

**This is our life
This is our child**

**Mothers dancing in the
margins of disability**

Thesis submitted by

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Statement of Access

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A handwritten signature in black ink, reading "Natnael Anre Ypinazar". The signature is written in a cursive style with a large, decorative flourish at the end.

Saturday, 1 November 2003

Statement of Sources

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Information derived from the published or unpublished work of others has been acknowledged in the text and a list of references is given.

A handwritten signature in black ink, reading "Naima Anre Ypinazar". The signature is written in a cursive style with a large, decorative flourish at the end.

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Statement on the Contribution of Others

In undertaking the research for this PhD thesis I have received financial support through being awarded an APA Scholarship. In addition, a student stipend from James Cook University of up to \$1000 has been made available.

Editorial and critical feedback has been provided by my supervisor, Dr Paul Pagliano and my co-supervisor, Dr. Kay Martinez. My husband, Dr Stephen Margolis has also provided editorial assistance.

Ethics approval for the research was granted by the Ethics Review Committee of James Cook University.

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I thank the 15 women participants for your time, for the narratives you chose to (re)tell and for the gift of that (re)telling. It was my honour and privilege to have had the opportunity to listen to your stories.

This textual dance is dedicated to 'Norah' one of the participants who passed away during the writing of this thesis, and to 'Melanie' who passed away aged 11½ before the interviews commenced.

ABSTRACT

This study examines the narratives of 15 mothers who each have (or had) a child who is medically, educationally and socio-culturally constituted as having a disability. This research interrogates the mothers' narratives to consider motherhood from the discursive multiple position/ings of the society in which they live. The central research questions are: What are the lived experiences of these women who have a child who does not fit the dominant socio-cultural expectation of a 'normal' child? What subject positions are available for these women? How do they position themselves and how are they positioned in multiple discursive sites such as medicine and education?

By drawing on multiple methodological frames, the study explores the lived experiences and meanings as these mothers (re)construct the discourse of motherhood. Qualitative methods were used to design the research and gather data. Poststructural and feminist perspectives are added to provide additional methods of data analysis. Poststructuralist theorisings are considered new to the field of disability studies and hence provide an opportunity to re-examine subjectivity, power/knowledge and agency in fresh ways, as various mothers in this study reject, (re)construct and even rupture dominant non-disabled assumptions not only of disability, but also of motherhood.

The women's narratives transverse multiple discursive sites but particular attention is paid to medical and educational discourses and the complex interplay of relations of power constituted with/in these sites. The outcome of analysis suggests many women with a child with a disability actively take up the subject position of 'good mother' in keeping with the dominant discourse and ideology of motherhood available in Western society and (re)construct their lives as 'normal', while simultaneously encountering societal and attitudinal barriers which continue to marginalise their child named with a disability and by association, their families. Professionals can do much to dismantle barriers encountered by these mothers and work collaboratively to ensure inclusive life experiences are available. This thesis adds to the body of literature in disability studies by adding new forms of analysis of the interaction between the lived experiences of mothers and society, serving to challenge Western socio-cultural ways of 'knowing' about the intersection of motherhood and disability.

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SECTION ONE

**RAISING THE CURTAIN:
SETTING THE STAGE**

Chapter 1

Setting the stage

We look at dance to impart the sensation of living in an affirmation of life, to energize the spectator into keener awareness of the vigour, the mystery, the humour, the variety and the wonder of life. (Martha Graham, 1990, p # na)

Providing the backdrop: making the research question visible

This thesis investigates the lived experiences of non-disabled women who have a child with a disability. To begin this exploration I retrace the steps that led me to this research. The path is an indirect one that has as its genesis my love and enjoyment of dance. I have learnt many styles of dance since I was 6 years old and it was, and still is, a constant source of joy and desire for me. In 1980, prior to working as a special educator, I had the opportunity to view a documentary featuring a group of adults with Down syndrome learn and perform a movement version of Madam Butterfly. What impressed me most about the documentary was the impact movement had on other aspects of these people's lives, in particular, communication. As a teacher, I recalled my experience with children with disabilities with whom I had worked briefly during the final year of my initial teacher training. As a dancer, I marvelled at the power of movement and wondered what impact movement would have with children with disabilities. At the time, though, the opportunity to explore this further did not present itself. I began teaching in a rural coastal town in North Queensland and was transferred to a city in North Western Queensland. I got married, resigned from primary teaching and had two children. Life moved in other directions.

Upon my return to Deira (a pseudonymous town in Queensland) I commenced my own dance school, teaching children from the ages of 3 years and up. It was not until my marriage ended in 1989 that I recalled my interest in working with children with disabilities through dance and movement. Due to my limited experience working with children with disabilities, I volunteered to work at a Special Education Development Unit (SEDU) for preschool children with disabilities. This SEDU was a small converted

house, complete with its own entrance, located in the lower corner of the grounds of a State primary school. The school and the SEDU were separated by a fence, geographically bounded. I did not question why this was, I simply accepted, without conscious thought that children with disabilities were taught separately to 'regular' preschool children. Looking back I now concur with Kitchin (1998) who proposes that we are "taught how to read and react to the cultural landscape" of disability in our childhood, and are thereby "indoctrinated into perpetuating and reproducing the meanings and messages that spaces convey" (p. 350). I had been taught to think that it was acceptable for students with disabilities to be separated. A product of my experiences as a child and adult, the separation and segregation in educational spaces was a 'knowledge', an 'essential truth' (Davies, 1992). It was for me, a naïve acceptance of the separate spaces children with disabilities inhabit (Kitchin, 1998; Clear, 1999a).

The language of inclusion: the spaces of exclusion

Because of this voluntary experience at the SEDU, I next gained employment as a special education teacher aide working with a small group of children with disabilities in an early intervention program. I remember being informed by the teacher-in-charge of the program that the children we were working with were being 'integrated' with the 'regular' preschool children and that this 'integration' was new within this education region.

I could not understand how having the children with disabilities located in the small withdrawal room next door to the regular preschool room was being 'integrated'. What did it mean to be integrated? What was really so different to being in a separate building, divided by a fence? Was simply being 'seen' enough? What was the impact of 'the gaze' (Foucault, 1973) as the children were geographically integrated (the same building) yet appeared to spend most of their time in separate spaces (the withdrawal area)? Physical spaces represented and reinforced the boundaries which existed between children with disabilities and those without – boundaries I now read as constituting the binary abled/disabled. Perhaps my experiences and questions could be read as echoing

Slee's (1999) argument that the dominant discourse of traditional special education remains in place even though it geographically moves in/to 'regular' educational spaces and becomes phrased in "fashionably inclusive discourse" (p. 125).

My next experience of special education, space and 'inclusion' came when I received a contract to teach at a Special Education Unit (SEU). Once again the spaces and places for children with disabilities were distinct, separate, to children silently constituted as 'regular' or 'normal'. The SEU was located down one end of the schoolyard, self-sufficient with its own entrance; 'special education' teachers separate from 'regular' teachers, 'special education' children separate to 'regular' children. Physical, educational and socio-cultural boundaries were kept in place by discursive practices inherent in education bureaucracy.

It was the experience of working in SEU where the tensions which exist in implementing inclusive practices with and between regular education settings came to the front for me. It appeared to me that the oppositional discourses of special education and regular education fuelled the binary of abled/disabled. It was here that it became more visible. Teachers' attitudes influenced whether a child would be accepted into a regular classroom or not. I recall the difficulty attempting to have one of 'my' children, a child with a disability, included in a regular classroom; my search to find a 'regular' teacher prepared to have the child in their class. Yet too, there were slippages of boundaries; regular teachers willing to include a child, special education teachers unwilling to dismantle the boundaries of special education spaces. The words of 'mainstreaming', 'integration' and 'inclusion' began to resonate with multiple meanings as they were enacted and spoken into existence. The lived experiences of children being 'mainstreamed', 'integrated' or 'included', depended on the polysemous readings of the words, and of those who spoke them:

Words do not stand for some kind of essential object but have a more open texture; their meaning is to be found in their use in thought and action in the description, interpretation, organisation and evaluation of behaviour. (Rizvi & Lingard, 1993, p. 5)

My experiences working in the SEU, in the discursive site of special education, talking with non-disabled mothers (as well as some fathers and other female carers) and

working with their children, activated a keen interest in parental right of choice regarding which educational settings they want their child with disabilities to attend. This interest led to my previous research conducted in 1994 utilising qualitative research methodology to explore the perspectives of Annette, a grandmother seeking an inclusive education for her grandchild (Ypinazar, 1997). During the research process Annette told many stories about living with a (grand)child with disabilities and I found myself becoming increasingly interested in the narratives of mothers who have children with disabilities; their life stories beyond the (special) education context.

Mothers' conversations and the stories they told me therefore (also) brought me to the writing of this research text. As Kvale (1996) has stated, "we exist in a conversational circle, where our understanding of the human world depends on conversation and our understanding of conversation is based on our understanding of the human world" (p. 296). In my experience, mothers were the parent usually involved with therapists and teachers, and often the ones involved in negotiating Individual Education Plans (IEPs) which are a requirement for students with disabilities. Mothers seemed to me to be in the forefront of advocating for change for their children, particularly in the areas of education, post-school options and residential living. It appears that many mothers continue to be the primary caregiver taking on the major responsibility of care for their children (Cuskelly, Pulman & Hayes, 1998; Smith, Tobin & Fullmer, 1995; D. Richardson, 1993; A. Richardson & Ritchie, 1989; Traustadottir, 1991; Willoughby & Glidden, 1995).

By contrast as I began reading the literature it became clear that the stories and 'voices' of non-disabled mothers who have children with a disability are rarely heard in the academic literature and that their stories and voices need to be investigated further. Taking into consideration women's lack of voice in academic literature, the traditional status of women in Western society, and the marginalisation of people with disabilities (see e.g. Corker, 1998; Read, 2000; Slee, 1999) I consider the move to "giving voice" (Pugach, 2001) to non-disabled mothers who have children with disabilities a relevant and timely research topic.

My interest throughout this thesis is in how non-disabled mothers who have children with disabilities position themselves, or see themselves positioned with/in various

discourses. What meanings do they give to their life experiences of having a child with a disability? How do they experience the physical and discursive spaces disability inhabits? I seek to answer these questions through this research by exploring the discursive, physical and metaphoric spaces inhabited by 15 women who have children with disabilities, and to examine the multiple socio-cultural discourses that help shape their identity (Golden, 1997).

Introducing the dancers: the participants of the study

I believed it would be interesting and informative to gather narratives from women of different generations. The women's stories would then originate from multiple time frames and provide a sense of historicity in the discourse of mothering a child with a disability. To achieve this I actively sought to interview women whose children were from different age groups as part of the formulation of my research plan. I set out to locate four to five women in each age bracket; mothers with young children in early intervention, those who had children currently at school and those with children who had finished their education. I believed that this number would be achievable in terms of my research methodology. Making contact with these women came about through "multiple gatekeepers" (Lincoln & Guba, 1985, p. 253). My initial contact with participants was made through an informal "gatekeeper"; a woman I knew, who gathered names of possible participants for me and I expanded from her list to garner other women.

I approached Therese (all participants' names are pseudonyms) whom I knew personally through my previous work in early intervention. Therese agreed to be involved in the research project and to contact three or four other mothers she thought would be interested in participating. After Therese had nominated the mothers and made initial contact, I followed with a phone call to the mothers offering further information about the study and seeking their participation. All agreed to participate.

Therese's list of mothers included three women I had met previously while working in the field of special education. Diane and Sandra were two women I had met when I

worked in early intervention. At the time I contacted Sandra, her daughter Melanie had only recently died, but she indicated her desire to be part of the research. Another woman on Therese's list was Liza, a professional working within the field of education, and whom I first met in 1995. My interactions with Liza had always been undertaken within a professional therapy/education discourse. Susan, the next mother on the list was new to Deira and I had not met her before. I also decided to ask a very close friend, Serena, to be part of the research process. I had been hesitant to ask Serena as I was concerned about the possible impact of the research process on our friendship, and our friendship on the research. The fifth mother on Theresa's list was Michelle. I had not met Michelle before, but I had met her son, Craig, during my employment in special education.

Because Michelle's son was now over school age I asked her if she would suggest other mothers whose children were also above school age, and she provided me with phone numbers of mothers she thought might be interested in participating. In this instance, I made contact with these mothers personally rather than asking Michelle to make initial contact. Of the mothers contacted only one declined to participate. Along with Michelle, the other women who have older children and are part of this study are Kathy, Elise and Patti. I personally approached Norah, whom I knew from my childhood, to be part of the research and she agreed. Norah and her daughter Cheryl were the oldest mother/child dyad in this study (Norah passed away during the writing of this thesis).

To collect stories from mothers whose children were not yet attending school, I phoned a teacher I knew working in early intervention. After explaining the research topic to her, she agreed to speak to some mothers and later presented me with a list of names and phone numbers of mothers she had contacted. Once again, I followed her initial contact with a phone call providing further explanations and requests for participation. The mothers who have young children are Melissa, Robyn, Oranea and Julia. By selecting the women (rather than the disability groupings of their children) it was inevitable their children be constituted/diagnosed as having a diverse range of impairments; autism, cerebral palsy, chromosomal abnormalities (including Down syndrome), as well as intellectual impairment are among the names 'assigned' to the children's impairment.

In total 15 mothers were involved in the narratives that constitute this thesis. A brief outline providing more information on each woman who participated in this research project is presented in Appendix A. The women derive from different spaces – physically, socially and economically. While there are obvious similarities (they are mothers, they are part of the study and so on) the range of women selected helps disrupt the notion of a homogenous group; ‘mothers who have a child with a disability’. Some mothers are not in paid employment working either in, or from the home, or in volunteer positions. Some of the mothers are professionals with tertiary qualifications working in their chosen field of employment whereas others have part-time work. In this study are mothers who are married, while others are sole parents who are widowed, divorced or separated from their husband or partner. They ranged in age from 26 years to 77 years at the time of the first interview. The women’s diversity stems from their age, socio-economic, education, work and/or marital status. Diversity does not derive in this instance from ethnicity, as 14 of the 15 women are white, although not all are Australian (details of the 15th woman withheld to avoid identification). Nor is there diversity in religion as all the women have a Christian background, but not all are actively involved in their religion. Each women’s stories are spoken through the multiple subject positions and subjectivities afforded by the discursive fields in which she participates.

The geographic space this text inhabits is Deira, a large town in Queensland. As is common in research texts, names of people, places and organisations, except for Education Queensland, are pseudonyms. The mothers who (re)told their stories all lived in or near Deira at the time the first set of interviews took place, however some have since moved from Deira. Six of the women were born locally, six were from different parts of Australia and three from overseas, two of whom currently live in Australia. All of these mothers expressed a willingness to be involved in this research project and all signed a consent form acknowledging their agreement. Additionally, all mothers understood that they could withdraw from the study at any time. Ethics approval from James Cook University was obtained for this research (see Appendix B).

It is necessary to now consider more closely the techniques which in/form the dance’s choreography, to construct an appropriate stage on which to step out the women’s words.

Beginning to choreograph: a layer of qualitative methodology

My quest to acknowledge the way in which I am positioned, and position myself, particularly as a white, non-disabled female, who is also wife, mother, dancer, choreographer, researcher and writer (among many other selves/subjectivities), motivated me to traverse readings in multiple fields, from feminism to human geography; from special education and disability studies to poststructuralism, to determine the conceptual framework. It is the individual and collective stories of the above women, their meaning-making and the way they (re)construct themselves as mothers who have a child with a disability that is the focus of my research. This focus brought with it the premises of qualitative research, which is interpretive, looking to how the social world is experienced, interpreted, or produced (Denzin & Lincoln, 1994). Typically, within the field of educational research, qualitative methodology provides a vehicle for stories to be told which “are anchored in real, local meaning and experience” (Pugach, 2001, p. 439). The aim in qualitative research is not to discover an essential truth; rather its focus is on the way people make sense of their life experiences (O’Day & Killeen, 2002) within the multiple discursive sites in which they interact.

Writing about the use of qualitative methodologies specifically in the field of disability, O’Day and Killeen (2002) contend that:

Qualitative research can clarify how the impairment itself, societal attitudes, and social environments work in combination to affect an individual’s experience. It can shed light on the personal meaning of disability through the life experiences of study participants. And it can be used to elucidate the evolving meaning of disability through study participants’ perceptions. (p. 15)

The use of qualitative research methodologies provides an appropriate mechanism to investigate my research question, as it provides the means to consider personal meaning-making, as well as the interaction between the individual and socio-cultural discursive sites. However, this is tempered with the knowledge that the information gleaned is particular to these women and the contexts in which they were involved. It does not pretend to take into consideration the perspectives of those other than these women, and hence this research has limited generalisability. As will be discussed more fully in chapter 2, I have used in-depth, conversational interviews to collect data pertaining to this research project.

My subjectivities and the subject positions I have taken up through available discourses influence the way I see the world, choose the questions I ask, analyse the mothers' narratives and (re)present their stories (see Denzin & Lincoln, 1994). By providing a brief personal narrative on the manner in which this research question evolved I have afforded a glimpse of some of my potential biases, particularly concerning inclusive education, the separation of regular/special education and parental right of choice. Within the constraints of a doctoral thesis, my personal bias and desire as a non-disabled white woman/mother/researcher is to (re)tell the many stories of the women using their words as often as possible to emphasise their voice – for as noted by Shakespeare (1996) the disability identity starts with stories and “having a voice” (p. 111).

Positioning myself as special educator, I acknowledge some insight into the needs of children with disabilities, but this insight is limited to the structured spaces and temporality of the school environment. It also affords me insight into educational policy and processes that take place when a child has a disability, and an insider's view into regular/special education. As a mother I believe I will have some common points which will allow empathy for the women and their narratives, yet as a mother of non-disabled children I cannot ‘know’ what it is like to be the mother of a child with a disability.

The literature I reviewed for this research project has not been separated into a neatly designated ‘Literature Review’ chapter, or written as a separate entity; rather it has been integrated throughout the thesis as part of the unfolding of the women's narratives. Integrating the literature also better represents the holistic nature of the research process, as the literature review was ongoing as analysis took place. The use of literature needs to reflect the qualitative methodological underpinnings of the research where literature may be “used inductively so that it does not direct the questions” (Cresswell, 1994, p. 21).

I made a conscious effort not to determine what I would find *a priori*. However, as a researcher I unavoidably enter the research process with preconceived ideas from previous research and my review of the available literature. There were specific purposes for which I used the literature before commencing the research – to perform an overview of previous studies conducted with/on non-disabled mothers who have

children with disabilities, and also to explicate methods of analysis, which are discussed later in this chapter. It must be emphasised at the outset that the initial literature review was not used to drive the thesis; rather the literature review progressed in tandem with the ongoing analysis of data collected through the mothers' narratives. It unfolded over time and as such is integrated throughout the thesis. For example, literature reviews which were conducted on motherhood, medical care, therapy and intervention, and the future were stimulated via the data analysis process rather than prior to the beginning of the study. This literature added to the theoretical perspectives arising from the women's narratives.

I was interested in (re)presenting the narratives of the women in this study and achieving an appropriate academic writing style was a challenge. Glesne and Peshkin's (1992) suggestion that "qualitative research has no conventional organizational format" (p. 168) allows me some freedom to write beyond the traditional positivistic research style. Yet their suggestion contains no guidelines on how to achieve this. I have made a conscious decision not to use the traditional numbered headings and subheadings within the chapters. To clearly delineate the verbatim words of the women who participated in this study, I have placed each woman's words in italics and have often indented their quotes throughout the thesis. At other times, their words are interspersed through my writings, again italicised. Narratives which focus on an individual woman's stories are introduced by the symbol ♪ before their name. Wherever possible I chose to use the women's words taken from their interviews as headings and sub-headings, and these too are italicized.

Throughout this thesis dance is used as an allegory in an attempt to bring another layer of meaning to the writing. An allegory is defined as a "figurative treatment of one subject under the guise of another" (The Macquarie Concise Dictionary, 1988, p. 22). Dance in its varied and complex formations is used to represent not only the research act, but also the multiple people involved – the participants, audience and researcher. Dance represents the lived experience of many societies and cultures across time. Henry, Magowan and Murray (2000, p. 253) suggest that dance can "be viewed as historically embodied, contextual, discursive and interconnected domains of lived experience". As such, I contend that dance is suited to act as an allegory for the thesis, where the women's' narratives can also be considered in this manner. Numerous

headings and sub-headings throughout the thesis refer to the performative act of dance and its relational connection with the performative acts of research, reading and writing.

Chapter 1 has begun with a description of the way the research question evolved, an overview of the women who agreed to participate, and has laid the foundations of my use of qualitative research methodology. The rest of this chapter provides the contextual frame in which the study is situated. The study is first located within the broad rubric of disability studies and then delves into the intersection of feminism and disability. Additionally a brief research and educational context for the study is provided. Poststructuralism is explored as an additional tool for analysis of the data.

Dancing into disability discourse

The social model of disability separates disability from impairment, and then attributes the creation of disability to the dominant socio-cultural environment. In the Western world this environment is largely an oppressive one which views disability as deviance, damage, dependence – the so-called ‘sick role’ – and perpetuates labels and stereotypes which stigmatise, disempower, deskill and marginalize disabled people. (Corker, 1998, p. 221)

My focus is specifically on non-disabled women who are mothers of children with disabilities. However, it is relevant to situate this study within the discursive site of disability studies. Socially, disability is seen and largely accepted as a personal ‘tragedy’ by Western society (Parker, Forbes & Findlay, 2002; Vohs, 1993), and is pathologised within a medical framework. The lack of disability is considered the normal, positive and universal experience by dominant society (Morris, 1995). While the women in this study are non-disabled and therefore could be considered part of the normal, universal experience, they also transgress the boundaries of able/disabled, normal/deviant in multiple discursive sites through their daily life experiences with their ‘disabled’ children.

The medical and social models of disability inform current disability discourse. Crow (1996) defines the medical model of disability as one whereby “a person’s functional limitations (impairments) are the root cause of any disadvantages experienced and these

disadvantages can therefore only be rectified by treatment or cure” (p. 57). The medical model, or personal tragedy model, “is ingrained in the social identity of non-disabled people. Non-disabled identity, as other identities, has meaning in relation to and constructs the identity of others” (Swain & French, 2000, p. 573). Disability is ‘Other’ to dominant socio-cultural expectations, assumptions and norms; “to be non-disabled is to be ‘not one of those’” (Swain & French, 2000, p. 573). Generalising discourses of impairment “contribute to the social construction of identities, cultural conventions and institutional orders” (Seidman, 1992, p. 70). The notion of the individual’s deficit in disability is heightened and perpetuated through available social, medical and educational discourses with dominant socio-cultural groups traditionally giving meaning to discursive practices. Christensen (1992) points out that “a disability implies a non-problematic pathological condition intrinsic to the individual; it fails to recognise that the concept of disability is socially constructed” (p. 11).

Within disability studies, the social model of disability (Oliver, 1983; 1990) has been considered the dominating narrative at the forefront of the success of the disability movement (Lloyd, 2001). The social model of disability has been responsible for “the analysis of disability as socially structured and shaped by common experiences of oppression, and it raised the profile of disability within the universal human rights political agenda” (Lloyd, 2001, p. 726; see also Scott, 1991). The principal aim of the disability movement “is to combat the barriers faced by disabled people” which are both “physical and social” (Branfield, 1999, p. 399). Branfield (1999) continues by acknowledging the work done by people with disabilities who are activists and academics, such as “Abberley, Barnes, Morris, Oliver and Shakespeare” who have “shown that it is an irrefutable fact that disabled people are an oppressed group” (p. 399). However, within the category ‘disabled’ there exists a “discourse of sameness” which “works to conceal the diversity and difference that exists between people who have a disability” (Fullagar & Owler, 1998, p. 444).

Much of the theorising of disability has been done by a specific group of people with disabilities – “white, middle-class, professional, physically disabled men” (Lloyd, 2001, p. 726; see also Branfield, 1999; Humphrey, 2000), or as Corker (1999) suggests, there exists a “malestream disability theory” (p. 629). The development of a social model by a particular group is at the cost of the “subjective experience and individual difference

within subgroups” (Lloyd, 2001, p. 726). As I read the disability literature, particularly on the social model of disability, I questioned: is it possible for academic activists with physical disabilities to speak for those with intellectual disabilities? Who speaks for the carers (typically non-disabled women/mothers) of those who cannot/do not speak? Do academics and activists tend to group people with disabilities into a homogenous group in their writings? Goodley (2001) suggests this may be the case when he asks, “are people with ‘learning disabilities’ really that non-human ... that they can be ignored by disability theory ... as an excluded category?” (p. 211). According to Branfield (1999):

The disability movement is already sidelined by the discourse of Academia. A discourse which has no time for knowledge which is experiential, subjective and emotive. As a political stance, all disabled people are oppressed. It is what disability is: a socio/political construction. (p. 401)

Debate currently exists within the field of disability studies about the need to include a sociology of impairment, a call to bring the body (and its biologically named impairment) into the theorising of disability. Disability theorists (Corker, 1999; Corker & French, 1999; Crow, 1996; Hughes, 1999; Hughes & Paterson, 1997; Shakespeare, 1998; Shakespeare & Watson, 1997) call for the inclusion of impairment and personal embodied experience to enhance the current social model of disability making it more relevant to the lives of people with a disability. Corker and French (1999) assert that the social model has as its basis the distinction between disability “which is socially created” and impairment which they define as “a physical attribute of the body” (p. 2). They go on to state that this distinction creates a dualism, a binary that in effect silences impairment. Impairment remains part of bio-medical theorising, rather than being part of the sociological theorising about disability. One concern with blurring the binary of disability/impairment is the possible return to the individualisation of the disability experience, returning to a personal tragedy and medical model and detracting from the political status and power the social model has gained in recent years.

A call also exists to tell the disability story of parents (Avery, 1999, p. 118). Researchers (e.g. Berg-Weger, Rubio & Tebb, 2001; P. Ferguson, 2001; Parker et al., 2002; Stainton & Besser, 1998; Thomson, 1994) have called for research which examines the perspectives of parents who have children with disabilities. The stories which will be (re)presented in these pages begin to answer that call, that “need”; for as

Avery (1999) goes on to state, “the act of telling one’s story is a crucial first step toward what [the writer] bell hooks has called a ‘coming to voice’” (p. 118). By utilising qualitative methodology and offering mothers the opportunities to speak of their experiences of living with a child with a disability, I anticipate that multiple possibilities of narration will arise; and multiple storyings be (re)told. As my research aims at investigating the meaning-making of women and how they experience their life as a mother of a child with a disability, “research as stories can uncover the many experiences of disability” (Nagel & Raxworthy, 1998, p. 94).

Disability studies is a growing field of research interest with “many facets and numerous styles” (G. Williams, 2001, p. 124) which lacks a “unifying theory or perspective” (p. 125). The discourse of disability studies lacks definitive boundaries (Gleeson, 1997), and I use this lack of boundary keeping by drawing on multiple disciplinary areas throughout the analysis and (re)presentation of the data collected. Gleeson (1997) contends that the “lack of disciplinary boundaries is a potential advantage, allowing disability studies the freedom to integrate the rather arbitrary divisions of thought institutionalised in Western academics” (p. 180). Consequently, readings from nursing and medical discourses, education, human geography, poststructuralism and feminism amongst others have influenced the writing of this text.

Movements of education: bringing education into the frame

The contexts for the educational discourses in which the women participants and their children are/have been involved, reveal extensive changes in models of educational delivery for children with disabilities. As the women have children in different stages of education (early intervention to post-school), their experiences of educational services for children with disabilities range from no provision in the 1960s in Deira, to segregated institutions through to a more ‘inclusive’ approach to the education of children with disabilities currently in place. The evolution of educational models of service delivery is in response to social, political and legislative guidelines, such as the *Queensland Anti-discrimination Act, 1991*, the *Queensland Disability Services Act, 1992* as well as Commonwealth legislation; *Disability Services Act, 1986* and the

Disability Discrimination Act, 1992 (Department of Education Manual [DOEM], *Action Plan: Educational Provisions for Students with Disabilities* [EPSD], 1998, p. 3). However, special education has come from the discourses of psychology and medicine and this informs current discursive practices (Paul, French & Cranston-Gingras, 2001; Slee, 1999; Slee, 2001; Ware, 2002).

In response to societal and educational changes, Education Queensland has released policy documents which relate specifically to the education of students with disabilities. The pertinent documents are the *Action Plan: Educational Provisions for Students with Disabilities* (DOEM, 1998) and the *Ascertainment procedures for Students with Disabilities* (DOEM, SM-15, 1998). Policy documents are instrumental in shaping school practice and delegating responsibilities through the various personnel involved in the education sector.

Education Queensland, in its policy documents, maintains they have a system-wide commitment to inclusive schooling whereby “schools will include and value students through the provisions of a range of flexible curriculum options that allow access and participation and which ensure that educational outcomes are maximised” (DOEM, CS-05, 1998, p. 2). The words “access” and “participation” are not defined and it is arguable whether these terms refer specifically to access and participation in the spaces of a regular classroom. The definition of inclusive schooling in the policy document does not make it clear where curriculum programs for students will be implemented, which in turn determines placement options (spaces where a child will experience her/his school day). According to *The Framework for Action on Special Needs Education* (UNESCO, 1994) adopted at the Salamanca Conference, the underlying principles of the inclusive school are:

That all children should learn together, wherever possible, regardless of any difficulties or differences they may have. Inclusive schools must recognise and respond to the diverse needs of their students accommodating both different styles and rates of learning and ensuring quality education to all through appropriate curricula, organisational arrangement, teaching strategies, resource use and partnerships with their communities. There should be a continuum of support and services to match the continuum of special needs encountered in every school. (pp. # na)

Schools, as defined in the Education Queensland policy statements, include preschool, primary and high schools, as well as special schools. While special schools remain a 'school', segregated placement in a special school can be considered inclusive schooling following the above definition. This outcome does not appear consistent with the international UNESCO definition of inclusive schooling.

The Curriculum and Studies section of the DOEM, *CS-15: Principles of Inclusive Curriculum*, states that "Education Queensland is committed to providing an inclusive curriculum which meets the needs of students and society" (DOEM, *CS-15*, 1998, p. 1). The policy statement determines that a curriculum is inclusive, in part, when participants involved in the learning process "identity and address barriers that limit students' opportunities, participations and benefits from schooling" (p. 1). The policy statement does not, however, stipulate in which educational space an inclusive curriculum will be provided – an "inclusive curriculum" could be delivered in a segregated setting.

While the language of policy documents appears to speak to a discourse of inclusivity, dominant exclusionary practices may still be retained and justified. The interpretation and implementation of policy is dependent on the attitudes and beliefs of administrators, teachers and other professionals (Loxley & Thomas, 1997; Mousely, Rice & Treganza, 1993). The way policy is "made and interpreted at the levels of discourse, attitudes, assessment, curriculum and pedagogy, and the distribution of resources" can act as barriers to successful inclusion practices (Barton & Armstrong, 2001, p. 703).

To determine the educational needs of children with disabilities Education Queensland has developed an "elaborate ascertainment schedule" (Slee & Allan, 2001, p. 179). The policy document supporting the process by which individual support needs are determined is the *Ascertainment Procedures for Students with Disabilities* (DOEM, *SM-15*, 1998). At the completion of the ascertainment process, one of six levels of support is recommended with level 6 viewed as providing the greatest amount of resource support. It is the "nature and severity of disability" which is used to determine the resource provision (Slee & Allan, 2001, p. 179). The program for the student "may occur across an array of educational settings, namely primary (including preschool), secondary and special schools or other approved educational locations" (DOEM, *SM-15*, 1998, p. 5).

While providing a mechanism to determine support allocation for students with disabilities, the ascertainment process also acts to inscribe the bodies of students and adds yet another label to the child – this time a particular ‘level’, another category into which the child with a disability is placed and named; ‘she’s a level 5’. However, the process of naming and defining levels of need into “master-status categories, cultivates the misconception ... that individuals can easily be located within the discontinuous categories that such names construct” (Gordon & Rosenblum, 2001, p. 8). As Slee (1999) notes, “discursive practices have constructed the category, official knowledge and treatment (Foucault, 1973) of the special educational needs student. This discourse continues to inform policy blueprints for inclusive education” (p. 124). The emphasis on individual impairment and needs speaks to the medical model of disability rather than constructing education and inclusion as a social issue and acknowledging that schools are disabling to students with disabilities; that there exists what Slee (1999) refers to as “educational disablement” (p. 119).

My experience in special education has been that many parents desire inclusive educational opportunities for their children with disabilities. In particular I wondered how current policy as explicated in this section impacts on those mothers whose children are currently with/in the discursive site of education.

Dancing within feminism: adding a feminist frame

I familiarised myself with existing studies which focused on non-disabled mothers who have children with disabilities. Searches through the ERIC abstract database and hand searches located research which investigated areas such as models of family functioning (e.g., Bernier, 1990; Crnic, Friedrich & Greenberg, 1983; Gallimore, Weisner, Kaufman & Bernheimer, 1989; Gallimore, Weisner, Bernheimer, Guthrie & Nihira, 1993; Nihira, Weisner & Bernheimer, 1994) stress and coping (e.g., Beckman, 1991; Bruce & Shultz, 1994; Crowley & Taylor, 1994; Donavon, 1988; Dyson, 1997; Erickson & Upshur, 1989; Hanson & Hanline, 1990; Krauss, 1993), employment (e.g., Cuskelly et al., 1998; Freedman, Litchfield & Warfield, 1995; Willoughby & Glidden, 1995), grieving (e.g., Bruce, Schultz, Smyrnios & Schultz, 1994; Olshanky, 1962; Wikler, Wasow &

Hatfield, 1981) and support networks (e.g., Marcenko & Meyers, 1991; Bright & Wright; 1986; Hadadian, 1994; Trivette & Dunst, 1992). Much of this research contains discursive frames which constitute disability as a negative social and cultural construction.

Many of the above studies I reviewed compared stress and coping across two groups of mothers. The ‘dominant’ group of (usually) white, middle-class, Western mothers with non-disabled children were generally the comparison group against which mothers who have children with disabilities were measured (e.g., Beckman, 1991; Dyson, 1993; Kazak & Marvin, 1984; Krauss, 1993; Harris & McHale, 1989; Noh, Dumas, Wolf & Fisman, 1989; Rousey, Best & Blacher, 1992). Establishing an able/disabled binary within the discursive site of motherhood highlights Morris’ (1995) contention that “white middle-class women’s experiences have been taken as the norm and other women’s experiences have been treated as ‘different’” (p. 265). The above-mentioned studies were typically conducted from the assumptive standpoint of the medical model and “based on the assumption that parents of a child with a disability were different in some way to parents of non-disabled children” (Pagliano, 1994, p. 43). This assumption posits the construct of non-disabled women who have children with disabilities as ‘Other’ to (white, middle-class, non-disabled) mothers of non-disabled children.

Like other women in Western society, many non-disabled mothers who have children with disabilities continue to be the primary caregivers, taking on a large proportion of child care and housework (Cuskelly et al., 1998; Darling-Fisher & Tiedje, 1990; Freedman et al., 1995; Marcenko & Meyers, 1991). Additionally, limited employment options due to the needs of their children (Cuskelly et al., 1998) and limitations on lifestyle choices (Cant, 1994) also have an impact on women who have children with disabilities. Despite the importance of motherhood in/to society, it is “relatively neglected in terms of academic interest” (Packwood & Sikes, 1996, p. 341). Thompson and Walker (1995) suggest that there is only a “handful of feminist scholarship on women’s experiences as mothers” (p. 856) which explores more marginal topics such as motherhood and disability (e.g. Bright & Wright, 1986; Traustadottir, 1991). Gross (1998) also emphasises the lack of feminist scholarship on motherhood, when she points out that “mothers as subjects cannot continue to be ignored” (p. 2).

I had not initially contemplated using a feminist frame to situate this research; however the aforementioned studies challenged me to investigate feminism further. While these studies focused on non-disabled women who had children with disabilities they were generally not feminist in methodology or intent. I came to see the value of adding a feminist perspective to my research by taking what I perceived to be relevant from various feminist theorists (e.g. Davies, 1992, 1996; Flax, 1993; Hays, 1996; Stanley & Wise, 1993; St Pierre, 2000; Oleson, 1994; Weedon, 1987; 1997) and applying it to the conceptualisation and methodology of my research. I noted that there are multiple discourses among feminist writers (Fawcett, 1998; Sheldon, 1999; Thompson & Walker, 1995), and “many feminisms, hence many views, some conflicting” (Oleson, 1994, p. 158). Feminism is an “extremely broad area covered, with many differing orientations, central rallying points, and political agendas” (Fawcett, 1998, p. 265). Sheldon (1999) asserts that “broadly speaking, feminism can be defined as the ideology of women’s liberation” (p. 644) and continues to explain that feminism has become fragmented and is now “an umbrella term” (p. 644). Feminism is considered multiple and fragmented and I intend to clarify the aspects of feminism I have taken up for this study. I have made a conscious choice to take from feminist scholarship that which is relevant to the research question.

