cures for children with attention problems, on the other hand they were being vilified for their potential dangers. Our reluctance to accept particular labels and treatments for our children, and then the associated guilt, reflect the confusion created by contradictory statements, all seemingly coming from those whom we, as mothers, recognised as 'the experts'.

Mothers are caught up in the changing discourse on early childhood development and the changing expectations of how children behave socially and achieve academically. Over the past fifty years, medical and psychological discourses have promoted 'norms' of child development through discursive rules and practices that are endorsed by a wide range of health professionals. These rules and practices have become embedded in a complex matrix of institutions (Ho, 2004), including the practices of motherhood and the education system. Health professionals generally

support the use of diagnoses in their practice, to 'give a sense of legitimacy, confidence and predictability' both to themselves and to their patients (Gergen, 1996, p.4). Educationalists also adopt medical diagnosis as a way of legitimating management and control of children who do not reflect the 'competent child'. Some mothers seemed to be 'wanting' to have their child diagnosed in order to establish this same sense of legitimacy, but this 'wanting' is not a personal matter, it is a reflection of the socially constructed discourse that influences the thoughts and actions of mothers in our society today.

Diagnosis: A way of gaining control or a form of self-surveillance?

In stark contrast to the argument that diagnosis is a powerful control mechanism that is used by powerful groups to maintain control over others, most of the mothers felt that they were in a more powerful position once their children were diagnosed with a medical problem. For mothers, diagnosis legitimised their concerns and gave them the opportunity to 'take control'. Once diagnosed, mothers formulated their actions, expectations and experiences around the diagnosis, revealing how medicine becomes important in 'fabricating the individual experience and identity' (Armstrong, 1997, p. 22).

It can be argued that the dominance of the biomedical discourse consumes and obscures other approaches to health care. This very potent discourse colours how society interprets children's development and behaviour and, as a result limits the choices that mothers can make in regard to 'getting help' for their children. In today's society, however, the hegemonic adoption of this model of health means that a medical diagnosis provided one of the few socially acceptable platforms from which mothers could 'take control' of their child's health and education.

From the transcripts, it can be seen how a diagnosis sometimes placed the mothers in a more powerful position within the educational discourse, they knew more about their child's problem than the teaching staff. Once Alana's daughter, Betsy, had been diagnosed with dysgraphia, Alana was able to learn about Betsy's learning problem, but when Betsy returned to school:

> …it was kind of met with a bit of a blank misunderstanding, not really knowing what it was (Alana, p. 8, 5-6)

However, Alana was able to educate the teachers about the disorder, and as a result, Betsy has a 'better' time at school.

….so we ended up getting some of her files down and the test results that the psychologist had done and gave them to the teacher to read through...and I think then the level of understanding was raised, so yeh, I think she's probably been given a bit of grace I suppose, because of it… (Alana, p. 8, 6-10).

Since her son had been diagnosed with ADHD, Maggie had sourced a lot of information from her contact with the ADHD support group and found that these diagnosis specific resources much more useful and successful than books written for general parenting skills.

Maggie I have been to a couple of parenting courses years ago, one was through life line, I think it was called the step program…that worked really great with the other three boys, but not with him…yeh, nothing worked….yeh, so, it's just…I've got books over there….I should be an expert…you know, "How to raise your sons"…you know, Steve Bidduluph's books….Dr Green's books, I've got them all….(laughs) and I just read them constantly, you know, it's just amazing….

Jane Do you find them helpful?

Maggie Yeh, basically, with the other boys yeh,

Jane But they haven't helped with Peter?

Maggie No, not with Peter… through the ADHD support group, a lot of people have donated books and I've got hold of some good books through there that have a different way of….because I was always trying to tell Peter off, and he wouldn't listen and I felt like I had to stand over him…because it didn't seem to work…and one of the books I read suggested that you just speak to them in an everyday matter of fact voice, like you don't really care, and you just love them and you let them know that you love them and that seems to be the best way…(Maggie, p. 9, 12-35).

Rebecca remarked on just how much she had been able to learn about her child's problems since his diagnosis:

Rebecca I must say though, when my eldest one went to school, started off grade one, he had a boy start in his class and his mum used to talk about ADD and ADHD and blah, blah, blah, blah…and I used to say "oh, yes, yes, yes", pretending I knew all about it, and knew nothing, I didn't even know what she was talking about..and used to wonder what the heck is she going on about?..[ ] ..and I used to think there was something wrong with her…..(laughs)….and then the table turned…(Rebecca, p. 6, 29-35, 40-42).

Rebecca Like I said I have done a lot of research…that purple folder over there (*points to sideboard on which sits a large folder of assorted documents and writings*) and that's just David…[ ]

Jane So what this tells me is that all the research you've done and all the reading you've done that the diagnosis was so important to you to have a diagnosis for David, so you knew what to do…

Rebecca Yes, and I have actually, when I started reading this book (*referring to a book written by a young man who has ADHD*), I have an exercise book and I've written about ½ an exercise book on David….just things as they've come to mind, or things that have happened to David. right through from grade one…things that I can remember happening and things like that I have written down in this book…(Rebecca, p. 8. 44-46, p. 9, 28-36).

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Journaling her experiences also gave Rebecca a way of gaining a perspective on the situation and retaking control when she thought her son needed further support at school:

> I found that I was losing perspective on what to do…how to deal with the situation…then, when I read your letter in the paper and I was talking to mum, I got my book out, my book on David out…and I thought, I read something in there that um…it was something that I read…and I thought, why didn't I do this last year…[ ] yes...but see, I had forgotten about it, and just because I'd written it in this book and I reread it, because I'd written it down, it reminded me I need to do that, I need to tell the teacher that.. (Rebecca, p. 10, 7-15, 30-33).

Like Rebecca, Mary also kept a journal of her and her son's journey. She had two enormous folders full of carefully sorted letters and assessment results and she told me that she had written a comprehensive document detailing her experiences and feelings. From a Foucauldian perspective this research and journaling could be interpreted as a form of self-surveillance, where mothers control both themselves and their children by self-examination and self-regulation. Journaling is a method whereby mothers search for ways to improve and understand themselves and their children while they attempt to move closer to achieving the label of normal (Rose, 1990).

Foucault suggests that surveillance of oneself and self-imposed control is concerned with the controlling of populations by dominant discourses to conform to socially constructed belief and value systems. While Foucault observed the phenomena of self-surveillance, he made no judgement on whether it is repressive or productive for the individual (Lupton, 1997). Gramsci (Abercrombie et al., 1980), however, would argue that by engaging in self-surveillance, mothers are colluding in their own oppression through hegemony. As a result of the findings of this study, I would argue that mothers cannot easily extricate themselves from socially constructed beliefs that are dominated by the medical discourse. The medical discourse governs the values and beliefs within the social, educational and political domains with which the mothers must interact. Even when individual medical practitioners, teachers or lay members of the community do not agree with the discursive practices and rules of the medical discourse, it continues to dominate. It could be argued that mothers are blackmailed into accepting the medical approach, however, if mothers do not adopt it they are unable to gain the necessary support for their child's education, nor move towards helping their child 'fit' in with the demands of modern society. By adopting the discursive practices and rules of the medical discourse, mothers, like

large educational or political institutions, are able to legitimate, justify and validate their own approaches to assisting their children. Without the backing of the medical discourse, most children would not be able to access additional support services that would assist them to achieve academically or socially. In this way, the very nature of medical power is shared by mothers and becomes productive rather than repressive (Lupton, 1997).

Once the mothers understood their child's problems, they felt more confident advocating for their children (Mary, Nerida, Rebecca) and ensuring that assistance programmes were set in place for their child (Mary). Mary is involved in the education system and has not only advocated for her own son, but also for other children:

> …and I suppose the good thing about it, if there is a good thing to this….it has made …I am a great advocate for children with disabilities in my school and I fight tooth and nail, and when people say "oh, but so and so…" and I say…"no, sorry…." and I bombard my teaching staff with literature until it's coming out there ears…(Mary, p. 19, 37-44).

Taking back control became a major priority for the mothers. Diagnosis provided them with this opportunity. Rather than resisting the powerful medical discourse, mothers embraced the opportunity that it gave them to acknowledge that their children were different and needed additional support and assistance. Diagnosis enabled mothers to resist the powerful misconceptions (based on myth) of society that labelled them as 'bad mothers' because their children behaved differently from the 'accepted norms'. While the 'norms' that drive these misconceptions are those enunciated by the medical discourse, the very same discourse provided mothers with an opportunity to develop powerful positions of their own.

The stories all highlight how mothers, once their children are diagnosed with a medical problem, developed strategies that allowed them to come to terms with their child's problems, and put in place personal, social, academic and behavioural strategies for both themselves and their children. Mothers no longer blamed themselves for their children's problems and actively advocated for their children's educational and social needs. Mary, Alana, Rebecca and Melanie all kept in regular contact with the schoolteachers, while Maggie and Nerida had strict behavioural protocols for their sons to follow in their homes. Kimberley took her son along to Child Mental Health services for (reasonably) regular appointments and was seeking out support services for herself, and Justine engaged with her son in learning and behavioural-based activities in the home.