The way the world has come to be ‘known’ and ‘understood’ is considered to have been generated by a patriarchal “malestream” (D. Morgan, 1998, p. 651). This construct of “malestream” knowledge is consistent with the critique already offered on disability studies (Corker, 1999; Sheldon, 1999). “Malestream” knowledge is andocentric, perpetuating the dominance of a patriarchal society (Leslie & Sollie, 1994; Riger, 1992). Feminists have long argued for a social knowledge that is not stated from a white male perspective (Leslie & Sollie, 1994). However, early feminist research tended to universalise the experiences of/for all women. Nicholson (1992) asserts:

Feminists have been forced to deal directly with the methodological issues of objectivity and universalism. In pointing out the partial and biased nature of much of traditional and contemporary scholarship, feminists have quite frequently become suspicious of all claims to impartiality and generality. (p. 9)

“The problematic nature of terms such as ‘patriarchy’, ‘women’ and ‘oppression’ was for those ‘at the margins’ of feminism further highlighted in the debates within the feminist movement” by women of colour (Brooks, 1997, p. 16). The critique generated from

research by women outside of the white, middle-class and heterosexual group encourages us to see and acknowledge the many differences with/in the category 'woman'. By troubling the 'essential' identity of the category 'woman', feminism has produced "an array of critical subgenres ... each an acknowledgment that every woman is never simply a 'woman' but is multiply identified across a spectrum of cultural categories" (Thomson, 1994, p. 1).

While feminism typically has as its focus the impact of gender on the lived experiences of women (e.g., Lather, 1992; Weedon, 1987), Ramazanoglu (cited in Brooks, 1997) states that "feminists that maintain a metanarrative of male power ... fail to address the issue of women who are marginal or framed as 'other' in mainstream feminist discourse" (p. 66). Within this thesis my feminist frame will be to investigate the experiences of the women participants who are 'Other' because they have a child with a disability, as opposed to the more typical focus of gender in feminist studies. Sheldon (1999) proposes that there are divisions among feminist writers as to whether "feminism should organise around issues of commonality among women or embrace the many ways in which individual women are different from each other" (p. 645). While feminism has embraced the concept of diversity among women, there remain many women who "feel that their voices are marginalised by feminism" (Sheldon, 1999, p. 645).

Arising from my literature searches I contend that non-disabled women who have children with a disability are constituted as 'Other' not only in general academic research, but also in the feminist research purportedly carried out for and on behalf of women (Corker, 2001; Morris, 1995, 2001; Sheldon, 1999). By locating non-disabled women, who are mothers of children with disabilities, as the central focus in my research, the voices and narratives of the participants will provide an opportunity to enrich the existing body of literature in feminist scholarship. I endeavour to look at the commonalities as well as the differences and diversity amongst the individual women who participated in this research act. Lacking in recent research are the narratives, and voices, of mothers located outside the dominant discursive constructs of motherhood. In a study completed by Parker, Forbes and Findlay (2002) they report that parents who have raised a child with a disability claim that "the idea of disability result(s) from a

deficiency of imagination, which prevents people from believing that the experiences of people in other groups can be as rich and rewarding as their own” (p. 10).

Feminism and disability

Attempting to locate an intersection of feminist and disability theory in the literature was difficult. Searches in Expanded Academic ASAP with the keywords feminism and disability, disability and motherhood, disability, feminism and motherhood, produced few results. Thompson (1992), a feminist writer, acknowledges diversity among women, yet disability is missing from her listed categories of diversity. While some theorising by non-disabled academics who are mothers of children with disabilities exists (e.g. Avery, 1999; Landsman, 1998) there appears to be a silence, a gap, in the academic literature at the intersection of feminism and disability.

While studies and theorising on/for disabled women are largely absent from feminist attention (Clear, 1999b; Morris, 1995; Sheldon, 1999; Slee, 2001; Thomson, 1994), Sheldon (1999) states that feminist methods of analysis have been applied by disability theorists to disability studies at the structural, cultural and individual levels. Feminism has used the slogan “the personal is political” (Sheldon, 1999, p. 650) and Sheldon (1999) suggests that this approach is implicated in the lack of feminist scholarship on disability: “It is often thought sufficient to examine only the personal experiences of privileged, white, non-disabled, heterosexual women” (p. 650). Sheldon claims that “those on the margins are overlooked” and further comments that “disability has not been addressed in a positive way by mainstream feminists” (p. 644). There is a dearth of academic literature at the intersection of feminist theorising(s) and disability and the lack of feminist literature becomes even more pronounced when considering non-disabled women who are mothers of a child considered on the margins, a child who is ‘Other’.

Non-disabled women living with/in disability discourse do not appear to be visible in the academic theorising of motherhood discourse. Acknowledging the unmarked category ‘abled’, Sheldon (1999) situates society as “disablist” and considers that

“perhaps it is inevitable that non-disabled feminists should share society’s negative attitudes towards disabled people” (p. 650). As Morris (1995) a white, female, feminist, academic with disabilities contends, “disability and old age ... [are] ignored by feminists” (p. 265). Two recent editions of *Hypatia* (vol, 16, 2001; vol, 17, 2002) focus on the theoretical work on disability identity and “feminist philosophical reflections on women and disability” (Kittay, Schriempf, Silvers & Wendell, 2001, p. xii). The editors make the point that “this publication marks the first time a philosophy journal has devoted a full issue – in this case a double issue – to what can be learned from and about disability” (Kittay, et al., 2001, p. xii). Within these issues, Corker (2001) claims that “in feminist texts, disability is commonly placed in the category of the ‘undefined other’” (p. 36).

Non-disabled women who become part of the disability experience through their children are not included in the philosophical discussions contained in these issues of *Hypatia*. Nor are they discussed in feminist accounts of motherhood. Lloyd (2001) recently contends “there is in fact a remarkable absence of a disability perspective in feminist theorising about motherhood” (p. 720). The tension/problematic in the intersection of feminism and disability is highlighted in the current debate concerning genetic testing (e.g. Hume, 1996; Parker et al., 2002; Sheldon, 1999; Thomson, 1994). While feminist theorists who have disabilities are lamenting the lack of feminist research in which they are considered (eg. Morris, 1995), there continues to be a ‘group’ of women, namely non-disabled women who are mothers of children with disabilities, who are not considered in theorising in feminist or disability studies. The use of feminist scholarship within this thesis then, will focus on the non-disabled women’s lived experiences with a child with disabilities, their meanings, subjectivities and positionings, the complexity and diversity of their lives, and at the same time, examine how their lives are socially and culturally constructed within existing power relations in numerous discursive sites. The lived experiences and meaning-making of non-disabled women who have children with a disability represents an area of study lacking in feminist literature and disability research.

Movements of poststructuralism

The dance is a poem of which each movement is a word. (Mata Hari, 1990, p #
na)

Pugach (2001) comments that “one of the primary characteristics of contemporary, postmodern qualitative research is the commitment to bring to the surface stories of those whose voices have not been heard” (p. 443). Continuing to explore ‘voices’ that are not heard, I turn now to poststructuralist theorising(s) which will add to the body/ies of knowledge concerning non-disabled women who have a child with a disability. I add poststructuralism to the conceptual frame already developed, namely qualitative research methodology, disability studies and feminism.

My readings in poststructuralism fascinated me with the notion of multiple meanings, boundary keeping and binary divisions (Davies, 1996). Poststructuralism does not embody a unified theory and as such encompasses a range of theoretical positions and interpretations (Brooks, 1997; Nicholson, 1992; Weedon, 1987; 1997). Poststructuralism rejects the idea of essential truths; the notion that there is one reality (Lupton, 1993); it rejects “totalizing, essentialist, foundationalist concepts” (Lye, 1997, p. 1). In recent years epistemological debates “have shattered the traditional picture of science as neutral, disinterested, and value free and have replaced it with a view of knowledge as socially constructed” (Riger, 1992, p. 737). Returning to disability studies, Corker (1998) proposes that the idea that disability is a socio-cultural creation is “more at home against the scenery of the cultural and intellectual movements of postmodernism and/or post-structuralism” (p. 222).

Poststructural theorists such as Davies (1992, 1996), Weedon (1987, 1997) Fox (1993), Foucault (1973), Lather (1992, 1995) as well as theorists who work the boundaries of feminism, disability and/or poststructuralism (Corker, 1998, 1999, 2001; Crow, 1996; Morris, 1995, 2001) have influenced my writings and shaped the way I have taken up poststructural theorising(s) within this thesis. Poststructuralism takes up a number of constructs in its theorising(s) predominantly the concepts of language, power, discourse, subject and subjectivity. Poststructuralism can be seen as being “bound up with issues of meaning, representation and identity” (Corker, 1998, p. 224). Scott (1992) states,

“words and text have no fixed or intrinsic meanings, that there is no transparent or self-evident relationship between them and either ideas or things, no basic or ultimate correspondence between the language and the world” (p. 254). Yet it is through language that we construct our subjectivities, take up the selves we present to the world, and our ways of being in the world. Language is privileged in the social construction of subjectivity (Weedon, 1997).

A number of key elements of poststructural theory outlined by Davies (1996) are relevant to my research question of exploring non-disabled mothers’ (re)construction of their lives when they have children with disabilities. Davies argues for the dismantling of the concept of power held by the traditionally dominant group and the breakdown of the “metaphysical nature of binary divisions between people (such as male/female, white/black, heterosexual/homosexual)” (p. 12). Throughout the thesis the concept of power and the dominant positionings in society are explored through binary divisions, which as Davies (1996) stipulates are “not ‘natural’ divisions but constructed ones” (p. 12). This is particularly important when one takes into consideration that disability is considered a social construct by disability theorists, yet little work has been done within disability studies utilising poststructural frames.

Language is not fixed, nor is it unitary. As Corker (1998) illustrates, “words, signs, pictures, book, jokes and so on change their meaning over time, from context to context and from person to person” (p. 224). The extent of change in language use can be seen in the discursive field of disability, where language employed to talk about and describe people with disabilities has changed over time. Words previously used to speak of people with a disability such as ‘moron’, ‘crippled’, ‘retarded’, have been replaced by the use of the label ‘intellectual impairment’; the use of ‘handicapped’ has changed to ‘people with disabilities’, and in the UK changed again to become ‘disabled person’. However, as this research is Australian I use the Australian terminology, ‘people with disabilities’. Hence, in this brief example, language and its associated (temporal) meaning, can be shown to be slippery and unstable (Scheurich, 1995). Since the meanings of words are not fixed it is proposed that “meaning is shaped contextually within institutions and by prevailing social practices” (Bensimon, 1995, p. 3).

Addressing the poststructural perspective of power drawn from the work of Foucault, Corker (1998) states that power “is held by those who are able to draw upon discourses which allow their actions to be represented in the light of ‘knowledges’ currently prevailing in society” (p. 226). Discourses are described as “the production of knowledges, including the social practices and power relations that inhere in such social knowledges” (Bensimon, 1995, p. 2). A discourse is not simply a language or text, “but a historically, socially and institutionally specific structure of statements, terms, categories and beliefs” (Scott, 1992, p. 254). Lye (1997) explicates further:

The production of discourse, [that is] the (historical, material) way we know our world, is controlled, selected, organized and distributed by a certain number of procedures. Discourse is regulated by rules of exclusion, by internal systems of control and delineation, by conditions under which discourses can be employed, and by philosophical themes which elide the reality of discourse. (p. 3)

Discourses exist in multiple sites and are established and maintained by dominant hegemonic practices. St. Pierre (2000) contends that “once a discourse becomes ‘normal’, ‘natural’, it is difficult to think and act outside it” (p. 485) and Hirst (2002) reiterates this when she states “hegemonic practices are often invisible and disguise dominance as naturalised practices” (p. 7). It is possible to locate disability as outside the ‘normal’ experience of the dominant socio-cultural groups, and for this marginalisation to be accepted. Crang (1998) acknowledges that “categorising people is a political process, where the stakes are often to define taken-for-granted natural, unquestionable categories” (p. 60).

Subjects are formed in and through discourse (Lye, 1997), and as Davies (1992) explains:

The meaning of subject in poststructuralist writing takes its meaning in opposition to the liberal humanist idea of the subject. The various discourses in which one participates, or in terms of which one gains a voice or becomes a speaking subject, also are the means by which one is spoken into existence (even prior to one’s birth) *as subject*. (pp. 63-64)

In a Foucauldian analysis, discourses “offer ‘subject positions’ for individuals to take up” (Brooks, 1997, p. 21). Returning to the allegory of dance, I am made subject through my participation in a discursive site of dance and therefore able to take up, or resist taking up subject positions which are available within this discourse. The subject positions I take up in dance include dancer, performer, teacher, mother (of a child learning dance) and watcher. Each subject position constitutes different ways of being

within the discursive site and at times these positions are contradictory. Dance is but one of the multiple discursive sites in which I am made subject. Discourses “subject each person to the limitations, the ideologies, the subject positions made available within them” (Davies, 1992, p. 64). This notion of discourse and the subject positions which are available will be relevant in the analysis of the data provided by the women who participated in the study.

The subject and the concept of subjectivity are central to poststructuralism (Weedon, 1997). Of note is the importance of language in “constructing people’s subjectivity, or their lived experiences, self-perception and conceptions of reality” (Lupton, 1993, p. 298). Subjectivity may be defined as:

That combination of conscious and unconscious thoughts and emotions that make up our sense of ourselves, our relation to the world and our ability to act in that world...the concept of subjectivity can capture both the notion of people as intentional subjects – actors in the world – and at the same time as subject to forces beyond their conscious control” (Crowley & Himmeleveit, 1992, p. 7).

Subjectivities exist in the languages perpetuated in discursive sites and are continually spoken into existence. With/in dominant discourses and discursive sites the mothers in the study narrate their experiences bringing into play the subject positions they have taken up and/or resisted. Weedon (1997) states that “the individual is both the site for a range of possible forms of subjectivity and, at any particular moment of thought or speech, a subject, subjected to the regime of meaning of a particular discourse and enabled to enact accordingly” (p. 34).

According to Derrida, dualisms, which can be defined as “the oppositional pairing of terms”, are “not stable” and the “the separations they make cannot be sustained. Furthermore the dualisms are not just oppositions, they are characteristically inequalities; one element of the pair is considered the basic, more profound, or otherwise dominant element” (Cuff, Sharrock & Francis, 1998, p. 290). The first term is silenced and is considered dominant; the second term in the binary is named and defined by the first. Being non-disabled – or ‘normal’ – is the dominant status in society and is not named, whereas ‘disability’ is named; we do not speak of people named as ‘able’ – that is the taken-for-granted status. Flax (1993) contends that normal “acquires meaning only in and through its function as the (apparent) opposite of deviant” (p. 96). Sarup (1993) proposes that the “‘privileged’ term depends for its identity on its excluding the

other and demonstrates that primacy really belongs to the subordinate term instead” (p. 51). Similarly, Davies (1996) proposes that the “binary division systematically disadvantages one half of each binary” (p. 12), and that the first in the binary is the privileged term. The poststructural process of deconstructing binary divisions occurs by making visible “language or discursive practices through which these differences and patterns of privilege are spoken into existence, and by searching for alternative ways of constituting identity” (Davies, 1996, p. 12).

Subjectivities as “notions of the self” are “dynamic and responsive to shifts in discourses” (Lupton, 1993, p. 53). Each woman therefore has the possibility of “resistance to as well as acceptance of dominant discourses” (Lupton, 1993, p. 53). By decentering the subject and acknowledging the death of the essential subject/subjectivity, a women’s subjectivity is open to change (Weedon, 1997). Within the current academic literature relating to families who have children with disabilities, is limited acknowledgment of women who have taken up new forms of subjectivity within available dominant and taken-for-granted discourses; who have taken up or resisted available subject positions.

➤ Valmae’s story: dancing into poststructuralism

I acknowledge Riger’s (1992) succinctly stated sentiments; “entering the terrain of poststructuralism at times feels a bit like Alice falling into a Wonderland of bewildering language and customs that look superficially like her own, yet are not” (p. 734). To arrest my fall I found it opportune to (re)turn to personal experience as a way of moving around and within this new ‘wonderland’. In the following autobiographical segment, I take up multiple subjectivities as dancer, daughter, sister, teacher, researcher and writer as I take a very personal dance and investigate the language of movement. Dance has always been a significant part of my life experience. No matter where I lived, what was happening in my life, I somehow managed to include dance, whether it was performing, taking class, or teaching.

Using dance as a metaphor for qualitative research is not unique; Janesick (1994, p. 209) uses a “metaphor of dance” to explore qualitative research design. She invokes Dewey (1934/1958) in recalling his notion that “there is no work of art apart from human experience” (p. 210) and goes on to propose that “because dance is about lived experience, it seems ... the perfect metaphor for qualitative research design” (p. 210), thereby linking a premise of qualitative research with dance. Janesick explains the process of a dancer warming up the body, followed by exercises, finishing with a cooling down period and likens these to three stages of research design. Throughout her analogy, she likens the dancer, and sometimes the choreographer, to the researcher, constantly searching and making decisions. I position myself, in general terms, as a qualitative researcher and liken the researcher to that of a choreographer throughout my thesis, as I too search and make decisions about the movements of stories presented by the mothers “in a contextual, personal and passionate way” (p. 217).

While Janesick likened the dancer/choreographer to the research process, I suggest a more complex use of a dance analogy with/in this text. Dance may be seen as an extended metaphor, in other words, an allegory, where dance can be read in its literal form simply as movement and story while simultaneously having another layer of meaning. Dance can be read as more than existing in a space filled with choreographic shape and form, but can be seen as “an active, fraught and dynamic force in human social life” (Henry et al., 2000, p. 259). Like the stories of the mothers (re)presented on the stage of this thesis, dance is about lived experience, deriving through and out of the historical, social, religious and cultural milieu of experiences of dancer, choreographer and audience. Dance as movement is removed from the description contained in these words; the bodily, embodied and aesthetic aspect distanced from its new (re)presentation in textual form.

Pursuing the dance allegory further, I concur with Henry et al. (2000) when they position dance “as a performative moment of social interchange that is not merely reflective of prior political, personal, social, and cosmological relations, but also constitutive of them” (p. 253). Dance reflects past and present multiple discourses, subjectivities and subject positions which shape its performance. I liken the “performative moment of social interchange” as representative of the multiple discourses which make up our socio-cultural world; each moment of social interchange

reflecting a discursive site representing political, social and historical institutional practices and ways of being in the world.

Similar to our life experiences, dance and the stories they can tell are imbued with multiple meanings and layers. Whitehouse's (1997) beautifully illustrated example of multiple meanings and readings as she explored her thoughts while sitting on her verandah watching some small birds in a milky pine tree enabled me to see how dance could be read with multiple meanings. Whitehouse (1997) explains that poststructural inquiry "dislodges the notion of the one, true story, and makes explicit multiples of stories and makes possible multiple ways of being" (p. 2).

I move to consider multiple meanings of one particular dance to illustrate my point. My sister Carmen choreographed this dance over the months of October and November 1989 and it was performed by Carmen and myself at the end-of-year performance of my dance school. The dance reflects her storying, in choreographic language and form, of our father's death from a brain tumour in May that same year.

So, imagine if you will two dancers in this dance. The stage is bare except for a rectangle of light sharply focussed on the stage floor, downstage and centre. The remaining lighting is soft and the music is solemn, haunting – cellos and violins. We are dressed in sleeveless long white dresses with full skirts, a red sash around our waists. At times, we move together as one performing the same movements. At other points in the dance, we move alone, or perform different movements to each other. Movements are performed both to and away from the rectangle of light. Within the dance, movements suggest comforting each other as we place our arms around one another, each taking turns to be the comforter/ed. The dance finishes as we scatter rose petals on the rectangle of light, turn and join hands, holding them skywards to a motive of light (the motive of a rose) on the backdrop of the stage.

For many in the audience, the dance was simply that – a dance made up of intricately woven movements holding no other meaning. The dance read entirely as movement with 'knowledge' of what constitutes 'good' dance; technique, choreography, sound, costuming, lighting and design. The performance can be read by the audience with a focus on the dancers – their presentation, technical ability, whether (or not) the

movements were harmoniously synchronised with the music and each other, the way it was presented, and what emotion it invoked in the watcher. The performance can then be read in terms of its choreographic composition – the ability of the choreography to impart emotion, its relationship with the music, use of stage and space, and its aesthetic shape. Perhaps some in the audience may have read the symbolism in the rectangle of light, and the scattering of rose petals, adding another layer of meaning to the dance.

For the dancers, who are the insiders, there are yet other meanings to be explored within the dance. There is movement – the response to the music and to each other, the giving to the audience, the joy of dance and performance infusing the dance. A new layer of meaning is added in the awareness that the dance had its origins in our father's death. Throughout the dance are many movements, the language of dance, which represent the brain tumour, movements of touching and supporting the head, movements which symbolise Dad's loss of movement to the left side of his body. The rectangle of light is symbolic of the grave site, the scattering of rose petals on/into the rectangle is the (re)presentation of the funeral.

Adding a poststructural reading of positioning and subjectivity I read the dance with yet another layer of meaning. While Carmen and I have our own stories, movements and perspectives within the dance, we also share the same space and similar storyline, that of our father's death. Carmen was positioned as the single daughter living overseas, who did not come home for what was to become the last Christmas with Dad. I was positioned as a married woman with two children who lived in Deira, an hour's drive away from where my parents lived. We each brought multiple subjectivities to this powerful experience in our lives – for example, daughter, married/single, and dancer/choreographer – just as we brought different aspects of our selves to the performing of the dance. The dance is positioned with/in the discourse of Catholicism and the ritual of death, with its use of genuflection, of the grave, of the scattering of rose petals. The dance illustrates my resistance to this discourse as I turn away from taken-for-granted expectation of visiting the gravesite. Henry et al. (2000) suggest that “movement is able to infuse space with socio-religious and socio-political meaning” (p. 253) and religious overtones were visible throughout the dance. The dance can also be read with/in a medical discourse with the symbolic representation of the brain tumour and the embodiment of pain. Movement spoke to the loss of Dad's ability to move, and

movement spoke to our emotional response to Dad's death through and within our bodies.

This single performative moment of dance has been read in multiple ways, with a palimpsest of layers (Davies, 1996) uncovered for the audience and for the dancers. It is demonstrative of the multiple readings and multiple storylines that are available to be taken up in poststructural theorising(s). Additionally it has touched on subjectivities and position/ings within multiple discourses.

I end this autobiographical segment by reflecting on the allegory of dance and turn to the common perception of dance as a theatrical performance. Dance as performance is the style of dance in which I am highly involved. Ballet, in particular, defines the embodiment of a category of dance, and as such, determines those who are made subject to its discourse. Ballet is often considered an art for the elite of dancers; for highly trained and skilled dancers with specific body types. I read dance as being movement, usually to music (but not always) and not as one particular category, or another. At the

intersection of dance and disability, there are performance groups which have as their focus people with disabilities, and I contend that it is appropriate to include this disruption of common taken-for-granted expectations of dance and performance, as I allegorise dance in the research and text.

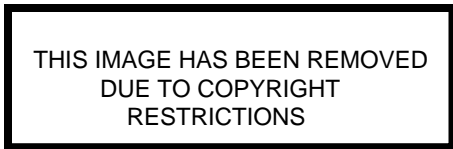


Figure 1 Anjali Dance Company (no date [n.d])

The uses of language

For the remainder of the thesis I will generally refer to the children as 'named with' a disability, rather than the poststructural term "constitute" (Davies, personal communication, December, 2002). I will use the term 'impairment' when referring

specifically to the biological/medical diagnosis. “Naming ... is a key process in the creation of categories of people” (Gordon & Rosenblum, 2001, p. 6). I use the phrase ‘named with’ to highlight and reinforce that ‘disability’ itself is a social construct, given a name, and continually reinforced and constituted through numerous discourses such as medicine, education, therapy and other socio-cultural discourses. The naming of ‘disability’ is to situate the word as oppression by dominant Western society (Morris, 2001).

The diagnostic/medical name/label/category of specific or non-specific impairment serves to confer status of ‘disability’ upon a heterogeneous group, simultaneously having the effect of constituting them as marginal and ‘Other’. The name ‘disability’ which is more frequently used than ‘impairment’, has the potential effect of creating a homogenous and essentialised group which ignores the myriad of difference within the category of the named biological/medical impairment. As already established by Fullagar and Oowler (1998) a discourse of sameness can be applied when speaking of ‘disability’ thereby having the effect of turning a diverse range of people into a homogenous entity, ‘the disabled’. The designation of ‘Other’ is through “the attribution of characteristics that distinguish categories of people from some presumed (and usually unstated) norm” (Scott, 1991, p. 773). While established statistical norms are used to define and categorise impairment, these diagnostic/medical categories often become the defining characteristic, and are implicated in the designation of disability as ‘Other’. Hughes (1999) stipulates that “the impaired person, becomes synonymous with the ‘condition’, is made meaningful and becomes wholly known by it alone” (p. 165). Additionally, categories function “to create and justify social organisation and exclusion” (Flax, 1993, p. 96).

While women who have children named with disabilities re/construct discourses of motherhood and family with/in disability discourse they continue to be enmeshed with/in the language of non-disabled discourse showing the constitutive power of language. The words available to mothers to speak, to describe and inscribe their child, in medical, educational and social discourses continue to speak into existence disability as a discourse of negativity and tragedy; “something’s wrong”, “a problem”, “disability”, “labels”, “levels”. Weedon (1997) notes that “the meaning of the existing structure of social institutions, as much as the structures themselves and the subject

positions which they offer their subjects, is a site of political struggle waged mainly, but not exclusively, in *language*”(p. 37). Language continues to categorise and separate their children, naming them as ‘Other’. Language is used to deal with the powerful institutions that structure and govern their lives. Over time, many words have been applied in discourse to people that differed from the ‘norm’ – ‘retarded’, ‘sub-normal’, ‘handicapped’, ‘spastic’. Currently the term in common use in Australia is ‘people with a disability’, yet this also continues to label and by doing so works to subject and categorise two seemingly distinct, and separate, groups, able/disabled. It is binaries such as this, which are located within discourse, that poststructural theorising(s) seeks to deconstruct.

Applying poststructuralist and feminist theorising(s) to the storying of the women who participated in this study provides an opportunity to recognise “the importance for each individual of finding ways of recognising the powerful shaping ... that takes place through language and of finding ways to counteract that force” (Davies, 1996, p. 13). Through the mothers’ narratives the play of language and power, resistance and acceptance constituted in disability discourse and played out across multiple discursive sites is displayed throughout the thesis. Discourses can be read as sites of resistance and struggle. Additionally, the use of poststructural theorising(s) provides “a way of analysing constructions of meaning and relationships of power” which question “unitary, universal categories” (Scott, 1992, p. 253) such as disability. As the mothers dance their stories onto the stage of this text, their words will demonstrate their struggles within/against dominant socio-cultural discourses. I heed Branfield’s (1999) sentiments as I (re)present the storying of the women when she contends that “non-disabled people must attempt to listen to our voices, and to be non-disablist and non-supportive of the old oppressive structures” (p. 403).

An acknowledged characteristic of poststructural theorising(s) is the exploration of difference and diversity (Fawcett, 1998). Throughout this thesis, I explore the fragmented, diverse realities of non-disabled women who transgress the binary able/disabled. The women in the study may be read as ‘Other’, as different to who they once were, now defined by their child with disabilities and, I contest, a marginalised group. They exist in multiple spaces and subjectivities, multiple binaries, abled (as they are read), disabled (as their children are read); mother/self; wife/mother; teacher/parent;

public/private; professional/parent; medical/lay. They move within spaces created out of the abled/disabled binary – they choreograph their lives in multiple spaces, dancing their selves, their stories on a multitude of stages.

Blending the movements: feminism, poststructuralism and the women's voices

There needs to be a change to established processes of research in order to “give audience to marginalized voices” (Dhunpath, 2000, p. 550). The act of taking up feminist and poststructural theorising(s) on mothers' narratives provides an entry point for analysing the mothers' acts of meaning-making through the stories (re)presented in the following chapters. Davies (1996) emphasises a “celebration” of difference for those groups who are outside the “discourses and practices of the dominant cultural group” (p. 12). Corker (1998) proposes that disability is now situated in a “postmodern world” and that looking at “the relationship between the individual and society ... can bring marginalized voices to the fore in a positive way” (p. 232).

In research methodologies much is written about giving ‘voice’ to the participants, giving voice to the disenfranchised, the marginalised groups in society (e.g., L. Richardson, 1992; Denzin, 1994; Hatton, 1998). Yet, can one ever ‘give’ voice to another person? In the taking up of poststructural theorising(s) comes the awareness of multiple voices; a polyphony of voices (Denzin, 1994; Packwood & Sikes, 1996). There are many meanings of the word ‘voice’ and it is used in multiple ways for the purpose of this study. As researcher and writer of the thesis, I (re)present the participants' voices as text to be read by the reader. The disembodiment of the text from the speaker results in losing different readings of voice – readings of laughter, of, happiness, of frustration, of sorrow, of grief, of moving on and of acceptance. Yet, these are my constructions of voice, and I write simultaneously of emotive and spoken voice of the individual, and of the voices of the marginalised. Rudduck (1993) expresses this clearly:

Voices are more emotive, more disembodied, more disturbing. At one level they can ‘represent’ individuals or groups who have been denied the right to contribute or who have simply not been heard. Such voices speak to our conscience. At another level, voices remind us of the individuality that lies beneath the surface of

institutional structures whose routine nature pushes us to work to ‘sameness’ rather than to respond to difference. (p. 8)

Qualitative research acts “as a vehicle for purposely hearing the voices of those who have not been heard before” (Pugach, 2001, p. 443), and Oleson (1994) contends that the question of voice and the associated account form part of the foundations of feminist research. Reissman (1993) states that “we cannot give voice, but we do hear voices that we record and interpret” (p. 8). Additionally, Slee (1999) adds that while feminist writings have established the importance of voice it is “suppressed in the special needs research agenda” (p. 125).

While motherhood may be considered a universal metanarrative, it is distinctly an individual experience (Packwood & Sikes, 1996). Oftentimes the only thing that the participants in this study have in common is that they have a child named with a disability. This ‘common bond’ can be read as problematic, for classifying or even categorising children with a ‘disability’ as a group ignores the myriad of differences existing with/in the category named as disabled. The categorisations and study of mothers who are grouped because of ‘disability’ is also problematic. As indicated previously, the individual in poststructural thought is fragmentary and there is a “clamor of different women’s voices contesting orthodoxy and demanding recognition for their unique experience of womanhood” (Seidman, 1992, p. 67). “It is time to ask new questions about families in all their diversity, rather than search for the bad things that are assumed to befall any family that does not match this standard” (Thompson & Walker, 1995, p. 858). A poststructural lens provides a filter through which to problematise such taken-for-granted categories of motherhood and disability.

Utilising poststructural and feminist approaches with qualitative methodologies “offers a useful, productive framework for understanding the mechanisms of power in our society and the possibilities of change” (Weedon, 1987, p. 10). The association of feminism and poststructural theorising(s) makes it “possible to acknowledge and to respond to difference and diversity, whilst continuing to maintain an emphasis on social divisions and particular manifestations of power” (Fawcett, 1998, p. 268). This thesis focuses on the socio-cultural discourses that impact on the women’s storying through an analysis of power structures and binaries. The voices of mothers in this study and the meanings they make of discursive practices provide the narratives which will

acknowledge diversity and difference in their lives. What are the women's stories, when provided an opportunity to speak? What stories do they tell outside questionnaires of stress and coping? As "post structuralist approaches understand the self to be produced constantly anew through language" (Fullagar & Owler, 1998, p. 446), how then do the women construct themselves, individually and collectively, as they move into the different physical and metaphoric spaces that disability inhabits in multiple dominant discourses?

Using in-depth, conversational interviews and policy documents to undertake the research, I then apply poststructuralist and feminist theorising(s) to analyse the data. I read each of these methodological and analytical frames as fluid, blending, shaping and informing each other as they are choreographed to form a complex whole. I call on, and take from, the theoretical frames that which is relevant to investigate my research focus. Each theoretical frame is used purposely with varying degrees of intensity throughout this thesis.

I have already established that the 'theories' of disability, poststructuralism and feminism are many and varied, and at times, may be conflicting. Within these theories, or ways of understanding the world, I have selected particular areas which guide the way I analyse the data. The choices involved in data analysis include many decisions which arise from my multiple subjectivities, values, attitudes and beliefs and I have provided a brief insight into my beliefs concerning inclusive schooling, parental right of choice and the lack of voices from mothers who have children with disabilities. My conviction concerning bringing the mothers' voices to the fore strongly influences how I analyse the narratives (re)told. The discourse of disability as socially constructed guides my analysis, rather than a discourse of disability as tragedy, and this has been influenced through my experiences as a special education teacher, and also through my friendship with mothers who have children named with disabilities. As such, poststructuralism with its emphasis on binary divisions, and the notion that these divisions are not natural ones but are socially created, allows an opportunity to analyse the narratives from a social construction point of view. The lack of voice of mothers who have children with disabilities in disability studies literature also impacts on the data analysis as I seek to focus on the women's perceptions and experiences.

My analysis derives not only from my multiple ways of understanding the world and my multiple attitudes, values and subjectivities – I strive to use aspects of poststructuralism, feminism and disability studies as a blended methodology to allow the women’s voices to be heard within academic literature, taking from each that which provides an opportunity for voices to be heard. From a poststructural perspective I intend to analyse the women’s narratives in search of dualisms and binary divisions, the subject positions made available to them and those they have taken up and/or resisted, power/knowledge and the boundaries which surround the multiple discourses in which the women participate. My feminist analysis focuses on adding mother’s voices to disability studies which has tended to be dominated by academics and researchers who are typically male with physical impairments. Additionally, feminism does not traditionally focus on the perceptions and experiences of mothers who have children named with disabilities. My analysis seeks to explore the discourse of motherhood within a disability discourse.

My data analysis is also influenced by my previous readings of the literature. For instance, during my previous research writings in the field of special education by researchers such as Ferguson (1995), Fulcher (1989), Lipsky and Gartner (1987), Slee (1993), Skrtic (1991) and Thousand and Villa (1990) strengthened my thinking and beliefs concerning inclusive education for children with disabilities. My knowledge of disability studies was shaped in the first instance by the writings of researchers such as Barton and Oliver (1992) and Oliver (1983, 1990) and expanded over the course of this current research to include Corker (1998; 1999; 2000; 2001), Hughes and Patterson (1997) and Shakespeare (1996; 1998) among others. These influences provided the backdrop to my understandings, values and beliefs which impact on the way I read and analyse the data. Additional readings arising from the development of the contextual, theoretical and methodological frameworks in which I situated this thesis and the analysis of the women’s storyings were then choreographed to form multifaceted textual layers.

The textual dance: outlining the structure of the thesis

This thesis is organised into five main sections and comprises one or more chapters in each section. This first section, 'Raising the curtain: setting the stage', introduces the origins of the research focus, and outlines the theories used to conceptualise the research and the methodologies employed to collect, analyse and (re)present the data. Chapter 1 has provided an outline of the research question, the participants, and the theoretical and methodological underpinnings of the research process. In chapter 2 the methodological component of research interviewing – collecting and analysing the data – and the textual (re)presentation of the women's narratives within this thesis are discussed in further detail.

Section 2 of the thesis, 'The dance of motherhood: the intersection of motherhood and disability', focuses on non-disabled women (who are mothers) who are positioned within the dominant discourse of motherhood and is concerned with the way constructs of 'good mother' (e.g. Lupton, 2000) and 'intensive mothering' (Hays, 1996) come to be taken-for-granted. Words such as 'stress', 'coping', and 'acceptance', are spoken into existence in/by research literature on mothering/parenting a child with a disability. I focus on the mothers' meaning-making and transformations as they (re)construct themselves with/in the binary able/disabled. The conclusion of this section deals with the future. Mothers and I explore simultaneously their memories of their thoughts of the future when they learnt of the diagnosis of disability of their child, and of the future yet to come.

Sections 3 and 4 are dedicated to (re)presenting the mothers' stories. In these sections mothers' stories are given prominence as they dance their way across the pages. The stories are set in medical and educational spaces and discursive sites as these were the narratives that came to the fore in the interview process and were of import in the mothers' storying. The women's stories are examined in terms of the way individual mothers position themselves, and are positioned and made subject with/in discursive sites. The stories are placed in socio-cultural and political contexts in their retellings and issues of power/knowledge are analysed. Concluding the thesis is section 5, 'Lowering the curtain'. Mothers' thoughts on the impact of the interview are brought into the

discussion. Additionally the multiple movements which in/formed the textual performance are discussed as well as implications and considerations for further research.

Chapter 2

Words and movement: interviews, narratives and (re)presentation

It is the story which enables us to remember important moments of the past that in turn moves us forward. Stories moreover give us a means to reflect upon our experiences, to consider what we liked and didn't like and why. They become the reservoirs of memories, enabling us to recall the pleasure and effort it took to master something new, or to overcome a fear. In other words, narrative enables us to remember the moments when we experienced ourselves differently, to continue the positive vein of our life story into the future. (Fullagar & Owler, 1998, p. 448)

Steps in the rehearsal studio: collecting the stories

Stories are powerful ways of learning which convey knowledge within the complexity of life itself, expanding our understanding of others and developing a sense of community within them. (Nagel & Raxworthy, 1998, p. 94)

This chapter focuses on data collection and analysis, and the (re)presentation of the voices of the women who narrated parts of their life experiences. The chapter also investigates the methodology of the conversational interview and the use of narrative and storying as meaning-making.

In the previous chapter I displayed the techniques with which I have chosen to choreograph this text: the application of a blend of poststructural and feminist analysis of the data using qualitative methodology to undertake the research. This chapter is concerned with showing the process of the research more clearly and continues to use the allegory of dance in representing the research act. Interviewing “forms the basis of the reconstruction” (Crowe, 1998, p. 342) of the women's storying which in turn in/forms the thesis. As my focus was on the women's storying and the subject positions available to them, and those they have taken up and/or resisted with/in discursive sites, I chose a conversational approach to interviewing (Burns, 1994; Kvale, 1996; Patton,

1990). Conducting interviews as conversation provides the possibility “of the interviewee and the interviewer developing a shared understanding” (Limerick, Burgess-Limerick & Grace, 1996, p. 451).

The more traditional approach to research interviewing is considered to be “grounded in a masculine, positivist paradigm” (Limerick et al 1996, p. 449) often denying the participants a voice, positioning them as subject and the researcher as author/authority figure. In the postmodern era, the narrative has gained increasing prominence providing an opportunity for the reader/audience to hear the ‘voices’ of those who are members of ‘Other’ groups (Luttrell, 2000). The possibility for women to speak their narratives in the conversational interview provides opportunities “for individuals to re-examine and reconstruct their own perceptions of personal experience” (Dhunpath, 2000, p. 546.) Invoking Derrida, Dhunpath (2000) suggests that the individual narrative “becomes a type of architecture, a vast array of impulses, instincts, memories, and dreams – visualized, theorized and told as a story” (p. 546).

Utilising the interview as informal conversation means that questions act as a form of “narrative incitement” as the interviewer questions in such a way “to prompt, if not provoke, narrative roles and elaborations” (Gubrium & Holstein, 1997, p. 154). As I was interested in the mothers’ stories, the use of conversation as interview seemed to provide a method allowing the narrative priority, to provide an opportunity for mothers to speak of issues of import within their storying. I often refer to the interviews as storying representing to me the way the interviews were filled with multiple, individual, yet interwoven stories of the lives of the women who spoke with me.

By constructing interviews as conversations, the participants “move toward discourse and negotiation about the meaning of the lived world” (Kvale, 1996, p. 42). Privileging the narrative through conversational interview, the women are accorded the opportunity to tell their narratives in their own way (Cotterill & Letherby, 1993). While being subject in the interview situation they were able to take up a subject position which allowed them the possibility of choosing the stories they wished to (re)tell. In poststructuralist terms, “language constitutes reality, each language constructing reality in its own way ... it is the structures of language that speak through the person” (Kvale, 1996, p. 43). In this interpersonal context, the “local, manifold, and changing language

contexts come into prominence ... The contextuality of the meaning obtained is central in the narrative approaches” (Kvale, 1996, p. 44). The narrative approach provides opportunities to explore the contexts – the discursive sites – in which the women are positioned, and position themselves. Additionally, individual experiences are validated and the (re)presentation of storying in textual format, as opposed to oral, provides the means by which the experiences of the women in this study can reach a wider audience (Cotterill & Letherby, 1993).

As already stipulated in chapter 1, pseudonyms have been used for all women and members of their families to acknowledge the ethical issue of “right to privacy” (Fontana & Frey, 1994, p. 372). Even though some women believed this unnecessary, pseudonyms were given to all rather than risk identification of some. I came to realise, however, that there are tensions with the use of pseudonyms and the protection of privacy. My supervisor commented on a sense of “vagueness” that featured in some of my writing (Pagliano, personal communication, August, 2002). In some instances I have modified the particular disability to avoid identification of the child and mother. Additionally, parts of some stories have been heavily edited or left out in their entirety. My concern was that their (re)telling might unintentionally identify some of the women and children involved, or perhaps others peripheral to the research. At times information on/about the women’s husbands/partners is sketchy; as such information could have hindered the women’s right to privacy. The need for anonymity clearly impacts on parts of the (re)telling and limits some discussion. I have endeavoured to make the narratives as clear as possible; however, on occasions, the ethical issues of confidentiality, protection and privacy of participants outweighed the concerns for clarity.

The importance of these ethical issues of privacy, confidentiality and protection from harm is in many senses a moral one and reliant on the researcher to fulfil. I believe that the metaphor of the interview as a gift, suggested by Limerick et al., (1996), best describes my intent not only during the interviews, but also through the (re)presentation of the women’s storying:

It is useful to conceptualize the interview as a *gift* of time, of text, and of understanding, that the interviewee gives to the interviewer ... there is an ingredient of trust ... that the researcher will not betray them, abuse their power, or misuse their words. (p. 458)

By conceptualising the interview as a gift, I can also acknowledge the sense of responsibility I began to feel towards the mothers and their narratives once we commenced the storying/interviewing process. The metaphor of a gift is to celebrate “agency of the interviewee, and to shift and disrupt conventional notions of power”, thereby compelling “the researcher to treat data with a degree of respect and to be continually sensitive to the giver” (Limerick et al., 1996, p. 458).

The storying of the women: outlining the interview process

The stories woven through this text were collected during three sets of interviews held over a 15 month period from May 1999 to July 2000. Of the 15 women originally interviewed, eight completed three interviews. Due to a variety of the women’s personal reasons, five women completed two interviews. One woman left Deira after the first interview to travel around Australia and was not contactable by phone. Another mother could no longer be contacted in Deira after the first interview despite many attempts by phone and also visiting her place of residence. I left Australia after the first round of interviews, as my husband secured a job in the Middle East and I moved there with him and my son in July 1999.

The first set of interviews was held with the women over May and June 1999. With the women’s permission, I audio recorded all interviews. This enabled me to concentrate on the mothers and the stories being told, without the need for copious note taking. The cassette recorder did not appear to hamper conversational/interview flow. In all interviews the women spoke freely and with considerable detail. On two occasions I was asked to turn the cassette recorder off, because the stories being recollected and (re)told triggered an emotional response and the mother became visibly upset, and commenced crying. After I left all interviews, I entered comments into my personal journal, adding details not possible to capture in the recording. Additional observations, my response to the interviews, questions and thoughts were included for later reflection.

I opened conversations with each woman in much the same manner: I asked for a brief background description of themselves and then to talk about their family experiences

when they were ready. Most women gave a quick outline of where they were born, some background information on themselves, their childhood, meeting their husband or partner, and then moved quickly into telling their family story, generally beginning with details about their child named with a disability. However, other women provided quite detailed storying about aspects of their childhood and the years before having children. I chose to follow the flow of the women's narratives with probes for detail and clarification, rather than commence from a starting point of *a priori* questions. Interviews with each woman lasted approximately 1½ hours, during which time the women spoke readily with a sense of "narrative urgency to tell it like it was" (Luttrell, 2000, p. 3). Their stories moved and flowed in/across time as memories surfaced in their (re)tellings.

Between my return visits to Australia, each interview was transcribed and two printed transcripts were produced, one for myself and another transcript for the mother. The printed copy was rechecked against the recording and corrections made. Each mother's transcript was posted to her approximately three weeks before my return to Deira providing an opportunity for the women to clarify, change, add to, or delete from, the transcript before the next interview. One mother made changes to her transcript, thereby choosing her own (re)presentation in text. All others left the transcript stand with their grammatical errors and only corrected sections that were unclear if they remembered what was said. Over the 35 interviews which were held across all of the women, very few made textual corrections, changes or additions to the interview transcript.

The second interview (held in December 1999) and third interview (July 2000) built upon the stories already told. I sought clarification on issues raised and asked questions based on issues other mothers had mentioned. For example, Julia stated that she felt she had entered "*another world*". I was interested in the immediate sense of binary this statement captured and asked other mothers if they felt this. I also asked about the impact of the storying contained in the transcript. For mothers whose children had spent many months in Intensive Care Units, most of their first interview dealt with this part of their life's experience. The second and third interviews provided opportunities to move on to the other stages in their lives.

Choosing the steps: analysis of the narratives

As researcher I had innumerable pieces of data, like the choreographer with multiple options of dance movements trying to decide which movements best (re)present both the dancer/s and the story/ies to be told. As writer, I needed to select from all the data available those movements which would make it to the final performance. I spent many hours deliberating how the way to (re)present the mothers' narratives for the purpose of this thesis. I struggled with the question of how to harness the power of the mothers' tellings, how to take their hours of speaking, and then to confine the resultant stories with/in/to this text. My research focus was broad allowing for the telling of many stories, yet I understand the stories as a partial (re)telling. The stories could not be detached from the lives surrounding them; the multiple discourses, positionings, subjectivities and spaces out of which the stories evolved. They were contextually based in temporal and spatial frames, specific to the individual and simultaneously integral/integrated in/to the socio-cultural discourses in which each woman interacted, and therefore difficult to artificially separate for analytical purposes.

The women's narratives did not necessarily have one single clearly defined storyline, with a neatly structured plot. Often their stories were fluid, moving in time, not easily read in a linear or chronological progression. While there sometimes existed the semblance of a chronological structure, stories were started, interrupted in their (re)telling as old memories surfaced and other memories triggered, revised as dates and time were amended, explained as issues arose and the narrator traversed in time and space to provide me with relevant background information. Their stories were partial and discontinuous. I noted, as Polkinghorne (1995) claims, "the cumulative effect in narrative reasoning is a collection of individual cases in which thought moves from case to case" (p. 11). The transcripts showed numerous examples of such occurrences. The multiple stories arising out of the fluidity of retelling, could be thought of as themed, or episodic, serving to enhance, clarify and/or explain the particular events being (re)told.

Embedded within the life stories presented were multiple stories each illuminating different aspects of the mothers' lives. The "storied memories" contain not only the multiple and complex stories but also "the emotional and motivational meaning

connected with it” (Polkinghorne, 1995, p. 11). How then could I take the multitude of stories and emotions and place them in this thesis? How could I (re)write the stories and which stories would I select for that (re)writing? I was aware at all times “the text that is produced from the interpretations of the texts generated in the interviews is *the researcher’s* story of their lives. Only they could tell their own stories” (Limerick et al., 1996, p. 458).

In answer to these questions, I re/searched the transcripts for the stories which the mothers spoke about in length and detail, the dominant discourses in their narratives. These dominant discourses formed sections 3 and 4 of the thesis text. For example, four of the mothers whose narratives in/form this thesis focussed almost exclusively on their experiences in medical spaces in the first interview, forming a large proportion of their total storying. Other stories that were prevalent for some mothers were to do with the impact of therapy intervention and those narratives feature in chapter 9. All mothers (re)told stories concerning the discursive site of education with varying degrees of intensity and section 4 is dedicated to their narratives of/on education.

I read and reread transcripts of the interviews as I began the process of analysing the mothers’ storyings. I made copious comments and marked potential themes in the margins of the transcripts. Segments of data which appeared relevant to my research question were underlined. On further readings sections of the mothers’ narratives were also highlighted to delineate sections the mothers had seemed to attach importance to in their (re)tellings – for example, narratives which dominated parts of the interview or evoked emotional responses. Additionally there were themes that several mothers had identified and these were also noted in the transcript. The ongoing literature review added to the analysis of data. The interviews were read again to ensure that I had not inadvertently missed important issues, to verify the relevance of data already marked, and to check themes across interviews. I endeavoured to search across participants for similar and contradictory data, yet retain an awareness of the individuality of each woman.

I then labelled the highlighted segments on my computer version of the transcripts and compiled a list of all segments. Next, I printed this list and cut each segment so that I could physically manipulate the emerging themes. Numerous lists of emerging themes

were compiled and rearranged many times. I analysed the interviews looking at the women's interactions with/in numerous discursive sites, their language use, power and knowledge and the subjectivities they had taken up and/or resisted as well as the subject positions which were available to them. Additionally, I examined the impact of having a child named with a disability on their subjectivity as mother within a motherhood discourse and how they (re)created themselves within a discourse of motherhood. This process of data reduction was fluid and open-ended as I continuously re-worked the data. I also collated the women's comments on the interview/research process.

I often found it difficult and frustrating to have to 'choose' from the multitude of moving and interesting stories; I wanted to include all the stories. My early attempts to step out this dance saw me write many women's individual stories of specific events with no clear idea of how they would eventually be choreographed together. I then wrote numerous outlines based on themes that came out of the interviews, trying to determine the order of the thesis and the manner in which the mothers' movements would perform. This approach failed to work adequately as oftentimes I found the need to explain an event or situation before its allocated 'space' in the order, and hence the stories became confusing. As indicated above, analysis of the transcripts revealed three dominant discursive sites: motherhood, medicine (including therapy) and education. These formed the basis of the three major sections of the thesis. Continuing to search for a devise to structure the textual representation, I turned to the concept of temporality as an organising strategy across the sections.

Dance and research: theorising the interview process

Dancing is much like abstract painting: two viewers will be moved differently by the same dance, and the same viewer will be moved differently by the same dance seen on different occasions. (Pohren, 1990, p. # na)

The dance already documented in chapter 1 can be used further. Not only has the dance been useful to explore poststructuralism, it also demonstrates an applicability to theorising the storying/interviewing process. I continue to use the dance described in chapter 1 and link it to the research act:

Like the choreographer, the researcher must find the most effective way to tell the story, to convince the audience. Staying close to the data is the most powerful means of telling the story, just as in dance the story is told through the body itself. (Janesick, 1994, p. 215)

In this written format, I use the women's words in multiple ways. I choreograph their voices consistently through the text; standing alone in block quotes, as poetics or plays, and woven in juxtaposition with my words, as well as those of current academic writers from multiple fields.

In (re)presenting Carmen's story of the dance I position myself as an insider and partner which contributes to my awareness of the story being (re)told; yet I also position myself outside, moving between the boundaries. I experienced the same event but only ever in my way. Carmen tells the story in her way, from her multiple subjectivities, from that temporal position in her life. The women in this study are also positioned both inside and outside the research act. They were intensely involved in the interview process; yet stand outside in the analysis and final textual embodiment of their storying. They are insiders, yet outsiders in a disability discourse, being non-disabled, but living with a child positioned as disabled. Simultaneously they are positioned inside, yet outside the dominant discourse of motherhood; blurring the boundaries of multiple discourses. The multiple ways the women are positioned and the subject positions they take up/resist are choreographed throughout this text.

My narrative of the dance can only ever be my (re)telling of Carmen's story, as only she could (re)tell her own story, just as it is with the women who (re)told their stories to me. As the writer of this thesis I select/ed stories from the women's narratives which would communicate their many and varied experiences of mothering a child with a disability and become the textual stories performed in this text. I am aware that both the women and I construct "a particular and partial story" (Berg & Mansvelt, 2000, p. 173). Berg and Mansvelt (2000) assert that "the process of writing constructs what we know about our research but it also speaks powerfully about who we are and where we speak from" (p. 173). In the act of writing this thesis, I choose/have chosen the segments and select/ed the narratives of the mothers' storying to (re)present to the reader, and in doing so to (re)present the mothers' voices. This act of writing also exposes where I am positioned. I reflect on the difficulty in choosing the stories to include and importantly

the unavoidable silences. I use the mothers' words to provide detail, to bind their voices to the written text. Surrounding the mothers' storying I add the multiple discourses in which their stories are situated, providing a socio-cultural context to the narrative telling. Like all stories, dance is temporally situated in time and space, yet dance has the possibility of powerfully connecting the past to the present and to be reread in the future – like the movement of words of the women. Dance is bound in choreography and performance, and the telling of it constrained within this text, while our individual life stories move and change to be seen and read again in multiple ways.

Dance is imbued with many meanings and can be seen from numerous perspectives. An audience will “read” dance “from the perspectives of their cultures and personal experiences” (Hanna, 2001, p. 41). Each person in the audience brings to the complexity that is a dance performance their own beliefs, values and subjectivities. They bring their perceptions of what dance is, or should be, and expectations of what is aesthetically pleasing. Hanna (2001) comments “although spoken language can simply be meaningless sounds, and movements can be mere motion, listeners and viewers tend to read meaning into what they hear and see” (p. 41). Each person responds to more than one aspect of the dance, sees simultaneously more than just ‘the dance’. Movement, music, costuming, lighting, stage design, and emotive embodiment situate the dance in many contexts. Dance is not one, but a multiple of events which come together before the audience, seemingly as a single, seamless entity. So too readers of the written research text bring to the reading their own judgements and expectations on research design, methodology and writing style, along with personal bias, values and beliefs which impact on the reading of this text. Denzin and Lincoln (1994) state that “any gaze is always filtered through the lenses of language, gender, social class, race and ethnicity” (p. 12). Additionally Packwood and Sikes (1996) note that “which forms of representation are acceptable to the research community is an epistemological and political matter” (p. 343). This was stressed to me through innumerable emails with my supervisor as I worked to clarify meanings that I thought were clear, but which were ‘read’ differently by him.

Reissman (1993) maintains that “meaning is fluid and contextual, not fixed and universal. All we have is talk and texts that represent reality, partially, selectively, and imperfectly” (p. 15). The talk and texts deriving from the women's storytelling provide

the backdrop of the thesis, the dance which is located in multiple discourses. This argument is continued by Weedon (1987) who states, “every act of reading is a new production of meaning. Positions from which to read and the discourses with which to read are in principle infinite and constantly changing” (p. 139). I come to the act of writing with multiple subjectivities positioned and positioning myself in multiple discourses as I take up writing the thesis. I have struggled with this task as the more lyrical, writerly self desires to (re)present the text differently from the strictures of the academic genre.

Conversations and storying: interviews as conversation?

Research is conducted for a purpose. The field is entered with the purpose of telling participants’ stories with respect to the specificity of their lives, of making their experiences visible, and of giving them a voice in the groves of academe and in the community. (Limerick et al., 1996, p. 457)

Although my intent was to engage in conversational interviews (Burns, 1994; Patton, 1990) with the mothers, I found that the interviews were not conversations with the usual attendant rules of conversational exchange. Rules are required in the telling of stories. If we play ‘games’ with language, each player knowing the rules, what impact does that have on the way both participants see the interview process? Is it possible to disrupt the interviewer/interviewee binary and have a ‘real’ conversation with its own attendant rules?

In analysing the interview transcripts I became aware the mothers had their stories to tell and a willing audience, me, who listened, interested in their storying, prompting and consciously seeking to hear their stories. Sandra acknowledged this in our last interview by stating:

I think when something’s so dear to your heart you become an absolute authority on it and you just love an audience (laughs), somebody who’s actually interested in listening to you.

Gubrium and Holstein (1997) state that the conversation and the narrative are a “collaborative venture” (p. 153) where expectations for exchange exist. However, they also point out there is a requirement for “conversational cooperation for stories and

responses to emerge, for extended turns at talk to develop” (p. 153). In an interview situation the interviewer provides “motivation and precedence” (p. 153) and allows conversational space for the narrative to unfold. Each participant needs to know the rules, if a story is to be told:

One needs conversational ‘space’ if one is to tell an extended story; teller and listener must work together to create the conversational environment in which a story might emerge. Indeed, listeners are often active coparticipants in both the elicitation and production of stories, working with the machinery of ordinary conversation to shape storytelling. (Gubrium and Holstein, 1998, p. 10)

Within a conversational space, the women (re)told detailed and complex stories. I found my intended role as conversational partner changed, as I increasingly became almost solely the listener. I wrote in my reflexive journal after my first interview with Liza:

Liza told the story of Lily’s early life in great detail, with little prompting by me. In some ways it wasn’t a ‘conversation’ with an equal give and take of turns. There seemed to be no requirement from Liza for me to give personal information, no need for reciprocity. I feel as if there was almost a welcoming of the chance to tell her story. There was an acknowledgment at the beginning, before we started, that this was an interview. Liza said that she felt she was “flying by the seat of her pants” as she didn’t know what I wanted. I am positioned by Liza at the outset as the interviewer, the researcher. How to (re)turn to a conversation from these starting spaces of unequal positionings?

This segment also spotlights the unequal power relations that can be identified in the interview situation. Liza immediately positions me as the interviewer, as the one who wants to “know” something. She positions herself as the one who is providing information, yet is concerned that she provides the information that I, as researcher, wants. From this positioning it is difficult to read the interview as a conversation.

Perhaps, though, it was with my friend Serena that I could perceive most conspicuously the difference between ‘conversation’ and ‘conversation as interview’, again bringing to the fore the relations of power which shape the research act. A difference existed in the way Serena and I interacted in the research interviews. The give and take usually inherent in our conversation was no longer part of our talk. In its place were different spaces Serena and I now inhabited as researcher and participant. As researcher I probed for more detail and Serena responded by bringing hidden memories to the surface for (re)telling; memories that had not been revealed previously during our close friendship. Serena explains her thoughts of the interview and its impact on her memories:

Doing the original interview with you, when you asked me specific questions I found that I'd locked it away and that I'd blocked it out. I'd worked through that so much that I didn't need it any more. But then when I went back into that locked area and opened it up again, it triggered many emotions and feelings and pain, real pain that it was hard to describe or to talk about it in the interview. But it came back like as if it was just yesterday or today. ... So the emotions and the feelings and the sensations are all there. They haven't been erased.

To continue the dance metaphor, the spotlight was on Serena in the storying process. She has the stage to dance her stories and there was no expectation from her that I would share my own stories. This was her time and her (re)telling, and Serena allowed her stories to fill the stage.

Many researchers, particularly qualitative and feminist researchers (Cotterill & Letherby, 1993; Harry, 1996; Hatton, 1998; Limerick et al., 1996; Pugach, 2001; Scheurich, 1995; Stanley & Wise, 1983), have examined the power issues that exist in an interview situation between the researcher and participants with the researcher generally thought to hold more power in the interview process. However, Limerick et al. (1996) propose that there are shifting dynamics in the relative powers of the interviewer and interviewee, and that changes occur at different stages of the interviewing process. They suggest the researcher has power in the initial stages in choosing who to invite to participate and the manner of approaching participants. Yet they note that there is a certain “vulnerability” and “dependence” on the participant to be willing to participate. They suggest that the balance of power then lies with the interviewee at the beginning stage (pp. 450-451). I was reliant on mothers to agree to participate in the storying, to be present for all three interviews, yet as mentioned previously in the chapter this did not occur, and eight mothers completed three interviews.

The researcher aims to at empowering the participant by allowing them to choose the setting to reduce the differential power effect of the researcher. Giving the women the opportunity to choose time and place “influences the politics of the interview itself through the consequent choice of seating arrangements, level of privacy, nature of hospitality, and so on” (Limerick et al., 1996, p. 454). Usually the interviews were held in the home of the mother; however there were times when some mothers chose my home as a quiet location, free of disruptions for them. One mother chose to have her interviews at the early intervention centre in an office while her son attended his lesson.

The interview sessions were held in different locations within the homes. At times we would be seated at the kitchen table, at other times in the lounge room. I have sat around pools, under old timber Queenslander houses, in family rooms and bedrooms, on outside verandahs surrounded by tropical plants, and on the floor with a cat curled up in my lap. Nearly all interviews started with an offered cup of coffee and incidental conversation while I set up the audio-cassette recorder.

Moving into the private spaces (Sheldon, 1999; Twigg, 1999) inhabited by the mothers affords opportunities to witness aspects of their lives not told in their narratives; of lives as they were lived at the time of the storying. I have a vivid memory of sitting with Therese and hearing one end of a telephone conversation requesting a 'potty' to be brought over to the woman looking after Therese's daughter, Kimberley. The woman lived across the street from Therese. This then entailed four young boys around 9 years of age carrying a rather large 'throne commode' across the road. This was an aspect of life which had become 'normal' to these boys, Kimberley's brother and his friends, and an opportunity for me to see the normalcy of this for the family. Cotterill and Letherby (1993) refer to the "group lives" and "significant others" (p. 5) who form parts of a participant's narrative. This was brought to the fore for me as in some interviews family members passed in and out of the storying space, occasionally sitting in and offering their thoughts. Even when no other person was present 'significant others' were part of the women's storying process, highlighting the tensions involved in studying the category of 'mothers' or 'women'. The women's lives are multifaceted and complex and do not exist in isolation. The analysis of the women's storyings for the purpose of this research carries with it an artificial separation of the lives about which they speak.

Accordingly, the way the interview is brought to closure is similarly situated as negotiated practice between the interviewer and the participants (Limerick et al., 1996, p 457). On several occasions I had thanked a woman, packed away the cassette recorder, only to set it up again as our closing conversation raised new areas to discuss. Often the 'conversation' missing in the conversational interview occurred after the interview was completed and the recorder turned off, providing me an opportunity to share stories of my family and my experiences in the Middle East.

Scheurich (1995) examined his interviews using a postmodern critique and proposed that “interviewees carve out space of their own: that they can often control some or part of the interview; that they push against or resist my goals, my intentions, my questions, my meanings” (p. 247). He continued by stating that “interviewees are not passive subjects; they are active participants in the interaction. In fact, they often use the interviewer as much as the interviewer is using them” (p. 247) and stressed a need to critically analyse what occurs in the interview situation. As noted in the previous chapter, with/in poststructuralist theorising(s), individuals have agency and have the possibility to choose which subject positions to take up or resist in the interviewing process. The women had particular stories to (re)tell based on their knowledge of the research focus and, as Cotterill and Letherby (1993) suggest, are able to foist their own structure on the interview “making explicit the limitations on what information” (p.5) they are prepared to contribute.

After my first interview with Susan, I wrote the following in my reflexive journal:

Susan already knew what she wanted to say and started talking about how hard it must be for parents without a medical background, before we had formally started. ... There seemed to be so much Susan wanted to tell, to cover in her storying, there was no hesitation in speaking at length and in detail.

I began to wonder, who sets the agenda for the interview? Where do the issues of power and control begin? The boundaries of power in the interview situation, to me, are blurred, moving between the people involved. The interview space is continuously negotiated as the storying shifts between teller and listener, researcher and participant. Questions came to mind regarding the doing of conversations as interviews. I had approached the mothers and explained to them that I would like to hear their stories about living with a child with a disability. How did the mothers read this request? Gubrium and Holstein (1998) contend that “as texts of experience, stories are not complete prior to their telling but are assembled to meet situated interpretive demands” (pp. 2-3). What then was my impact as researcher on the mothers and how they chose to tell their stories? Mothers brought to the interviews their (re)tellings, their agendas perhaps based on their beliefs of both what they thought I wanted to hear, and what they wanted, or were willing, to (re)tell. Perhaps as Luttrell (2000) suggests about her interviews, “stories represented what the women wanted me most to know and what

they construed as being worth talking about” (p. 4). As such, the construct of power remains elusive in the contextual interview.

Everybody has a story to tell (Serena)

If we wish to understand the deepest and most universal of human experiences, if we wish our work to be faithful to the lived experiences of people, if we wish for a union between poetics and science, or if we wish to use our privileges and skills to empower the people we study, then we *should* value the narrative. (L. Richardson, 1995, pp. 218-219)

We share our life experiences in the stories we tell. It is proposed that “our lives are intrinsically narrative in quality. We experience the world and re-present our experience narratively” (Dhunpath, 2000, p. 545). Indeed, “qualitative researchers have often gathered stories through interviews, later transforming them through transcriptions into written form” (Polkinghorne, 1995, p. 8). Each of the multitudes of stories chosen by the women in the study for (re)telling illustrates and explicates a myriad of life events and happenings. While the women are the tellers of their experiences, it must be stressed that the stories they choose to tell are constrained and partial, and consequently are “determined by the discourses and histories that prefigure, even as they might promise, representation” (Britzman, 1995, p. 232).

Stories help shape our understandings of our selves, of our experiences, and are set in specific cultural and social contexts. Stories shape too the way we choose to (re)present our selves to others and to ourselves. However, as researcher, and writer I acknowledge that in the final text it is my decision as to what stories are (re)presented (Gubrium & Holstein, 1998, p. 6). Britzman (1995) speaks of a “contradictory point of no return, of having to abandon the impossible desire to portray the study’s subjects as they would portray themselves” (p. 233). I have struggled with this impossibility as I worked with the women’s narratives, wanting to (re)present each mother in the entirety that she (re)presented to me. Within the constraints of a PhD thesis I cannot provide all the data on each mother. Silences exist – not only in what has (not) been told to me by the women, but also in the stories danced in the rehearsal room that I chose to leave behind.

Oral storying can be seen as a partial account of life's experiences as words are used to describe, understand, make sense of, and share. The stories told by the mothers throughout this text are the steps, the movement of words that I as choreographer arrange to become the temporal performance. The mothers' movements resonate with images of motherhood as they speak in emotional voices of sadness, grief and loss, of fights and struggles; yet also of hope, learning, loving and growth. This text, named as a thesis, highlights specific points in time; moments mothers have chosen to (re)tell in their storying and the ones I have chosen to (re)present. This textual (re)telling cannot cover all the events, the stories, the moments of the mothers' lives. Norah suggests, "you'd want to take a whole week I think to tell all the stories". The stories contained within are read by me as partial, unfinished, and ongoing.

The moments and the stories recalled and told move and shift, while the written text remains constant. As Dunn (1990, p. # na) so aptly notes, "a dance disappears as you see it. ... The nature of a dance includes impermanence". Like the dance which passes once performed, so too does the mothers' storying pass, perhaps to be (re)told in different ways to different audiences. Yet, in this textual form the stories are bound not only in words but also in time (Packwood & Sikes, 1996). Narratives continue to develop, change, and grow as the women continue to interact with/in the discursive practices of their cultural and social world. Although the text remains constant, it can only be temporal; there are no conclusions and it can be read anew, differently with each reading/er. Each mother, the reader, and I move beyond the boundaries set in place by the written form to create and (re)tell new stories over and over again.

Serena commented to me during our first interview that "everybody has a story to tell" as she spoke of the role of support groups and of the importance for her of listening to and speaking with other mothers:

Everybody has a story to tell. And having the support group, listening to the people, how they survived and what they do within their families and how much support they get, whether it's none, they have all their own things happening in their lives. I learnt so much about what I do have, rather than thinking about what I don't have, or how hard it is for me. Or how hard it is to have Jason ... at least I was financially ok ... at least I was healthy; at least I had so many things. I didn't feel any worse off than anybody else.

The need and desire to hear and tell stories provides a commonality of experience, a sense of community and cohesion, a sharing of a similar space, and a similar language, within the discourse of disability. Other mothers also explore the import of stories in their lives. For example:

We would swap stories about how they were going at kindy and it's that communication thing really. It is really important I think for any mother, well it's important for any mother of a young child to have other mothers of young children in her life. And if your child has a particular problem, being able to talk with a mother who's got a similar problem, it's that sort of the bond I think that you have with someone ... things are similar. Talking over what might be. What's been. Or how you're going. Or how did you manage the toilet training? Very basic stuff like that. (Elise)

You want to hear stories you think you can relate to. ... I mean we laugh at some of the things. (Melissa)

It is within this framework of storying, of seeing and valuing “lives as acts of storytelling” (Gubrium & Holstein, 1997, p. 146) that this thesis is grounded. People speak their lives in a series of stories, interwoven to form a life story. Susan acknowledges that she is speaking her life as a story when she says, “*I'm pleased with the opportunity to be able to get some of the story out*”. Her words also reflect the partial nature of storytelling. She goes on to situate the act of storytelling in the ‘now’ of the interview, weaving her past story into the future; “*with Laura I think it's a story that's ongoing*”.

As indicated by the many stories (re)told in the interview process, the voices of women who were involved in this study clamour to be heard. Stories, told and previously untold, stories forgotten, brought to the surface in the remembering can only be (re)told from the perspective of now. The stories belong to the point in time in which they are spoken into existence. They exist in the now of telling. While the stories are manifested in the present, they are stories of the past. They are temporal; they are memories vivid and real in the (re)telling, yet at times partially forgotten and uncertain. However, the stories can never be (re)told as they happened, as they were. Memories as they exist in the present result from their existence in the past, and subsequently help shape future memories. Experiences, new understandings, build on the old memories, moving to create the future. Melissa points out the changing nature of memory when she says, “*at*

the time you think these things are just etched on your memory and you'll never forget them. But in time you do. You forget the sequence of things". It is not the major events that are oftentimes forgotten, it is the fine details. Memories are thought about, reinterpreted in the course of life and it is these memories of the women participants which give shape to the narratives which perform in this thesis.

The women and the interview process

Because I made a conscious decision to accept the women's' interviews as a 'gift' I was interested to know how/what the mothers' thought/felt about the interview process and resultant transcripts. When I returned for the second interview I asked the mothers for their impressions of the transcript. Many commented on 'how' they spoke:

I didn't know I spoke such terrible English (laughs). When I was reading through it I thought, "I don't um, I don't write like that, so surely I don't speak like that". But anyway, um, (pauses) and all these ... you knows, and sort of's, and um, and yeah ... I thought, "Ugh" (laughs). (Patti)

It's unnerving. ... To have your conversation recorded and spat back to you. Not unnerving, but I suppose it makes you realise how you put your sentences together and things like that. (Elise)

Other mothers mentioned the temporality of their narratives, of how the storying moved in time, noting that their tellings did not follow a chronological, linear pathway. Mothers also remarked on the amount of coverage they provided. Even though the transcripts annotated some parts of the recording as unclear, they believed they had covered the major events, the important stories in their first set of narratives:

I was surprised. I thought that I spoke reasonably well actually (laughs). Seemed to be, did you fiddle with it at all? Cause it seems to be quite lucid. I didn't feel like I spoke that way. I felt like I jumped all over the way. (Liza)

I think that's pretty thorough really. I can't, just going through it, it does, it chops and changes a bit from one time period and then I've moved on and then I've tended to regress because I've thought about something else that's happened. But most of it, I mean there's an awful lot there, but I think we got most of it. There are probably little things. I mean so many things happened, probably little things, nothing major. (Susan)

How did I find the transcript? Um, it was fine. Anything that, where there was an unclear thing or something, I can't work out what we might have said and I don't think there's anything particularly important in those areas anyway, just from

quickly going through it. Most of it appears to be as to what I would have said, and how I would have said it (laughs). (Elise)

However it was the intensity of emotional response to the reading of the transcript, for which I was unprepared until I spoke with Serena via an internet ‘real-time’ chat program in September, 1999. I had previously emailed Serena the transcript of her first interview and was asking if she had had a chance to read her transcript. Her response was, “*sorry Valmae, I did scan it and I just wanted to cry too much. It was a bit painful and I wasn’t ready*”. The intensity of her response was unanticipated and alerted me to the potential emotional responses of the other mothers.

I wondered if other mothers would similarly find it difficult to read their own stories and asked about any emotional response to their readings when I next spoke with them. I discovered that many mothers did experience a similar response to Serena in the (re)reading of their narratives. Many left reading the transcript until the last possible moment before I arrived to do the second interview rather than confront their stories, (re)live their lives, with its attendant emotions. While most had told their stories to me and kept their emotions in check during the interview, the private and personal reading appeared to allow the unleashing of emotion.

The emotional response seemed triggered by being confronted with the profundity and details of their storyings. The feelings, thoughts, and resurfaced memories from their past experiences impact on where each woman is situated in the present. Below are some typical responses:

I think sort of the most powerful thing for me was actually re-reading it. That’s when the emotion started to set in. When you re-read everything that you’ve said. (Diane)

When I first looked at it, I did (have an emotional response). I didn’t want to read it. I got through the first page and I couldn’t read any more that time. But I sat down last night. Maybe I was in a different frame of mind last night. (Patti)

Actually it was quite an interesting exercise. ... ‘Cause you really don’t think about it. When I sat there, when I first looked at it I thought, “My gosh, all this!” Yeah, it was quite interesting going through it because you never sit and think about it like that. (Michelle)

It was quite hard to read. I had it, I only read it this morning and that's 'cause I had to. I didn't want to read it. I didn't want to go through it all again (laughs). Funny isn't it? (pauses). ... It does, it just reminds you of all those emotions and things. And then you think, "Oh well, you know, we're still going. We're not doing a bad job". But, yeah it was quite emotional. (Liza)

The mothers gave so willingly of their time, and significantly, of themselves. The emotions that flowed through many interviews heightened my awareness of the gift presented each time I listened to the stories being (re)told. My reflexive journal reflects my thoughts after my first few interviews:

I wasn't prepared for the emotion. I had thought, naively, that seven to fourteen years later the stories would be easier to tell. They aren't. The emotions of the mothers are close to the surface – letting go and crying. Raw emotion, reliving the experiences of a baby in hospital, fighting for life, lives forever changed ... No I wasn't prepared for the honesty and trust from the mothers. Leaving Susan's interview made me conscious of the responsibility of my task, not only as a researcher, but perhaps more importantly, as a mother, another human being, to tell the stories with honesty and compassion, for these mothers who give so generously despite the hurt, the emotions, the memories – and for other mothers.