While it could be argued that the child's diagnosis gave mothers a sense of autonomy and power, I would also suggest that diagnosis released the self-imposed perception of blame and freed mothers to pursue new strategies. No longer were mothers controlled by the restrictions of a society that they perceived had accused them of failing to fulfil their roles as 'good mothers', rather, they could actively pursue information that would help them to further validate their role as responsible and caring mothers. Giddens (1984) would suggest that such perceptions of autonomy are misguided because agency is always associated with structure, a mother's autonomy will therefore continue to be influenced by existing institutional and societal structures. Structures control 'how decisions are made, by whom and for what purpose' (Hardcastle, 2004, p. 84-85). While Giddens (1984) does suggest that 'agents' have the capacity to act freely and are knowledgeable about social institutions, when they do act, they 'produce (create) and reproduce (recreate and maintain) the structures through their actions' (Hardcastle, 2004, p. 83). Mothers, while seemingly freed from the restriction of 'blame' and able to actively seek out information are not only restricted by structures that limit their access to knowledge and resources, they also replicate and maintain the very structures that they feel have obstructed access to assistance and support, and that they seek to dismantle. Everingham (1994) however, claims that it 'is mothers who are the creators of cultural meanings and human values systems' (p. 7) and so they act as active rational beings rather than simply responsive, irrational 'others' (Kent, 2000). Mothers are able to shed the burden of guilt and shift their responsibility from 'the perceived failure to satisfactorily support and protect their children' (Roe & Morris, 2004, p. 1), to a responsibility that is positively placed to address the needs of their children.

Chapter summary

Semiotic reading

From a semiotic perspective, 'diagnosis' comes attached with a complex array of social and political meanings. Diagnosis is not simply the act of attaching a medical label, nor is it a basic classification task. Diagnosis is closely associated with 'illness' and the social meanings attached to it. For mothers, diagnosis signified that their child had a legitimate illness that required special treatment, and that neither the child nor the mother could be held responsible for the illness. The children, however, were not considered 'sick', but rather, as having a 'healthy illness' that placed them 'at risk' of social and educational problems, and for these reasons mothers

anticipated that their children were eligible for support and assistance. Importantly for mothers, diagnosis also represented a way of validating their concerns. Diagnosis effectively relieved mothers of feelings of blame, as mothers replaced personal fault with a medically justifiable cause.

Diagnosis also comes closely linked to the human desire of hope, which in turn forms the basis of the search for the miracle cure. Health professionals hope that they can offer their patients a treatment that will cure them of their ills while the mothers hoped that diagnosis would enable their child to receive treatment that would cure their problem. Mothers also felt that diagnosis would lead to easier access to support services in the community and that educational services would provide intervention and support programs for their children. While some of the mothers in this study received support, others were less successful; this is because diagnosis does not come attached with the same meanings for all people. Some community members, teachers and health professionals still considered mothers the cause of their child's condition and were reluctant to acknowledge that the child needed support or assistance.

Marxist reading

A Marxist interpretation of the mothers' stories has drawn attention to a number of important issues:

- The infiltration of the medical system into the life world is reflected by the welcoming adoption of diagnosis by the mothers. While Goffman and Becker argue that labels negatively affect how others see labelled individuals and how those individuals see themselves, mothers are subverted by the colonising medical system into believing that a diagnosis will lead to support and assistance for their children.
- In society today, diagnosis is widely accepted as the legitimate proof of illness. Without a diagnosis and the accompanying label, access to formal support, and even informal sympathy, is restricted.
- Adoption of a medical diagnosis as the basis for educational assistance, the management of children with behavioural and learning difficulties has moved out of the lifeworld of the home and educational environments into the domain of medicine. This is exemplified by the increasing numbers of children are being diagnosed with, and treated for, neurodevelopmental disorders. In this way, medical diagnosis becomes the main route to

identifying a child's difficulties and determining the provision of intervention services.

- Diagnosis reinforces the powerful position of the medical profession in the area of early childhood development, particularly when adopted by education institutions as the main means by which children's levels of competency are identified and categorised.

- In a bid to legitimate and rationalise its allocation of resources, Education Queensland has adopted an approach that utilises medical diagnoses to categorise learning and behavioural problems in the classroom. Educational ascertainment, or EAP, is the process through which children justify claims for additional classroom support. The complex process often excludes children whose mothers cannot fathom the intricacies of the paperwork, reducing potential claims thereby reducing costs to the government.

- Reliance on the *DSM IV* criteria as a basis of judgment and categorisation, means that the ascertainment process is unresponsive to a child's wider needs and circumstances. A child's categorical diagnosis excludes functional needs, and favours children who have profound physical and intellectual disabilities. Adoption of the medical model does not favour the child; rather it serves the interest of the government by restricting eligibility to access resources, and increases the power of the medical domain into areas not traditionally associated with health care.

Foucauldian reading

Foucault (1977), would suggest that medical surveillance represents a form of disciplinary technique, whereby mothers and children are controlled by more powerful institutions. Increasing social control becomes particularly apparent when the children commence school and widen their social contact. However, while diagnosis was utilised to identify children who required management of their social and educational competencies, a diagnosis in pre-school years was rare. The adoption of competing discursive constructions of diagnosis by the medical profession, point to the collusion of powerful groups that prefer mothers to manage their children in the more economically viable environment of the home.

While much of the discussion surrounding the social construction of diagnosis focuses on the concept of disability, the mothers in this study appeared to subconsciously avoid the word 'disability' when referring to their child's learning or

behavioural problem. While diagnosis is often linked to the concept of disability, and theorists developing social models of disability argue that there is increasingly positive social and political action in the area of disability, the mothers assiduously avoided the use of the term. Historically based meanings of disability still impact on how community members view 'disability' and for mothers, 'disability' represented a more negative outlook for their children.

Diagnosis is adopted by the educational discourse as a way of determining a child's educational competence. While diagnosis has little to do with measuring a child's competence in the classroom, by adopting the discursive rules and practices of medicine, educational institutions justify resource allocation and the incorporation of their own discursive rules required to manage and control children. Adopting a medical approach to educational control, children are constructed as objects of deviance and are managed accordingly.

Not all members of society accepted the adoption of a medical approach to managing and controlling behavioural and educational problems. Competing discursive arguments about the value of diagnosis were apparent within the social, discourses where individuals resisted dominant rules about certain diagnoses, particularly ADHD and the use of Ritalin®. These arguments often caused the mothers to be confused about the best course of action for their children. However, the dominance of the medical discourse in society is such that diagnosis enabled mothers to develop management strategies, both within their homes and within the local communities, such as schools. While Giddens (1984) argues that mothers replicate the very structures that have been obstructive to their own needs, the mothers felt more in control and able to manage their child's problems, because they were no longer overwhelmed by maternal responsibility that had been measured in terms of failure. While this sense of being in control further reinforces the structure and dominance of the medical institution, Giddens (1984) argues that it can be both beneficial and constraining to mothers. On one hand, mothers found diagnosis was used to control access to resources and community support, on the other hand they felt that diagnosis legitimised their concerns and provided them with the confidence to actively take increased control of the social and educational aspects of their children's lives. Even though the medical discourse, through its discursive statements and rules, controls how a child's development is viewed,

mothers were able to take advantage of the social acceptance that a medical diagnosis bought.

Self-surveillance did not appear to repress mothers; rather it empowered them to take control of both their own and their children's lives. Mothers articulated satisfaction in being able to educate themselves and other members of the community in the area of their child's problem and develop more confidence in understanding their child's problem. Several of the mothers expressed the pleasure associated with being able to advocate for their own child and other children with similar problems, particularly in school communities.

Riding the waves

Diagnosis is not the end of the ride for these mothers. They all know that the future path is long and hard. There will be both pleasures to be had, and challenges for themselves and their children to meet. The optimism with which these mothers face their and their child's future is inspiring. It is with much gratitude that society should thank these mothers, and the thousands of other mothers like them, for their time and commitment to their children. A commitment that will continue, no doubt, for the rest of their children's lives, even though the road will be long, there will be storms to weather and rough waves to ride. Like Max, the journey these mothers and their children take will be over the years, and in and out of weeks and through the days, and they will go to *Where the Wild Things Are* and back on many occasions, yet, there is little doubt that when the children need the support of their mothers, they will be there. As Kimberley's story concluded:

> …yep…that's it…so...but you now, I don't know, I'm just riding the waves..(Kimberley, p. 19, 45-46).

Chapter 7: Findings and recommendations

Introduction

A large percentage of children with subtle developmental problems are not identified until school age when they begin to have difficulties academically and/or socially (Glascoe, 2000a). Concern for these children is heightened when one considers that they are 'at risk' of long-term emotional and social problems (Shonkoff & Phillips, 2000). Understanding why these children are not detected prior to school age and given the opportunity to engage in early intervention programmes, backgrounds this study. While there are ongoing discussions about the use and efficacy of scientifically developed early childhood assessment tools, and the continual fine-tuning or development of these tools, this research takes a broader approach, proposing that historical, social and environmental factors play an important role in the detection and acknowledgment of children with subtle developmental difficulties.

The stories of mothers provided an important perspective in this study, as mothers are those who are most often associated with the daily interactions, and raising of, young children. Listening to, reading and analysing the stories of mothers' experiences enabled a multifaceted picture to be assembled of the socially constructed ways in which people interact with other people, respond to those interrelationships, and make decisions. Drawing attention to these interactions highlighted a number of reasons why children with subtle developmental problems were not detected prior to school age.

Overview of methodology

Based on the theoretical framework of social constructionism, this study utilised a metasynthesis of two methodologies, interpretive biography (Denzin, 1989) and literary folkloristics (Stahl, 1985), to develop a post-structural approach to the reading and analysis of the stories of mothers whose children had not been identified with developmental problems until school age

Such an approach enabled me to focus on the meanings that arose from the text, particularly in terms of their social and historical position. An interpretive biographical approach drew on the turning point moments in the lives of mothers,

helping to unravel the complex interplay between individual experiences and wider social influences. Literary folkloristics placed the focus on the relationship between personal stories and wider cultural traditions. Literary theories were utilised to critically deconstruct the text, to identify themes and attitudes that reflected existing societal expectations that influenced how the mothers' experienced life and told their stories. In this study, three literary approaches were used to read the mothers stories, including Roland Barthes' semiological interpretation of mythology; NeoMarxist criticism, particularly Habermas' theory of communicative action, and Foucault's post-structural discourse analysis.