Therese and I explored the impact of reading the written word as opposed to the oral (re)telling of the same story bringing into play an oral/written dualism. For Therese, having the life story she had told (re)presented in text, and in turn reading the textual embodiment, emphasises the wholeness of her family's experience with Kimberley. The written form is at once a different (re)telling; there is more intensity, more detail, and more time for Therese to ponder that which was told, to see her narrative in the entirety she presented, instead of as a series of fragmented episodic stories. Therese is being confronted, in a sense, with a past that she has already experienced and lived through, yet acknowledges that the narrative, the stories in the transcript, told in the present have a future yet to unfold:

Therese: I'm quite pleased with all of that. It's a bit scary reading it.

Valmae: Why?

Therese: Um, oh just because you don't realise I think how much you go through, till you actually see it written.

Valmae: So it's different to see it written down?

Therese: Yeah, yeah. I was reading it and thinking oh my God, so um, mm.

Valmae: Oh my God?

Therese: Well just what we've gone through. You tend to talk about it, but I guess it doesn't really sink in as much as when you're actually reading it, and going through it again. But I, mm, I thought then we'd really gone a long way and that's really not all of it yet ... I think when I sat and read it, I kept thinking, "My God, all of this has happened". And you know it has, but you're sort of reading it as another person's life and if you read that sort of stuff as another person's life you'd think, "Oh you poor bugger", you know (laughs). So yeah I think you sort of read it as if it's somebody else, not yourself. So that then when I did read it and I thought, "Oh my God all that happened to us", it really hit home. And I guess too, it's sort of all at the one time. Whereas when you think about it you only think of bits and pieces of it rather than as the full picture of your life with Kimberley. That probably hasn't sunk in either.

Valmae: Yeah, you deal with small pieces.

Therese: Yeah you deal with fragments rather than the whole.

It is Oranea who I feel captures the epitome of the storying process as a (re)presentation of a life, of her life, when she simply and succinctly says to me during our second and final interview:

Valmae: What was it like for you to read (pauses) your transcript? Read about

Oranea: (Cuts in) My life? (laughs)

Valmae: Yeah. What was that like? Did you find it hard?

Oranea: A little bit, yeah (pauses)

Valmae: Why?

Oranea: It's going back. (pauses) What I've been through. It wasn't really hard, but it's a funny feeling about it (pauses)

Valmae: I know a couple of mums couldn't read it straight away. They sort of got it out and looked at it and said, no, it's too painful and put it away.

Oranea: Yeah? No, not for me though. It wasn't painful, but it was sort of, this is me. This is my life (laughs).

Spaces of another world

I had never had anything to do with anyone with a disability when I was young. There used to be a fellow, I think he was Down syndrome, and he used to sit on

the fence at the railway crossing and wave to all the cars as you went past and we always gave him a wave. And I think that was as much as I had ever had to do with anyone with a problem. (Patti)

During my analysis of the women's storying, I noted that many women used spatial metaphors which spoke of geographical boundaries with/in a disability discourse. I was unprepared for this and (re)turned to the literature to investigate this metaphor of space that I had noticed. Theorists in disability and human geography studies contend that spatiality has been neglected in disability research (Freund, 2001; Imrie, 2000). Issues of space and time are also often neglected in research endeavours: "Discursive practices are generally analysed in terms of conversations or dialogical encounters, and rarely conceived spatially or temporally ... in relation to the reproduction and production of different spaces and times" (Hirst, 2002, pp. 1-2). I saw the relevance of inserting a motif of space, taking up space as a geographical and physical entity, as well as a socio-cultural discourse in my theorising and analysis.

Space can be defined as "the medium in which people act, intersect, move and locate themselves" (Freund, 2001, p. 694). This medium is also the outcome of social relations and has "social significance and is socially constructed" (Curtis & Jones, 1998, p. 646). Because space is the place where interaction occurs, it is therefore implicated in its role in defining groups who are considered 'Other' (Crang, 1998). The term 'othering' is often used to describe the process by which groups of people are set up in unequal relationships (Crang, 1998). Hughes (2000) describes this process of 'othering' as having its roots in modernity:

Modernity is marked by the constitution of alterity, by ubiquitous and marginalizing social processes of 'othering' in which subjects are constructed as either one or the other. ... Alterity, however, is not a given. It is best understood as a process; the process of othering in which groups of people are pushed to the margins of the social world, constituted as a threat to social order and a challenge to the integrity of the community" (pp. 557-558).

Unpacking the impact of space is helped by a (re)turn to the allegory of dance. Typically in a dance performance, the stage presents a bounded space to the audience, the reader of movement, just as the women's storying in this text is bounded. The space of the stage is contained, a given, existing and recreating itself with displays of lighting,

backdrops, scrims and scenery, continually changing and fluid. As Hirst (2002) highlights, “the spaces in which actions occur are not just environments, or backdrops or places” (p. 2). Space defines the boundaries in which the action occurs. Beyond that boundary is that which makes the stage possible; the dancers exist in a space beyond that which can be seen, beyond that presented. The theatre stage does not exist without the sides, the wings, and the spaces behind the backdrop. Without these, the stage is not seen as a stage, for there are no things to define it as such. So too for the abled/disabled binary – one comes into being through the existence of the other. The binary stage/backstage is deconstructed into spaces which do not exist without each other.

The postmodern turn in the arts deconstructed the taken-for-granted performative space and actions of dance. The opening of the Judson Dance Theater is considered the beginning of the postmodern era in dance where multiple artists involved in dance worked together to disrupt the taken-for-granted ‘theatrical’ and dominant traditions of dance. Movement was deconstructed allowing pedestrian movement to be brought onto the performative dance space of the stage. Choreographers such as Merce Cunningham and Tricia Brown disrupted the space of the stage and moved dance to alternate spaces for performance. Dancers performed in “street clothes, leotards, naked, with bare feet and with sneakers. They danced in the theater, in city streets, parks, museums and churches” (The development of modern dance, n.d.). The assumptive model of ‘dance as story’ was disrupted and dance no longer needed to make sense in the classical

tradition; “there was no implied meaning beyond what the viewer saw” (The development of modern dance n.d.). Just as space (however conceived) is essential for the dance performance, so too are issues of spatiality important in the analysis of the mothers’ narratives.

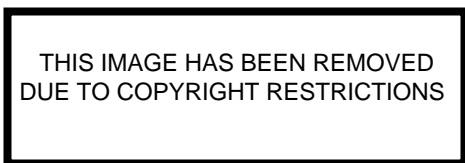


Figure 2 Tricia Brown Dance Company (n.d.)

Most of the women in this study had previously been part of a non-disabled society, with many of them having limited knowledge or experience with/in the discourse of

disability – particularly those mothers with older children. Three of the women had a greater awareness of disability due to members of their family being involved with people with disabilities, while another worked with people who had mainly physical impairments. The other women expressed how their experiences had been generally limited to ‘seeing’ people with disabilities ‘in the distance’. However, despite these experiences their lives were typically lived within the dominant space of able, where disability was that which was other than ‘normal’, the ‘Other’. It is suggested that “the dominant group’s cultural practices are promoted as the norm and the cultural practices of Others are portrayed as deviant” (Kitchin, 1998, p. 346). The social model of disability uses the term ‘disability’ “to refer to disabling social, environmental and attitudinal barriers rather than lack of ability” (Crow, 1996, p. 57). Forms of oppression “are played out in space and are given context by space” (Kitchin, 1998, p. 346). Western society is made up of the spaces which shape and form patterns of exclusion. For the women in the study, their assumptive space was within the realms of non-disabled society. Socio-cultural constructs of normalcy are based on multiple assumptions made over innumerable years, filtered through values, beliefs, and understandings that subsequently inform mothers’ conceptualisations of the construction ‘normal’.

“People are always in a place, and places constrain and enable” (Sack, 1993, p. 2). I ask in this thesis, what of the women who suddenly, unexpectedly enter spaces and places with which they are unfamiliar. What is the impact of space in/on their lives? How are they constrained or enabled in the multiple spaces of disability? While Imrie (2000) argues the need for researchers to “conceive of space as an important constituent of socio-political and cultural processes” (p. 7), the mothers in this study are already speaking of the social, political and cultural aspects of the spatiality of disability in their narratives.

(Re)presenting the ‘Other’: writing about mothers and their ‘voices’

The question of how to (re)present the ‘Other’ is one of broader debate in educational, poststructural, and feminist research (Denzin & Lincoln, 1994; Hatton, 1998; Packwood

& Sikes, 1996; Pugach, 2001). I have made a decision to analyse and extend the (re)presentation of the mothers' stories within and through my writing style. Many researchers have pursued new methods of data representation (e.g. Brearley, 2000; Hatton, 1998; Lather, 1996; Packwood & Sikes, 1996; L. Richardson, 1992). I seek to achieve the necessary academic content of a PhD thesis within a framework of a more lyrical and creative style of writing. In D. Morgan's (1998) presidential address to the *British Sociological Association*, he referred to the range of writing styles available within sociology. Of particular interest to me was that D. Morgan mentions a literary style which uses "a more personal voice, a less predictable structure and a relative absence of scholarly references" (p. 659).

Denzin (1994) contends that the "postmodern sensibility encourages writers to put themselves into their texts, to engage writing as a creative act of discovery and inquiry" (p. 504). Similarly, a postmodern, narrative approach to the writing of the research report can be accepted as an alternative to the positivistic style of research writing (Packwood & Sikes, 1996). Packwood and Sikes suggest:

If ... you are prepared to challenge the authority of the scientific method as the best way to study both natural and cultural phenomena, then personal, stylistic features need no longer be excised from the text as irrelevant, and the metaphorical postmodern conceptualization of *Research as Narrative* within which multiple stories are told becomes an acceptable and valid approach. (p. 344)

My intent throughout this thesis is to explore the creativity within myself, as a research journey of discovery and inquiry, and to bring the mothers' (and my) multiple storyings to the fore. In my writing I wish to disrupt the traditional academic approach to authorship and Doctoral writing and investigate alternative forms of (re)presentation.

I take Denzin and Lincoln's (1994) statement, "we are in a new age where messy, uncertain, multivoiced texts, cultural criticisms, and new experimental works will become more common" (p. 15), and use this to inform my work. Searching for new ways to report the women's stories is consistent with the taking up of poststructural research (Fontana & Frey, 1994; Packwood & Sikes, 1996). One should look critically "at the ways in which we tell our sociological stories and the extent to which the conventional forms might from time to time, inhibit the sharing of imaginative understandings of social process" (D. Morgan, 1998, p. 660). Similarly, Pugach (2001)

speaks of the use of “multivocal texts” and “experimental texts where data may be interpreted as poetry or drama or fiction” (p. 444). I have drawn upon different forms of data (re)presentation to convey the breadth and detail of the mothers’ storying.

The use of poetry, or as I prefer poetics, is said to engage the audience emotionally as well as intellectually (Hatton, 1998). Poetic representation has been used as a means of writing sociology; for example L. Richardson (1992) chose to represent her data about an unwed mother in her poem, “Louisa May’s Story of Her Life” which she describes as “a transcript masquerading as a poem/a poem masquerading as a transcript” (p. 127). Hatton (1998) provides powerful examples of the use of “poeticized text” (p. 218) in her study of the lived experiences of both Maori and pakeha working class parents and their interaction with the educational system in New Zealand. The use of poetics to express and (re)present the voice of the ‘Other’ “enables a more adequate expression ... because the author is linked (aesthetically, politically and emotionally) with those about whom they write” (Hatton, 1998, p. 218).

Following L. Richardson (1992) and Hatton (1998) I have chosen to use a poetic format at different times throughout the thesis to (re)present some sections of the particular mothers’ stories. I have also investigated and included the use of a one-act play as a means of (re)presenting one of the narratives. During my first interview with Norah, her daughter Jan and son-in-law Mark were present. Once Norah began to answer my questions and talk about her early years with Cheryl (her daughter with a disability), I became concerned about the interview, as it was not only Norah who responded. Jan became part of the conversation, at times answering for Norah, at other times cutting into Norah’s answers, and often triggering memories. The multiple responses worried me at first, but I came to see this as a joint construction of shared memories. Cheryl’s illness and subsequent disability impacted on the whole family, and it was a shared life. Having Jan present helped in framing Norah’s storying. The question then became, “how do I (re)present this shared retelling”? I eventually decided to (re)present parts of Norah and Jan’s storying as a short scene placed within the thesis. This style of (re)presentation makes visible each person’s role in constructing the shared memories.

The experience of shared meaning-making emphasised to me Cotterill and Letherby’s (1993) comment that “life histories are ‘group lives’ where the narrator weaves her

story with those of her ‘significant others’; her children, parents, husbands, lovers and friends” (p. 5). Norah and Jan actively embodied the “weaving” of the group life in sharing their life history. Other mothers also did this to varying degrees as they spoke their story into the present. However, in many cases the voices of their ‘significant others’ were silenced in the women’s storying as they narrated their lives from their perspective. Consequently these voices are usually silenced as I (re)present the women’s narratives.

Both the poetic representation and the scenes from the play use the mothers’ words as they spoke them – the verbatim transcript of their interviews was used to create these additional forms of data (re)presentation. Through numerous reworkings the thesis has become a multivocal text where poetics, drama, the mothers’ words, and verbatim segments of interview transcripts are choreographed together with analysis, my storytelling (both the mothers’ stories and mine), and the literature, to create a textual performance for the audience to behold.

This thesis not only (re)presents the voices of the women involved, but also my voice as researcher. Following Packwood and Sikes (1996) I develop three voices within this writing. The historical and personal events leading to the choreography of words, constitutes my personal voice. One of the tasks of the researcher is an “examination of one’s sense of personal identity and the predispositions that prepare one for certain roles” (Harry, 1996, p. 294). I endeavour to do this throughout the text through the addition of my own biography. My transformative voice outlines the present and the way I position myself multiply including as woman, mother, dancer, teacher and researcher and what that positioning brings to the research act. An exploration of my search to locate my study within, and at the same time beyond, the demands of academia becomes my professional voice. However, my voices do not always follow a linear framework as they choreograph different movements. My multiple voices work to disrupt the one voice of the researcher and present layers of voices and selves as I write them into the thesis. Each step, each voice, is distinct yet they move in time, informing and guiding each other.

In addition to my three voices outlined above, I have chosen to write my ‘self’ in to the thesis in two distinct ways. As L. Richardson (1992) says, “in writing the other, we can

(re)write the Self” (p. 136). One way of writing myself in is like a choreographer creating a visual performance, exposing my thoughts, emotions, responses to the storying of the mothers displayed in and through my writing. As a choreographer, I work with the words of the mothers, the movements of the dancer, and my interpretation is present/ed in the final performance. The second way my self is present/ed is in the very writing itself, (re)creating my self as I write my self within.

I remain ultimately the choreographer of the textual embodiment of the women’s narratives; I use their words of their stories to in/form this thesis, along with the textual voices of academic scholars. As researcher, I become part of the research act, selecting and (re)telling the stories that are constructed with and by the mothers. The “I” is present in the research act and is “interwoven” with other “I’s” (Davies, 1996). While conceptualising the stories shared by the mothers as a gift, and writing from within that space, the text in which the stories are situated remains ultimately my interpretation (Limerick et al., 1996), for as Reissman (1993) comments, “representational decisions cannot be avoided” (p. 8). However, my decision to use alternate forms of data representation is an attempt to write beyond my authorial voice, as is my constant awareness as I choreograph the women’s movements. By utilising alternate writing formats I wish “to bring into question the unified authorial voice of ‘truth’” contesting the “author’s omniscient voice” (Pugach, 2001, p. 444). While the women told their narratives in oral form to me, the (re)presentation of their stories “occurs through the mediation of a researcher who has a vested interest in the story” (Dhunpath, 2000, p. 549).

Bringing the movements together

These first two chapters have introduced my research focus and the women who participated in the storying/narrative process. I have demonstrated my intent to use alternate forms of data representation believing that this is “significant for audiences who are ‘Other’ to the subjects of the research” and that “poetic language arguably has a greater potential to enable the reader or listener to ‘vicariously experience’ and empathize with the lives of the researched” (Hatton, 1998, p. 222). “More than a few”

researchers “are attempting to produce reader friendly multi-voiced texts that speak to the worlds of lived experience” (Denzin, 1994, p. 512). I choose to do this to privilege the women whose storying provided the words and movements of this thesis and to expose my more ‘writerly’ self.

Additionally the use of qualitative methodology with poststructural, feminist and spatial theorisings to analyse the narratives has been established. Gough (cited in Whitehouse, 2000, p. 2) states that the utilisation of poststructuralism offers “a freedom to explore the multiple stories, multiple subjectivities and multiple discourses that constitute our lives”. The importance and relevance of this research has been accentuated: non-disabled women who are mothers of a child named with a disability have been shown to be a marginal group not only in society but also in the academic literature, particularly within the literature of disability, poststructuralist and feminist studies. Narrative has been privileged in this text, as it is the way in which we experience and speak of our life experiences. The existence of “different stories” provides an opportunity to “decentre the normal as given” and “challenge any dominant notion of social homogeneity” (Fullagar & Owler, 1998, p. 445). What is needed in research is “more and varied voices, more collections of personal accounts of disability” (Thomson, 1994, p. 3). While the mothers are non-disabled, they work the boundary of able/disabled and their stories too are lacking in the disability studies literature. The narratives told by the mothers constitute many meanings, many subjectivities and selves, and the discourses in which they exist are choreographed together in the stories which are (re)told in the following chapters.

SECTION TWO

**THE DANCE OF
MOTHERHOOD: THE
INTERSECTION OF
MOTHERHOOD AND
DISABILITY**

Chapter 3

Images of motherhood

If you've got a child, you'll be a mother till the day you die. (Elise)

What being a mother means will depend not only on the conditions in which women give birth to, and rear children, but also upon the beliefs and expectations they hold about motherhood. (D. Richardson, 1993, p. 18)

As I analysed the interview transcripts I observed many inescapable images of motherhood spoken into existence. It has been noted that the construct of motherhood operates “as a narrative pivot in the construction of a reflexive biography” (Bailey, 1999, p. 351) and motherhood certainly appeared to be the pivot around which many stories were (re)told. The experience of motherhood that permeates these mothers’ storying resists an artificial separation for analysis, for the movement of mother is interwoven, enmeshed, in the dances the women perform, and the stories they tell. The movements and subjectivity of mother/hood in/form the dance/s they perform. As the body of the dancer cannot be removed from the dance, many times in the women’s narratives it was difficult to remove the embodiment of mother; body and movement and storying merging. Yet, for the purpose of this textual embodiment the steps will be delineated more clearly to illustrate the performance of motherhood. A discourse of motherhood surrounds the stories told by the women as they spoke of their children and their lives with their children, and this section turns to the dance of motherhood. In Western socio-cultural constructs, there exists a “deep parental investment in our culture’s conflated ideologies in the areas ‘good’ parenting and ‘perfect children’” (Avery, 1999, p. 119). The conflation of good parent and perfect child is problematic when the child is named with a disability, as the taken-for-granted subject position of good mother/perfect child is brought in/to tension.

This section is broken into four chapters. Chapter 3 explores a dominant Western discourse of motherhood that the mothers in this study take up as their own and which has in/formed their motherhood subjectivity. I do this to situate motherhood as

“discursively constituted” (Davies, 1992, p. 54) and highlight the limitations of this motherhood subjectivity for non-disabled women who are mothers of children named with disabilities. By taking oneself up within familiar positionings and story lines as mother, “to the extent that one’s moral commitments, patterns of desire, and ways of knowing and being are constituted through these positionings and story lines, then *they have become part of the subjectivity of that person*” (Davies, 1992, p. 54).

Chapter 4 turns to an exploration of language; specifically focusing on language-in-use in research on disability and parenting children named with disabilities. I then ask the mothers to reflect on their meanings of the language found in such research. The women in this study appear to be positioned by, and position their selves within a socio-culturally dominant motherhood discourse as/of ‘good mother’. As mother, they are “discursively constituted as one who belongs in that category” (Davies, 1992, p. 54) and un/consciously take up the dominant motherhood story line. However, the women experience a rupture in their motherhood subjectivity as they can also be positioned as being a ‘mother’ outside the dominant discourse of motherhood. This is interrogated further in chapter 5. During the interviews, the women also spoke of/to the future, both from their rememberings of the past, and also of the future yet to come for them, and their children, and this is considered in chapter 6.

The mothers’ stories which are (re)presented throughout this section are situated poststructurally in “specific, local and historical contexts” (L. Richardson, 2001, p. 35). Narratives of the mothers are placed in and constituted by these contexts, and danced through temporal and spatial frames. Academic literature is interspersed throughout the thesis, yet, as previously mentioned, the desire in my writing is for the women’s stories/voices to have presence; to add their voices to the academic literature. From feminist and poststructural perspectives, it is important that their stories be read within the socio-cultural constructs and discourses informing their (re)tellings.

Being a ‘good mother’

As already established, much of the literature I initially reviewed on parenting a child with a disability dealt with the very real concerns of stress and coping (e.g. Beckman, 1991; Dyson, 1993, 1997; Krauss, 1993; Singer & Farkas, 1989), and employment and caregiving work (e.g. Cant, 1994; Cuskelly et al., 1998; Freedman et al., 1995). Often these studies were constituted in a negative discourse in a partial exploration of lives lived with a child named with a disability (Abbott & Meredith, 1986; Kazak & Marvin, 1984; Stainton & Besser, 1998). Clayton, Glidden and Kiphart (1993) assert that research has moved from emphasising “crisis, pathology and dysfunction” to concentrating on “levels of adjustment, both strengths and weaknesses of families, and the benefits as well as the problems of rearing children with disabilities” (p. 313). However, a literature review of health, medicine, psychology, nursing and dissertation abstracts from 1980-2000 was conducted by Glassock (2000) to examine “the consequences of families living with infants and children with disabilities” (p. 407). Glassock found that many of the 564 studies identified focused on “problem areas associated with parenting” a child with a disability (p. 407). She goes on to suggest that studies providing descriptions of “experiences of living with a disabled family member” (p. 407) are lacking. So what of the women I interviewed? Did they focus on stress and coping? What were the stories of their experiences they wanted to (re)tell? As will be demonstrated later in this, and the following sections, the mothers in my study did not speak their lives into existence in terms of stress and coping. How then did they position themselves within a motherhood discourse?

Many of the women spoke to me of the changed ‘dreams’ that accompanied the diagnosis of impairment of their child. However, it must be acknowledged that their original dreams, “their patterns of desire” (Davies, 1992, p. 54) of being ‘mother’ originated with/in a Western social and cultural discourse of motherhood; expectations of what they envisaged motherhood to be were/are based in the socio-cultural discourses in which they were constituted. Ideals of motherhood formed prior to becoming a mother reflect the discourses existing in their socio-cultural world and multiple subjectivities are taken up with the construct of mother.

Oftentimes the dominant socio-cultural view of a family remains one of “a heterosexual couple, with a husband who goes out to work and a wife who stays at home to care for her husband and children” (D. Richardson, 1993, p. 27). Later feminist and disability research also suggests that mothers continue to be typically located as the primary caregiver (e.g. Case, 2000; Hays, 1996; Read, 2000). The view of woman as primary caregiver “exerts a powerful influence on commonsense ideas about what is normal” (D. Richardson, 1993, p. 27). This taken-for-granted view appears to exclude those non-disabled mothers who have children named with disabilities, and as such leaves a space where the non-disabled women need to (re)construct themselves as mother in the light of the diagnosis of impairment of their child. A socially or culturally appropriate ‘dream’ or discourse is not available for mothers to take up when their babies/children are named with a disability. The dominant view of Western motherhood determines what is considered ‘normal’ as woman and mother, and it is within that frame of normalcy that the women in this study expected to be mother.

Lupton (2000) conducted a longitudinal study in Melbourne of 25 women aged from 23 to 35 years who were in their first pregnancy. Fifteen of the women were employed in white-collar occupations, such as clerical and administration positions, while the remaining women had one or more university degrees. A semi-structured interview schedule was used before the birth of the child and several semi-structured interviews were carried out after the birth at preset intervals. Lupton found that the women in her study ascribed to a discourse of ‘good mother’ in their construct/ion of motherhood. A ‘good mother’ was portrayed as one who had “the capacity to give love unstintingly” (p. 54). A ‘good mother’ was one who provided a “constant presence and guiding role”, placed the needs of her child above her own needs, developed a relationship with her child, and would “have patience, remain calm and be able to cope and deal attentively with the demands of infants and small children” (p. 54). A discourse of motherhood is enacted, and subject positions are available to be taken up based on the construct of the ideal of a ‘good mother’. Furthermore, ‘good mothers’ were positioned as “selfless, able to give unstinting love and time to their children and as having the ability to regulate their emotions so as to best interact with their children” (Lupton, 2000, p. 55).

A study of 30 women aged between 25 and 38 and in their third trimester of their first pregnancy conducted by Bailey (1999) also demonstrated the way in which mothers-to-

be take up a familiar story line of motherhood. The women in this study were all in what Bailey describes as “lines of work which were middle-class” (p. 337). Bailey reports the women in her study acknowledged motherhood “as necessitating less selfish behaviour” (p. 339). For the women in Bailey’s study, motherhood “involved progress, and not simply change” and each felt they actively chose their identity and positioning as “mother” (p. 339). Additionally, through their choice of adopting a particular position in a discourse of motherhood, they “described themselves as becoming more ‘adult’, which they construed as behaving ‘responsibly’” (p. 339).

Interestingly, in neither of these studies conducted prior to the birth of their infant, is it reported that the women considered the possibility of giving birth to a child named with a disability. Lupton (2000) states once at the end of her article that motherhood may be considered a “source of self-fulfillment (*if all goes well*)” (p. 62, italics added). This comment can be read as ‘throw-away’ remark emphasising the taken-for-granted assumption of the birth of a normal child. The comment “if all goes well” is not explored further. It also suggests that “self-fulfillment” as mother is possible only if “all goes well”, that is the birth of a ‘normal’, healthy baby. Diane comments similarly:

When people think about falling pregnant they think about all the wonderful, happy, glorious things that you’re supposed to go through, but nobody tells you what can go wrong.

Silence surrounds the discourse of disability in pregnancy, with the expectation being the birth of a ‘normal’, and healthy, baby. While there may be fears during pregnancy of the baby having an abnormality, the expectation remains of giving birth to a ‘normal’ child as the assumed outcome (Ziolko, 1991).

It can be argued that it is an “apparently natural instinct that we have children who are healthy, happy and progress easily through the different stages of childhood into adulthood” (Murray, 2000, p. 691). Ziolko (1991, p. 1) writes of the “idealized child” imagined during pregnancy. Similarly, the dominant discourse of pregnancy is a taken-for-granted one whereby “a normal pregnancy is one whose course can be controlled and explained, and whose outcome is *favorable*” (Talbot, Bibace, Bokhour & Bamberg, 1996, p. 12, italics added). Furthermore, pregnancies that do not end with a “favorable” outcome are considered “inconsistent with the normative claims of motherhood” (Talbot et al., 1996, p. 2).

With the increase in prenatal care, women are expected to take up a discourse of responsibility as part of their motherhood subjectivity to do all they can to give birth to a healthy and normal baby (Talbot et al., 1996). Robyn expresses her sense of responsibility as mother-to-be clearly when she asks herself, “*what did I do?*” during her pregnancy to cause her child to have a disability. Her thoughts are (re)presented in poetic format:

What Have I done?

*In a way I felt
like I'd done
something wrong.*

*I mean,
I never drank
I never did drugs.
I smoked cigarettes
but
I gave them up
when I was pregnant.*

*I just kept thinking to myself,
“What did I do when I was pregnant
that was so bad?”
You know?
Going though all this –
it was my fault.*

*What have I done?
Trying to work out
what I did wrong.*

*And everyone kept telling me,
“It's not your fault”.
“There's nothing
you could have done about it”.
“It's just
the way she is”.*

*I went through that for awhile.
I just kept trying
to work
it out.*

*Every time we went to the doctor
I'd come home
and*

*just sit down
and cry
because I couldn't understand it.*

*What have I done
that was so bad?*

Robyn's words highlight the way she positions herself in a discourse of responsibility, and self-blame – as mother-to-be Robyn positions herself as responsible for the outcome of her pregnancy. She asks what she did wrong, taking up the dominant expectation of the birth of a 'normal' baby. Similarly Kathy states, "*I remember reading an article saying that drinking and smoking causes disabilities in babies ... but I wasn't a drinker, I wasn't a smoker. It was just one of those things that sort of happened*". While Kathy acknowledges a discourse of responsibility she resists positioning her self in this discourse, stating that her child's impairment is "*just one of those things*".

Diane continues to speak during our interview of the societal lack of thinking and speaking about disability prior to birth, and queries how much should be told to expectant parents about the possibility of disability. Yet, Diane perceives that people named with a disability are becoming more visible in society and she believes there would be a corresponding increase in the level of awareness; "*people themselves are becoming more aware I suppose because there are lots of kids with disabilities*". However, this growing "awareness" does not seem to be incorporated into the discourse of motherhood which is spoken into existence, especially in the motherhood literature, maintaining a silence and a boundary around/separating motherhood and disability. A passive and silent discourse works to position the mothering of children named with disabilities in the margins of motherhood. In effect, this silencing creates an 'Other' and establishes a binary normal/abnormal within the discourse of motherhood, as well as in the broader social-cultural context.

Images and expectations of motherhood

Motherhood is something that society thinks, "This is motherhood and this is what is expected of mothers". (Diane)

Images of children, child rearing, and motherhood do not spring from nature, nor are they random. They are socially constructed. ... Ideas about child rearing, like all ideas, bear a systematic and intelligible connection to the culture and organisation of the society in which they are found. (Hays, 1996. p. 19)

The women in this study (re)told their thoughts of motherhood, both as individual statements on what being a mother meant to them, as well as being interspersed throughout their narratives. During the interviews, the women often revisited their thoughts about the motherhood subjectivity they had taken up in the stories they told. Yet, they (re)tell these thoughts from their perspective of now. It is difficult to separate the present from their thoughts and memories of the past. The mothers' narratives move and develop across space and time:

A person's narrative may reflect where he or she is in the meaning-making process at the time the narrative is produced, or a narrative may actually show a progression to new understanding as the person talks through events and weaves together different interpretations. (Skinner, Bailey, Correa & Rodriguez, 1999, p. 483)

Additionally, stories change as the women "encounter new experiences and people, and tell their stories to different audiences" (Skinner et al., 1999, p. 483). It is not possible to 'know' or investigate the way time has rewritten the memories the mothers (re)present, or the stories they (re)tell, but these are the story lines they have taken up as their own to (re)construct their individual selves as mother in the present, and the ones which influence their ongoing experiences of motherhood. While these women explore motherhood, they do so against a backdrop of past experiences, and the fluidity of life events which continuously rewrite the stories they (re)tell. The stories (re)presented through this dance are the mothers' stories as they chose to speak them to me in the contextual embodiment of the interview process, within particular temporal frames.

When asked directly about motherhood, many mothers speak in terms of the nurturing qualities they believe necessary to be a mother:

I see a mother as loving, caring, nurturing. Has tolerance for whatever thing they [their child] can or cannot do. (Serena)

What is my image of motherhood? Where do you begin? Motherhood of course is being a mother (laughs). It's the caring side. (Elise)

Motherhood? Love, caring and accepting. Which is something that you learn I think, well I've learnt. And that applies to any child. Acceptance of where your child is and what their abilities are. (Liza)

Just caring and raising children and tending to their needs. (Michelle)

A mother to me (pauses) is my whole life. I've been a mother throughout my whole life (laughs). Yeah, and I love it (laughs). I don't know any other life I think, looking at it now. (Oranea)

The nurturing qualities of caring, acceptance, tolerance, and tending to their child's needs, reflect the unstinting love referred to by women in Lupton's study (2000). In this way the women in this research project can be read as ascribing to and (re)inscribing the discursive construct of 'good mother'. As female and mother, they position themselves as caring and nurturing. By so doing they ensure the ongoing socio-cultural discourse of motherhood and preservation of the status quo. Weedon (1997) notes that women are considered to engender specific qualities to be a 'good mother' and wife, namely "patience, emotion and self-sacrifice" (p. 2). According to the women in Lupton's (2000) study the construct of 'good mother' necessitated performing "to the best of one's ability" (p. 58). The mothers involved in the thesis also demonstrate this 'performance' and the way in which they take up these story lines in the storying that flows throughout their narratives.

Other mothers expand their image of motherhood beyond the nurturing qualities mentioned above. Throughout the many narratives, many mothers were the primary caregiver, even if they also worked (voluntary, from home, part or full time), yet few specifically articulate their positioning as primary caregiver when speaking of their motherhood subjectivity. Being the primary care-giver is a 'natural', socially expected way of being positioned as mother, and is silenced in the women's storying. For those who did, their motherhood subjectivity includes the dominant societal construct whereby mothers assume primary responsibility for the well being of the child and family (A. Richardson & Ritchie, 1989; D. Richardson, 1993; Hays, 1996; Weedon, 1997). Both Sandra and Elise mention multiple positionings they see as part of their motherhood subjectivity while continuing to be primary caregiver:

It [motherhood] would be a very soft, patient person (laughs) surrounded by children. Female, obviously, juggling a hundred different things, having a hundred hands, a balancing act (pauses). Bit of a peacemaker, keeping everybody happy, caring and nurturing, I guess. (Sandra)

I suppose mothers are 'jacks of all trades'. Nurse, mother, cook, cleaner. Many roles. The many roles mothers take on, and do so willingly, without a thought basically. (Elise)

Mothers are considered the “‘creators’ of the family environment” (Krauss, 1993, p. 402), and it is through the taking up of multiple positionings that mothers create a discourse of the family environment. Elise appears to position herself within a socially accepted group named as mother as her words speak to a collectivity of mothers. Her language is plural, hinting at an ‘essential’ group of mothers and demonstrates how she perceives mothers to be positioned in society. Elise also alludes to the social construction of a dominant motherhood discourse, when she says that women take on the “roles” of motherhood “without a thought”. Particular ways of being as mother are accepted and expected as natural and taken-for-granted.

In 1989, A. Richardson and Ritchie emphasised that mothers bear the main responsibility of care because she is “traditionally the one who is at home” and this is a result of the “common acceptance of a division of responsibilities within a marriage” (p. 20). This traditional expectation does not appear to have changed much over time; “fathers still assume a role which is primarily financially defined, while mothers assume home-maker and child care roles, regardless of the extent to which they participate in paid employment” (Cuskelly et al., 1998, p. 331). Despite increased participation in employment, mothers continue to take up traditional subject positions in a discourse of motherhood. Most mothers in the study position themselves as primary caregiver in accordance with the/ir societal constitutive force of motherhood and in concert with the construct of ‘good mother’. Elise continues:

When we look at mothers and fathers we think, the father at work, and the mother as the carer, whether she goes to work or not. Somehow that gets lobbed in your lap.

Typical motherhood positions “require women to sacrifice themselves for their children and husbands” (Gross, 1998, p. 2). A Queensland study comparing non-disabled parents with and without a child with a disability found that “housework and child care has remained a woman’s domain, with little paternal support, and that this is true whether or not there is a child with a disability in the family” (Cuskelly et al., 1998, p. 330).

You live with what's expected (Patti): taking up subject positions as mother

As already noted, mothers in this study position themselves with/in a socially accepted discourse of 'good mother'. Mothers' beliefs of the way in which society views motherhood support and reinforce their construct of, and subjectivity as 'good mother'. I asked the women to examine their perception of society's image of motherhood. Changing discourses of motherhood and the subject positions available over time are evidenced in the older women's comments.

Michelle, an older mother, perceives society's previous discourse of motherhood as one in which the "*mother was at home and she looked after the children. She raised them to be able to stand on their feet*". Again there is the taken-for-granted positioning of mother as primary caregiver. The mother is also expected to take up a positioning of teacher who would raise an independent adult. Michelle goes on to say, "*in my days that was probably the way it was looked at*" and adds, "*whereas now it is quite different*". Her words suggest that she perceives a contemporary view of society having different expectations of motherhood. Elise concurs, noting, "*the generation that I mothered in, there were probably more mothers who weren't doing the dual role*". Elise is referring to the dual positioning of working as well as being mother and primary caregiver.

As an older mother, Patti also acknowledges changes over time in societal expectations of motherhood:

Well today's expectations are different. Women of today, don't, on the whole, want to be home just being a mother ... They want to be out and have a life for themselves and have their own fulfilment.

Within this view, Patti points to a subjectivity of individuality in which mothers want "*their own fulfilment*". A tension and resistance demonstrates the "blurring boundaries between self and child" (Lupton, 2000, p. 61), which can also be seen in Patti's comment that mothers of today want "*a life for themselves*". Patti contrasts the tension of boundary between mother and child with the social expectations when she became a mother:

Today's society is different. You've got a lot of mothers who've always worked and they expect to continue working after they've got married. And in my days we were home, we were the home-maker, and we didn't have the anticipation that girls of today have. Even mothers of young children like to get out and have some freedom because they find looking after children too limiting. They need to have their own space, which we didn't demand. It wasn't expected and so I think you live with what's expected.