Reading the stories through the lenses of these three theories allowed for the development of an extensive contextual interpretation of the mothers' experiences. Stahl (1985) recommended pooling the information gained through the multiple literary interpretation so that an integrated account of what was going on could be developed. In this way, a holistic and realistic explanation has been given for the reasons why some children were not identified with developmental problems until school age.

Constructing an interpretive model

The adoption of a multiple theoretical framework for analysis drew attention to the influence of historical and cultural events on members of the community, including mothers, health professionals and others. Roland Barthes' semiological interpretation of mythology drew attention to underlying social myths in the texts, reflecting social and cultural values that influence an individual's interpretation of their experiences. NeoMarxist criticism enabled the social and historical context of the texts to be seen as fundamental to interpretation, and Foucault's approach made it possible to employ the text as a site for understanding how power was established, reaffirmed and tested. While these three theories are all used separately to interpret the stories of mothers, they are in fact closely linked.

Previous research dialogues had warned me that conflicting theoretical viewpoints would make it hard for me to juxtapose these findings, yet, rather than finding that each theoretical interpretation sat in opposition to each other, I found that they were often drawn together by past knowledge and practices. Just as Roland Barthes, Karl Marx and Michel Foucault argued, social practices in society today do not sit in isolation from the past; rather the past and the present are integrally linked. All three

focus on the importance of history as influencing what, how and why people think and act.

Myth is one form of social knowledge that connects the past with the present and from my analysis I have found that myth continues to influence certain social and institutional practices that exist today. Thought and action, according to Barthes (1973), is a reflection of underlying social myths, and while these myths are historically constructed, some of them continue to influence members of society today because they are reinforced by social groups and organisations that benefit from their replication. While there are different degrees of influence and levels of connection between myth and social practices, some myths provide a very obvious and powerful core to the establishment and operation of socio-political policy and the development of institutional rules and practices. In this study the constituted myth of motherhood, the myth of the healer and the myth of diagnosis are all shown to be integrally linked to how society establishes certain views, practices, rules and regulations about mothers, children, health professionals and access to resources and assistance. The following Venn diagram (Figure 7.1) provides a simple impression of how myths, policies and practices interlink and overlap.
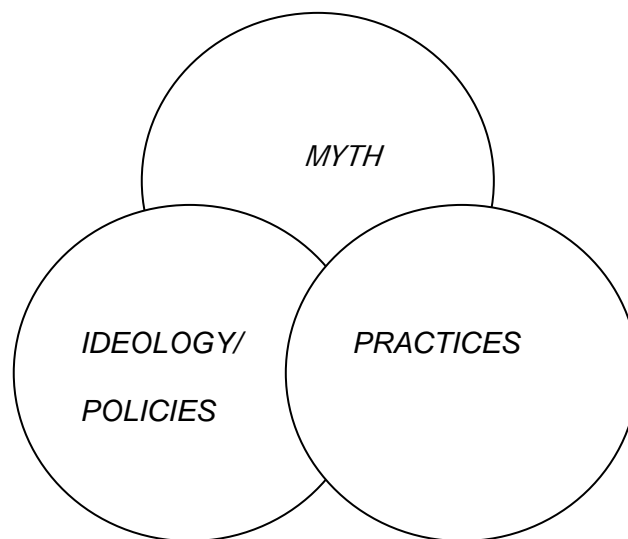

Figure 7.1 Myths, ideology and practices: A theoretical model

Some societal myths more than just colour our lens of perception, they directly influence how people recognise and enact their roles, they afford governments with a standard for developing policies and laws and provide organisations with a principle on which to base their rules and regulations. Hegemonic adoption of

ideologies formulated through myth by members of society, development of public policy, institutionalisation of knowledge brokers, and limitations on public funds, all consolidate myths into actuality.

The constituted myths of childhood and motherhood, while based on historical stories of mythical figures, were shown to play a major role in how mothers viewed their children and themselves, and how health professionals, and others, viewed mothers and their children. Media, language and social rules and practices were continually reinforcing these myths. While it has been argued that myths provide a means through which basic social rules are communicated to members of a community (Barthes, 1973), in today's society, these rules are legitimated through their endorsement by professional practitioners, and enforced through the development of State policy. For example, when health professionals adopted the socially derived beliefs and values that arose from mythically based, social ideals of motherhood and childhood, these values gained further legitimacy. The myths assumed further significance in society when governments structured policy and legislation around their basic tenets. Children with developmental problems that were not physically obvious did not have their problem legitimated through medical channels. As a result, the problem was not categorised according to specific developmental measurements, and the child was excluded from assistance. Because policies often reflected and reinforced myth, they were accepted by the general community as 'the way it has to be'. Mothers actively engaged in, and reinforced an ideological (im)position that supported the belief that mothers were totally responsible for their children's well-being. When children's development did not follow a smooth and trouble-free path in their early years, the spotlight shone on mothers, rather than on the failure of the government to provide adequate support or resources.

The rules and practices within the discourse of medicine further amplified the influence of the myths surrounding motherhood. Past scientific research reinforced mythical beliefs claiming scientific proof that mothers were responsible for their child's behaviour problems yet, even now, when these 'truths' are no longer held as scientifically sound, many health professionals still considered mothers to blame for their children's problems. This was particularly so when health professionals, utilising scientifically validated medical technology such as developmental assessment tools, were unable to deduce a medical explanation for a child's

problem. Rather than looking at the shortcomings of the assessment tool, or at their failure to use the tools appropriately, health professionals relied on their subjective interpretation to determine the cause of the child's problems. While professionals considered their knowledge to be grounded in scientific explanations of the world, it was likely that their own worldview of children and mothers influenced their interpretation of 'what's going on'. When health professionals relied on their own subjective judgements to determine the 'cause of the problem', they failed to recognise that their opinion was not only influenced by their scientific/medical knowledge base, but also by their personal and social beliefs. The study has suggested that these beliefs were influenced by the communal folklore, or myths, of the society in which they lived.

The myth of the healer affected how mothers and health professionals viewed the roles and responsibilities of health professionals, particularly doctors. Some mothers repeatedly sought advice and confirmation of their concerns from doctors. A fundamental reason why mothers took their children along to a doctor in the first instance was their belief that doctors were healers and able to solve their children's problems. This belief was reinforced by media that urges mothers to 'seek medical advice' when concerned, and by public policy that emphasises the role of the health expert in society today. Medical doctors also held strong beliefs in their ability to heal, sometimes to the exclusion of other evidence and ideas. Medical expertise and its associated power were confirmed by the profession itself through the adoption and use of special language that isolated 'outsiders' from medical knowledge. This power was heightened further when state institutions adopted rigid requirements that required mothers to obtain medical diagnoses for their children, in order to be eligible for service provision.

The myths surrounding diagnosis drove mothers to focus on seeking out an answer to their child's problems. Because 'cure' is so often linked to a medical diagnosis in Western society today, mothers often expressed relief when their child was formally diagnosed, and gave them the opportunity to actively engage in a search for a potential cure. Diagnosis was also a tool that governments used to regulate access to services, and to manipulate the provision of assistance. For example, educational ascertainment was a process that required a definitive diagnosis by a medical specialist, without which mothers were unable to receive additional educational services for their children. Health professionals, because they often acted on behalf

of the State, regulated through assessment who benefited and who did not. While this control may have been unwitting, it reflects the power that health professionals have, in part a result of the mythical concept that diagnosis equates to cure. Health professionals such as doctors are placed in a position of power to make important health decisions that affect access to resources and assistance. There is no doubt that some doctors recognise the gatekeeper role that they play for the State, and rather than restricting entry into intervention programmes, use their power to 'redefine' assessment guidelines so that children who do not ordinarily 'fit the guidelines', can access assistance. For many children and their mothers, however, this diagnostic pathway to assistance is a nightmare and one that might be relinquished.

The following section represents a synthesis of the three literary theories under the general umbrella of a social constructionist account, and, consequently, I may no longer refer to each theory individually. Also, the degree to which each theory is utilised in this interpretation varies from finding to finding.

Findings

Just as the work of Glascoe (1998; 1999a; 1999b; 2003), Thompson and Thompson (1991) and Schoen and Parker (1998) would have predicted, most of the mothers in this study noticed that their children's development was not as they expected it to be in the child's pre-school years. This was regardless of their educational level or socio-economic status (Glascoe, 2000a). Mothers became concerned about their child's development when their personal experiences (private folklore) did not match the communal folklore about 'how children should be'. Their concerns for their children may have arisen because of their personal experiences with other children, whereby the behaviour of their own child did not replicate the behaviour of the other children for whom the mother has cared (Kimberley); as a result of the difference between a child and his or her siblings (Nerida, Melanie, Maggie); or because of a child's 'unusual' behaviour (Mary). Grandparents may also have raised their concerns (Alana, Mary), as may teachers (Justine, Rebecca).

These concerns were noted at different times in a child's life. Nerida noticed that her son's behaviour was 'different' from birth, Melanie worried about her daughter's behaviour in her first year of life, and both Kimberley and Mary began to worry about their boys' development when they were just two years old. Alana's daughter was

three years of age and in kindergarten, both Justine and Rebecca's sons were 4 years old and in preschool, and Maggie was worried about her son's behaviour from early infancy. Yet, the point at which mothers raised their concerns with 'others', such as nurses, doctors and teachers, varied considerably.