Patti notes that being a mother was “*what all your friends did. That's what our mothers did. Our mothers never went out to work*”. Generational as well as societal influences impact on the subject positions available within the discursive field of motherhood, and these in turn influence the way mothers individually take up particular positionings as mother. Patti, Michelle and Elise speak to the fluid and temporal nature of meanings attached to the language and construct of motherhood. Their words demonstrate the movement they see as boundaries of what motherhood is within dominant discourse, and the subject positions available as mother, shift over time. A discourse of motherhood is constituted within a temporal space and is continuous and open to reinterpretation. The spaces afford opportunities for resistance to dominant motherhood discourse.

Other mothers highlight different aspects of their perception of society's image of motherhood. Diane draws attention to the media's role in the social construction of motherhood when she states:

Different little snippets you see on the news and that is that mothers should still always be there. Even if they're working, they should still be there for the family.

Liza perceives that in Australian society, “*you're expected to love your kids, to look after them, to educate them, probably not much more than that*”. Then she goes on to add, “*I guess you've got the stereotypical view of the mother that never gets stressed and does all these wonderful things*”. The women in this study are continually socially constituted with/in a non-disabled discourse of motherhood.

Not only is there still the dominant social discourse of mother as primary caregiver, there is an expectation that many women will continue to work once they become mothers. Motherhood in contemporary society is “a site of cultural and social contradictions and tensions” (Lupton, 2000, p. 50). Lupton (2000) goes on to contend that mothers “have been encouraged to construct their subjectivities increasingly

through activities in the ‘public’ domain, including through paid labour” yet “they are still expected to conform to the ideals of ‘good motherhood’” (p. 50). It is this tension that some of the mothers spoke to when reflecting on the public/private subjectivities of mother; they take up the role of ‘good mother’ yet also interact in the public space.

Oranea, a younger mother, also speaks to the fluid and multiple subject positions mothers are expected to take up, as she speaks to the changes she perceives in society:

I think mothers were expected to be in the kitchen and look after the kids and don't have another life. Mother's were viewed, before, as how good they are by the children. You know, how well brought up the children were. Now there's more pressure on mothers to go out and work as well as to be a good mother at home, to do both things at the same time. Whereas I think it doesn't work that way. You're either a mother, a stay at home mother, or you're a career person. That's how I see it.

In this quote, Oranea not only adeptly brings in a historical subject position of mother-at-home, but she singles out the taken-for-granted position as ‘good mother’. The construct of ‘good mother’ as one who is responsible for the outcome of their children is the way Oranea positions herself in a motherhood discourse. In her storying, a public ‘gaze’ (Foucault, 1973) judges the manner in which women mother. Being a full-time mother is prioritised by Oranea despite the socially changing positioning of mother as both caregiver and someone in paid employment (Cuskelly et al., 1998; Freedman et al., 1995). Oranea clearly expresses her belief that the subject positions of mother and “career person” are contradictory. Evident in her storying is her belief that a woman is either a mother, or a career woman; to be both is to deny the possibility of being ‘good mother’.

Susan believes there is a “*stigma out there*”, in society, if a woman is “*just a mother*”. As she says:

I think admitting that you're a fulltime mother doesn't hold great weight in society to be honest. And I think that's pretty sad, because I don't think there's anything wrong with making that choice if that's what's for you.

Susan’s words suggest an agreement with Oranea’s view of contemporary society as one where women mother and work outside the personal space of the home. However, unlike Oranea, Susan believes that it is possible to “*combine motherhood and working, and do a good job*” and she currently works full-time in a paramedical profession. Oranea is a full-time mother and feels that the dominant discourse of motherhood is in

conflict with her motherhood subjectivity. As she perceives, “*society views mothers as, it’s not as important as a paying job, as a career*”, concurring with Susan’s statement.

Oranea uses a collective “*us*” in her storying, positioning herself with other women who are fulltime mothers. She believes dominant social expectations “*put a lot of pressure on us. It makes us feel that we’re not good enough*”. Oranea posits that her subjectivity of motherhood is judged by society as inferior and this creates conflict and tension in the subjectivity she has taken up to position her self as mother. Yet, for Oranea being a mother “*is the best. The hardest job on this earth is to be a mother*”. Again, while coming from a different subjective positioning, Susan concurs with Oranea on the difficulty and demands of child rearing when she emphasises, “*it’s such a hard job. It is*”. Oranea resists what she believes to be the dominant discourse of motherhood as she constructs her motherhood subjectivity with/in a more traditional discourse of motherhood, while Susan has taken up multiple positionings of mother and working woman.

Conversely, Sandra constructs a contemporary social discourse of motherhood quite differently to that of most of the mothers in the study, and indeed to that of the current literature. Sandra strongly views motherhood as a natural construct, one that is biologically determined, and narrates her subjectivity around that framework.

I think basically that it is the mother’s role as the person that bore that child [who] is able to nourish the child and whatever; I think it’s a basic animal condition that is quite under-rated a lot. Different periods in different centuries, they’ve hailed women and their social standing has become more important to be a mother and I think that’s the way our society’s going now, trying to rekindle that respect and basic necessity of women in the mothering role in our society (pauses). I guess I just naturally undertook that role.

Sandra’s words acknowledge her perception of Western society’s temporal, fluid and changing discourse of motherhood, and she believes that currently society is moving (back) towards a more historical discourse of the fulltime mother. Although Sandra desires being a fulltime mother, she continues working part time.

The mothers’ perceptions on the way in which society views motherhood parallel their preconceived ideas and desires of motherhood. It can be argued, “personal histories of being positioned in particular ways and of interpreting events through and in terms of

familiar story lines, concepts and images that one takes up as one's own effectively constitutes the me-ness of me separate from others" (Davies, 1992, p. 57). The dominant Western socio-cultural discourse of motherhood informs the women's knowledge and story lines of mothering and influences the taking up of a subjectivity of 'good mother' as familiar story lines. The women in this study had ideals and dreams about the way they expected their life to progress, as mother and child, and mother and family. These dreams are part of the usual thoughts parents have prior to parenthood (Ziolko, 1991). Expanding on her image of motherhood, Therese, a primary school teacher, paints a vision of her dreams of the future before giving birth to Kimberley. It is a dream sharing common elements from many mothers who spoke with me:

You're going to have this wonderful child. There's never going to be a problem. You're not going to be like all those other parents whose kids you've taught. There's never going to be an issue. The kid's going to be perfect, they'll grow up, they'll get a good job. They'll get married and then you'll have grandkids.

The societal gaze is clear in Therese's comment, "*you're not going to be like all those other parents*". In these words Therese echoes the thoughts shared previously by Oranea, that mothers are socially judged by the way they mother, there are particular subject positions which are expected to be taken up as woman and mother.

Similarly, Patti states she thought "*life would just go smoothly ahead*" and Diane envisages a "*lovely little bouncing baby*" and a belief that they would have "*a dandy little life*". Therese also speaks of her expectation that life would be "*really smooth*". Diane explains that the only problems foreseen by her were what she describes as the regular problems she believes faces new mothers:

The learning to change nappies and feeding ... And learning to understand them and just all the regular little things I suppose you think are normal.

Obvious in their ideals and projected dreams of the future is the taken-for-granted assumption of giving birth to the perfect child (e.g., Landsman, 1998; Murray, 2000; Talbot et al., 1996).

The women's beliefs of motherhood are fashioned out of their past; their experiences, their values and beliefs, and their interactions in their socio-cultural world. Hays (1996) expands:

Every mother's ideas about mothering are shaped by a complex map of her class position, race, ethnic heritage, religious background, political beliefs, sexual

preferences, physical abilities or disabilities, citizenship status, participation in various subcultures, place of residence, workplace environment, formal education, the techniques her own parents used to raise her – and more. (p. 76)

These individual differences give shape to a diversity of positionings taken up by individual women as part of their motherhood subjectivity. Yet, within this diversity there exists a societal sameness, a common discourse, which gives rise to the construct of ‘good mother’.

Intensive mothering – good mother/bad mother

Pre-conceived images of motherhood which constitute the taking-up of ‘good mother’, are spoken into existence by mothers in this study. They speak of changes they expected to occur in their transition to motherhood. Sandra expresses foreseeable changes similar to those explored by the women in Bailey’s (1999) study. Sandra explains she expected some change to occur in her life, once she became a mother:

I expected that I would have this rosy-cheeked baby that would just sit in a bouncinette and I could do a bit of washing and keep on with my life as such, and just have to modify it a little bit to fit this new baby in it. As a family group, a family unit, our lives would change because we’d have to consider the child’s needs as well and not party till 4:00 in the morning and those sorts of things. But I really didn’t think that life would change that much. Certainly I wouldn’t be working so that would be a change. I’d give up my job and stay at home with the baby.

Despite an awareness that change would occur, Sandra believes the changes would not impact too much on her life. Yet she also acknowledged a major change to her life would be giving up fulltime work. This change follows the construct of ‘good mother’, that of staying home with her child. As evidenced in Sandra’s storying there is no expectation or discussion that the father will undergo a similar change emphasising the gendered expectations of parenthood noted earlier.

There exists “pressure on the mother to conform to the traditional role of the selfless, giving mother who devotes her whole life to her child and her family” (Traustadottir, 1991, p. 217). Hays (1996) has identified a model of mothering which she terms ‘intensive mothering’ which exists as a “historically constructed cultural model for child care” (p.). The construct of ‘good mother’ appears to follow this intensive mothering

model closely, with its emphasis on maternal self-sacrifice, a child-centred approach to rearing children and the belief in mothers as the primary caregiver. Hays explains intensive mothering in the following way:

The model of intensive mothering tells us that children are innocent and priceless, that their rearing should be carried out primarily by individual mothers and that it should be centred on children's needs, with methods that are informed by experts, labor intensive, and costly (p. 21).

A number of women speak of the role of teaching their children as they present their construct of motherhood. According to D. Richardson (1993) social attitudes towards women's role as mother came to the fore during the twentieth century when women were regarded "as 'Saviours of the Race', engaged in the vitally important task of moulding the next generation" (pp. 111-112). Teaching and raising children to be good citizens was part of the responsibility of motherhood as the child was seen "as the symbol of the nation's future" (Hays, 1996, p. 44). For Michelle, motherhood involves "teaching them about life and how to deal with it". Other mothers also expressed the pedagogy of motherhood. For example:

Hopefully mothers are the guiding hand, guiding light, having to guide your child through the pitfalls of life as they grow up, and training them, guiding them to be a person who can cope with life. (Patti)

I wanted them to learn as much as they could from their environment, from everything that's around them. I was wanting them to take in life with me, around me, and the things I could provide for them and just learn from that. (Serena)

The hardest job on this earth is to be a mother, is looking after your children and bringing them up the right way. (Oranea)

These mothers emphasise their involvement and responsibility in raising their children and engaging in the practices of intensive mothering.

The narratives from some of the women in the study suggest a commonality of experience amongst mothers, hinting at generalisations and placing them with/in a particular socio-cultural group named collectively and homogenously as 'mother'. A collectivity that intimates a sense of sameness in the experiences they expect to face through their transition to motherhood; a sense of belonging, motherhood statements. When I ask Therese what her perceptions of motherhood were, she replies, "I guess like most people's" and went on to speak about having the 'perfect' child. Sandra also

indicates her belief that motherhood was a common experience faced by women over time; *“I sort of felt it’s all fairly well routine. Every other woman who’s ever had a child has been through the same process of change and new life as parents”*.

Elise expands on the notion of intensive mothering and her perceptions of a collectivity among/of mothers. As a mother who has been, and continues to be highly involved in community-based groups, Elise basis her generalisations on personal experiences with numerous other mothers:

My experience of mothers is that in general they will go to all sorts of lengths to secure the well being and so forth of the child or children.

As these women take up a subjectivity of motherhood, they draw on the dominant discourse and locate themselves with/in their socio-cultural group. There is a contention that “the notion of a good mother as one who sacrifices all for the sake of her children is a powerful motif found in many cultures” (Skinner et al., 1999, p. 487; see also Gross, 1998). The mothers in my study appear to dance this same motif through their narratives.

Spaces and silences: the invisibility of mothering a child with a disability

The discourse of mothering is a public and commodified discourse played out in the images of television talkshows and sitcoms, in magazines, advertising, and on the shelves of toy and department stores. These public sites and texts encode constructs of childhood and parenthood, and act as powerful public pedagogies in the production of social identities of the ‘child’, ‘family’, ‘gender’ or ‘race’ (Luke, 1996, p. 169).

Luke (1996) collected magazines on parenting and mothering over a 6-month period in 1992. Of those magazines analysed, Luke states that only one version of motherhood is presented in specialised parenting magazines. The presented view of motherhood continues to emphasize “a conservative and traditional vision of femininity, motherhood, and family” (p. 184). Excluded from the magazines are “women and children of color, single mothers, poor mothers, fathers, and nonheterosexual family

formations” (Luke, 1996, p. 184). It must be emphasised that children named with disabilities and their families also seem to be excluded, both from the magazines and interestingly, from Luke’s analysis of exclusion.

Not only are women who have children named with a disability silenced in the cultural media representations of parenting, Luke (1996) goes on to highlight that “men for the most part are excluded from the visual and textual discourse” (p. 175) of the magazines she examined. I noticed throughout the interviews that the father was often, but not always silenced in the mothers’ storyings. Some fathers were (re)presented as playing a more active role in parenting than were other fathers and this concurs with other findings (e.g. A. Richardson & Ritchie, 1989).

Disability is silenced in the multiple discourses of social identity identified by Luke (1996). It is invisible, not constructed as part of the social construction of child, family or motherhood. Societal images of norm, which are to be found in numerous discursive sites, such as parenting magazines and other media representations, appear to exclude those families, those non-disabled mothers, who have a child named with a disability. It can be read that “the category children really means non-disabled children, while those who are disabled are assumed to be in a separate and exceptional grouping” (Read, 2000, p. 116). Strong public images portray those who belong and those who do not and the separate groupings referred to by Read (2000) speak to other spaces to which non-disabled children belong. Landsman (1998) questions what the “impact of cultural imagery is on women who bear children who fail to meet society’s standards of quality” (p. 7). How and where do mothers who have children named with disabilities determine their place and space in these public pedagogies?

The mothers who (re)told their stories fall outside the dominant Western discourse of motherhood, no longer part of the meta-narrative of mother. Mothers who are firmly located with/in the world of non-disabled find themselves being made subject with/in a discourse of disability, as they have babies/children named with disabilities. A socio-cultural expectation is associated with motherhood and to have a child named with a disability brings that expectation into tension:

Images of motherhood ... are based on healthy able bodied children. To be a mother of a disabled child is to be different – a mother because she undoubtedly

has a child, yet somehow not a mother in terms of the conventional notions of motherhood with pervade our society. (Gregory, 1999, p. 123)

The socio-cultural discourse of motherhood appears to silence disability, yet these women are mothers too and come to motherhood with preconceived images of the discourse of motherhood based on available socio-cultural discursive texts. Luke (1996) expands:

Magazines offer visions of childhood and motherhood which both model and reinforce normative ideas of feminine desire located in idealized motherhood and childhood: of cute babies and stylishly dressed toddlers, of powerful emotional moments of bonding, tranquillity, and symbiotic identification which these texts and images consistently claim as intrinsic to the “most important time in a mother’s and baby’s life” (p. 174)

Within the study, the women’s subjectivity of motherhood is bound up in the construct of ‘good mother’ and the ideal of ‘intensive mothering’. How do they (re)construct motherhood with/in the discourse of disability? How do they fill the spaces created by the silence?

I (re)present next part of Serena’s narrative. This segment brings to the fore Serena’s taking up of the construct of ‘good mother’ and intensive mothering. As Serena struggles with understanding her son Jason, she initially constructs herself as a ‘bad mother’. Serena takes up the story line of ‘good mother’ in her motherhood subjectivity and as such her perception of the social expectation of ‘good mother’ is discursively constituted in the dominant discourse of motherhood.

☞ Serena’s story: *It’s something I’m doing*

Serena is close friend whom I have known since working with her son Jason at a Special Education Unit in Deira in 1995. When I first met Serena she was highly involved in the Deira Autism Support Group which she had founded. Serena briefly provides details about her childhood before quickly telling of her marriage to Kevin, the birth of her first son, Jessie, and then the birth of Jason. Serena’s early storying is noticeably one of motherhood as she explains and explores her early years with Jason.

Serena recalls the period of time when Jason was a baby as one where she was under great stress. Not only was Serena involved in a court case regarding the loss of their home to landfill problems, she was also experiencing difficulty in mothering Jason. Serena has difficulty recalling her memories of this period in her life:

A lot of stuff I find is a bit of a blur, like it's lost in my memory 'cause I don't want to remember it, regarding him as a baby. The stress I was under... but yeah [the screaming] would go on for a long time – I couldn't calm him. There was nothing I could do that would calm him down, and then all of a sudden he'd stop and I'd have this calm baby and I wouldn't know what I'd done.

Serena attempts to block past memories, those which trigger emotions rooted in the uncertainty of why her baby behaved the way he did. Serena brings in the discourse of 'good mother', and her positioning that as mother she should be able to settle and calm Jason, as she did with her first child.

A sense of embodiment exists between Serena and Jason, an interaction between mother and child, and for Serena the interaction that was occurring was not expected, nor could she determine its causes or outcomes. Lupton (2000) proposes that motherhood is not only shaped through the dominant discourse of 'good mother' that Serena can be seen to adhere to, but is also "constructed through the embodied relationship that women have with their infants" (p. 60). Lupton goes on to add that the experience of being mother "potentially involves an existential experience that may move beyond the boundaries of autonomous existence" (p. 60). It is in part the tension of boundaries between "selfhood/embodiment" (p. 60) that Serena finds difficult to resolve as she attempts to take on the 'good mother' role.

As Jason develops Serena continues to experience uncertainty and difficulty in her subjective positioning as mother. In her storying Serena is able to look back from the present to make sense of her past experiences:

I couldn't work out his behaviour at all. Because it was like he'd be screaming and carrying on. Now I know it was frustration that he couldn't get what he wanted. And so yeah, it was a very frustrating, frustrating and stressful time for me not knowing what it was, and I took it all on board of how, I just took all the guilt of how I was treating him on board.

Serena's subjectivity of motherhood is threatened as she attempts to determine and work with Jason's behaviour. It has been suggested that mothers link "their own subjective well-being with their feelings of success in mothering and their child's progress"

(Larsen, 1998, p. 868). Serena is aware that Jason's behaviour is different to what she experienced with Jessie, yet she blames herself. Her construct of mothering, the subjectivity and story line which she has taken up as her own, leaves her vulnerable and provides no space for resistance. Serena reports feeling guilty, believing it is her mothering that is at fault. She internalises and constructs Jason's behaviours as being directly connected with her mothering, creating a tension as she struggles to maintain her construct of a 'good mother' even though previous mothering techniques do not appear to be successful. Serena examines and retells her narrative in terms of who and how she positioned herself as mother. Her storying remains focused on her construct of self as mother, rather than Jason.

Jason looks so normal

Serena notes obvious differences in non-verbal and verbal communication, and other areas of development between Jason and her first son, Jessie. Although seeing differences between her two children Serena frames the differences as developmental, believing all children grow and develop at their own rate:

I still kept thinking it was me, and that I wasn't going to worry about the differences, every child grew up normally, you know they had their own things. But regarding his behaviour and how he was, I just kept on thinking well it's something I'm doing.

As Serena separates Jason's behaviour from his development, she continues to construct her inability to be a 'good mother' as cause. Jason appears visually 'normal' and there is an expectation that he is 'normal'. It is therefore difficult for Serena to 'see' that something could be wrong, that Jason's behaviour could be symptomatic of a different reason. The conceptualisation of looks, a visual 'knowledge', as a determinate of normality creates tensions as Serena struggles to understand Jason. A gaze of normalcy is applied to Jason by Serena and a bodily inscription that reads Jason as 'normal'.

When Jason is 2 ½ years old Serena takes him to her family doctor. She explains, "I'd click my fingers and I'd get no response" yet Jason would be "afraid of a loud noise or an unusual noise". Serena expresses her concerns to the doctor:

I explained to the doctor that I felt that the fact that he wasn't talking, there might be something wrong. Does he need some help in being able to speak? Again I took that onboard that because he's not speaking I'm not doing enough with him to get that communication across.

Serena takes on the roles and expectations of intensive mothering as she continually positions her self as 'good mother.' It is her responsibility to teach her child to speak, to communicate, and because he is not communicating, she takes on a discourse of blame and guilt.

I felt absolute relief

Despite taking Jason to kindergarten, kindy-gym and to speech therapy in order to provide opportunities for Jason, Serena says that she "*still couldn't work out that ... there was something wrong with Jason*". Serena continues to believe she "*still wasn't doing enough to make him better, to fix him, to help him*". The ideology of intensive mothering continues to inform Serena's construct of 'good mother' with its emphasis on a "reliance on experts" (Hays, 1996, p. 44).

Eventually an appointment is made for Serena to have an assessment with the Education Department. During the initial assessment of Jason, Serena is given the opportunity to begin to understand Jason in a different manner. Serena explains:

By Pat asking me those questions, all those things, that they were ticked and they fitted into some box, some category to say that well there's a child that doesn't do all those things too, made me think well maybe there is something wrong with him and it's not me.

The labelling and ability to categorise Jason's behaviours into "*some box*" provides Serena the opportunity to begin to (re)construct her self as mother. Questions provide answers allowing Jason to be placed in a category with other children. Jason fitted the same space as 'Others'. His behaviours could now be read to fit in a different space to that which Serena expected. The spatiality of disability is read in/to the metaphor Serena uses to describe the space in which Jason is placed – "*some box*".

In many ways the initial diagnosis of autism offers a chance for Serena to escape her self positioning of blame and feelings of guilt. It offers her a profound sense of relief,

not only because she finally had an answer to Jason's behaviours, but because his behaviours were not attributed to Serena being a 'bad mother':

I felt absolute relief. Tears just poured out my face because I just thought, "At last, there is something here that says all those things that he is doing are because he has autism, not because of anything I'm doing or because there's something wrong with the way he's been treated or anything".

Serena's storying exemplifies Larson's (1998) statement that "mothers linked their own subjective well-being with their feelings of success in mothering and their child's progress" (p. 868). Serena clearly linked her motherhood subjectivity and positioning as 'good mother' with Jason's behaviour and development.

Making motherhood visible in the text

Throughout this chapter the dominant discourse of motherhood as it has been imagined, desired, taken-up and enacted in this study has been made visible. The narratives from the mothers in this study show the way in which they take up familiar story lines of 'good mother' and intensive mothering. Additionally this chapter brought to the fore the silences and spaces which exist for non-disabled mothers who have children named with a disability and emphasises the lack of a motherhood discourse within the discursive field of disability.

A societal surveillance of motherhood is evidenced as the constructs of 'good mother' are taken up as dominant discourse and practice. Through a public gaze, as suggested by the mothers quoted, motherhood is monitored, reinforced and judged, with an awareness of surveillance, of being watched and judged as 'good mother' and one who is responsible for the future of the race (D. Richardson, 1993). Motherhood is socio-culturally determined, and power and control are exercised through media and other textual embodiments which position women as mother, yet at the same time, subject positions within motherhood are shown to be fluid as discursive practices shift and change. The following chapter turns to the mothers' storyings of the time of diagnosis of disability of their children, and this in turn leads to the exploration of the language-in-use in academic literature surrounding non-disabled mothers who have children named with a disability.

Chapter 4

Choreographing movements of words and meanings: mothers, language and meaning-making

For parents of children diagnosed as disabled, their anticipated world included the birth of a normal child. On diagnosis of disability, the parent encounters to a greater or lesser extent a threat to pre-existing conceptions and ideals of parenthood. (Bruce, Schultz, Smyrnios & Schultz, 1994, p. 40)

The mothers in this study represent a diverse group of non-disabled women who have children named with disabilities. Some women were already mothers, while for other women the child named with a disability was their first child. Some of the children's impairments/abnormalities were diagnosed at birth, others between birth and 3 years of age, while at the time of the interviews one child, aged 4 years, had no known diagnosis. As such, these women form a heterogeneous group, brought together simply by the similarity of having a child named with a disability. This chapter begins by choreographing the movements of diagnosis, and the mothers' steps demonstrate diversity through their movements of words. Each mother narrated the diagnosis of her child in detail, giving it priority in her narrative, choreographing meticulous steps portraying how she came to be informed of the diagnosis and her emotive reactions/responses of that time. Due to the spatial constraints of this thesis, the stories of diagnosis for most mothers have not been included in detail, despite the importance of the (re)telling to them.

Words, language, and meaning-making from individual mothers' perspectives make up the rest of this chapter. The mothers and I talk through and explore words such as loss, grieving, acceptance and stress, and look at the meanings these words have for them; as these words are often used in much of the academic research surrounding non-disabled mothers who have a child named with a disability. Through the use of mothers'

narratives, poststructuralist analysis is applied to investigate how language is used by individual mothers to give meaning to this particular experience. What meanings do words hold when mothers are able to speak the meaning into existence?

Given a name: diagnosis and labelling

I commence this section by providing a brief sketch collating the mothers' stories of diagnosis for the audience's information. I also bring together mothers whose children have similarly named categories, although their individuality precludes (re)presenting them as a homogenous group.

Elise and Melissa received the diagnosis of their children having Down syndrome at birth. Elise speaks of David's diagnoses at birth:

He's Down syndrome, Mongoloid, all the rotten words they use. You're given a sheet of paper that tells you nothing. ... All this is going through your mind, how bad is he going to be? Will he live a normal life? Will he do this, will he do that? All that is going on while you're trying to breastfeed a baby (pauses). And then there's the telling friends, telling family.

Elise's words speak to the tension of motherhood and disability as she notes how the diagnoses raised numerable questions, at the same time as she was trying to breastfeed. Elise also mentions during our conversation that social and educational expectations for people with Down syndrome were not high when David was born in 1972.

However, Melissa's mother had worked with children who had Down syndrome, and Melissa explains she had an idea of what Down syndrome was: *"I knew slightly what he [the doctor] was talking about when he said Down syndrome because I'd had contact with it"*. Melissa words portray the way John was inscribed by his looks when she says she could *"see it in his face, and his eyes, and his flat head"*. Melissa goes on to explain that her first concern was whether John was going to live:

Was he going to die? Would he live? And then gradually you kind of come down from that. You just get a bit more sort of comfort and relief that he's not going to die. It's ok, he's not going to just die".

Melissa also told of the amount of time her and her husband spent choosing a name for their baby: “*We felt we had to choose a really good one*”. She explains this need to find a “*good*” name in more detail in our second interview:

We felt with John having Down syndrome, we don't want him to be the nameless baby with Down syndrome. At least if he's got a name he starts life the way the other two [children] started life. ... If he had a name he was always John, and he was always called John. He was always a little person in his own right. ...He was always a little person in the family.

The importance of naming John as a person, rather than as a category, is evidenced in Melissa's comment. Her words speak of the binary normal/abnormal, for if John is not named as person, he is labelled and named as ‘Other’ and his category is synonymous with who he is.

Sandra too experiences a diagnosis of abnormality of her baby immediately at birth, but Melanie presents with a rare and unknown abnormality. Melanie had no label attached to her, apart from a generic unknown chromosomal abnormality. Therese found out a week after giving birth to Kimberley of her unknown chromosomal abnormality. Both of these mothers are positioned within a disability discourse, yet neither has a name nor label to attach to their child.

For other mothers, the diagnosis of disability for their children did not occur immediately. Michelle, Kathy and Diane did not know their children had cerebral palsy until a period of time had elapsed. Robyn still has no diagnosis for her daughter who shows signs of developmental delay in communication and mobility, despite repeated testing by medical professionals. Susan is the only mother who knew prior to birth that her child's disability was highly probable. Norah, Patti and Liza experienced children named as ‘normal’ until disease changed their child's life course resulting in intellectual impairment and other medical and behavioural concerns.

Meanwhile Serena, Oranea and Julia tell similar stories of their oftentimes desperate struggles to find a diagnosis for their child – finally receiving a diagnosis of autism. They speak through their motherhood knowledge that their child was not developing according to standard milestones, yet when they went to seek advice from family doctors they were told a similar story “*he isn't that far behind in his development*” (Julia). When a diagnosis of autism is finally made, the three mothers report that

amongst their multiplicity of feelings is one of relief. Oranea expresses her multiple emotional responses clearly when she says, *“I was sort of relieved and also wanting to know more at the same time, and at the same time was also depressed”*. Like Serena and Oranea, Julia states that the diagnosis confirmed her suspicions that something was wrong with her son. As she says, *“finally I had a name for something that had been bothering me for so long”*. Serena too reported that at last she had *“an answer”*.

The mothers in my study expressed their feelings concerning the diagnosis of disability in various terms. These emotional responses indicate the “complex manner in which emotion, cognition, and the lived body intertwine” (Ellis & Flaherty, 1992, p. 2) and are explored in the following section. The mothers expressed emotional responses included shock, anger, depression, devastation, fear and, for some, relief. Michelle tells me she *“jumped for joy”* when Craig was diagnosed with cerebral palsy as she had believed something was *“not right”*, yet no-one else acknowledged her nurturance knowledge. Michelle brings into play the discourse of motherhood and her subjectivity as mother, when she explains she felt she was not a ‘good mother’ for thinking there was something wrong with her son. Julia similarly states, *“I wish people would address a mum’s worries with a little bit more concern. ... They still seem to deny the mother’s right of her knowledge ... I wish somebody had listened to me a bit sooner”*. Julia’s words bring to the fore Ellis and Flaherty’s (1992, p. 4) comment that “subjectivity is situated such that the voices in our heads and the feelings in our bodies are linked to political, cultural, and historical contexts”. Julia raises the issue of how a mother’s nurturance knowledge is not given as much credence as professional knowledge and the binary profession/lay comes into play.

Words and meaning-making: grieving and acceptance

With the exception of Susan, all the mothers in this study had an expectation of the birth of a non-disabled child. The news of disability means “the ideal, the wished for, the expected perfect child is lost” (Bruce et al. 1994, p. 39). Much research has been conducted on the impact of disability on non-disabled mothers, in particular on the stages of grief and of mourning (see Bruce et al, 1994; Davis, 1987; Kendall & Buys,

1998; Landsman, 1998; Milo, 1997; Olshanky, 1962; Wikler, Wasow & Hatfield, 1981; Ziolkko, 1991). Stages of acceptance “assume right or wrong adjustment, implying that deviation from the sequence is psychopathological” (Case, 2000, p. 273). There is a lack of consensus about the process of adjustment as a linear stage model or a recurrent model (Kendall & Buys, 1998).

Most of the disability-related grief literature comes from the general grief literature, as well as clinical observations, and small-scale studies (Powers, 1993). Additionally there are “widespread generalizations and misconceptions among professionals and the public regarding the nature and management of disability-related grief” (Powers, 1993, p. 120). An emphasis on stages of grief means “parents’ responses are thus often designated by scholars and service providers in terms such as ‘denial’ ‘compliance’ ‘acceptance of reality’ and ‘coping’” (Landsman, 1998, p. 3). Mothers are made subject in the academic discourse on disability and parenting. Likewise, Larson (1998) states, “blanket terms used by health professions such as acceptance, and denial do not clearly capture the mother’s emotional processes in parenting a child with disability” (p. 868). Conceptualising the adjustment process implies a passive subjectivity for the women involved (Kendall & Buys, 1998). I was interested in how mothers in my study gave meaning to the words in common usage. Were words used by professionals and academic literature, part of the mothers’ chosen language? How did they understand the words they used? To investigate these questions I asked mothers the meaning of words commonly referred to in the literature relating to the mothering a child with a disability. For the purpose of this analysis I focus on the words of grieving, acceptance, and stress as these were the words which were frequently used in the literature I had read. Stress, in particular, is often researched in the literature dealing with parenting a child with a disability, and is thus considered in this section of the thesis.

A loss of your dreams (Liza)

Mothers spoke in general of grieving in terms of loss and sadness. As they (re)told their stories, sadness and loss were present in their narratives, and in their voices. However I also asked mothers specifically what grieving meant to them, as it is the “subjective significance and meaning of the loss for the individual”, which is of importance (Bruce

et al. 1994, p. 39). Their responses to grieving are analysed in three areas – loss, ongoing or transitional grieving, and no grieving.

Some mothers speak of the grieving process they went through when they first learnt of their child's disability, whether it was present at birth or diagnosed later in the child's life. They speak simultaneously of their own loss of the dreamed-for-child, and also for what they perceive their child has lost. Their words suggest they grieve for their child because the childhood their child will experience no longer fits the predetermined and accepted discourse of childhood. The following quotes are representative:

Ah, grieving. Grieving for what might have been. A loss. A loss of what might have been. A loss of your dreams. ... Your dreams for your child, but you always want the perfect child, and you've never got the perfect child. But it's also a loss of a family, of the type of family that you thought you'd be. Because it does change family dynamics, there's no question about it. It may enhance it, but it does change it. (Liza)

For not having the normal child that I (pauses) thought (pauses), let me rephrase that. For Michael and knowing that he will not be as normal as my other children. That he will not go off later in life and have his own family and have a career. That's what I was grieving for. (Oranea)

You look at all the things that they're not going to do, not going to have and it's (pauses) yeah, you feel sad because you've lost, they've lost something that you expected for them. (Melissa)

I suppose it's grieving for what you don't have. Or for what you think you don't have. Sometimes it would be, for me, to grieve it would have been grieving, always the longing for the normal life. Not to have to worry about the things I had to worry about. Not having to go through the experiences I went through. (Diane)

There's a grieving for not having the things of the other children. ... It is a loss in the sense of it's a loss of what your expectation might have been for this child you've been carrying for 9 months. Suddenly all the things that you expect for the child are going to be different. (Elise)

I think I guess grieving is a loss. I think you grieve for the loss of the normal child you thought you were going to have. (Sandra)

[Grieving is] something to get through. A sadness and a sorrow that passes. (Serena)

The mothers are positioned in a world where the dominant discourse is of non-disablement, and they now have to reconstruct their motherhood expectations based on the child they have. Loss therefore can be defined as being perceived “when the reality

of life is changed in such a way as to make it less preferred than wanted or expected” (Powers, 1993, p. 121).

It's not something that's a forever (Serena)

Some of the mothers in the study also felt the above-mentioned loss at transitional periods in their child's life (Bruce et al., 1994; Davis, 1987) and speak to the “recurrent adjustment” that takes place over their life course (Kendall & Buys, 1998, p.4). Serena believes that her emotive response of grieving passes, but will return as different situations arise:

I'm sure I will grieve again in a different situation maybe. But again that will be something that passes. It's not something that is a forever for me. I'm not grieving at the moment. I went through a grieving and I've gone through, I've worked through it so that it's not there.

Elise also mentions the transitional stages, or the expected (‘normal’) developmental milestones as being the time when one might grieve. However she queries the use of the word ‘grieving’ and suggests that the process is more one of temporal adjustments:

I think there are stages through the child's life where milestones perhaps happen and there's this process you work through, which probably isn't grieving in the true sense, but it's still, you have to work through it. So yes, it's a process of adjusting I would describe it. (Elise)

Elise's suggestion that the word should be adjustment rather than grief echoes Kendall and Buys' (1998) work on the psychosocial adjustment following acquired disabilities. The feelings of sadness reported by parents many years later “are typically not recurrent and occur in response to specific events that the parent associates with the original diagnosis” (Powers, 1993, p. 123). This concurs with Read's (2000) study which suggests that transitional times are “critical points” in mothers' lives (p. 65).

Therese considers the process of grieving in relation to Kimberley's age (13 years) and it is the comparison with another child of a similar age who lives in the same street that highlights to Therese and her husband what Kimberley would have done at particular stages in her life. The social environment provides opportunities for comparisons for both Therese and Sandra:

Now it's become very much a grieving for what Kimberley can't do. ... Amy's starting to go out to the movies with her friends and do all those sorts of things ...

And that's really hard because ... it's sort of in your face all the time. And if Kimberley wasn't like she was, she'd be doing all these things now. (Therese)

As she got better and healthier and whatever I used to grieve. I'd feel it for instance when I saw her sitting in the wheelchair in a row with other kids [Sandra is speaking of a situation where Melanie was lined up at a SEU] my heart just ached for her. Situations like that I'd think, "Oh you poor bugger". (Sandra)

I can't remember grieving (Kathy)

A number of mothers reported they did not perceive that they had gone through a stage or process of grieving:

I went more through denial. Denying there was anything wrong with my child. Mum kept saying to me, "There's something not right, something not right". And I'm just like, "No don't be stupid". ... That's the main thing that I went through I think. (Robyn)

They say, "Oh you're going through all these processes of grieving ... and you have to go through the blame, the grieving and all the rest of it to get on with your life". ... I can't remember grieving when Alex was (pauses) finding out he had cerebral palsy. ... I can't really remember grieving. I mean it'd be nice not to have a child with a disability, but is that grieving? (Kathy)

Interestingly, Michelle's response to my question on grieving shows an active resistance being positioned in/to the dominant construct of disability as tragedy:

Well I don't see Craig as having disabilities as being something that's bad. What I have the problem with is getting the things that I need for him to have his so-called normal life. I don't see him having a disability as something that's terrible that I'm so upset about. To me, he's Craig, and I accept him for the way he is. He's just my son, just as much as the girls are my daughters.