Finding 1: The pushmi-pullyu effect on mothering

Competing messages about how mothers go about the activity of mothering impacted on when, how and from whom mothers sought advice or support about their concerns over their child's development. Mothers could be likened to Dr Dolittle's pushmi-pullyu, because they often found themselves pulled in one direction, only to be pushed into another, which resulted in either going around in circles or going nowhere. Harriet Marshall (1991) identified a number of conflicting messages about motherhood in relation to the care of children. The following table expands on Marshall's proposal that motherhood is natural and guided by biological instinct and commonsense in contrast to the view that mothers must consult experts to learn what is best for their child.

Table *7.1* The pushmi-pullyu effect on mothering (Adapted & modified from Marshall, *1991)*

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Mothers were caught between competing messages about how best to go about the activity of mothering. On one hand, the myths surrounding motherhood lead communal folklore to constitute motherhood as a natural state of being, with a mother's intuition able to guide her to competently raise her child. On the other hand, the discursive statements emanating from the discourse of medicine advocates that mothers seek expert advice to do the job competently. While intuition is communally understood to be a mother's guide, expert advice based on scientific, objective knowledge was considered a superior form of knowing. Furthermore, the myth of the good mother, which dominates communal folklore, is such that good mothers are those who would do any thing for their children. In contrast, mothers who express too much concern for their children, for example by repeatedly attending a doctors rooms, are objectified by a scientifically based discourse that considers 'over concern' as problematic. Importantly, these two positions are not to be associated with any particular group. Mothers and health professionals stand on either side of this divide, and quite often they stand with a foot in each camp, choosing the side that best suits them at any given time.

Such discursive dichotomies, however, raised issues of doubt as how best to go about their responsibilities as mothers and, as a result, mothers responded in different ways to their concerns about their children. Some mothers chose to withdraw into the micro-system of the family for support and assistance (Maggie, Rebecca, Justine & Alana), while some mothers sought advice from others in the community, such as health professionals (Kimberley, Nerida, Mary, Melanie).

This may, in part, explain why some children with subtle developmental problems were not detected until school age. Children of mothers who chose to conduct their mothering within the confines of the home and with little demand on State services did not come within the educational or medical surveillance radar and, as a result, the children's developmental problems were not 'picked up' until school age. However, there were also mothers who, when concerned about their pre-school child's development, sought advice from sources outside the immediate family, usually health professionals, and in particular, medical doctors. It was notable that the mothers who raised their concerns in their child's pre-school years were *no more likely* to have their child's developmental problems identified earlier than those whose children were not taken to health professionals until they reached school age. Maggie and Justine, who did not raise concerns outside of their families prior to

school commencement, were receiving assistance for their children's developmental problems within 12 months of beginning school. Kimberley and Mary, who repeatedly expressed concerns from the time their son's were two years of age, and were both in year two at school when their child's problems were acknowledged and assistance offered. Nerida's son, whom she was concerned about from birth, was in grade 4 when finally diagnosed, and this is in stark contrast to Rebecca, who had not noticed any problems with her son prior to commencing school. Rebecca's son was assessed, diagnosed and receiving treatment by the end of his first year at school. Alana and Melanie's daughters were both in year 5 when they finally received assistance. The following table provides an overview of this information.

Table 7.2 Comparison of mother raising concerns and child's age at diagnosis

Mother's name	Action on concern	Child's age at diagnosis
Rebecca	Did not notice problems prior to commencing school.	6 years old, ADHD, ODD
Justine	Concerned about social skills at 3. Did not seek assistance outside of close friend.	5 years old ADD
Alana	Concerned about behaviour at 3 years of age. Saw dietician. Did not seek medical help.	9 years old. Dysgraphia
Maggie	Concerned from birth, but confined concerns to family.	6 years old ADHD
Mary	Concerned about behaviour from two years of age. Constantly sought medical and other health professional advice.	6 years old Aspergers Syndrome
Kimberley	Concerned about son's behaviour from two years of age. Sought advice from local G.P. and other specialists.	6 years old ? Aspergers Syndrome and ADHD
Melanie	Concerned when her daughter was one year old. Regularly sought advice from G.P and specialists.	10 years old ADHD
Nerida	Concerned about son's behaviour from birth. Constantly sought advice from multitude of health professionals.	8 years old Double Y chromosome

It is apparent that even if a mother raised her concerns about her child's development, it was not until the child attended school that those concerns would be acted upon. Mothers often felt that their concerns were marginalised. This was seemingly so in the pre-school years because, for several of these mothers, it was not until the children began school and teachers raised their own concerns about the child's development, either behavioural or cognitive, that made it difficult for the child to manage in the classroom situation, that health professionals listened more closely and attended to the concerns.

The competing messages of motherhood affected not only the mothers and community members, but also health professionals who engaged with mothers and children on a regular basis. The next finding draws attention to wider historical and social reasons why children with developmental problems in the preschool years were not identified and acted upon, even though mothers may have raised concerns with health professionals about developmental idiosyncrasies in the first five years of their child's life.

Finding 2: The influence of societal myth

Societal myths influenced how mothers, others and health professionals viewed the role of mothers and their responsibilities to their children. From the women's perspectives, even before the children attended school, the communal folklore - informed by myths, ideological notions and scientific statements - of 'normal childhood development', drew attention to their child's developmental problem. When family and community members perceived children as different, mothers felt an enormous burden of guilt. Children were measured according to their ability to 'fit' into a society where rising expectations of children's achievements and narrowing levels of tolerance places pressure on those responsible for children to 'do something' if children do not perform to expected societal standards. Mythical ideals of motherhood, adopted as ideological standpoints, placed mothers in this responsible role.

Mythical beliefs about the perfectibility of children and ideological notions that stress the central link between mothers and children combine with statements about childhood that have arisen from the discourses of psychology and medicine, and provide 'standards of measurement' that identify 'what's normal and what's not'. Individuals within society (including mothers and others) adopt these standards as

their own, over-viewing and regulating both mothering and child behaviour. While these statements did background a mother's concern, they also created an environment in which expectations of a child's development may have been exaggerated. When the Western notion of the innocent and perfect child, linked to the influence of Judaeo-Christian mythical ideal that characterises people as imperfect beings, is juxtaposed with medically sanctioned 'norms', the pressure on mothers to raise the 'perfect child' increases. Mothers whose children failed to meet societal ideals often blamed themselves and felt guilty about their perceived failure and that of their child. These feelings were exacerbated by the stigma and isolation they encountered from a less than supportive community.

Mothers did not wish for their children to struggle in life and, if concerned about their child's development, often sought advice and assistance, usually from medical professionals. By doing this, the mothers were attempting to find a way to 'normalise' their child in relation to the pre-set standards of society. By encouraging mothers to 'seek medical advice' when concerned about their child's development, the medical discourse manoeuvres itself into a position where it becomes regarded by other members of society as the primary source of expert advice on developmental matters. Political statements that support medical assessment and intervention for children with developmental concerns reaffirm this position.

Mythically driven ideals about mothers and children, and supporting ideological principles, also infiltrated the values and beliefs of health professionals. This was particularly so when the children looked 'OK' physically, behaved 'OK' in the clinic and scientifically based 'norm' measurements of the child did not validate a mother's expressed concerns, leaving the health professional to determine alternative explanations for a mother's anxiety. Because mythical ideals, supported by ideological stances, are so embedded in society, health professionals could not separate their professional knowledge from the personal knowledge accumulated through membership within a social discourse. It was particularly difficult to discard beliefs based on myth when they had been reaffirmed by scientifically based research, even when that research had been discredited by more recent studies. As a result, if a health professional could not formulate a scientifically valid interpretation of a child's problem, it appears that they were liable to resort to personal beliefs and values to explain what was occurring. Mothers, whose young children who had more subtle forms of developmental problems, for which there is

no obvious physical manifestation or neurological explanation, were often those who became the object of the medical gaze, because the children 'looked OK', behaved 'normally' in the short visit clinical environment and were less likely to score a remarkable result on scientifically validated child development assessments. This was particularly so for mothers who raised concerns about their children in the preschool years without their concerns being ratified by other professionals. These mothers were more likely to become the object of medical concern and, as a result, their child's problems were overlooked while the mothers' behaviour became the focus of attention.

The mothers themselves were highly sensitised to mythical expectations of motherhood and any implication of blame by a health professional exacerbated their guilt. While all mothers accepted full responsibility for their child's development and wellbeing, recommending a mother undertake parenting classes reinforced feelings of inadequacy and fault. If the health professional suggested that the child 'spend sometime in respite care' the mother's feelings of failure were further reinforced. Rather than giving mothers 'a rest', mothers were left with the feeling that their mothering skills were inadequate and that they were to blame for their child's problems.

When mothers did not receive support for their child's problems from health professionals, the child's developmental problem remained unacknowledged. This created a major problem for mothers, as they were unable to access help for their children, as overarching political policies affected how need is determined and how resources were allocated. Without medical sanction that identified the children as having a categorical problem, the children fell outside the definition of 'those who need help', and mothers were left to 'cope' in their own in a home, often isolated from family and community.

Finding 3: Health professionals' knowledge is valued over mothers' knowledge

When mothers visited health professionals, they brought to the consultation knowledge about their child that was based on personal judgement. A mother's judgement of how her child developed was often referred to as 'intuition'. Comments such as '…for some reason, I wasn't sure what it is, but I just felt that something…(*was wrong*) (Melanie), or 'I felt there was something wrong with him'

(Nerida), and 'there is something wrong with my child' (Kimberley), suggests that mothers were able to recognise subtle developmental problems due to intuition. Mothers actually based their 'intuition' on previously acquired knowledge, perhaps through their own experience as a child, by babysitting as a young person, through comparison of their child with siblings or other children, through information gleaned from books and magazines or from family and friends. Mothers also hold intimate knowledge about their children through the constant contact that child rearing brings. The mother sees her child in all situations, is exposed to all facets, and is aware of every nuance of behaviour, in a way that is denied anyone else. A mother's 'intuition', however, was given little credibility by a profession that controls knowledge through its scientifically based 'truth' statements, its own protected discourse.

Health professionals are trained in institutions that place value on the scientific 'way of knowing' and this is what will determine and define 'truth'. This belief about the nature of truth developed as part of the scientific worldview, which developed in 'the Age of Reason', and the changes in thinking this brought regarding the philosophy of knowledge, scientific method, and religious belief. Medicine distances itself from alternative forms of 'truth' and, as a result, regards scientific knowing as holding greater truth-value than the 'intuitive' knowing of a mother. Consolidation of this form of truth occurs as the powerful medical discourse infiltrates into communal groups who then accept it as 'the way it is'.

When mothers took their children to health clinics the health professional may have used scientifically validated screening or assessment tools to determine whether the child had a problem. When tested, children with subtle developmental problems were likely to 'fall within the normal range' of the test result. Because of a belief that scientifically validated assessments deliver the 'truth', this measure was taken to be more valid and reliable than the mothers' subjective concerns.

The discourse of medicine promotes scientifically validated knowledge as being the basis for its practices, and considers it superior to other forms of knowledge. The emphasis on evidence-based practice exemplifies this focus. Some of the practitioners operating within the discourse, however, appeared to make decisions based on communal folklore, a subjective form of knowledge, rather than rely on the scientifically validated knowledge, available as developmental screening and assessment tools. Some of the medical practitioners did not utilise these tools,

instead preferred to rely on 'gut feelings'; yet, they still considered their interpretation to be a more accurate representation of the 'truth' than the mother's concerns.

Even though the 'objective' interpretation of the health professional was questionable in regard to its objectivity, doctor's statements were accepted as 'the truth' because of his/her membership in a discourse that continues to hold a powerful, and influential, position in society. Mothers tended to accept a doctor's interpretation as more accurate than their own concerns because of their belief that doctors are the experts, a belief reinforced by mythical notions of the healer, societal acceptance that the scientifically based model of healthcare promotes 'the truth', and public policy that promotes information such as 'if concerned seek advice from your doctor'.

The power of the practitioner's interpretation was further consolidated by the medical requirement that a mother's knowledge on its own was not sufficient evidence that a child's development may be going awry. Mothers had to obtain supporting documents from professionals whose knowledge was considered more valid than their own. The *Diagnostic and Statistical Manual IV* (APA, 1994)*, for example,* declares that a mother's concern is insufficient in determining a child's developmental problem, particularly when involving behavioural problems. Teachers, occupational therapists, nurses and others trained in the ways of professional 'knowing' were required to provide documentation that stated a child's difficulties in the classroom or child care centre. When mothers' concerns were considered as insufficient evidence for diagnosis, children with subtle developmental problems were not detected, nor able to access support and assistance, until coming into regular contact with teachers, or other professionals.

When 'evidence' is only considered legitimate when arising from practitioners who are educated in a discourse that advocates the superiority of scientifically based knowledge, 'other' forms of knowledge are excluded from the process of problem solving. While it has been shown that health professionals also utilised 'other' forms of knowledge, such as knowledge arising through exposure to communal values and beliefs, their interpretations were still considered superior to those made by mothers.

Finding 4: Different expectations

Expectations differed between mothers and health professionals when mothers attended health clinics. Mothers arrived at the health clinic with preconceived expectations (Davis et al., 2002) based on previous experiences of attending health clinics and the expectation that the problems they were encountering with their children were solvable. Mothers arrived at the clinic with these expectations because of their belief that doctors, as healers, would be able to determine the nature of their child's problem and provide a solution to the problem. Because of these beliefs, mothers appeared to willingly hand over responsibility of assessment and diagnosis to the doctor.

Health professionals had similar expectations of the consultation, yet, while they had similar beliefs in the nature of a doctor's role, doctors were influenced by additional parameters, affecting how consultations were conducted and interpreted. Like the mothers, it appeared that doctors held a fundamental belief in their role as a healer and, therefore, most probably set out to determine the cause of the mother's concern. Specifically, they had been trained to identify if any signs or symptoms on examination of the child matched with known developmental aberrations (Silverman, 1987). However, it was likely that these signs and symptoms often had to be identified within 10 minutes, the usual length of time for a consultation. Assessments and decisions needed to be made quickly and efficiently, yet children with subtle developmental problems, particularly behavioural ones, often did not display their problems, such as anxiety, aggressiveness, agitation or anger, in a short consultation.

If a child displayed no particular signs and symptoms to which a health professional could legitimately attached a diagnosis then there was no medically legitimate problem, leading the health professional to conclude that nothing was wrong with the child. By saying *there is nothing wrong with your child* the health professional may actually have meant: 'according to codified knowledge of medical disorders, I cannot apply a medical diagnosis or suggest a treatment'. However, from the mother's life-world perspective, there wa*s* something wrong with her child, and this was why she had made the effort to seek advice. This mismatch between expectations and outcomes caused the mothers much consternation and they left the doctor's clinic feeling that their concerns were unheard, and unsure about what course of action to take for their children.

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Expectations of health professionals are also influenced by whom they are employed. In Australia, most health professionals are trained, and work in, government-operated organisations. So, while serving the interests of their clientele, they also serve the interests of the State, and the State influences how time is allocated and how need is determined. Hugman (1998, p. 157) argues that health professionals become selective about who accesses what services, where and when, because they are aware of the limited resources available in State provided health care services. While I have suggested that it is likely that most health professionals did not deliberately set out to deny mothers and children access to resources, their previous interaction with support services had probably drawn their attention to the limited services for mothers and young children. As a result, health professionals would be encouraged to select only the individuals they considered the most in need. Influenced by ideological statements that promoted particular manifestations of the 'developmentally correct' child, mothers were confused when their children were not considered to be 'in need', or eligible for early intervention services. The conflict between political rhetoric and actual service delivery was (and remains) highly problematic in the area of early intervention for children with subtle developmental problems.

Myth-driven ideals about the role of mothers may also have led practitioners to believe that children with subtle developmental problems should, and could, be 'dealt with' in the confines of their home. In this study, it was not until children attended school that their developmental difficulties began to impact more obviously on their ability to learn, or directly affected other members of the community, and so they warranted more attention and assistance.

Finding 5: Communication between health professionals and mothers is distorted by different approaches to language and understanding

When engaging in conversation with health professionals, mothers' concerns arose from their day-to-day life experiences, and it was in the voice of these life experiences that they communicated. As can be seen in the way Nerida described her concerns: 'he always screamed, he was frustrating…you couldn't comfort him'. Professionals, on the other hand, are trained to communicate in a rational, scientific way because their training is based on the biomedical model of health care (Barry et al., 2001). What health professionals therefore *wanted to hear* were particular physiological or behavioural problems that they could use to form a diagnosis and

recommend treatment accordingly. When a mother came to the clinic complaining of a number of 'non-specific' problems with her child the health professional often transformed the practical problems into technical ones. By decontextualising the mother's concerns, and applying technical standards, the health professional was attempting to *hear* specific scientific constructs (signs and symptoms) that isolated the cause of the problem. The transformation from subjective-life based experiences to objective decontextualised signs and symptoms may have resulted in a misinterpretation of the problem.

When technical-rational conversation dominated the conversation mother's felt that their concerns were unheard, or disregarded. These feelings were exacerbated when mothers were not included in professional-to-professional communication. Mothers were reluctant to question this exclusion, or to criticise unsatisfactory interactions with health professionals, concerned that they would no longer be able to access their services. This was particularly so for mothers living in rural communities. The power of the medical discourse, and the acceptance by the general community of the expertise associated with practitioners operating within the discourse, severely restricted the options mothers had, including their opportunity to seek advice from alternative sources.

If mothers feel unvalued, misunderstood and ill informed and are in conflict with the advice they are given, their role as a parent is compromised (Davis et al., 2002). While Davis et al. suggest that mothers are less likely to 'comply' with doctor's advice when they feel unvalued and misinformed, improved communication is not about compliance with medical doctors decisions, rather, it is about developing a mutually satisfying outcome. Compliance is a term that implies the health professionals are right and the mothers are wrong. Improved communication is about improving relationships with mothers that incorporates shared responsibility, shared decision-making and shared understanding.

Finding 6: Competing arguments about diagnosis and labelling

While mothers considered diagnosis as important for legitimating their child's illness, validating their concerns, exonerating them from blame and enabling them to gain assistance for their child, it was found that diagnosis came attached with a complex array of meanings. As a result, not all members of the community, health or educational professions viewed diagnosis as mothers did. Competing arguments

about the value of diagnosis and labelling, especially of pre-school age children, prevented mothers accessing assistance for their children. These arguments were evident within both the medical discourse and in the wider community. Diagnosis represents an essential element of how a medical healer goes about his/her trade yet, sociological arguments point to concerns about the long-term negative ramifications of certain diagnostic labels. Contradictory discursive rules within the medical discourse reflected these arguments, particularly in relation to young children with subtle developmental or behavioural idiosyncrasies, with doctors often choosing not to label a child with a particular disorder. Unfortunately, while health professionals may have had a child's long-term interest in mind, the consequence was likely to be the exclusion of a child from early intervention programmes and activities, since diagnosis was normally required for entry into the programme. Rather than long-term negative implications resulting from (mis)conceptions about diagnostic labels, the children in this study suffered from the long-term implications of missed early intervention programmes. This was particularly so when mothers needed assistance from State operated services that defined 'need' on the basis of a medical diagnosis.