Michelle, as agentic, rejects disability as being inherently negative and in doing so takes up an alternate construct of disability as she separates impairment and disability. Read (2000) reports that in her study, non-disabled women who have children named with disabilities "become convinced through their own experience that many of the most restrictive features of their own and their children's lives are not an inevitable or necessary consequence of having impairments" (p. 117). Michelle speaks to the social model of disability and reframes disability in terms of societal constructs rather than positioning Craig as a problem, as having something "that's bad".

Susan was the only mother who faced the possibility of disability during her pregnancy. Laura's premature birth was followed by many months of intensive medical intervention to save her life. Susan's response to my question, "what is grieving?" is as follows and reflects Laura's survival:

Susan: Obviously a sense of loss (pauses). Yeah, just an overwhelming sense of loss of something.

Valmae: Did you go through a grieving process?

Susan: No, because it didn't happen. We came so close.

Valmae: Because some people talk about

Susan: (cuts in) I didn't ever decide that she was gone before she was, to prepare myself for it

Valmae: Some people go through a grieving process of the loss of the perfect child

Susan: No. Cause I still maintain that we were so bloody lucky to have what we got, so no.

Like Michelle, Susan places value on her child, and disability is positioned as accepted, preferable to not having her child. Susan has no reason to grieve as in her perception grief is synonymous with death, not disability.

The small but diverse group of mothers in the study illustrates wide variation in the way they respond to the diagnosis of disability of their child, and this concurs with the literature (see e.g. Bruce et al., 1994). While the experience of grief is considered normative, it is not necessarily a universal response (Powers, 1993). Therese highlights the role of individual personality when she says grief "*can be a multitude of things and it can, it really depends on the person as to what sort of process you go through with grieving*". However, it must be noted that the loss experienced with the diagnosis of disability is "in part, reflective of predominant cultural norms that emphasize health and able-bodiedness as criteria for happiness and full acceptance within society" (Powers, 1993, p. 121).

Getting on with it (Elise)

When I asked the mothers the meaning of ‘acceptance’ in relation to their child named with a disability, I received a range of responses. Many found it difficult to articulate acceptance as a construct or to give meaning to the word. For some, acceptance meant actually coming to terms with and believing the diagnosis presented of their child. Oranea highlights her acceptance as occurring with a definitive medical diagnosis of autism:

For me acceptance happened when I realised that there is no (pauses) question mark about Michael’s diagnosis. That he is autistic (pauses). Then I have to tell myself I had to accept it. What can you do? You can’t deny it. ... I mean, what can I do? I can’t wave a magic wand and make him, you know, be a normal child.

Diane related her acceptance to moving through the stages of grief, followed by denial, before she believes she accepted the diagnosis of cerebral palsy. Similarly, Elise mentions her perception of moving through a stage of grief before moving on to an acceptance and “*dealing with*” the situations which then arose.

For other mothers giving meaning to the word acceptance became enmeshed in their tellings of ‘dealing with’ and ‘coping’ with the impact of the child’s disability on their lives. Therese asserts, “*coping is just to accept the fact that this is your life and make the best of it*”. Mothers appear to experience difficulty in separating acceptance of their child’s disability from the living of their lives. Kathy explores acceptance in terms of doing the “*best you can for your child*”, a reflection of the construct of intensive mothering and her motherhood subjectivity as ‘good mother’. Many of the mothers also speak of acceptance in terms of “*getting on with it*”; getting on with their lives – where acceptance becomes part of daily caregiving and family life. Following are individual mothers’ explorations of what acceptance means to them:

It’s a process, I think, of acceptance and getting on with it. Getting on with your life. Getting on with the child’s’ life. And then making, doing the best you can with whatever resources you have. And I use the word resources as in your own personal capabilities, not necessarily financial, of what you do to make that child’s life as normal as possible. (Elise)

We were upset initially. ... But after that we probably then just got on with it. (Michelle)

There's no use getting up in the morning and crying, and hearing her crying. That's why I took this up [indicates smoking]. I use to nurse her and then walk around the verandah. (Norah)

Getting over it ... is I think part of that acceptance, that working out what the realities are, seeing the worst, coming back to where you are now, going one step at a time so that you're only dealing with ... what is there now. (Serena)

This is just an acceptance. Ok, well this is what we've been dealt, and then just make the most of what you've got and try and make everything around us as comfortable as we can. (Susan)

We just accepted it as it came along each day, and each little step, then he's got a bit further. (Michelle)

Acceptance of and coping with appear to become constitutive of each other as mothers try to find meaning for the word 'acceptance' when used in relation to their child named with a disability. Therese states "you just accept the fact that there's something different about Kimberley". When I ask her how this acceptance comes about, Therese finds it difficult to put into words, and instead provides an example grounded in valuing Kimberley as a person:

Therese: I don't know Valmae, we just accepted it

Valmae: So what does it mean to accept?

Therese: Ok, it means things like, that fact the Kimberley isn't rolling over, that's fine. Yeah, we tried, we tried to get her to roll over, but when she achieved something, we celebrate that achievement.

When I spoke to Liza about acceptance, she expresses her difficulty in accepting the label/name of intellectual impairment for Lily. Liza tells me that it took her 11 years before she would allow IQ testing to take place to officially (and professionally) determine and categorise/name/diagnose Lily as having an intellectual impairment. Until that time, Liza maintained that Lily had a learning disability, rather than apply the label of intellectual impairment, underlining the negative social impact of the naming of intellectual impairment. I have chosen to use a poetic format as Lily speaks of how acceptance changed her attitudes and expectations.

A really long haul

*I probably didn't really accept it,
start to accept it
until she was about 11.*

*Yeah,
it was a really long haul for me
I can tell you.
A really long haul.*

*See,
now that I've accepted it
my expectations
aren't as high.*

*That's all I would say that's changed
and the fact
that I don't cry
as much
I guess.*

*This is our life
this is our child
I can't change it
any more.*

*And that's ok.
That's fine.
But
it took a long time.*

Serena expresses acceptance differently to that of the other mothers. Serena states that she did not have to accept Jason's label of autism, rather she had to position herself in a (re)constructed subjectivity of motherhood. To Serena Jason was "*just my child who I had to help*". To me, Patti expressed the deepest sense of loss as we spoke of acceptance:

Patti: She's my child. Nobody's going to take her away and nobody's going to do anything about this problem, we've got to cope with it as best we can.

Valmae: So does that acceptance come over time?

Patti: (pauses) I think that's when you die inside and just go on autopilot (laughs).

A discourse of motherhood is evident throughout the mothers' explorations of meaning-making. They speak of their child, their positioning as 'good mother' and the dealing with daily caregiving as part of acceptance.

Mothers and stress: speaking the word into existence

The impact of a child with a disability is a complex one that cannot be easily described or predicted. (Erickson & Upshur, 1989, p. 256)

Research and academic literature over the previous 15 years conducted with/on non-disabled parents who have children with named with disabilities generally focussed on parental stress and coping (Beckman, 1991). In preparation for this research project, I searched for and reviewed literature relevant to non-disabled mothers who have children named with disabilities. I reviewed numerous articles from the 1990s and 1980s and I found myself increasingly immersed in texts of stress, stressors, coping, grief and sorrow (e.g. Beckman, 1991; Hanson & Hanline, 1990; Krauss, 1993; Noh et al., 1989; Olshanky, 1962; Trivette & Dunst, 1992). The discourse surrounding research of non-disabled mothers and families who have children named with disabilities appeared to me to be framed within a construct of disability that was inherently negative, emphasizing the tragedy discourse. Perhaps, as Read (2000) suggests "existing professional paradigms" at that time assumed "that severe disablement in children invariably went hand-in-hand with individual and family pathology" (p. 11). Although my research focus is on the stories the women in my study tell, of what is important to them, rather than an active seeking of either positive or negative factors influencing their lives, it is important to investigate the previous research.

Studies in the 1990s continued in a similar vein, for example, studies examining stress as perceived by mothers and fathers in relation to their own appraisal of family functioning (Dyson, 1993, 1997). Dyson (1993) maintains, "a central research question has been whether the disability generates the greater parental stress and less satisfactory family functioning than that occurring in families without a child who has a disability" (p. 207). Many studies searched for and compared differences between two groups,

parents who have a child named with a disability, and those who do not. This research was conducted using the medical model as a theoretical underpinning. Methodologically, most of the research I reviewed was quantitative, with an emphasis on questionnaires and surveys, self-administered scales and very occasionally, the use of semi-structured interviews, to gather and subsequently analyse the collected data. Very few research articles were qualitative or concerned with the stories of the mothers' lives, of the way in which they brought meaning to their life experiences, of how they were/are positioned and how they position themselves. This lack in the research literature has been noted by Berg-Weger et al. (2001) who assert that "researchers have typically used quantitative measures to assess such negative caregiver outcomes as burden, stress, strain, physical and mental health problems, health care and medication usage" (p. 263). Further, as established in chapter 1, feminist and/or poststructuralist theorising(s) are lacking in the literature.

Other researchers have reported on this preponderance of focus on negative stressors. It has been suggested that "much of the literature on families with handicapped children has approached family stress from a deficit model" (Kazak & Marvin, 1984, p. 67). Erickson and Upshur (1989), Rousey et al. (1992), and Stainton and Besser (1998) also highlight this emphasis on the negative factors in much of the research relating to parenting a child named with a disability. Research moved from an individual, pathological model of stress to one that encompassed a broader perspective taking into account the familial and the social context, yet still retained an emphasis on stress and coping.

In Australia, Llewellyn, Dunn, Fante, Turnbull and Grace (1996) undertook a literature review as part of their report to the Ageing and Disability Department, New South Wales, which investigated factors influencing parental decision-making in seeking alternative care for their young child with disabilities. Their review noted the heavy emphasis on research on stresses/stressors associated with caring for a child named with a disability, as well as the increased costs incurred by parents. They assert that research has also concentrated on personal factors such as grief and chronic sorrow faced by parents who have children with disabilities.

My review of the research literature suggests a societal and perhaps, an academic attitude and belief in disability as an inherent tragedy. Society holds the common-sense knowledge, “that disability is an inherently tragic event with an enduring negative impact on families” (Powers 1993, p. 120). In positivist frameworks and modernist assumptions disability as tragedy can be read, explained and understood as an ‘essential’ truth. That disability is negative appears to be presupposed in the literature thereby framing disability in one particular worldview, providing a meta-narrative of disability as tragedy, and in doing so creating an ‘Other’ group within society and similarly within academic research. The attention focused on the negative impacts of disability on the family unit is significant in terms of the volume of research literature available. It reflects the prevailing societal attitude towards disability in general and specifically in society’s “response to childhood disability as an unanticipated, negatively defined event” (Llewellyn et al., 1996, p. 27). However, in recent years “there has been a growing resistance to research and professional literature which represents disabled children as tragedies or burdens” (Read, 2000, p. 12), and it is into this space that I situate this textual performance.

Having noticed the strong emphasis on ‘stress’ in the literature surrounding mothering a child named with a disability, and having noted during my analysis of the women’s initial interviews that they rarely used the word ‘stress’ I specifically sought mothers’ perceptions of the meaning ‘stress’. Did they speak the word into existence? Serena offers the following thought: “*Mothers of children with disabilities are tended to look upon that they have more stress than other people, other families*”. In reviewing and analysing the mothers’ narratives I found they (re)told many stories about events that could quite easily be read as stressful, but few spoke the word stress in their storying and when they did it was not necessarily related to their child, but more to do with multiple life experiences. When asked specifically what the word meant and their definition of stress, there were numerous responses from the mothers.

Many of the mothers describe an emotive reading, a feeling, when exploring the meaning of the word stress:

To me stress is not being in control. Feeling that you’re not in control. (Therese)

Stress. (Pauses) I used to wish I could go into a padded room and scream my head off (laughs). ‘Cause that’s what I felt it was like. You’re just butting your

head against the wall that you never, ever could find your way through. Life was a tunnel. Sometimes you'd get a little glimmer of light at the end, and then it would close up. It was just a long, dark tunnel to walk through. (Patti)

Stress to me is emotional charges going through the body that, whether they be good, what we judge as a good experience, or a bad experience it doesn't matter, it's just when there's, you're not in that peaceful state and that centred state and it's like your body is just being overcharged with emotion. (Diane)

Additionally, some mothers speak of the tiredness that comes with caring for their child and implicate the role of fatigue in the stress they experience:

Stress? Oh yes (laughs). Stress is not wanting to get up in the morning (laughs). (Oranea)

Stress. Stress. I was so tired that I'd lie in bed and I'd be like this [asleep]. I just lived with stress for years. (Patti)

Issues of time-management are also mentioned in the mothers' exploration of what stress means, suggesting the importance of managing and organising time effectively as a way to 'deal with' fatigue and stress:

Stress (pauses). ... Just feeling, not being able to cope with what you're having to cope with at that particular time. Feeling pressured, feeling that there's too much to do, and you either don't have the time or you're just not able to cope with it physically because you're so tired, or mentally because it's just too much to take on at one time. (Melissa)

Stress? Oh well I suppose it means you don't sleep very well and (pauses) you're tired, really bone-weary, really mind and body weary – and uptight. Sometimes you just jump at everything that's said and you don't think things through. Things can get on top of you. And they do. ... Seems to be like you're trying to split yourself into a hundred little pieces. ... These are your jobs today and you do that and then there's always more jobs tomorrow, there's always something to do with Lily in every day. (Liza)

I live my life in stress. I reckon I operate better under stress (laughs). My family think I do (laughs). When I was at work and that and I had less time, you get so much more done because you've only got that time to do it in, so you make yourself get in and get it done. Whereas now when I'm home I think, "Oh, I can do that tomorrow" (laughs). (Michelle)

Elise and Oranea draw on the discourse of motherhood as they reflect on stress. For them, the stress of looking after their children named with disabilities was different to

other stresses in their lives. The motherhood responsibility of care developed in the positioning of ‘good mother’ is emphasised in their responses:

I think it's different from, a little bit different from the other stresses in life, because you are responsible for this person that you're worried about. And it's your child. If it's a brother or sister or cousin then maybe the level of stress is not as high, but because it's your child, yeah, the level of stress is so high. (Oranea)

There are stresses which happen in families anyway, but some stresses are aggravated if it's the situation where the care of your child is important. (Elise)

➤ *Serena's story: I was numb to stress*

A study by Singer and Farkas (1989) found “that many mothers of young multiply disabled children find meaning and enhanced self-esteem in coping with caregiving despite the stresses involved” (p. 447). Serena speaks of the meanings she discovered in her life as she was exploring the word stress with me. Serena’s initial experiences of mothering Jason were in tension with her motherhood story line and were explored in the previous chapter. Motherhood caregiving did not initially provide Serena with the self esteem noted above. This is perhaps because of a tension with the normative assumptive positioning of motherhood as taken up by Serena and the non-normative behaviours exhibited by Jason.

Serena vividly illustrates her early response to the stress she was feeling in the following segment which is temporally situated prior to Jason’s diagnosis of autism. It is a time when Serena is taking up a discourse of guilt in her role of ‘good mother’ as she endeavours to understand Jason’s behaviours. She also positions herself as being depressed:

I was numb to stress. I was trying not to feel any stress by doing that [feeling numb]. I would feel numb. ... I remember driving along ... when I was really depressed ... it was a pain that I was feeling all the time. I'd be driving along with the kids in the back of the car and they were screaming or whatever, I can't remember ... and I thought to myself, “If somebody punched me in the face I wouldn't feel it”, ‘cause I was feeling that much pain.

As Serena continues to narrate her story she considers the change in her perceptions of stress over time. From a changed motherhood subjectivity she looks back on her feelings of stress, and then forward to what she believes to be the long-term, and

positive impacts of stresses in her life. She describes how, for her, stress is not limited to mothering Jason and reflects on other events that have occurred in her life, which have also created stressful situations. Presented next are Serena's words taken directly from her narrative and arranged in poetic format:

Having Jason

*I did feel that having Jason
was very, very stressful.*

*It's hard to look back
on that time
and see
the amount of stress
that was involved.*

*It was painful
going back.
But it was also painful
going back
through the stress of a court case.
Going back
through the stress of a family
that never spoke to me
for 13 years*

*I realise
every person has stress –
they have their own levels,
their own thing.
It's how you handle the situation
that allows you to get through it.*

*It doesn't matter
whether you have a child with a disability
or not -
you're still
going to have
stress
in your life.*

*I looked at that
and realised
that having Jason in my life
yes
it was very stressful
but it was just one part of my life*

*that I then had to work through
and deal with
and learn to live with
and not blame.*

*Not say
that it's because of a disability
that I'm more stressed
than anybody else.*

*By having these stresses
or pressures
or different things
happening
I've learnt how much
it's making me stronger.
And by making me stronger
I'm able to deal with those stresses better.*

*And so
I feel so grateful
that I've had Jason
because
I've learnt so much from him.
So much about myself,
about raising children.*

*I've learnt so much
by having Jason.*

Serena has taken a discourse of stress and reframed it in a new way, a way meaningful for her. She actively resists a social expectation equating disability with stress and instead makes us of stress as a source of personal growth and learning and in so doing concurs with Singer and Farkas (1989) about finding meaning despite the stresses involved with raising a child named with disabilities.

Stress: It's part of life (Kathy)

Kathy experiences difficulty in defining the meaning of stress when I ask her to confront its meaning. She appears to find it hard to differentiate between the stresses in her life specifically because of Alex, and the stresses of other normative life events. It can be seen by the end of the following segment of conversation that Kathy does not

necessarily equate stress with disability. Here I ask Kathy what the word stress means to her and we explore this together:

Kathy: (Laughs) Lots of that (laughs). Um, (pauses) actually now you've said the word stress, there's no such word as stress if you listen to Stan Zamalic (laughs). ... He's a guy on TV or on the radio or something; there is no such thing as stress. He said stress can be, you can have emotions or frustrations, but stress doesn't exist. So I suppose no, not really stress, just times when things aren't going to plan and the phone rings and you're halfway through bathing Alex.

Valmae: But did you think of it as stress, despite what Stan said (laughs)?

Kathy: (Laughs) Um, (sighs) (pauses) stress? (pauses) I don't know (pauses) no, I don't know. You had times, (pauses) what is stress? Is stress when you're trying to get them bathed and everything to meet the taxi, or you've got to be at that appointment at 2:00; but he's just had an accident in his pants and you've got to change him; or when they're [Kathy's three children] doing a little video at home and one of them runs off the lounge and the other one dirties his pants and this one spills the drink? So, um, what is stress (laughs)?

Valmae: And that's not just having a child with a disability? Stress?

Kathy: Oh, I never thought of that.

Valmae: It's just life?

Kathy: That's life.

Later in our interview when Kathy was exploring the meaning of coping with me she makes the following comment: “*When Alex would have his operations that would be pretty stressful. Oh no, there's that word, stressful*”. For Kathy, stress appears to be associated with specific events rather than a constant presence in her life because she has Alex. She does not appear to have formed a definition of stress, especially when asked to consider disability and stress together. Disability, for Kathy, seems to be accepted as part of life and stress consequently forms part of that life course.

Likewise, Sandra does not use the word stress when narrating her life with Melanie. When I ask her about the meaning of stress she responds that stress was “*where you just want to scream*”. Sandra then goes on to remark that she did not usually use the word stress when speaking of Melanie. She explains that work can be stressful for her, but that Melanie was not:

I've got stressed at work. I've been stressed with having to go to work and having to keep going. But I never got stressed [with Melanie].

Stress: An overwhelming feeling of concern (Susan)

Norah and Susan were two mothers in this study whose children had severe medical problems when they were infants. Norah's daughter Cheryl, contracted meningitis in 1959 at the age of 6 months, while Susan's twin-daughter Laura was born at 29 weeks gestation in 1991, after a complicated pregnancy. Laura spent 8 months in the Neonatal Intensive Care Unit. When I asked each of these mothers what the word stress meant to them, they referred back to the period in time when their daughters were critically ill and they were unsure whether they would survive. Norah comments on the impact of stress on her:

I was really tense and [would] jump and scream at anything, you know? ... Nobody knows; nobody has any idea when you've got a very sick baby and you don't know whether you're going to get up the morning, "Is it going to be the last scream she's going to have?" and she's in your arms.

Cheryl's life and death struggle experienced by Norah is the story she chose to tell when talking of stress. Although Cheryl is 43 at the time this interview occurred, it is the illness and possibility of Cheryl's death of 42 years ago that embodies the meaning of stress for Norah.

When I asked Susan how she defined stress she laughed and exclaimed, "grey hair". I asked her to explain her answer:

Oh, (pauses) it's just an overwhelming feeling of concern, of worry, of how, in our situation of how the child is going to, are they [Hannah and Laura] going to survive it? Just going from day to day. The stress of having to find out how the night's gone. Just the way it manifests itself is, it's physical changes. For me it just turned my hair grey overnight, seriously. ... It just takes over everything until things settle down.

While not denying the day-to-day stresses, Susan goes on to describe the current stresses in her life as being those perhaps more 'typical' and common to all families. In doing so Susan demonstrates the normalising of family life which is evident in her comment. Given the opportunity to define and speak of the meaning of stress in her own way, Susan is able to reflect on the highly stressful times she experienced with Laura during the early years, particularly in NICU, while being presented with the chance to add the positive, the "pleasure" of Laura:

Now that she's sort of relatively stable and she only goes off the rails occasionally, I don't find the day-to-day stresses as a major thing now. I mean

you get more stressed over your husband's work and stuff like that (laughs). I mean Laura is a pleasure. You can get big smiles and everything out of her.

Therese reflects that the personality of the person impacts on the way stress is perceived and therefore consequently dealt with. She constructs herself as someone who accepts life as it is and tends to “keep going” and “get on with it”. Here Therese explains this in more detail:

I guess too it depends on how people deal with stress. I tend to keep going and just get on with it. Nobody can take it [the stress] away. It's not going to go away when Kimberley dies, and it's when, not if. When Kimberley dies that stress will be there I'm sure, because there'll be all the extra grieving that we do after that. So (pauses) you can be stressed but I guess it's whether you let it get on top of you and whether (pauses) I think it's whether you accept the fact that it's like that. I could be stressed out of my brain because there's so much work to do at school, and I've got stuff to do here and I just think, 'It'll all be there tomorrow', and I know that all that stuff's there and what's the point of getting stressed about it. Let's just get on with it and do it. And being realistic about the fact that yes, my life is unpredictable. I could sit and moan and groan about that all day or I can just accept the fact that it's unpredictable and get on with it.

While living with the knowledge that her daughter Kimberley will die and the associated stresses that this unpredictability causes, Therese also acknowledges the stresses caused by other life events, such as her professional work. For her, acceptance of the variations of life is of key importance. Similarly, Liza notes that personality effects the perception of stress and constructs herself differently to Therese.

It probably depends on what your personality is like. I probably get uptight pretty easily. And things can build out of proportion with me pretty easily. I've learnt to give things time now.

Liza speaks of stress as being fluid, of changing as each new challenge occurred, rather than as a constant state.

Stress: *Let's not say they're because the child has a disability (Elise)*

In the next segment, Elise raises numerous issues as she speaks of stress. As the mother of David, her fifth child, born in 1972, Elise is able to reflect on many years of mothering experience.

Stress? Well, I think it's there with every child (laughs). Let's be honest about this (laughs) eh? There are probably added stresses because when your baby's little it

may not feed as well so you may be up half the night. You have to deal with the business of telling other family members and so forth. That's stress. You probably have a bigger workload because you're dealing with therapy and all those kind of things. As your child progresses through you deal with, you deal more with people who teach your child, who are involved in the social life of your child. And some of those can be good. When things are going bad I can assure they can be bloomin' stressful (laughs).

In this comment Elise moves through the stresses involved in sharing the diagnoses of Down syndrome with family members and David's early years, to education and other social issues. Elise interweaves the stresses involved with David, with the stresses of parenting in general.

I also asked Elise if she felt stress was an overwhelming part of her life. Again, Elise mentions the stresses involved in parenting children in general, stresses arising from mothering "normal children". Elise responds at length:

Oh I can think of the times when things were going rotten, you think, "Oh is this ever going to end"? Like every stressful situation with a child, a normal child, children can have stressful [times], it moves, it passes on. I often think about the time David walked off and got lost. Yes, sure that was pretty stressful, but any normal child could do that. A lot of the things these kids do, let's not say they're because the child has a disability. Children in general will do some pretty horrific things (laughs). ... That's the reality. The first time the stress of that kind of situation happens it's like, "Ok what have I got to do now"? Because it's a bit of a self-protection for yourself and your child. Both of you have to deal with whatever the situation is. See because David was a hyperactive child (pauses) I relate to that. But if you had a child who was cerebral palsy and totally dependent, the stresses would be totally different. So for me the stresses are probably different to a lot of other mothers. Stresses never stop, in the sense that they happen from time to time.

Elise's storying suggests that stresses move and are fluid. At the same time, Elise also compares her situation with other mothers who have children named with disabilities and comments on her perception that the stresses would be different dependent on the named disability of the child.

Meanings outside a discourse of tragedy

As has been evidenced through the above mothers' storyings there is variation in how language in use is given meaning, and what particular words mean to individual women.

The mothers demonstrate multiple responses to the diagnosis of their child and these were expressed in an emotive embodiment in the choice of words they used. The word grieving brought to the fore multiple meanings, from a sense of loss through to grieving only being related to death, not disability. Acceptance was difficult for the mothers to give meaning to, and typically became caught up in the meaning and living of every day life and care. As such, acceptance appears to be constitutive of the way in which mothers 'coped with' living with their child.

The word stress also demonstrates a multitude of meanings and many mothers did not consider stress to be always related to having a child named with a disability. For many, stress was given meaning in relation to life events. Serena was able to draw on the stresses she felt to find meaning in her life. Other mothers spoke of the role of the personality of the mother in how stress was 'dealt with'. Work was also factored into the discussion of stress, emphasising 'typical' life events as potential stressors. For Norah, Therese and Susan the life and death struggle of their children is/was considered stressful. Elise, among other mothers, highlights that 'normal' children also create stress and that stresses are part of being mother. The stresses are shown to be fluid, transitional and not dependent only on disability. While I could have chosen to 'read' their narratives as stressful there appears to be a resistance by the mothers to speaking the word stress into existence in their storying. As they take up a subjectivity as mother they ascribe meaning to their children outside a discourse of disability as tragedy.

Chapter 5

Resistance and transformations

When you have your baby, you can't just (pauses) I can't really think of the words that I want to say, but it's not like a cake mix. If it turns out a dud you don't throw it away sort of thing. And I mean he looks so perfect to us; how can you say, "I don't want you?" (Kathy)

Resisting a discourse of disability as tragedy

Researchers have noted that despite increased stress levels reported by parents who have a child with a disability, most families develop successful coping strategies (Kazak & Marvin, 1988; Krauss & Seltzer, 1993; McCubbin & Huang, 1989; Powers, 1993) and display an ability to adapt to their child's disability and consequent impact on the family system (Dyson, 1997). It is now generally accepted that parenting a child with disabilities does not necessarily lead to dysfunction or distress in families (Beckman, 1991; Diamond, 1994). While these findings have led to research that examines the coping strategies parents adopt, there continues a viewpoint of disability as crisis:

Although no one disputes the highly stressful effects on both mothers and fathers of learning that their child has a disability, research is now focused on understanding the factors associated with the amelioration of the 'crises' and on the similarities and differences between mothers and fathers in their perceptions of and responses to the experience of parenting a child with special needs. (Krauss, 1993, p. 394)

As studies moved beyond the individual family response, it was suggested that "personal, familial, and social attributes affect parenting stress and the family's adaptation to the experience of caring for a child with disabilities" (Krauss 1993, p. 394). Implicit in this statement are the other contextual factors which impact on the family. However, an emphasis remains on stress and disability that does not allow for an alternate reading of the lives of parents who have children named with disabilities. This chapter is devoted to exploring an alternate meaning, a reconstructed motherhood, which is part of the subjectivity of women who participated in this study.

Little seems to have changed in the intervening years since researchers drew attention to the dearth of studies on anything but the adverse effects of parenting children who have disabilities. Of the few examples I located, Rousey et al. (1992) cite a study by Turnbull and Behr conducted in 1986 that recognised the “positive contributions that a child with handicaps can offer his or her family”. It has been suggested that research focussing on the negative stressors in the lives of families presents “a very unbalanced view of what [is] involved in being the parent of a child with a disability” and further, this view is “narrow and exclusive” (Pagliano, 1995, p.43). There appears to be a tendency for “researchers and practitioners to focus upon negative and pathological parental reactions at the cost of recognising positive reactions” (Case, 2000, p. 274).

Abbott and Meredith (1986) comment on the paucity of studies that report or examine the positive experience that a child with disabilities may have on their families. They state “most of the research has been problem-centered with researchers documenting only adverse effects of the retarded child on the family system” (p. 371). Their study found that families used the following coping strategies:

- Defined the situation positively
- Accepted child as they did their other children
- Willingness to work through their child’s limitations
- Emphasized the child’s unique strengths and positive qualities
- Strong religious beliefs
- Participated in parent support groups (p. 374).

The positive coping strategies employed by families help to situate the impact of disability on the family in a more affirmative light.

As recently as 1998, Stainton and Besser reported on the continuing negative discourse in which research on disability and the subsequent impact on the family is framed. Stainton and Besser note that “studies of the positive contributions of people with disabilities are infrequent in the professional literature” (p. 58). Their study provided an opportunity for mothers to express the positive discourse in which they positioned themselves. Nine themes were found from the data collected from the mothers in their study regarding living with a child named with a disability:

- Source of joy and happiness
- Increased sense of purpose and priorities
- Expanded personal and social networks and community involvement
- Source of increased spirituality
- Source of family unity
- Source of increased tolerance and understanding
- Source of personal growth and strength
- Positive impacts on others and the community
- Interaction with professionals and services (pp. 61-66).

Given the opportunity to speak about disability in a different manner, the mothers in Stainton and Besser's study show a resistance to the dominant discourse of disability as tragedy.

How then did the mothers who (re)told their stories to me define their experiences? Of importance is the question, how did they (re)construct themselves in the socio-cultural discourse of motherhood? The narratives (re)told by mothers did not resonate with stories of coping, although they could perhaps be read/analysed in such a manner. What became evident to me throughout the storying process was a story of being mother.

Reconstructing being mother and personal transformations

The mothers' narratives appeared to conceptualise the taking up of story lines of 'good mother' and intensive mothering. The construct of motherhood they visualised prior to the birth of their child continues to reinforce and in/form the mothering practices and positionings women in this study take up after their child is diagnosed/named with a disability. Located in their narratives is the discourse of motherhood which steps itself through their dance, despite their move into a different space, a space they had not previously occupied. While many mothers previously had little or no experience with disability, once they have a child named with a disability they are "put in the position of forging an identity of both herself and the child in relation to the disability" (Skinner et al., 1999, p. 488). Similarly Landsman (1998) claims that mothers may "require a

transformation of an identity that was already developed in another culture ... to one's newly emerging identity as a mother of a disabled child" (p. 5).

The stories of the mothers in the thesis are often invisible in margins of the dominant social discourse as their stories fall outside the taken-for-granted discourse of motherhood, and the dominant socio-cultural discourse of 'normal'. They are not part of the meta-narrative of mother and as such the women need to (re)construct their subjectivity of motherhood. Mothers whose children are named with disabilities have to make their way in a society "that devalues their children and in which their motherhood has 'failed' to follow the culturally appropriate trajectory" (Landsman, 1998, p. 5). As Sandra poignantly tells me:

I even went through a stage in the very early weeks or two, feeling like I'd produced a monster. It was just so unnatural and I was ashamed to tell a couple of my friends. I told them later that I'd felt I couldn't tell them and they said, "Why"? I said, "Because I felt like I'd produced this monster and all of a sudden everybody was so horrified about it". I mean she was a beautiful baby, but they couldn't see that, they just couldn't see that side of it.

Sandra's words are representative of Landsman's (1998) statement that in the "age of having 'perfect babies' ... mothers must break new ground and struggle with developing a vocabulary to explain the meaning of their child and of their own motherhood" (p. 13). The birth of Melanie signals an end to the 'perfect baby' and Sandra is aware of a social gaze which visually inscribes Melanie. Hughes (1999) forcefully argues:

Vision is an act of judgement which extends well beyond the sense that grounds it. It is a carnal point of view which is always simultaneously a cognitive, aesthetic, moral and political point of view. (p. 163)

Sandra demonstrates her awareness of the social expectations of the gaze applied to a baby. Her initial response is followed by her visual inscription of Melanie as "*a beautiful baby*" resisting taking up a discourse of blame or tragedy.

A 5-year longitudinal qualitative study using open-ended interviews and observation with 150 Latino mothers who had young children named with disabilities was conducted by Skinner et al. (1999). The average age of the mothers was 28.5 years and the children, 3 years, with the children named with a range of disabilities. One of the researchers stated purposes for using mothers' narratives is:

To depict how these mothers, as authors of their stories, choose to juxtapose, synthesize, and orchestrate cultural and religious understandings of disability to make sense of their own experiences and identities, and to position themselves in certain ways vis-à-vis the child and others. (p. 482)

Their analysis found the mothers reconstruct themselves as ‘good mother’ even as they fell outside the norm of motherhood. The use of narrative is of central importance to providing the mothers an opportunity to speak differently about disability and about being mother.

While Skinner et al. (1999) did not set out to specifically ask the women about themselves as mother, they found that mother/hood was “what had salience” (p. 486). Part of the construct of the ideology of motherhood taken up as a discourse of mothering is socially constructed and enacted and the mothers continue to position themselves as ‘good mothers’. Similarly, the women who participated in the research for this thesis did not always or only speak directly to/of their subjectivity as mother, yet this aspect of who and how they positioned themselves as women came clearly to the fore in their narratives. Davies (1992) maintains:

Women’s desires are the result of bodily inscription and of metaphors and story lines that catch them up in ways of being/desiring from which they have no escape unless they can reinscribe, discover new story lines, invent, invert, and break the bounds of the old structures and old discourses. (p. 58)

Continuously the dance of motherhood insinuated itself into the narratives told by the women, and continuously resists separation from the movement of their stories. The mothers whose stories in/form this thesis continue to take up the subject position of ‘good mother’ while they (re)position themselves in a new story line of motherhood.

It’s changed me for the better (Susan)

My analysis of the mothers’ narratives found they were not framed in a discourse of negativity, with the possible exception of Patti’s story, whose story could be read as one of sadness and loss. As most mothers spoke their stories they shared stories not only struggles and sadness, but also the joys of their child and positives that they perceived had come about through having a child named with a disability. The mothers’ choreographed their movements in tension with “the misery-and-affliction script which

has traditionally had a stranglehold on the nondisabled imagination” (Thomson, 1994, p.3).

Larson (1998) refers to the tensions between the negatives and positives of the experience of mothering a child with a disability as “paradox”. The notion of paradox, of embracing the child while simultaneously wanting the disability gone, was not a strong theme in the mothers who shared their narratives with me. That is not to say however, that this did not exist. This paradox was only sometimes mentioned briefly, and it was not emphasised in their (re)tellings so did not form a significant theme in this thesis. Oftentimes the struggles the mothers spoke most definitively and emphatically about, were more to do with the social construct of disability in discursive sites such as medicine and education, rather than the negatives of impairment. This finding concurs with Skinner et al. (1999) who note that when the mothers in their study narrated their stories, “they do not always, or even primarily, focus on the deficits or pathologies of these experiences” (p. 482).

Landsman (1998), an academic as well as a mother of a child named with a disability, conducted a study involving mothers who have infants or toddlers with disabilities. The results presented in her article are part of data collected in a pilot study carried out over 1993-94 and also part of a larger study which began in 1995. She examined 25 mothers’ narratives. The mothers were predominantly white and were from a variety of socio-economic classes and the children’s disabilities differed. Landsman found that the mothers “derive their identities as mothers in part from what they interpret as newly acquired knowledge of what should really matter in life” (p. 10). Lupton (2000) proposes that “features of contemporary motherhood are shaped not only through the dominant discourse of ‘good mother’ but are also constructed through the embodied relationship that women have with their infants” (p. 60). A discourse of love moves through the storyings of the mothers in my study which in turn shapes their motherhood subjectivity.

A theme throughout the Skinner et al. (1999) study was that the narratives presented by the mothers demonstrated “personal transformation[s] – how the experience of having a child with disabilities changed them and their lives” (p. 489). They cite the work of Frank (1995) who terms the narratives of personal transformations, “quest narratives”:

The genesis of the quest is some occasion requiring the person to be more than she has been, and the purpose is becoming one who has risen to that occasion. This occasion at first appears as an interruption, but later comes to be understood as an opening. (p. 128, cited in Skinner et al., 1999, p. 489)

I too found that mothers told stories of the way in which they experienced personal transformations during their narratives. Personal transformations, which the mothers perceive have come about because of the experience of having a child with a disability, are spoken into existence during their narratives in turn shaping their reconstruction of who they are and how they position themselves as mother. However, as Melissa comments, “*it’s very difficult to tell. I suppose it must change you. But you can’t tell what you would have been like anyway*”. Oranea’s thoughts of her personal transformations are presented in poetic format:

Behind the body

*I have
so much
compassion now.*

*I see
children with disabilities
I understand.*

*I see
behind
just
the physical body.*

*I see
what’s behind
it.*

*The families
And what the child
is going through.*

*Yeah,
before
when I saw
a disabled person
it’s
just
a disabled person.*

*I didn't know
what
it
was all about.*

*Now I have
more understanding.*

Mothers who (re)told their narratives for this thesis ascribed mothering a child named with a disability to have brought about positive changes in their life. All could relate personal transformations that caused them to (re)construct themselves as 'better mothers' and at times, better people. Following are some mothers' thoughts on personal transformations:

Strength

I feel I have an inner core. Found strength that I never knew I had to cope with this. (Patti)

I'm much stronger I think in myself. (Susan)

It has made me stronger in a way because I know that I've got a goal. ... I can't just sit around, I've got to actually get in there and teach her. (Robyn)

Made me stronger as a person and as mum as well. I see that I can cope. I can. That I have the strength to deal with it. ... At the time[of diagnosis] I thought "Oh my gosh my world is crashing down around me", but now I feel different. I feel like, yep, I can do it. (Oranea)

Reassessing Priorities

I think she's made me search for the bottom line. Because we all have dreams and things like that (pauses) but every time one's knocked down you search for the bottom line. And the bottom line is her being happy. (Liza)

It makes you sit back and think about how easy it is to get kicked in the arse. ... So you do a double take on what's really important and what's not so important. (Susan)

I'm a much better person now. I feel at ease with myself. No longer strive for that glass house (laughs). I take life more seriously now. (Oranea)

Growth

I'm not the person I was many years ago. If it wasn't for Peter I would be a very selfish, bitchy person ... I've changed a hell of a lot since having Peter. So it's

been a wonderful gift. And having my other two children too. Having the three of them has just helped me grow, expand, see things from a totally different perspective. (Diane)

Growth, personal growth. This has really forced it upon me. (Serena)

I was a very shy standoff person. I probably wouldn't have become involved in things as much as I have. It's given me much more confidence. ... I think it's just made me grow as a person. I think I've done things that I would never have done if I hadn't have had Craig. (Michelle)

Assertiveness

I've become much more assertive and much more aware. I had to make myself aware and I had to find out that by myself. (Sandra)

You have to become more assertive. (Kathy)

Assertive because I would have been definitely a very unassertive mother who, if I asked for something I would be almost apologetic. Now I will be much more confident in asking for what I feel is needed, is right, is a right. (Elise)

That's the one thing I don't like. I have become very, very assertive.... I think it's a shame that you have to change your nature otherwise your child will miss out. They will. They'll just miss out. They'll get nothing. (Michelle)

Tolerance, understanding, compassion

I'm more tolerant. She's brought good qualities to me. Under sufferance I might add (laughs). (Liza)

I think it's changed me for the better in a lot of cases ... I think I'm more compassionate now. (Susan)

You become a lot more compassionate I suppose to other people, and a lot more understanding of other people with children and you know if you see someone badly behaving you're more likely to say oh I wonder's wrong? (Melissa)

There's a lot more understanding towards what people need in life. What your capacity to be able to give is. (Julia)

Certainly I've learnt a lot more tolerance. Patience. Humility, I think. ... So Lily has taught me humility (Liza)

Hope

It's also changed my life in hope I guess. Recognising hope. That there is hope in all the things that you do, even though you don't feel it sometimes. (Serena)

Numerous words are used by the women to describe the personal transformations they perceive have occurred and these words are suggestive of positive and socially valued changes: strength, compassion, consideration, tolerance, understanding, humility, patience, responsible, assertive, more aware, fighter/advocate, better person, confidence, hope, ability to prioritise, and the ability to give to others. Mothers (re)frame and (re)construct themselves through the meaning-making they engage in as they narrate their stories. Throughout their narratives, they continue to position themselves as ‘good mother’ enabling them to take up a subjectivity of motherhood which resists the notion of disability as tragedy.

Now I look for the little goods (Therese)

The mothers in the study expressed how they look for the positives in their lives. The following quotes come from my question about finding the positives in life:

I guess we, most people, if a bad situation occurs they either collapse in a heap or they try to find something positive out of it. And we do. But the positive may be a tiny, miniscule positive that other people don't see as a positive. (Therese)

I don't think it's a good thing to go back and think well this is what we're left with and this is how it's affected our lives and what would it have been like if this hadn't have happened. I think that's incredibly negative and I'm more of the thinking, ok, this is how things have worked out, let's get on with it. Let's deal with it and make the best of what's happened. (Susan)

Sometimes I'd be yelling at Michael, you know, telling him off for doing something. And then I'd be sitting here ... and he's just come up to me and gives me a kiss. Like out of the blue, or do something that really makes me think that it's all worthwhile. I'm doing something right. (Oranea)

You've got to turn away from all the negatives and look at the positives which is what I did. I was amazed at the transformation within myself. (Patti)

I think you've got to try and enjoy what's there. (Liza)

Mothers also use downward comparisons (Affleck & Tennen, 1993) or favourable comparisons (Turnbull & Turnbull, 1993) to preserve a sense of positiveness. These comparisons occurred across different levels of disability. For example, the following

quotes are from mothers whose children do not have high support physical caregiving needs:

You can cope with different things on different levels, and I would say that in terms of problems we really only have one or two. ... If your whole life was a complicated situation of stressful situations where you maybe had poorer living conditions, poorer financial situations, poor family situations, then I don't think anybody, I mean you'd need to be a saint to cope with all of that. (Melissa)

I could also look at it and say, "Well at least they're all healthy". I mean there's other people out there with much more problems than me. (Serena)

I didn't have to deal with a child who had physical, an obvious physical difficulty, as in a child with cerebral palsy. That's a whole new ball game if you've got high support needs. And if I think in terms of some families whose child is always having to be fed and dressed and physically moved, I can't imagine how those mothers cope. We've had our problems sure, but I'm not physically feeding and dressing an adult. People who are incontinent and they're adults, goodness sake that has to be a difficult situation. (Elise)

However, other women such as Therese, whose daughter is severely multiply disabled and chronically ill, also use comparisons. She looks to the fact that Kimberley is still alive, where other parents have lost their children:

The fact that there always were people worse off than you. Whenever you went to Cameron Memorial Hospital, there was somebody worse off than you. ... Instead of saying, "Oh poor us, we've got this child with all these problems", it was, "Aren't we lucky that we still have her".

Similarly, Kathy whose son Craig has cerebral palsy with severe multiple disabilities says:

You always found there [were] plenty of people worse off than yourself. So it wasn't much use thinking, "Oh, poor me how am I going to survive or whatever". You'd think, "Gee aren't we lucky that we've still got each other". [My] husband doesn't drink, the kids don't see their mother getting belted up. So we used to look at how lucky we were, because there's plenty of other people out there who are worse off.

While the cognitive coping literature focuses on specific coping strategies (e.g. Turnbull & Turnbull, 1993) I found I usually needed to ask mothers specifically about some of the strategies outlined by Turnbull and Turnbull as these were not spoken readily into their storying.

One of the coping strategies outlined by Turnbull and Turnbull (1993) is determining a reason for being 'given' the child. For some mothers, the child was given by God in order for them to learn something about themselves:

I believe there is a reason to why everything happens. Maybe He made her. Maybe she came out the way she has to try and make me more responsible. Make me wake up to myself and realize that I've got this child now. She's not perfectly normal so I've got to get off my butt and do something about it. There's a reason for everything. (Robyn)

I look at him and thought well maybe there's a reason why Michael was autistic and I'm the mother of, it's to teach me something. ... I look at it spiritually that Michael was part of God's plan for me. (Oranea)

Other mothers did not talk of the child being given by God, yet believe there was a reason, something for them to learn from having their child.

I've always been concerned about what people think of me (laughs). Maybe that's my lesson, that's the reason I got chosen. (Julia)

I think we draw to ourselves what we need to learn from life and that specialness that I have, those special skills are there for me to learn, and they're there for Jason to learn. (Serena)

Therese and Michelle voice their beliefs that their child has contributed to the wider community:

I've seen that over the years that what having Craig in the family has done to like the family as well as outside the family, so that these people [named with disabilities] do things for other people. (Michelle)

I believe there's a reason why everybody's put on earth ... I've looked at Kimberley not as, well she's got nothing to offer, but what is it that she has to offer? And she has done heaps for people. (Therese)

Just one of these things (Melissa)

However other mothers did not look to a higher Being or perceive there was any particular reason for having a child with a disability:

Excuse the French, it's a case of shit happens, because I did everything right and that's how it turned out. I just accepted that that's my lot and that's one of those things that happen. Just deal with it. Just get on with it. (Susan)

I think it's just more, just one of these things. I don't see (pauses) I don't see us as the chosen ones, you know, God looked down, saw you and thought, that sort of

thing. I think it's just one of those things. I kind of see life as being a bit like a pie chart. You get big bits of some things and little bits of some things and we've got John with a disability, but we've got other things that compensate for that. (Melissa)

I've never felt that I've been special enough for anybody, God or any reason ... that anything like that would happen. It just happened and it certainly has taught me a lot. And we're probably living quite a different life to what we would have imagined, but that's just life. I think there are lots of other things that happen to people that are the same, deaths of spouses and things like that change people's lives. (Liza)

Liza highlights that disability is one part of life, one of many things that can occur in life, a non-normative life event which brings about significant change.

The focus in the literature on coping with a child with a disability tends to ignore the subjective taking up of motherhood and in particular the discourse of 'good mother'. Isolating coping strategies from a discourse of motherhood and a discourse of love that mothers take up does not present a total picture of loving and caring for a child named with a disability. The discourse of caring and a discourse of love are often enmeshed, each a part of the other (A. Richardson & Ritchie, 1989; Traustadottir, 1991). It is the discourse of love which the mothers in this study emphasized. While their storyings involved caregiving work, they spoke this as part of their positioning as mother, rather than speak the word care into their narratives; the caring work they performed daily often hidden in the stories they told.

I love her to pieces (Susan)

I asked a number of mothers whether they perceived their image of being mother had changed once their child had been diagnosed with an impairment/abnormality. The following two quotes are exemplary of the responses:

When you look at it I'm still a mother. It's just that my child has a few extra needs than what a normal child would have. She's still my daughter. I still love her like my daughter. Like I should. ... It doesn't actually make any difference. It's just that some kids need extra help than others. (Robyn)

It challenged me in that there was a different need for David. I knew instinctively that his life wouldn't be the same as my other children's life. I had to mother him the same as I mothered the others. And I had to mother a baby a lot longer than I mothered, you mother the average child. (Elise)

For mothers who had older children there was an awareness and knowledge of mothering from prior experience. Elise says, *“I guess I was pretty strong in the things of mothering ... it’s the knowing you can do it, knowing that you know what to do”*. They had already developed a subjectivity of mother from previous mothering experiences and employed this subjectivity in being mother outside the norm of a motherhood discourse.

Many mothers spoke to variations of the theme, ‘this is my child’ accentuating the discourse of mother/hood and demonstrating the interrelatedness of subjectivity of mother and the subjective self:

She’s your child, you accept it. (Norah)

Back then [1981] ... you had a choice ... If you felt you didn’t want a child with a disability you just put them in a home. ... But we thought, “No, he was ours. We’d do the best we could for him”. (Kathy)

She’s my flesh and blood and I love her to pieces, [and] I would never, I would never leave her under any circumstances. (Susan)

I felt if Belinda didn’t have me to look after her, who did she have? (Patti)

I guess we felt we didn’t have a choice. She was ours. She was our responsibility. We brought her into the world. We loved her to bits and because she’s ours we had to cope. (Therese)

This was our son, you know. Why we would want to give him away? I mean that’s the way we’ve always looked at Craig. He’s our son and we care for him just as we care for any of our other children. (Michelle)

A subjectivity of mother, and a discourse of love, is spoken throughout their narratives as the mothers speak of their child. While some mothers say they did not have a “choice”, they justify the comment with a discourse of love. A ‘motherhood statement’ in the above comments acknowledges both a biological and societal discourse. The apparent simplicity of saying ‘this is my child’ hides the complexity of living a life with a child named with a disability. The mothers who (re)told their stories are not part of the meta-narrative of mother, yet they continue to take up the construct of ‘good mother’ within a discourse of intensive mothering, and many continue to fashion their lives as normal.

We're all different aren't we? (Kathy): Questioning what is 'normal'

What the literature refers to as a process of parental adjustment may be a matter not of becoming resigned to the tragedy of not have a normal child but rather of being challenged by, and redefining through experience, existing cultural understandings of what constitutes normality and perfection. (Landsman, 1998, p. 13)

Landsman (1998) suggests that “many mothers of infants with disabilities revise their interpretations of ‘normal’” (pp. 13-14). While her study focused on mothering infants, I found the mothers in my study whose children represented a diversity of ages also (re)interpreted and questioned what constituted ‘normal’. Again poststructural theorising(s) points to the slipperiness of language as the mothers express the way the word ‘normal’ is spoken into existence and privileged as dominant discourse. Diane succinctly comments, “*normal’s one of those strange, floaty words that have many meanings*”. Kathy speaks to the binary able/disabled when she talks about ‘normal’ just as Liza and Michelle also question what is ‘normal’:

People just seem to use the word normal and they put their little fingers up and make that move [indicating inverted commas] (laughs). We talk about normal and people with a disability but (laughs), actually, what’s a normal person? We’re all different aren’t we? (Kathy)

Normal? It’s a horrible word isn’t it? And I try not to use it. Sometimes use regular, but then you think about All Bran, which seems terrible. Normal, I suppose that’s the thing, there’s no normal. (Liza)

Normal (laughs). What do you say is normal? I think it’s probably not a word that I’d use, ‘cause I really can’t see how you can. What is normal? Who says what’s normal? ... I think that we’re all normal and then as I say, some people, they just have needs that have to be met. (Michelle)

Bury (2001) writes of a process of “normalization” which forms part of the illness narrative. I consider that this process is of relevance to the mothers in the study as they (re)construct and take up their subjectivity of motherhood. Bury emphasises two meanings of the process of normalization. The first is where the mother tries to keep her lifestyle prior to the diagnosis of disability of her child intact and this may “involve the maintenance of as many activities as possible” (p. 272). The second process involves

incorporating the disability into the changed lifestyle; what constitutes a 'normal' life is redesignated and accorded 'normal' status (p. 272).

In Landsman's (1998) study she also notes that while mothers acknowledge the "'downside' to disability" (p. 13) many mothers normalise their experiences. Furthermore she goes on to comment that "they have also come to define their own motherhood, while counter to expectations, as nevertheless normal in its own terms" (p. 13). Similarly, A. Richardson and Ritchie (1989) observe how life for women who have children named with a disability becomes "a normal life and their routine a normal routine" (p. 25). While numerous mothers provided a multitude of examples of the way they continued living their 'normal' life, and incorporated changes so they were able to fashion their lives as normal during the course of their storyings, I have chosen to use a segment of my interview with Oranea as representative:

Valmae: You said you never treated Michael differently than the other [children], and then you went, "except, I was doing more for him". Do you mean that (pauses) does it become sort of normal to do be doing more for Michael? Does it change the way you see normal?

Oranea: *Yeah. I think so (laughs). Other people look at me as if, how can you cope? How can you cope with doing all that for Michael? But for me it's just so natural now. It's so natural for me to do whatever extra that I have to do for him. It's just part of me being a mother. That's how I look at it. But other people can't cope. They look at me and they say, "I don't know how you do it".*

Valmae: How do you do it?

Oranea: *(pauses) I don't know (laughs). I have no idea (laughs). But I just do things. For me it's normal, but for other people it's not. It's not normal.*

Dancing a new dance: reconstituting mother/hood

This chapter demonstrates the way in which mothers actively search for meaning in being mother and how they fashion their lives as normal. In doing so, they are able to resist dominant assumptions about disability and redefine what constitutes 'normal'. They carve a new discourse of motherhood out of the spaces of the old and highlight personal transformations which occur in this new space. They continue to position themselves as 'good mother' as they enter the spaces disability inhabits. Diane notes

differences she perceives in the reconstructed version of mothering a child with a disability:

I think motherhood, or being a mother for me, and motherhood, have taken on different roles because I've had Peter and I've had to use that role in a totally different way to what is the norm, if you want to call it, of what mothers normally do. They don't normally have to deal with specialists and doctors on the levels that parents in our situation, or mothers in my situation have to deal with. And the extra concern and worry I suppose, health wise, and societal wise, and emotional wise, and spiritual wise, that you have to deal with of another person in the family that, for me, I'm trying to help. For him to discover he has his own talents, he has his own self-worth. He has his own part to contribute to the family and to society as a whole. (Diane)

Diane points to additional positionings in a (re)constructed discourse of motherhood; those which involve dealing with various professionals at a different level to what she considers typical for mothers with non-disabled children. The professional/lay binary comes into the dance of motherhood as mothers endeavour to do what “they feel would be good for their children” that at times entails new choreography which challenges “the dominant social order” of normalcy (Read, 2000, p. 113). The final chapter of this section delves into issues of the future as mothers explore their hopes and dreams arising from their taken-up subjectivity as mother.

Chapter 6

You just focus on the now (Julia): the uncertainty of the future

I just wonder if sometime in the future it will all come back and hit you in the face. But you can only do what you think's right at the time. (Liza)

It's hard to put into words really. Um, it's ongoing. It changes (pauses) It's probably the most difficult thing to talk about because (pauses) the feelings and the dealing with it, it's different. It's different to your other children. I imagine it's probably similar to if you have a child with a very serious health problem. You know it's the uncertainty, the unknowing. It is still there. There's just change. We still don't know what David's future is. ... Our life is still not our own. (Elise)

The unpredictability of the future that some mothers live with was brought to the fore across two of the interviews I had with Liza. Over 6 months, plans Liza had made for her daughter Lily, then aged 16, changed dramatically. It was in the telling of Liza's story that the difficulties involved in planning for the future became visible to me. It was her story that became the catalyst for this chapter on the future. I discovered when I went to research the literature on mothers' perceptions of the future that very little was written. Most research on the future dealt with aspects of permanency planning (e.g. Bigby, 1996; Greenberg, Seltzer & Greenley, 1993; Smith et al., 1995) rather than how mothers perceive the future. This chapter therefore is exploratory, turning to the mothers' narratives to in/form how the shape of the future is imagined.

Throughout the storying process most mothers at some stage spoke of their goals, hopes, and dreams for the future, their plans for their children. Occasionally I asked directly how mothers thought of and constructed the future, but found oftentimes images of the future were caught up in their memories of the past and in the stories they (re)told of time yet to come. Images of the future were expressed in different ways through the narratives of the mothers and often the future appeared to be dependent on the particular point in time that the mothers were experiencing in the living of their lives. For many mothers the future was inextricably woven within their child's

impairment and/or illness that can mean they are facing an “indeterminate future for their child with disability” (Larson, 1998, p. 868).

Mothers’ thoughts of the future were at times fluid, moving and changing as life unfolded. Drawing on the literature of illness narratives (Hydén, 1997), I find similarities with the stories told by the mothers with/in disability narratives. Hydén (1997) contends it is “the absence of an ending” which he considers a central problem in illness narratives (p. 61). He states that illness narratives are “narratives forever in search of meaning” as there exists no “temporal horizon to give them meaning” (p. 61). As different events occurred, mothers actively constructed and reconstructed their future within this fluidity. The fluidity that I noted throughout the mothers’ narratives concurs with Hydén, who suggests that narratives are “constantly changing and being renegotiated, depending on changing perspectives and other perspectives” (p. 61). Many mothers’ narratives told of change over time and of time yet to come; they spoke in the now, the present, of their narratives. For some of the older mothers, their visions for the future are re/constructions from their experiences and memories from the past. However, for some mothers, the future still cannot be visualised, a time and place unimaginable.

Liza’s narrative on the events which transpired thereby bringing the chapter into being is (re)presented first, and then I move to investigate other mothers’ thoughts on the undecideability of the future.

☞ Liza’s story: *I had very high hopes and ideals*

During our second interview in December 1999, Liza and I discuss the discursive site of education. Liza speaks confidently about her plans for Lily’s short-term future of transition from high school to the work force which include work placement while at school. She comments on the effort and energy that she expects she will have to contribute to this planning:

I know I’m going to have to have energy in the next two years for Lily because this is a huge step from education into the work place. As much as there’s been problems in education, the work place certainly does not have any, they don’t

have to give her a job. The school has to give her a place in the classroom. Whether they educate her or not's another matter, but in the workplace it doesn't happen. So there's a lot of work to be put in and I just, there are some times when I think I just don't even want to know.

Aide time provided by Education Queensland to support Lily would be 5 hours per week. Liza explains that the support would cover her for one day of work experience and then be no time left for aide support in the classroom. In Liza's narrative, she explains that professionals at the Catholic High School did not attempt to locate funding to support Lily. Consequently, Liza searches for funding options and is successful in securing two avenues of funding to allow Lily to access work experience for the following year of 2000.

Liza had made a 2-year plan for Lily's short-term future, and had activated this through a process of meetings held with teachers as well as the securing of funding resources. Providing work experience was the next step in planning Lily's long-term future, providing her with possible work options. They appeared to me to be carefully thought out plans. When I returned to interview Liza in August 2000, I discovered those carefully made plans had been unavoidably changed.

Liza tells her story:

At the beginning of the year [Lily] got a viral infection and basically had a mild relapse. Her signs and symptoms of her disease came back and it was a bit disappointing, but you know we managed (pauses). They got a bit worse and she had time off school. ... Her specialist came up with a team from Brisbane, so we lobbed in and saw him and he said, "Yes it was a relapse" and felt that we needed to use medication, that it was getting serious enough that she should have to. ... She had medication ... and for a short while she got better and we thought we were on the track back and we stopped the medication.

And then she just, every day it got worse and she started with signs that had never been there before. Quite bizarre neurological [signs such as] athetoid movements, sudden incoherent babbling. ... There was this sudden disintegration and (pauses) she was in a wheelchair. She was unable to feed herself, unable to shower herself, she couldn't stand to be touched, she would have sort of withdrawal to any sensations, the shower would make her just withdraw completely. It was terrible. Everything was terrible ... we were concerned it was a tumour. ... Even though we'd done it [the examination] with her initial relapse and hadn't seen anything. ... So we'd again searched it. She was moving all the time, involuntary movements. She was never still. She was only still at night when she was really fast asleep, and then not all the time. So we went through all the drama and palaver of looking for a tumour and finally didn't find one.

Liza went on to describe travelling to Brisbane as Lily's specialist was based there, and seeing a psychiatrist. Eventually a diagnosis of a "conversion disorder" was received.

Liza continues:

Lily couldn't verbalise her emotions very well. ... I knew there was a problem [at school] and I would go in and fix it. Because I fixed it and she wanted to please me, she would go back. But she kept going back to the same situation. ... I fixed the situation but I didn't fix the problem. [The psychiatrist] was able to discuss with me enough that I understood that school was not an appropriate option. ... No matter how much I fixed the situation I was putting her back into the same problems. ... This year [2000] was going to be Lily's exiting year, so it wasn't like (pauses) it was a year where Lily had to go back and face all that academics, do you know what I mean? ... I think the reaction was from the previous 2 years ... I think her self-esteem was just completely ground down.

Liza's narrative examines the way in which the difficulties Lily was experiencing in school led to a conversion disorder, which in turn impacted quite clearly on Lily's future. As Liza explains, the future, their dreams, their life, became different to what they had so recently planned:

Our life this year is very different from what we had envisioned it to be, and I had very high hopes and ideals, which may still come to pass, but my greatest sadness this year is basically realising how unhappy she was. And that's really sad. That means like, you know, we failed, and that's sad because happiness is a basic thing in life. So, as much as I still expect her to get work and have an independent lifestyle I would really like her to be happy. I don't want to have to forgo that.

Liza's subjectivity of 'good mother' has been challenged by Lily's unhappiness and caused her to reassess what she wants for Lily in the future; that Lily "be happy".

You've got no idea of what's ahead (Kathy)

The birth of a child with a disability may shatter the dreams, the fantasies, the projections into the future that parents hold as part of their life mission. (Milo, 1997, p. 2)

Our futures are imbued with uncertainty, yet there are certain normative events which are expected to happen throughout the course of life and which occur at approximately the same time for most people (Krauss & Seltzer, 1993). However, there are also non-normative events which are "unplanned and unanticipated, and usually are not wanted

or desired” (Krauss & Seltzer, 1993, p. 173). Included in non-normative events are life situations such as divorce, traumatic injury, and chronic illness or disability. Many mothers spoke of sameness in the experiences most families face, of the normative events they expect to occur as their other children develop to adulthood. Elise points this out when she states that children are expected to “*grow up. They leave home, they marry, they do whatever. They have careers. They make their own decisions*”. This is not necessarily the case for a child named with a disability.

There often exists the possibility of a longer period of dependency on parental care (e.g. Cant, 1994; Cuskelly et al. 1998; Read, 2000); sometimes extending to when the parent becomes elderly. Liza explores this disparity, the difference between her 15 year old daughter Lily, and her perception of life with “*normal kids*” when she explains:

You know as a mother they're going to grow up, and yes, you still worry about them ... but you don't actually have that day to day organisation and worry about what are they going to wear. Like [Lily] coming in and saying, “What am I going to wear now? Can you do my nails”? She can't file her nails because she's too shaky. So I do her nails. Those things, as a mother with normal kids, you don't have to do after awhile. They grow out of it. Whereas we'll probably be doing it for a long time or finding ways round not to do it, so that she can live independently. So there's all that in front of us. And I did think, you know, it's still a long haul for us yet. Whereas at 15 there would be weekends when she wouldn't be home, if she was normal. And that never happens to us.

Planning and actively constructing the future features in many of the mothers' storying and is an ongoing and sometimes fluid activity. Elsie notes:

Your child with a disability will very likely always be dependent on you for something, whether it's care, directing care, just your involvement in their life. There is that constant responsibility, I suppose for their well-being, their health, their lives, their social lives.

In the mothers' narratives the initial diagnosis raised immediate concerns for the future for many of the mothers and often brought with it thoughts of an uncertain future: The following quotes are exemplary:

You had a thousand questions to ask because you wondered how was your child going to turn out because you'd seen other people down there [centre for people with disabilities]. And because it was all new to you, you sort of thought, “Well, what's ahead for Alex? Is he going to be able to get around or is he going to be like the other person there in the wheelchair with no speech?” We didn't know. (Kathy)

And when they tell you, you've got no idea of what's ahead. (Elise)

It was just really the Down syndrome that we had to focus on at that time and we just didn't know. We didn't know what the future was. We didn't know, just really didn't know what we didn't know sort of thing. (Melissa)

For most mothers, their child's diagnosis was their first experience and contact with disability. Pre-existing visions and dreams of/for the future shifted, moving the mothers into new unexpected and unfamiliar spaces. There existed in many of the mothers' stories a fear of the unknown, of not knowing what the future held for them, their child, and their families.

For some mothers the time of initial diagnosis aroused immediate questions regarding their children's long-term dependency. Oranea explains how she felt when she received Michael's diagnosis of autism; "*that was hard at first. Daunting, because all I could think was, 'Oh my gosh. I will be forever looking after this child for the rest of my life'*". Julia expresses the same fear; "*You start wondering, 'Oh he's going to be with us for the rest of his life'*". Similarly, Serena found acceptance of the possibility of long-term care one of the most difficult aspects to deal with initially. She had established typical societal expectations that her children would grow up and eventually move away from her:

In my mind my children were going to grow up and they were going to be, they were going to be separated from me and that was it. That was it. Once they reached a certain age, well they're gone, in my mind. ... So the thing I had to accept was that Jason may not do that. Jason may have to live with me for the rest of his life. And that was the thing I found hard to accept.

The construction of the progression of her children through to adulthood and the leading of lives separate to her is disrupted, changing Serena's vision for her future, a future that she had to (re)construct in a new manner.

I try to enjoy each day (Susan)

Many mothers in the study spoke of living their lives 'day-to-day', of not looking towards the future. I came to read this 'day-to-day living' as a strategy for coping with a significant and long term non-normative event. Living life day-to-day appears to

acknowledge the unknown, the uncertainty of the future in mothers' lives. Michelle looks back 20 years to when her son Craig was a young baby, and explains that it was the uncertainty, the unknown, which led her to not look to the future at that time:

You didn't know what the future was going to entail. And if you started worrying about the future too much, you didn't have a clue. No-one could tell you what the future was going to entail.

Michelle also speaks of the acceptance which occurred for her and her husband in conceptualising their lives on a day-to-day basis:

I don't think we really knew exactly what we were in for and as we just went through each stage we just accepted it as we went along. We never really knew, never really looked for what would be in the future. Just went along with it, day-by-day, as it came along.

As they worked through each stage in Craig's life, Michelle explains they were able to accept Craig's disability and continue moving forward in their lives. Maintaining a daily focus precluded long-term plans at that point in time.

Julia speaks of the future from a different perspective to Michelle. Her son Andrew is 3 years old and while Julia acknowledges living in the present, she continues her hope for the future:

I've still got my hopes for him, which I try to keep them a bit tucked away and just keep on working on the immediate. I think that's the way to deal with it. You just focus on the now, on the moment. And just trying your best to deliver the goods for them to learn by. ... Yeah I think that's it, you've got to keep your eye on the moment and not think of the future too much.

There appears to be a tension, and dualism, present in Julia's thoughts on the future. While admitting to trying not to think of the future, Julia is simultaneously and actively engaged in presenting Andrew with opportunities for him "to learn by", thereby affecting future outcomes for Andrew and for her. Additionally this calls into play the subject position of 'good mother' as one who does the 'best' they can for their child. Susan also says that she does not look to a future, "I try to enjoy each day as I come home and I read in her school book and find out all the good things that she's done". Yet Susan adds that the only future planning her husband and herself have done is financial, to "provide for her properly in the event of something happening to us". While existing in the present and focusing on each day, plans are made for the future.

For many mothers, (re)constructing their future involved significant planning and a number of mothers spoke of putting in time and effort when their children were young in order to help make their children as independent as possible in the future:

I knew that if he [Jason] got support and help early, with autism if you work on them early you get a better chance of them being able to be better as they get older. Meaning, the quicker they learn now all those things, the quicker they get out of those bad habits that they do, the quicker their behaviour changes and the less frustrated they get. All these things so that they can learn. (Serena)

I always felt if I put in the work now, I wouldn't have to deal with having to do it for the rest of my life. If I could get Peter as independent as possible, at least that would help. That has always been my goal since day dot. (Diane)

I think if I do the work now, just teaching him [Michael] how to survive, look after himself, hopefully he'll be fine (laughs) I hope. (Oranea)

As noted by Oranea though, there is an uncertainty that continues around the construct of future while making long-term plans. Oranea speaks to a discourse of hope that the future will progress as she envisages it.

Elise brings to the fore a discourse of hope when she explores her ongoing hopes for the future as she looks back over the years on her hopes and dreams for her son, David (born in 1972). She calls on her mothering experience and compares the differences she encountered in her mothering of David and her other children.

Mothering David has brought its challenges because (pauses) a normal child basically flows along. I think ... you're leading a child with a disability. Always thinking, 'Where are we going? Where are we at? What's next?' And you're always hopeful that things you plan, or hope for, will happen. You usually may, you may have a dream that that would work. For instance, that work might be a possibility. ... Those are the things that as your child grows through the years of the normal chronological years, the things you would hope for, that they eventuate. And you work, I think most parents would work towards that in whatever little way or big way or whatever, we work to our own abilities and (pauses) what's available, towards a better life. You do that for every child.

Within these thoughts, Elise draws a comparison to the dominant discourse of motherhood as she speaks of her mothering of a child named with a disability. While she constructs her mothering of David as different to the mothering of her other children, she also argues that “you do that for every child”, highlighting the subject position of ‘good mother’. Elise reflects that working “towards a better life” is something she perceives all mothers do for their children, positioning women in a particular way of being mother. Elise is at once working within and across the division

of able/disabled, blending the boundary between the socio-cultural discourses of ‘good mother’, of non-disabled children and of disability; creating a new space in which to explain her discourse of hope and dreams for her child and for the future.

For some mothers the future was “*a blank*” which necessitated living a daily existence. It seemed to me that this most often occurred when children were very young, the impairment/abnormality was rare, or when illness was involved. For Norah having a young child who was ill precluded her visualising a future: “*The future was a blank. It was just every day for me. Until I could see that she was getting better*”. Similarly Therese, whose daughter Kimberley has a rare chromosomal abnormality, explains that she can only live life day-by-day, as they have no knowledge of Kimberley’s potential lifespan.

➤ **Therese’s story: *My dream is that she’s happy***

In response to my question about whether she has a vision for the future Therese very quietly and emotionally answers “*you can’t (pauses). You can’t*”. Therese clearly expresses her thoughts about the future:

People say to me things like, “But what do you envisage Kimberley doing when she’s working”? (pauses) I don’t envisage anything after tomorrow. And I can’t (pauses). I’ve been to conferences where families have talked about what their dreams are for their child. I can’t (pauses). My dream is that she’s happy and she lives and that’s as far as I want to dream for her.

Therese (re)tells the difficulty of planning for a future for Kimberley when the very uncertainty of the future means they can only live their lives day-to-day. Their life experiences have been such that they construct their lives daily and long-term plans are not part of that construction.

Kimberley’s disability curtails much future planning. The rarity of her chromosomal abnormality means that the future is an unknown. As Therese explains:

That’s the thing that threw us when there was nobody else. We had no idea of whether she would be able to see, whether she would hear, whether she would speak, whether she would sit. None of that ... whether there would be intelligence there. There was nothing. Because (pauses) there was nothing to go by.

No other children with a similar chromosomal picture as Kimberley have been located who can provide information on its natural history to help Therese plan for the future with any certainty.

Therese spoke of a “*sibling workshop*” she attended where the unpredictability of life with a sibling with a disability was said to be one of the greatest stresses a sibling faces. Therese states that the uncertainty and unpredictability was also, in her perception, the hardest thing for parents to face:

There was a sibling workshop and a lady from Canada came ... she said something at that which was just so true and I thought, “You’ve really hit the nail on the head”. She said, “Most families, there is predictability all the time. In a family that has a child with a disability there is no predictability and that is very hard for siblings to cope with”. And I actually said, “And for parents” (laughs). And it is. The only predictable thing about our lives is that it’s unpredictable (pauses). It really is.

The uncertainty of Kimberley’s life emphasises the uncertainty of the family’s future. The lack of predictability means that Therese is unable to make plans for the future.

There’s just no predictability. You can plan to do things but then something can happen and it just won’t happen. So, and yeah, she said that is the most stressful aspect. Of all the research that they’ve done that is the most stressful. The fact that your life is not predictable. And she actually talked about the fact that most families have kids, they go to school, they go to work, they get married.

Yet, within this daily construction of living, there is a need to plan and this very need creates tensions and contradictions. As Kimberley was in year 7 at school it was necessary to plan her transition to high school which Therese describes as a difficult experience:

Therese: We can’t look down the track. We live day to day and it was very hard making the appointment to go to see them at [the high school]. Not the actual appointment, but just me plucking up the courage to ring to make an appointment

Valmae: For that far in the future?

Therese: Mm, but I knew I had to do it that early, otherwise it’s not fair on the school, but I still felt really weird planning something in March that wasn’t going to occur till next year.

Valmae: And you just live with that? You don’t have an image, a vision for the future?

Therese: You can’t. (pauses) You can’t (very quietly).

Valmae: You have said to me it's day-to-day

Therese: Yeah (quietly).

Planning and education

A need for future planning was particularly evident throughout their children's education, as education discourse often signified multiple sites of transition. Within Education there is the transition to primary school, (often from an early intervention centre) followed by a transition to secondary school, and then post-school options, either entering the workforce or obtaining leisure activities. Mothers with young children, such as Melissa, Robyn, Oranea and Julia were planning their child's progression to primary school. For Diane and Therese the move to secondary school was the next step in planning their child's education and future.