Finding 7: The diagnostic imperative

Requiring a medical diagnosis for social and educational services reduces access to early intervention and support programmes, particularly when the diagnosis must match strict classificatory guidelines. State intervention programmes and services nominate medical diagnosis as the most accurate way of determining a child's 'problem', yet it was highly unlikely that all but the profoundly physically or intellectually disabled were able to gain access these services. Children with subtle developmental problems were likely to be excluded from the nominated diagnostic groups. This was particularly evident in the Education Queensland process of ascertainment or EAP, where a child was required to show proof of a categorical medical diagnosis, as listed in the *DSM-IV TR,* in order to be considered for educational assistance. The sanctioning of medically derived diagnosis within Queensland state assessment procedures demonstrates the dominance of the medical discourse, through the infiltration of medically ascertained discursive rules about the importance of diagnosis. The government also benefited from adopting such a set of rules defined in this way. Using diagnostic terms as a tool for limiting access to services helps to keep state financial budgets under control and places responsibility back onto mothers to manage their children in the less costly

environment of the home. Just as Vimpani (1996) and Sidebotham (2001) suggest, the macro-cultural environment is highly influential with regard to how parents and their children are able to access support and resources.

The power of medical discourse extends far beyond the borders of health care and into social, educational and political domains. Because of the colonisation of rational, scientific knowledge into everyday social life (Habermas, 1984), a medical diagnosis held important ramifications for the mothers and their children, often fulfilling an important social function for the them. Mythological beliefs underlay a mother's confidence that diagnosis was integral to treatment and support and, that once diagnosed, their children could be 'normalised' back into society. Even if support was limited, it was usually more than they had experienced pre-diagnosis. Diagnosis also validated the mothers' concerns and alleviated feelings of blame, freeing up their negative self-perceptions and allowing them to discard responsibility linked to personal 'fault'.

Unfortunately, the very process that was purportedly in place to assist a child gain access to social or educational support may have discombobulated mothers and caused them to give up their fight for assistance. Their frustrations were exacerbated by a system that did not recognise the concerns of mothers in isolation from professional and/or medical interpretations. As a result, children with subtle developmental problems were less likely to be identified prior to coming into contact with teachers or other professionals who then raised concerns about their ability to engage in 'successful' social or academic interactions in a wider social environment.

Significance of findings

The synthesis of three literary theories has drawn attention to a number of reasons why children with subtle developmental problems may not be identified until school age. In particular, the use of semiotic, Marxist and Foucauldian literary theories highlight how multiple meanings can be extrapolated from the text and, in doing so, culminate in an integrated interpretation of 'what is going on'. However, acknowledging that multiple meanings are possible implies that there may be alternative explanations hidden in the text, which have not been identified. By reading the texts specifically through these three literary lenses, I am aware that I may have been blinded to other explanations and interpretations.

Regardless of how one reaches an interpretation, there is little doubt that there are a number of explanations as to why children with subtle developmental problems are not always detected prior to school age. Hopefully, this interpretation will raise awareness of possible influencing factors and will encourage health professionals to reflect on their own practice when working with mothers and their young children.

These findings highlight a number of issues:
- They draw attention to the influence of societal myths, policies and practices on how mothers' concerns about childhood developmental problems are viewed and acted upon.
- They support the argument that mothers play a pivotal role in early identification of their children's difficulties.
- They raise questions in relation to how health professionals interpret the concerns of mothers, and they
- Contribute to the debate about the role of diagnosis and access to early intervention.

As a result of these findings I have made a number of recommendations.

Recommendations

One of the aims of this research was to ascertain ways in which child health professionals may utilise the experience of parents to improve early recognition and diagnosis of subtle developmental and behavioural problems in children. These recommendations are therefore directed towards health professionals, as it is they who are most often in the position of assisting mothers to help their children, and to detect signs of developmental problems when children during the pre-school years. When mothers are concerned about their children's development, societal practices and rules direct them to seek advice from health professionals, particularly doctors. While not all mothers chose to seek assistance from health professionals, most of the mothers in this study did so. While it is difficult to detect children with difficulties if their mothers do not seek assistance, it is possible to improve the detection rate of those children whose mothers 'notice something' and raise their concerns with health professionals. Health professionals, particularly doctors are therefore in a prime position to detect children with subtle developmental problems before the children reach school and struggle with academic tasks or social relationships.

1. Recognise that competing messages about motherhood will influence how and when mothers draw attention to their concerns over their child's development.

Due to the competing messages about mothering, it is likely that there will continue to be a diverse response to when and how mothers raise their concerns about their children's development. It is important to recognise that mothers go about mothering in different ways because competing messages about motherhood will affect how they think and act. The provision of supportive services that value the concerns of the mothers and take them seriously are more likely to encourage mothers to raise their concerns and to seek advice and assistance while the child is in pre-school years. Such support services should be easily accessible and affordable, especially in rural areas.

2. Promote reflexive thinking among health professionals.

Part of being a reflexive practitioner entails the awareness of one's own biases. Health professionals need to reflect on how communal folklore infiltrates their interpretations of a mother's concern, particularly it is not closely matched to how the child looks, behaves and responds during a short clinic visit. When societal myths are reinforced by scientific research, and even if the research is no longer scientifically supported, myths tend to provide baseline interpretations about 'what is happening'. Myths influence even the most well educated people, and health professionals need to acknowledge that sometimes the decisions they make will not be unbiased, objective interpretations, rather their decisions will be fundamentally influenced by mythical beliefs that have become ingrained.

Rather than 'fall back on' personal beliefs to explain a child's developmental problem, when health professionals cannot scientifically validate a mother's concern it is essential to suggest follow-up visits, so that the mother recognises that her concerns are being listened to. Furthermore, subsequent visits can allow for continuing surveillance of the child and may provide time for subtle development problems to be manifested. Health professionals should:
- listen to and value the concerns of mothers, and
- recognise that children will not always display the behaviour that a mother raises as problematic;
- rely less on personal interpretations of 'what's happening here' as these are influenced by societal myths of childhood and motherhood, and

- use parent orientated checklists, such as *The Parents' Evaluation of Development Status* (PEDS) (Glascoe, 1999a), regular surveillance and comprehensive child development assessments.

3. Recognise the value of the personal knowledge of mothers as an important contribution to a health consultation.

Health professionals are educated through medical models that value scientific knowledge as 'more truthful' than knowledge gained through personal experience. When wider social lores and personal experience are disregarded as potential sources of information, health professionals will not be able to develop a complete understanding of 'what is going on'. This is particularly so for developmental difficulties that may have no obvious biological base. Recognising that there are other potential forms of 'truth' may help health professionals listen to what mothers have to say and recognise that there is more than one way to hear or see.

As Davis et al. (2002) state, listening to mothers involves 'hearing the whole story, seeing the full picture, knowing their main worries and learning their strengths' (p. x). It also involves believing mothers, following up concerns, putting aside prejudices and judgemental thinking that are influenced by societal myths and reinforced by discursive practices, and 'positively regarding' mothers (Rogers, 1959) as those who understand, care for and accept responsibility for the wellbeing of their child. Health professionals should show respect, trust and consideration for the mothers' concerns and recognise their knowledge and expertise.

5. Advocate for improved services for mothers and children

Child health professionals need to advocate directly for improved services for mothers when their children are in their pre-school and early school years. They need to advocate for improved funding for maternal and child health services, educational services, provider training and teacher-health professional collaboration. Maternal and child health nurses can also play an important advocacy role by lobbying for funding for the development of an continually up-to-dated website that presents parents with information that is accurate and easy to understand. Research that has taken place in the area of early childhood development could be translated into plain language so that parents are kept abreast of latest developments. Because many parents are now visiting the internet for parenting and child-rearing

advice, this is likely to be an effective way of assisting parents to increase their knowledge about early childhood and parenting.

6. Improve communication skills when relating to mothers by recognising that 'specialist' language may be distorting the picture and reducing understanding.

Health professionals must engage in constant questioning of assumptions, language, and processes when working with mothers who are concerned about their children. Health professionals have a responsibility to take a lead in addressing communication strategies that recognise and value the life experience of the mothers. By taking into consideration and conversing through life grounded values, health professionals are more likely to encourage mothers to actively engage in the conversation. If mothers are included in the conversation they will feel more respected, involved and heard. In this way, health professionals are more likely to develop a comprehensive picture of the child's problems. Health professionals should:

- actively listen to the concerns of mothers;
- provide information clearly, and clarify any points where misunderstandings may arise;
- encourage mothers to actively participate in the conversation by responding to their concerns in a language that they understand and through which they can ask questions or query advice; and
- include mothers in decision making, by giving them a range of options. Accept that mothers make decisions on the basis of both personal knowledge and the information obtained from the consultation. Mothers who feel included in the conversation are more likely to be satisfied with the service.

Economic considerations and the often-large number of clients that medical doctors must see in a day restrict how health professionals practice. If mothers raise concerns about their children then time must be taken in follow-up consultations to enable full histories, accurate screening and assessment to take place, and to listen to the mothers' concerns. Asking a mother to keep a diary of her child's behaviour will also provide a current source of information. Regular visits and follow-up are important because not only does the mother feel that someone is listening, but the child's development will be followed more closely.

7. Reconsider the 'need' for a diagnosis in order to access services.

Competing arguments about the value of diagnosis delay identification of a child who needs assistance. While state operated institutions, such as the education department or social services, base their determination of 'need' on a categorical medical diagnosis, the on-going debate about 'labelling' creates a problematic situation for health professionals and mothers. On one hand, in order to avoid long-term social repercussions, there is a reluctance to label young children. On the other hand, in order for them to access services, medical professionals may feel compelled to label school-age children. As a result, mothers feel that their concerns go unheeded until teachers provide supporting evidence. In a society where medical opinion is highly regarded, a medical diagnosis validates a mother's concerns and exonerates her from blame as an inadequate mother. Furthermore, a medical diagnosis provides a child with a reason as to why they have not been able to achieve to the expected levels of behaviour or learning that Western society demands. While it could be argued that the expectations placed on children are unreasonable and, in Australia, are by the neoliberal federal government's desire to ensure all children grow up to be productive citizens, it is difficult, if not impossible, for mothers to separate themselves from the exacting demands of the community in which they live.

Short-term solutions are unlikely to solve such a complex problem. Suggesting that children should not need a diagnosis to access service and intervention programmes, while well-intentioned and altruistic, is highly unlikely to occur in current social, political and economic climates. As governments try to curb spending on health related services and more severe illnesses attract the bulk of the funding, children with subtle developmental problems are unlikely to be factored into budgets in a significant way. However, as Vimpani (1996) suggested, changes at the macrosystem level where policy and structure influence a child's access to resources will have more pervasive effects on health and development than changes at the microsystem level.

Children should be able to access intervention programmes when functional difficulties are apparent, rather than restricting access to those who have a categorical diagnosis. It will take some time to change the way in which State services operate, however, particularly as financial restraint on health services will limit who is considered the 'most needy'. Once it infiltrates into the discursive

practices of the state-run institutions that what happens in the early years is very important (Shonkoff & Phillips, 2000), this need for diagnosis may shift to a functional assessment. Until that time, however, children with subtle developmental and behavioural idiosyncrasies will need some form of diagnosis to allow them to access services that will assist them in long-term academic, social and emotional development.

If children need to be 'labelled' to gain access to scarce resources, it is highly likely that increasing numbers of school-age children will continue to be identified with disorders such as ADD, ADHD, Asperger's Syndrome, Oppositional Defiance Disorder, dyslexia, dysgraphia and so on. As numbers of children increase, it is also highly likely that categorisation of these children will not necessarily guarantee access to services as they all dip into an extremely limited pool of funds. Diagnosing children in the pre-school years would exacerbate the increasing numbers in the short-term, although, in the long-term, expenditure would decrease. Waiting until the children reach school age and begin to fail academically or socially is not only detrimental to the child's mental health but is also a more expensive option. The older a child is at diagnosis the more expensive and long-term the intervention becomes (Shonkoff & Phillips, 2000). If children are identified with potentially concerning developmental idiosyncrasies in their early years a short-term intervention program is likely to ameliorate the problem and prevent later emotional, academic and social problems. Refocusing on the early childhood period of life, and providing resources and services to concerned mothers and their children is likely to result in favourable long-term outcomes.

Considerations for the future of health care and the role of mothers

The aim of this thesis was to determine ways in which health professionals could improve the detection of subtle developmental problems in young children, and in the process of this study, attention has been drawn to the important role that mothers play in identifying early developmental problems. There is little doubt that mothers are in a position that provides them with privileged information about their own children, and it is important that health professionals harness this knowledge for the long-term benefit of the child. Mothers need to be provided with the opportunity to utilize this information and to share it with the health professionals to whom they

take their children. Educating health professionals about the important role that mothers can play in early identification is one part of the solution, but empowering mothers is also a major strategy that can be utilized to improve the detection of children with subtle developmental problems.

There exists in the western world today, a general consensus that patient empowerment is a good thing (Segal, 1998). Patient empowerment enables patients, and their families, to actively participate in health care decision-making (Bruegel, 1998). Mothers of young children can make important contributions to health care decisions about their children because they spend so much time with them and are quickly alerted to any subtle changes in a child's development. Furthermore, mothers who can actively contribute to their children's wellbeing are less likely to feel that they are 'bad' mothers.

The purpose of empowerment, however, is not to make mothers feel good about themselves, neither is it an attempt to disempower health professionals, rather it is a strategy aimed at improving the detection of subtle developmental problems in children so that they may access early intervention. This strategy must, of course, be two-pronged. The health professionals must recognize that mothers can make an important contribution to the health care of the children, and the mothers need to acknowledge that through the action and care of health professionals, a child is better able to access assistance for their problems.

Developing a strategy that empowers mothers will take time. There are many myths and misconceptions that create and sustain barriers to new ways of thinking and understanding. The following suggestions are just a few ideas about how mothers can gradually develop a greater role in the health care of their children:
- Plain language medical statements: This study draws attention to the barriers created when doctors rely on professional language when speaking to mothers about their children's health problems. Consumer members need to be invited onto medical panels and boards, so that they identify language that is alien to the health consumer and recommend alterations into plain language that is more easily understood. Proponents of plain language statements have been active in Australia since 1976 and the Australian government has set out to regulate the language used by lawyers in legal documents (Mazur, 2000). By improving readability, all legal documents

have to be written in a language that ordinary people can understand. The Department of Health in the United Kingdom, for example, has recently published a White Paper - *Our health, our care, our say: a new direction for community services* (Department of Health U.K., 2006). This policy has been published in two formats: one document is the large, official, technical publication, the other is a brief, plain language publication that not only presents the information in a highly readable format, it explains the meaning of the more complex words, such as 'government', and is profusely illustrated. This same approach needs to be taken in regard to language utilized by the medical establishment in Australia when providing consumers with documentation and/or explanation about health issues. Plain language statements are an important way of assisting mothers to understand what doctors are saying about their children.

- Plain language information pamphlets: Consumers, such mothers, need to be invited to assist in the development of plain language information pamphlets that are available to mothers in the waiting rooms of doctors. These pamphlets are more likely to use language that is appropriate to users. In Australia, pamphlets such as these are being developed by and for the Aboriginal and Torres Strait Island health service users. They focus on aboriginal design, aboriginal culture and aboriginal language. Improved health knowledge, particularly among children in some communities has resulted from these consumer-driven information pamphlets (Rowley et al., 2000). Similarly, mothers and other primary care givers of children would be a valuable source of information for the development of health care pamphlets that relate to early children development and the needs of parents.

- Patient led services: The development of patient led services enables direct feedback about healthcare provision from people who have been patients, or clients of health services (Saltman, 1994; Segal, 1998). Mothers should be invited to join planning teams at every level of government, from executive boards to community service planning groups so that, as consumers of the health services, they are involved in decision making about what, how and where services are operated for parents and their young children. Being able to directly feedback information to these teams enables services to be adjusted accordingly. The National Health Service (NHS) in the United Kingdom, for example, has a *Patient Advice and Liason Service* through

which members of the public are able to feedback directly on health related care that they receive (National Health Service U.K., 2006).

- The development of a Patients' Charter and Standards of Care: State and federal governments need to insist on a patient's charter and standards of care, whereby health professions have an obligation to make sure that a patient, or their family, are aware of their rights in regard to their health care choices, decisions and treatments. Charters and Standards of Care exist in other health care areas, mental health being a prime example. The New South Wales (NSW) Health Department has a *Charter for Mental Health Care in NSW* that clearly states the rights of people who access mental health services in NSW (NSW Health Department, 1998). Until recently, the National Health Service in Britain had a *Patient's Charter* that informed service users what they could expect from health services. Clients of mental health services, for example, received this advice in booklet form (National Health Service U.K., 1997). The booklet identified clients' rights in relation to the service they would receive, the standard of facilities, the level of respect for their privacy they were entitled to, as well as what they could expect to happen while they are in the care of the service. Charters and standards such as these are most effective if clients can easily access, and understand, them. They must, therefore, be written in plain language and clearly displayed, or readily available. Pamphlets such as "What do I do if I am unhappy with my doctor's advice?", "Where can I go if I need to speak to someone about how my child is being treated?" will give guidance to mothers when they do not know what to do or who to turn to.

- Self-help groups: Self-help groups, where parents meet together on a regular basis provide opportunities to share experiences and to work out strategies for future encounters or problems. Self-help groups have played an important role in bridging the gap between health services and health users, particularly in areas such as mental health. Antenatal classes that operate in Australia are often the beginnings of self-help groups, as mothers who meet at these often go on to form close-knit communities of women and children who support each other throughout their children's childhood years and beyond. The newly formed mother and baby groups operated by the Maternal and Child Health Nurses in Australia may provide another opportunity for mothers with babies and very young children to discuss their healthcare experiences, and develop strategies and solutions for future

problematic encounters. As a group, mothers may be able to impress upon health professionals that their contribution to health consultations is important and should not be regarded as inconsequential. Several of the mothers in this study joined local support groups once their children had been diagnosed with developmental problems. These groups operated to keep mothers informed about latest research, availability of social services, appropriate health practitioners for their children as well as providing a source of support when mothers were stressed. Community groups such as these need the support of and promotion by local governments so that mothers know about their presence in the community and can access them easily. Groups such as these can also become politically active, lobbying for services for children with developmental problems, or for providing parents with more support. Health professionals and governments need to see these groups as making an important contribution to health services as they alert them to the needs of a particular community. They are an excellent example of consumer empowerment at grass root level.

These recommendations are just a few that outline the need for future action that empowers mothers and gives them a greater voice across many levels of government, on boards, committees and in the day-to-day operation of health centres and mothers groups. These recommendations will take time to implement and there will be those who rally against the intrusion of consumers into decision-making roles within the health sector. As technology enables mothers, however, to access more accurate, useful and easy to understand information about childhood, illness, developmental problems, and parenting, many mothers will begin to demand a service that acknowledges their concerns about their children and responds to those concerns in a way that respects their role as parents.

Future research

Research into the subtle developmental problems of children and the experiences of their mothers is relatively new. This research has drawn attention to the difficulties mothers face when seeking assistance for their children, the presence of conflicting opinions about how to identify and treat these children and the limitations of service provision. There is little doubt that more intensive effort needs to be put into the early recognition of subtle developmental problems. While large numbers of children

continue to fail at school, the long-term social and economic impact, on children, their families and the Australian economy is likely to be considerable.

In light of this, future research needs to:

- gauge the extent to which preschool aged children in Australia have subtle developmental problems. Quantitative research studies need to be instigated to provide large-scale measures of the incidences;
- determine the degree to which these subtle developmental problems are likely to impact upon later social and academic skills;
- gauge the extent of existing early intervention programmes for children in their pre-school years, particularly investigating the differences between service provision in rural and urban regions. Considerations such as the adequacy of the service in response to need, requirements for entry (such as diagnosis), and accessibility and cost to families need to be examined.
- initiate a systematic review to determine what early intervention programmes are effective in helping these children improve their social and academic skills prior to school commencement;
- develop effective intervention programmes so that once children are identified with development problems they can be referred to programmes and interventions that are shown to be effective in improving a child's social, emotional and academic future;
- develop more accurate and sensitive assessment tools that combine parental knowledge with what is known from scientific research;
- focus closely on the pre-school development of children who experience later learning difficulties such as dysgraphia, dyslexia and dyspraxia. Asking parents to recall their child's pre-school development may help to identify developmental pre-cursors;
- compare the school progress of children who are not identified with developmental problems until school with those who are identified before school, in order to determine how delayed identification affects later social and academic achievement;
- compare how mothers in rural communities find out about raising children, particularly those who have subtle developmental problems. Possible questions include: Is information more easily available for mothers in urban environments? Are single mothers in rural communities less able than urban mothers to access resources and information? Are children with subtle

developmental problems who are raised by wealthy, urban families more likely to be identified with a problem before school and attend early intervention programmes, compared to poor, single mothers living in a rural community?

- speak to fathers about their experiences of raising children with subtle developmental problems, and their relationships with family, friends, community, health professionals and teachers. Identifying differences between mothers' experiences and those of fathers may help to illuminate whether the responses and support received by mothers differs to those received by fathers;

- determine the alternatives to orthodox medicine that parents of children with subtle developmental problems can access. If parents access alternative therapists, how often do they consult them? Do parents ever abandon orthodox medicine in favour of alternative services?

- explore the perspective that doctors take on their interactions with mothers, or fathers, and the extent to which this differs from the perspective of the parents;

- measure the impact of educational ascertainment/EAP against the level of support children actually receive;

- identify the number of children not diagnosed with a DSM IV disorder, and therefore ineligible for ascertainment/EAP, but for whom learning support teachers identify as having functional problems that require substantial educational support and assistance;

- directly compare the Queensland ascertainment/EAP process that requires a definitive medical diagnosis with the Victorian educational system that relies on functional assessment for determining a child's educational needs. Measures should compare the number of children identified as requiring educational assistance, the amount of assistance and support the children receive, the duration of the support, financial reimbursements to the schools and the comparisons in the social and academic improvements in the children;

- engage in a consultation process with stakeholders in order to monitor the progress and effectiveness of the new EAP process. Teachers, health professionals, parents and administrators of Education Queensland need to participate in a comprehensive assessment and evaluation of EAP to

determine whether it is meeting the needs of the children who require access to support and intervention programmes in schools.

While the rhetoric of Commonwealth and State governments espouses the need for further support for children in their early years, expenditure in recent budgets does not reflect rising concerns. If the government is serious about supporting these children and their families, they must commit considerable funds to developing early detection strategies, pre-school intervention programmes, adequate support programmes for children in schools, educational strategies for aiding parent awareness, and training for medical professionals about the importance of detecting subtle developmental problems prior to school age.

Final reflection

In this thesis I have drawn on the experience of a group of mothers whose children had not been identified until school age, except by the mothers, as having developmental problems. For me, meeting with the mothers and listening to their stories was the highlight of this study and I would like to thank them for their willingness to share such personal and sometimes painful memories.

The experiences of this group of mothers have drawn attention to the historical, cultural and political influences that affect why and how mothers recognise developmental problems in their children, what they do when they are concerned and from whom they seek assistance. Professionals working in child health and education are also influenced by a multitude of environmental factors, affecting their responses to mothers' concerns and their chosen course of action. Child health professionals are privileged by their position, usually being the first professionals with whom mothers raise their concerns, yet these concerns are not always acted upon.

When health professionals relegate a mother's experience, to the fringe of what constitutes 'rational evidence', they fail to recognise the importance of the mother's information in building a comprehensive picture of 'what's going on'. Like a jigsaw puzzle, all pieces are important if the picture is to be completed. Successful puzzle-makers recognise the importance of puzzle edges. They deliberately seek out the edge pieces first because it is the edges that provide the framework on which further pieces of the puzzle can be selected and joined. When edge pieces are

disregarded, the puzzle takes longer to complete. Mothers who raise concerns about their children's developmental problems before school age are providing health professionals with the opportunity to construct the puzzle edges well before the child commences school and begin to have social or academic problems. Perhaps the puzzle may not be complete, but an awareness of the potential picture allows for close monitoring or intervention. Listening to mothers and learning from their experiences is an important piece of the puzzle in the detection of subtle developmental problems in pre-school children.

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Appendices

Appendix A: Letter of introduction

Mrs. Jane Williams

School of Nursing Sciences

James Cook University

Townsville Q 4811

Ph: 47 81 5324

Email: Jane.Williams@jcu.edu.au

30th January 2004

Dear

Thank you for agreeing to participate in my research study. My study aims to document the experiences of mothers' whose children have learning, development or behavioural problems that remained unidentified until they child attended school. In this study, mothers will be given the opportunity to talk about their experiences of their child's pre-school development and behaviour. Using this information I am hoping to identify ways that nurses and other child health professionals, with the help of parents, can identify problems that potentially lead to later difficulties. Early identification of difficulties may lead to more help for parents and earlier access to intervention programs for the children.

Parents willing to participate in this study will be asked to attend an interview. Attendance is voluntary and participants may withdraw from the interview at any time. It is anticipated that the interview will take approximately 1 to 2 hours. Your child will not be required to attend the interview. At times, I may require a follow-up telephone conversation or a follow-up interview to clarify information.

With your permission the interview will be taped and then transcribed onto paper. You can request the tape recorder to be turned off at any time during the interview. You can withdraw consent for this information to be used if you so wish. The tapes

and written documentation will be stored in locked cupboards within the School of Nursing here at James Cook University. No names or addresses or any other identifying information will be stored with these documents so your responses and comments cannot be traced to you.

Names and any other identifying information will not be included in the research paper that follows the study nor in any other related articles. False names will be used in place of your name and your child's name and any other person mentioned in the information that you give. These false names will also be in other publications that may follow the research study, including papers in research journals and articles in child development magazines. Presentations of the findings may also be given at conferences and documented in conference papers, again false names will be used to protect your identity.

If you would like to find out more about this study, please feel free to contact me on the telephone number or email at the top of this letter. You may also contact the James Cook University Human Ethics Sub-Committee if you have any questions or complaints. Contact details are as following:

Tina Langford, Ethics Administrator, research office, James Cook University, Townsville Qld 4811. Phone: (07) 4781 4342 Fax: (07) 4781 5521 Email: Tina.Langford@jcu.edu.au

Thank you for taking the time to read this information, if you would like to participate in this study, would you please contact me at the above telephone number or email address.

Yours sincerely

Jane Williams

Appendix B: Consent form

INFORMED CONSENT FORM: JAMES COOK UNIVERSITY

DETAILS OF CONSENT:

This project aims to document the experiences of parents whose children have learning, development or behavioural problems at school. In this study, I will be given the opportunity to talk about my experiences of my child's pre-school development and/or behaviour.

As a willing participant in this study I recognise that I will be asked to attend an interview. This interview will be conducted in the place of my choice and will last between 1-2 hours. Attendance is voluntary and I may withdraw from the interview at any time. I understand that a follow-up telephone conversation or a follow-up interview may be required to clarify information.

I give permission for the interview will be taped and then transcribed onto paper. I have been informed that I can request the tape recorder to be turned off at any time during the interview and understand that I can withdraw consent for this information to be used if I so wish.

I understand that this information will be used in the study document and publications such as papers in research journals, and articles in child development magazines. Presentations of the findings may also be given at conferences and documented in conference papers. Confidentiality will be strictly maintained and my personal details will not be known by anyone except the researcher and her supervisor.

I have been informed of the availability of the Parental Counseling Service 1 300 301 300, a free service, or I may prefer to ring my local doctor or a local counseling service such as 'BDM Solutions' 47240861, at my own cost, in case I need to discuss my feelings with someone after the interview. If my child has ADD or ADHD, there is a local support group in Townsville that can be contacted on 4789 0593.

I can find out more about this study or the results of the research, by contacting Jane Williams on 07 4772 3031, or email Jane.Williams@jcu.edu.au or via post to: The School of Nursing Sciences, James Cook University, Townsville, 4810.

CONSENT

The aims of this study have been clearly explained to me and I understand what is wanted of me. I know that taking part in this study is voluntary and I am aware that I can stop taking part in it at any time and may refuse to answer any questions.

I understand that any information I give will be kept strictly confidential and that no names will be used to identify me with this study without my approval.

Name: *(printed)*

Signature:	**Date:**

WITNESSED BY RESEARCHER OBTAINING CONSENT

Name: *(printed)*

Signature: *(Principal Investigator)*	**Date:**

School:	School of Nursing Sciences
Project:	The experience of mothers whose children are not identified with learning or behaviour problems until school.

Chief Investigator:	Jane Williams
Contact details:	07 4772 3031
	Jane.Williams@jcu.edu.au