Although there are significant planning issues involved in school transitions, perhaps most uncertainty exists with the transition from school to post-school options. Following are some mothers' thoughts

When Alex finishes school the Moving Ahead program, hopefully if he gets on it, will allocate some funding. At the moment he gets 5 days a week at school, so then we've got to try to fill in the gap when he leaves school. So Moving Ahead can look at 2 days of (pauses) funding and then we've got to work out what the goals are for Alex. I don't think, being realistic, I don't think that he's going to get into a work force because I mean, his hand are up like this. ... So it's probably still pushing on communication, accessing the community, community friends, lifestyle skills. So they'll probably be the things that we're looking at. (Kathy)

A lot of things in David's life have been very deliberate. Very deliberate decisions made on what do we need, or what does David need in his life? When he hit high school it was preparing for adulthood basically. (Elise)

When it came down to when he became an adult I think we had to look to the future then and see what we thought would be the best so that we could start aiming in that direction. (Michelle)

But now we're going to have to let her take risks on being on her own. Risks where she may be abused and that's something I don't know if I can do. And I've got [my Doctor] saying don't ever let her go on her own. ... I've got people, my friends in the profession, disability, saying you have to let them. So that's rearing it's ugly head. And that's quite difficult. It's easy to take risks when you know what the outcome is going to be. ... But this kind of risk when you get older,

there's a risk she might be abuse, raped, whatever and how do you deal with that? (pauses) So that must come up for every parent (pauses). Don't know if I'll live up to my ideals there (laughs). (Liza)

Planning for the future

Mothers of older adult children with disabilities spoke of active planning for residential or independent living for their adult children. Greenberg et al. (1993) claim that a common source of concern is for the “child’s future when they, the parents are no longer able to provide the needed care or supervision” (p. 543). An Australian study conducted by Bigby (1996) found that “most parents had undertaken some form of planning which ranged from vague expectations to comprehensive blueprints” (p. 300).

Older mothers in this thesis spoke of the plans that had already been established, as well as plans for future residential arrangements.

Our ideal for Craig would be seeing him living in the community with the support that he needs. That's our ideal, but we're still around to make sure that all his needs are met. (Michelle)

When you look at him it's good to know that if something happens and Ken and me, if we got killed in an accident tomorrow, I know Alex is happy and contented where he is. Whereas if it had have been the other way, I kept him home and then we were killed, there would be no-one there to fight for him, like we did, to get him into where he is now. He would more than likely end up in a place, well they were talking about an old people's home and that isn't the place for someone like our son. (Kathy – Alex is in support residential accommodation with three other young adults named with disabilities)

David's ability is such that we saw he would live with a reasonable amount of independence which has proven to be right. We've got to this level where we have support and David isn't with us all the time. (Elise)

I think it must be really hard for people who have kids with severe disabilities and there's nowhere for them to go. Whereas I know Lily will manage in some sort of shared accommodation. She will. I know she will. I mean we will still worry about her. But we don't think it's a good idea now that's she's at our home because we think well when we die she's a) then got to find a place to live by herself and cope with our death, whereas if she's moved already that situation is already set up. So then all she has to do is cope with our death. That's how far we've come at the moment. (Liza)

☞ **Norah's story: *I'd be lost without her now***

When I first contacted Norah by phone to ask if she was interested in participating in this study, she spoke briefly to me about Cheryl and mentioned she did not know what she would do without Cheryl. I ask her about this comment during our first interview and she responds “*and that's true. She's part of me; really part of me now*”. Jan, an older daughter who was present at the interview, then adds that it is often a case of, “find her glasses, do her bra up, find this, find that”. Norah continues, confirming their changing roles:

I'd be looking for my glasses and she seems to know all the time where they are. I'd wake up in the morning and think what the hell day is it? Is it a school day or is it the weekend?

As Norah and Cheryl have grown older the relationship between them has undergone changes. The mother-daughter relationship demonstrates both the role-reversal and changes in dependency which have occurred between Norah and Cheryl. This role reversal is noted in the work carried out by A. Richardson and Ritchie (1989).

Norah considers that the shifting boundaries of the mother/child relationship may have been triggered by the death of her husband 7 years ago and that she is therefore more reliant on Cheryl for social and emotional support:

I'd be lost without her now, with Vince gone and nobody round the place. Oh Jan comes out, yes, but she's got her family. She's got a husband and she works. See she's [Cheryl] here all the time. We talk. Don't talk that much, I mean we can't have a conversation like Jan, or you and I, but I ask her things, and I'll ask her what happened at school and she'll tell me and where they went and things like that. Goes to play bowls. She tells me she knocked the ball down (laughs).

With only Cheryl and Norah living in the house, the companionship developed over the years is accentuated and reinforced. This companionship is common for mothers who have become the sole carer through various reasons (A. Richardson & Ritchie, 1989).

Cheryl also contributes to some household tasks such as making tea, ironing, putting the washing out, and basic cleaning. Norah acknowledges the changes that have occurred over time, and the interdependence which now exists when she states:

I don't know who looks after who. Whether she looks after me or I look after her now. I think it's the other way round that she looks after me now.

This aspect of companionship that Norah refers to is identified by V. Williams and Robinson (2001) in their recent research on families and caring. As they contend, “caring was not only about physical care, but about companionship” (p. 10). This indeed appears to be the situation for Norah and Cheryl. Similarly A. Richardson and Ritchie (1989) suggest that as parents age “the son or daughter becomes a companion to the parent, a provider of help in the household but also someone to do things with” (p. 26).

Norah has made a conscious decision to live in the family home with Cheryl for as long as she is able. She has, however, made future residential plans for Cheryl’s ongoing care when she informs me that Jan will continue caring for Cheryl once Norah is no longer able. Smith, Tobin and Fullmer’s (1995) study on permanency planning among mothers caring for adult children suggest that because these mothers raised their children in a temporal frame where support services were scarce or unavailable they therefore do not perceive the same need for services currently available. This may be similar for Norah as she turns to her daughter to support Cheryl rather than use services. This is consistent with Bigby’s (1996) finding that most parents turn to “key person succession plans” (p. 300). These are described as “the explicit agreements or implicit understandings that parents had negotiated with others about their future role” (p. 301); in most cases the key person are siblings or close relatives. Liza speaks to this when she tells me that her son is aware of his role in his sister’s future: *“James knows that there is an expectation from us that he will look after her [Lily]. And we’ve never hidden it, and it’s hard for him, but there is that expectation, because we’re family”*.

This chapter highlights the uncertainty of the future the mothers face in multiple areas. Following diagnosis, mothers experience the loss of an anticipated future for themselves, their child and their family, and turn to an unknown and uncertain future. Dealing with the unknown presents a tension in the very necessity of having to create plans, either daily or transitional, at the same time as facing an indeterminate future. Many mothers spoke of living their lives day-to-day and in a sense they could be read as tending to “suppress the future” (Case, 2000, p. 284). For mothers whose children have medical problems there are ongoing unknowns which make future planning difficult. Discursive sites such as education also present many unknowns and create uncertainties and tensions as mothers negotiate these spaces for their children. Section 3 of this thesis shares many of the narratives (re)told by the mothers in the spaces of medicine and

education discourses and there is, within many of the (re)tellings, an unknowing of what the future holds for the mothers, their children and their families. An emphasis on educational and medical discursive sites which constitute disabled bodies as deviant is emphasised in the women's storyings. The next section explores the multiple positionings of the women as they enter discursive sites of medicine and education with a child named with a disability.

SECTION THREE

**STEPPING ONTO THE STAGE,
STANDING IN THE
SPOTLIGHT: MOTHERS'
NARRATIVES ON MEDICAL
SPACES**

Chapter 7

Stories of the mothers: dancing in the margins of a dis/placed motherhood

Few experiences are more frightening to parents than walking into a neonatal intensive care unit and seeing their baby with all the necessary, but strange, equipment and staff. Their new baby looks fragile and sick. Parents are surrounded by sights, sound, arid [sic] even smells that are unfamiliar and intimidating. A veritable “army” of people is present. (Sydnor-Greenberg & Dokken, 2000, p. 185)

Section 3 of this thesis has as its focus narratives of the women who participated in this study, and they are given precedence in much of the following writing. In this section, I choreograph their movements of experience and situate those movements into a performance of words; the women’s steps made visible on the stage of the thesis. Throughout, I endeavour to make apparent the women’s experiences of space and place, discourse, power and authority, using feminist and poststructuralist theorising(s) as explicated in the previous chapters. How women are positioned, what subject positions are available and how they take up or resist dominant discursive practices in which they interact, in/form this section. The women are caught up in multiple dances and while they are part of the dance, they usually dance in the margins of dominant discourse. This section is temporally framed; the stories begin with those mothers whose babies or infants experienced medical spaces, and then moves to investigate the way in which the spaces of medicine are experienced as the children get older.

The words of the women continue to be displayed in italics to distinguish between my constructions, my words, and their movements and their (re)tellings. My aim is to (re)present many of the mothers’ stories as they were spoken, to preserve the integrity of their ‘voices’, and so there are passages of uninterrupted text in this section. At times, I choreograph the mothers’ movement of words, and other times, they dance their own. I blend the two sets of movements, theirs and mine, ours, to develop a sense of joint choreography in the storying process. The husband/partner in the (re)tellings is usually

silenced, as in most instances the women were speaking their narratives, their perceptions, and did not always include their husband/partner in the storying process. I acknowledge the limitations in the storying and the difficulty in using language to impart ‘understanding’, as the words and language we share and presume we have in common cannot touch, see, taste, and feel the experiences, the differences in lives and in the spaces in which the mothers who participated in the study live.

Coming out the other side: narratives of medical interventions

One of our most important forms for expressing suffering and experiences related to suffering is the narrative. Patients’ narratives give voice to suffering in a way that lies outside the domain of the medical voice. (Hydén, 1997, p. 49)

Although doctors have the privileged stories in Western culture, they are by no means the only people who produce such narratives. (Brody, 1987, cited in Fox, 1993, p. 113)

Stories of hospital spaces feature prominently in many of the mothers’ stories. For four mothers in particular (Melissa, Sandra, Therese and Susan,) their first interview almost exclusively focused on their experiences of medical spaces. Other mothers in the study also spoke of hospital spaces, but to a lesser extent. Hydén (1997) explores the narrativity of chronic illness through “illness narratives” which can be described as stories of events, experiences or the like, whether true or fictitious, that individuals use to depict their lived experience of chronic illness. Many writers conflate chronic illness and disability (e.g. Hardy, 1998; Freund, 2001; S. J. Williams, 2000) and therefore I take from the illness literature as well as disability. The importance of narratives can be seen, “as a means of understanding the attempts of patients to deal with the life situations and, above all, with the problems of identity that chronic illness brings with it” (Hydén, 1997, p. 51). Similarly for the mothers in this study, stories (re)told in the interview provided a way for them to speak through their experiences, and several women commented that they had not told their stories in so much detail before. The four women experienced change in their transition to motherhood both through their temporal experience in the public space of the hospital, as well as through the disruption to their taken-for-granted expectations of motherhood. So, borrowing from Hydén (1997), I use the term disability narratives.

Illness and/or disability narratives can be told by individuals other than those who personally experience the illness. Stories can be constructed by family members (Hydén, 1997), as in a wife's story of a husband with senile dementia. Likewise the women in this study speak narratives of illness/disability that relate to their own child, one who due to infancy, illness and/or disability, is unable to speak for him or herself other than through the language of the body. These mothers' stories go beyond words to dance their way through this text, their storying of illness/disability narratives assuming particular significance.

Over the past decades there have been considerable technological advances in medicine which have resulted in higher survival rates of preterm and extremely low-birth weight babies – less than 1000 grams (Levene, Tudehope, & Thearle, 2000), as well as medically fragile infants (Becker & Grunwald, 2000; Saigal et al., 1999; Landsman, 1998; Raines, 1999) and infants with complex care needs who are technologically dependent (Read, 2000). While many of the children in this study spent time in various hospital settings, there were four children for whom these medical advances impacted positively on their survival at birth and whose stories as told by their mothers will be presented. Laura (Susan's daughter) was born preterm (29 weeks) and was extremely low-birth weight (650 grams), while Kimberley (Therese's daughter) and Melanie (Sandra's daughter) were both diagnosed with chromosomal abnormalities soon after birth which required intensive medical intervention to ensure their survival. John (Melissa's son) was diagnosed with Down syndrome and had a number of medical complications requiring intensive care. The birth of a baby with complex medical needs and/or born prematurely can result in the loss of the ideal or perfect baby (D. Richardson, 2001; Sydnor-Greenberg & Dokken, 2000), and thus influence the taken-for-granted assumptions of a motherhood discourse.

For Susan and Sandra hospital spaces (re)presented a familiar discursive site as they worked (and currently work) with/in a medical domain. Their positioning as professionals provides them with insider knowledge of medical discourses and hospital spaces. However for these mothers the time in hospital was now lived and experienced from an/other side. Their narratives tell of change in the way they are positioned, of moving to the other half of the professional/lay binary. There are tensions as Susan and Sandra take up multiple positionings in medical spaces, and power relations are

renegotiated. For Melissa and Therese on the other hand, this medical space was new and often daunting, and was at times, spoken into being as a traumatic experience. As pointed out, “positions are discursively and interactively constituted and so are open to shifts and changes as the discourse shifts or as ones positioning within, or in relation to, that discourse shifts” (Davies, 1992, p. 57). Through the mothers’ narratives shifts and changes are witnessed as they take up and resist their positioning within hospital spaces and medical discourse.

These four mothers reflected on, and (re)told, many narratives of highly specialized medical spaces; detailed narratives of the time spent in Neonatal Intensive Care Units (NICU) and Intensive Care Units (ICU). An ICU is “a specially staffed and equipped hospital ward dedicated to the management of patients with life-threatening illnesses, injuries or complications” (Oh, 1997, p. 3). A NICU is a subset of ICU for newborns (neonates) typically up to the age of 28 days, although the length of stay may be up to one year (Levene et al., 2000). NICU and ICU are part of a larger bureaucratic and structural organization, named as hospital, which Becker and Grunwald (2000) assert is “geared toward the medical care of patients, not care for their families” (pp. 63-64). The period of time spent in NICU and ICU often represented a major part of these four women’s children’s illness and attendant disability and consequently figured prominently in their storying. Entry into these spaces is potentially a stressful event (Doering, Dracup & Moser, 1999) and is often overwhelming (McGrath, 2001).

The birth of infants who are seriously ill present as not only a “significant threat” to the family, but the associated disruption to family life and other social relations is in itself threatening (Affleck & Tennen, 1993, p. 146). Not only were the children of these four mothers seriously ill, they were also medically diagnosed as impaired/abnormal immediately or soon after birth. How then did these mothers experience the spaces of medical discourse? How did they come to understand this threatening event? How did they experience the tensions between the motherhood they expected and the discursive site of NICU?

Discursive practices inherent within the spaces of NICU and ICU are imbued with issues of power, knowledge and authority as the professional/lay binary is enacted. It is the particular “training, qualifications and credentialing” (Clear, 1999a, p. 2) which

differentiates professionals and their scientific knowledge base, from lay people and lay knowledge. Professionals in the medical spaces are “powerfully constructed from particular disciplinary interests” (Clear, 1999a, p. 3). It is convincingly argued by Hardy (1998) that “once established, professions continue to patrol the boundaries of the work and develop strategies to retain or further exert their ‘professional dominance’” (p. 69). According to Fox (1993) the “caring” role of medical professionals “is imbued by discourses on expertise” and he continues by stating, “expertise takes control, possesses, the object of its desire” (p. 117). Because of the hierarchical structure inherent in medical discursive sites “the structure of the parent/professional relationship is underpinned by an inequality and an objectivity which commodifies caring” (Clear, 1999a, p. 3).

Foucault (1973) established the concept of ‘the gaze’ and of relevance to this chapter is the medical gaze, which Foucault describes as that “of a doctor supported and justified by an institution, that of a doctor endowed with the power of decision and intervention” (p. 89). A central tenet in Foucault’s work “is the way in which ‘the gaze’ constructs individuals as both subjects and objects of knowledge and power” (Allan, 1996, p. 221) and this is examined in this chapter. The ‘medical’ or ‘clinical’ gaze is considered a variant of Foucault’s concept of the ‘the gaze’ and “refers to the ways in which the object of medical knowledge and practices have been viewed and understood” (Heaton, 1999, p. 769). Continuing to draw on the work of Foucault, Heaton (1999) suggests that ‘the gaze’ “is conceptualised as an act of ‘discipline’ or power, a way of defining and regulating subjects” (p. 796). The women in this study show through their storying that they “can exert power, be the subjects of power, and may resist it ... individuals are neither ‘empowered’ nor ‘disempowered’ but are active mediators of the gaze” (Heaton, 1999, p. 771).

☞ Melissa’s story: *I knew there was something wrong straight away*

Melissa’s narrative of the spaces of hospital and NICU begins with her third pregnancy and a pregnancy she reports as having been uneventful. Because it is her third birth she has chosen to attend a small suburban hospital that only specialises in uncomplicated

deliveries and requires a “*very straightforward history*”. Melissa informs me her previous pregnancies and childbirth had been uncomplicated and therefore she was eligible to attend this hospital.

Labour begins for Melissa with back pain and upon admission to hospital she is monitored:

He put me up on the monitor where it just goes around your tummy, I don't know what it's called ... and she [the nurse] kept losing the heartbeat. But I didn't really think anything of it at the time. I just thought it just wasn't monitoring very well because I've found a lot of things [equipment] aren't that great ... so I didn't think there was a problem.

Melissa is aware that the nurse is experiencing difficulty monitoring her baby's heartbeat but is not concerned, as she believes the problem could be faulty equipment. Melissa is not informed otherwise. As she says, “*at the time I didn't realise they were concerned about his heart*”. She also displays a lack of knowledge with medical technology and the naming of equipment, knowledge that is not necessary to her in her every day life.

After John is born, Melissa tells how he is taken to the side, “*which they normally do*”, but then notes, “*I knew there was something wrong straight away because they took so long with him*”. Her two previous experiences of childbirth provide Melissa with an indication of the standard processes involved after birth. She states she became aware that there was a difference with John's birth because of the length of time it was taking for John to be brought to her. When the medical staff returns with John, Melissa and her husband, Luke, are informed immediately of the possibility that John may have Down syndrome:

When they came back, that's when they said, “We think he's got, we think he might have Down syndrome”. And we were just shocked because there'd been nothing in the pregnancy.

For many women, including Melissa, a good pregnancy brings with it an expectation of a healthy, and ‘normal’, baby (Landsman, 1998; Murray, 2000). Melissa and Luke's expectation of the normal outcome of pregnancy is disrupted with the suggestion that John might have Down syndrome. In Melissa's storying she displays an expectation of the birth of a ‘normal’ child and this ideal has now been ruptured. In Melissa's words,

they experienced a sensation of “*shock*” at the news of Down syndrome, and relates this shock to her uneventful pregnancy, when she explicitly explains the shock was “*because there’d been nothing in the pregnancy*” to suggest there would be a possibility of impairment/abnormality. It has been suggested that “in a society where prenatal diagnosis is increasingly common, most pregnant women seek, and assume the possibility of having, a perfectly normal child” (Landsman, 1998, p. 3). Melissa explains that as she was 33 years old she was considered at low risk for the birth of a child with Down syndrome and therefore had not had any prenatal testing.

Melissa explains that the GP (General Practitioner) systematically went through the types of physical features common to babies with Down syndrome and once these were demonstrated, she could recognize them in John. However, Melissa feels that some signs were not so noticeable, not visible, and that the doctor was presenting “*text book symptoms*” rather than the actual signs presented by John. John is immediately inscribed by his looks, his image, as having Down syndrome, of having an abnormality. Although it would not be until the next afternoon before a paediatrician could confirm the diagnosis, Melissa says “*to me it was already confirmed. I didn’t think there was any doubt. I mean I could just tell by looking at him*”. While there is a desire for formal confirmation, Melissa is confident in her visualising of John of the potential diagnosis given. The medical gaze has been applied to John.

Interestingly, in her (re)telling of John’s birth, Melissa expresses her desire to not have been informed of the diagnosis straight away. Having later read literature on disability, Melissa is aware that it is recommended that parents be informed immediately, but as she explains:

At the time I wished they hadn’t told me. I didn’t want to know. I’d rather have the night and then be told in the morning ... I suppose I would have known myself, but just having it confirmed there’s no going back. Sort of like, you can’t make it go away.

Melissa’s statement suggests that by stating/naming the impairment, there is no opportunity to simply and wholly experience the birth of her baby; she is “not given sufficient space to celebrate the birth” (Pagliano, 1999, p. 1). The immediacy of the diagnosis denies Melissa and Luke the time to dream, the time to cherish their baby as a baby, not as a baby named with a label and socially inscribed. They are thrust into a

disability discourse for which they have not prepared. There exists however a dualism in that Melissa believes she may have realized that John had Down syndrome without having been told. John begins to be inscribed by his appearance.

The next day John has a blood test to confirm the initial suspicion of Down syndrome. He also has a scan for his heart. It is then discovered that he has a heart murmur and polycythmaemia, which Melissa explains is “*thick red blood*”. Because John was experiencing feeding problems it was decided he would probably require a gastro-nasal tube and this necessitated a move from the small suburban hospital to a NICU which was located in the large city hospital.

Melissa describes her NICU experience as “*very, very traumatic*”:

When we arrived in the ward about 4:00pm what had happened was they were short-staffed and they were closing one of the wards. They're not really wards, they're bays. There's seven bays within this intensive care unit and number one is the most intensive where they're just hooked up to absolutely everything and then it worked its way down to seven where they're on either no or very little equipment. But when we arrived there was just this complete chaos because they were transferring beds, moving everybody about, closing off the bays. So we never really got to see anybody and we were left in a waiting room hanging about. We didn't know what was going on. Nobody seemed to have his case story. Nobody knew we were coming and it was just chaos. And then eventually they found him a bed and hooked him up.

I can't remember, like if we did speak to somebody it was only like a registrar. Just somebody who was on duty, it wasn't anybody of authority. Then I wanted to stay with him, but because I'd been discharged there wasn't a bed for me. ... so that was pretty horrible. ... they eventually said I could stay the night, and that's what I ended up doing. But it was really scary, because I'd never been in an intensive care unit.

Within her storying Melissa paints an image of NICU as one of “*chaos*” when they arrive. Although this may not be the usual scene on arrival in NICU it is the one experienced by Melissa and Luke. The memory of the specialized space of NICU has become part of their storying and their (re)telling of their experience.

Inserted into Melissa's narrative are descriptive details which provide information about the appearance of the NICU environment. She describes it as “*traumatic*” emphasising her embodiment of the medicalisation of John. Melissa's emotive reading and positioning within the spaces of NICU are present/ed in her storying. Melissa explains

that there are seven bays and they are ranked according to the severity of the illness, from most to least intensive, with number seven being the least intensive. John is placed in bay seven, a space that constructs how and where John is positioned in a medical discourse and by which Melissa comes to experience NICU.

Melissa and Luke's unfamiliarity with the spaces of NICU adds to a sense of uncertainty. Their lack of knowledge as they enter an unknown space comes to the fore; "*we didn't know what was going on*", and this is reflected in the passivity with which they wait surrounded by "*chaos*". This is a new space, unknown and unanticipated, creating stresses and tensions they had not expected with the birth of their third child. Freund (2001) contends that "spatial structures and places are not *just* cultural signifiers, but additionally their *physical* features make one feel 'out of place' and alienated, insecure and fearful in a particular space" (p. 700). The discursive site of NICU is a textual space complete with its own hierarchy, language, and meanings, and the physicality of NICU spaces can be read as adding to the tensions Melissa and Luke experience. The structure of the space of NICU is one into which Melissa and Luke do not speak, a silence reinforcing the hierarchy and power within this discursive site.

Melissa speaks of a hierarchy of authority within the medical profession when she says, "*it was only like a resident ... it wasn't anybody in charge*". She demonstrates a situated and lay knowledge of the positioning of medical staff within an organised social institution such as the hospital, and in particular the NICU, and in doing so positions herself. The "*resident*" is accorded a lower status than one Melissa appears to reserve for doctors and other medical specialists who are higher up in the hierarchy. Melissa and Luke have entered a new and unfamiliar environment and her narrative suggests the dominant discourse of professionals as the ones with relations of power (Foucault, 1973).

In Melissa's storying of the spaces of NICU she specifically mentions the medical technology "*where they're just hooked up to absolutely everything*". This technology serves to further position Melissa as a lay person and therefore unknowledgeable, and privilege those with medical expertise and knowledge (Fox, 1993). Medicine has become increasingly "very heavily 'technologized'" (Fox, 1993, p. 147). Fox (1993) goes on to comment that the use of technology has the effect of "bolstering 'expertise'

among health professionals and disempowering those who are subjects of medical technology” (p. 147). At the same time technology is partially responsible for John’s favourable outcomes, creating a tension between Melissa’s lack of knowledge and her desire for John’s survival, and the increasing expertise of the health professional.

Melissa describes the equipment, which inscribes John’s body, as well as her feelings of helplessness when the monitor’s alarm sounds. This helplessness positions her as powerless and passive as medical technology creates spaces in which she is initially unable to participate. She speaks of her fears of John having a cardiac arrest when the alarms activate:

John was hooked up to an oxygen saturation monitor and a heart monitor. A lot of these things when they lose contact, they’re just like pegged onto their toes, they bleep. So of course you think they’ve gone into cardiac arrest and all that’s happened is that the peg’s come off. So it’s pretty scary. And of course the nurses don’t jump. I didn’t realise when I first got in that Bay 7 is not intensive, intensive. So these bleeps can go off and nobody does anything because they’re busy doing something else. So that was a bit scary. ... At the start you think, “There’s a bleep and where’s the crash team”? If you watch hospital dramas that’s always what happens. You know, bleep, everybody bursts into the room. But that doesn’t happen.

As NICU is a discursive site it comes complete with its own languages, technologies and ways of being.

Melissa’s previous understandings of NICU (and ICU) spaces seem to have been both informed by, and formed through, media representations as she speaks of watching “hospital dramas”. Images of ICU dramas (re)presented on television or in film in/form some of her expectations, knowledge and understandings of the way ICU operates, or is expected to operate. Images from television and other sources of hospital drama mean it could be argued that “reality has thus been disposed of in the sense that our actual experience of the world around us is now thoroughly interwoven with and overlaid by virtual representations” (Cuff et al., 1998, p. 296). Melissa’s preconceived construct of the activity with/in intensive care spaces results from cultural representations of “hospital dramas” which associate certain meanings and actions to alarms. These media associations formulate Melissa’s knowledge. She held specific expectations of what would happen when the alarms went off based on hospital dramas that she has witnessed and internalised. Media can be seen to play a role in (re)formulating the

discourse of medicine; creating a belief system which in/forms social understandings, yet these understandings are often generalised and not applicable in the everyday world of the NICU experienced by parents, or indeed by the participants in that discursive site.

In media; drama, health, and medicine are constructed as popular themes available for mass communication (Fox, 1993). Fox (1993) has stipulated that constructions of medicines are “constituted in these popular culture representations as ‘floating signifiers’” (p. 154) with no inherent or stable meaning attached to ideas; rather ideas are “available as mediators of all sorts of different meanings or associations. As such ‘health’ and ‘medicine’ may come to have much less fixed significance because of popular culture representations” (Fox, 1993, p. 154).

For Melissa NICU is a new discursive site and she gradually comprehends the pertinent issues as they apply to John over the time she spends in the unit. She explains that she eventually becomes blasé as she learns to handle the various monitors and alarms; “*you just get up and look at it and give it a flick and it’s ok*”. Melissa is no longer passive, or fearful, as the temporality of living in the NICU space becomes familiar. Parents quickly “become sophisticated in understanding the nature of the technological data displayed by the infant’s monitors” (Becker & Grunwald, 2000, p. 65). Melissa demonstrates a move beyond her initial positioning of passivity, lack of medical knowledge and helplessness, to resist this positioning and becomes an active and informed agent in her knowledge and understanding of John’s monitors and care needs.

Melissa speaks of becoming more knowledgeable, demonstrating her resistance as lay, and non-expert. This is illustrated in the following segment:

If you’re there when they come round, like the changeover of the nurses; the nurses come out of a shift and they do a handover, and a lot of the time you think you could do it better yourself because you’ve been there and you can say exactly what’s happened, and the same with when the consultants come round. If you’ve been sitting there all day, you sometimes feel you know your own baby’s history better than the nursing staff because you’re there day in, day out ... you feel as if you can sit there and recite this baby’s got x,y,z, he’s been for this, he’s done that, the results are this.

In her storying Melissa positions herself as having similar, if not better, knowledge of her own child as the nurses who are passing on information to either other nurses or consultants doing rounds. Taking up this position provides a sense of control and

knowledge. The consultant's round "has long been an expression of power over medical students, nurses and patients" (Hardy, 1998, pp. 83-84). While the dominant medical discourse is one of the expert's knowledge being privileged such as in the consultant's ward round, Melissa takes up a story line where she positions herself as knowledgeable, an expert on her own child. Melissa's perceptions of technology change from being seen as strange and new, to being familiar. The dualism and boundary between technologized professional knowledge and lay knowledge is "deterritorialized" (Fox, 1993) as Melissa learns to read the monitors as lay expert. The medical professionals are no longer those with expert knowledge and Melissa simply a passive receiver. Her newly acquired lay knowledge about John's monitors now provides her with an opportunity to position herself with some control in NICU spaces. At the end of 4 weeks John is able to go home.

➤ **Sandra's story: *An average situation that went sadly wrong***

Sandra is a registered nurse with obstetric and paediatric experience working part-time in Deira. Her narrative commences with a brief description of her early years in Melbourne as the middle sister of 6 siblings with a full time mother who was "*always home*" and "*on every tuckshop*". She tells briefly of meeting her husband, Chris, her time working overseas and finally her marriage and eventual move to Deira where she and Chris managed three blocks of holiday units for a period of time. Sandra is also a nurse working part time, which she continued to do while pregnant with her first child, Melanie.

Sandra was booked to have elective surgery in a private hospital in Deira at 38 weeks with an epidural, as her baby was a breech presentation. However Sandra's membranes ruptured at 36 weeks gestation. She expresses her annoyance at being "*whisked off to do a caesarean under general anaesthetic*", because as she explains, "*we sat in the hospital for about 2½ hours waiting, and I knew in that time they could have got the anaesthetist in and given me an epidural*". Sandra reconciles her annoyance with her knowledge of the medical/hospital system and excuses the incident explaining; "*being a*

Monday morning it was really busy and there were three other women in labour which was a lot for [this hospital]. It was quicker to do me under general”.

Sandra’s narrative highlights a tension and dualism between two of the subjectivities she has adopted; as mother and positioned outside a medical discourse, and as a nurse, subsequently positioned within a medical discourse. Sandra’s knowledge as nurse that an anaesthetist could have been arranged to do the epidural in the time she waited is in contradiction with her positioning and subjectivity as mother-to-be. Yet, Sandra is also aware of the workings of the maternity section of the hospital and explains how it is busy for a Monday morning for this hospital and she uses this pragmatic knowledge to explain and justify why she was kept waiting instead of having an epidural. Inherent in Sandra’s dual positioning at this time is the exercise of power and its locus away from the mother, the lay person, and into the realms of the medical, the expert staff. Sandra notes that it was “*quicker just to do me under general [anaesthetic]*”. Convenience and time for the medical bureaucracy appears in Sandra’s storying to override her (mother) wishes – her subjectivity as nurse takes precedence.

In the following excerpt Sandra provides a description of her recovery after her caesarean and the birth of Melanie and demonstrates her knowledge that she is treated differently:

The first I knew about it was waking up in the recovery room and all I could hear them say was, “Oh quick. She’s awake”; thinking, “That’s really strange”. Usually they say, “Oh you’ve got a lovely baby boy, or a lovely baby girl”. They were very quick to push me out of the recovery room, back to the ward. And when I got back Chris was waiting near my bed and one of my friends who I’d worked with for awhile, she was waiting there as well, and she was in tears. I asked her what was wrong and she said, “Oh, there’s something wrong with your baby”. So I was trying to comfort her (laughs).

There continue to be tensions displayed in Sandra’s storying as a result of her multiple subjectivities. As a nurse and as part of the discursive field of the hospital, Sandra demonstrates her knowledge of the usual processes involved with the birth of a baby by caesarean and of informing the mother of the gender of her baby, the celebration and presentation of a normal, healthy baby. She is aware this is not the process following her recovery. Her storying is devoid of any explanation provided by the nursing staff for the change in procedure. This discrepancy is remembered by Sandra and forms part of the story she tells about Melanie’s birth.

Sandra is placed in a single room when she returned from theatre and explains that this separate space allocated to her is because of Melanie. The birth of child with abnormalities signifies a different way of being for the mother. Her separate space is accepted and spoken as usual; *“That was the usual thing if there was a problem with anybody”*. Melanie is inscribed with/as a ‘problem’ and for Sandra, her motherhood is considered to be different, placed in to a space away from other mothers. This placement emphasises that *“the cultural markers publicly acknowledging motherhood are sorely lacking”* (Landsman, 1998, p. 9). Sandra reports that there is no discussion with her as to whether she wants this space, this privacy; it is decided for her. This separate space can be read as privacy, but can also be seen to inscribe and position Sandra as mother, differently, separately, to other mothers. Sandra is effectively put in a place as Other. The physical space into which Sandra is placed serve as boundaries between normal and abnormal. When there is a problem, bounded space is used to separate.

Sandra recounts that the paediatrician had already informed Chris that something was wrong with Melanie, that she was not breathing properly and that further testing would be necessary.

I remember saying, “What’s wrong with her?” And he’s [Chris] saying, “They don’t know. They’re going to do some tests, and they think it’s Turner syndrome”. And because I knew what Turner syndrome was, I thought, “Oh that’s alright, they’re fundamentally quite healthy”.

Sandra’s medical background has provided her with knowledge of Turner syndrome. Concerns regarding Melanie’s health status override the diagnosis of Turner syndrome, because to Sandra *“they’re fundamentally quite healthy”*. Sandra says that she is worried, but also says *“I was just delighted. I was over the moon.”* The health of Sandra’s baby takes precedence over disability.

In our second interview I asked Sandra to explore her thoughts about health and disability further:

I don’t know whether it was because I’d been exposed a lot through my sister’s work with children with special needs in Melbourne. She lived in as a housemother. And I had been around children with special needs a lot in my working years, that that [disability] didn’t really faze me.

And I [have] a friend who has a sister with Turner syndrome, [and] I know her quite well. And yeah, that didn't, didn't worry me I guess to the point that I was terribly upset that there was something wrong with her. It was more that I was relieved that it was something I was familiar with I guess.

Sandra has previous experience in both her working and personal life with Turner syndrome and with children with special needs. She admits to not being 'fazed' by disability and suggests that her previous experiences account for her early acceptance. Sandra expresses relief that the diagnosis is one with which she is familiar and is one associated with good health. She tells me that she "didn't think there was anything life threatening" and goes on to add, "I hadn't asked, or didn't know, or wasn't told".

However, the initial diagnosis of Turner syndrome proves to be premature. Sandra explains that further chromosomal testing reveals that while Melanie has the chromosomal picture of Turner syndrome (which involves chromosome 23) she was also "missing a part of her second 18 chromosome and part of a third one was stuck on, so it was a translocation ... she was sort of a mixture of 2 syndromes". Sandra's original belief that they would spend a couple of days in hospital before going home soon changes. Melanie is transferred to a larger public hospital in Deira due to experiencing apnoeic episodes, where Melanie would temporarily stop breathing. Melanie is to spend much of the next 18 months in and out of NICU and ICU with multiple medical conditions, including chest infections, septicaemia, and epilepsy.

For Sandra these medical spaces are familiar territory and she explains the way in which her nursing and mothering subjectivities became blurred boundaries as she moved between and beyond the accepted parameters:

I dealt very well with the practical day-to-day care of her and often if she was in intensive care I can be there as well and I would do all of her care and all her tube feeding and even her blood tests, and a lot of these sorts of things. I didn't want anyone hurting her. I knew if I did it I'd do it properly and things like that. And I think that's what really helped me cope especially the first 6 months, [which] were her critical months.

Sandra went on to say that the caregiving helped her cope because "it was part of my daily routine at work and I dealt with that fairly well". The spaces of Sandra's work blur with her desire to mother and care for Melanie. The familiarity of the role of nurse enables Sandra to draw on multiple subjectivities to constitute her self in the spaces of

NICU. Motherhood and nursing are closely entwined in their caring role (Hardy, 1998), and Sandra explains that she takes up the dual subjectivities easily.

In her second interview Sandra considers how reading the transcript of the first interview allowed her to reflect on how, and who, she was during the time Melanie required medical care:

I felt like I really switched off the first sort of 12 months when she had medical care needs that I could fulfil quite easily in my role [as nurse]. I even resuscitated her one night in casualty. ... I was so comfortable with that role that I really switched off a lot I think emotionally ... not all the time, but quite a lot I think ... a lot of the situations we found ourselves in, I had been in professionally with people, neonates who were very ill and life threatening problems.

Sandra comments that “looking back through there [the transcript] I think that’s why I probably coped so well because it was familiar to me”. Sandra also expresses concern that Chris had to cope by himself in the early days while she was still under the influence of pethidine:

With all of that drama going on with his baby without, on his own, where I felt that I could have been a help to him. Doing it together is so much easier, if that’s a good word, than trying to deal with things on your own.

Sandra explains that the NICU space was “foreign” to Chris. However, like Melissa in the previous story, Chris gradually becomes knowledgeable with the technological environment surrounding Melanie. He reads her monitors and resists the boundary between roles of expert and lay. Sandra explains:

I remember by the time she was at the Base, in there for months in NICU he used to go and read all the monitors every morning, get all the readings (laughs). He just became so familiar with everything. I said, “Don’t touch those things”. He said, “No I just want to see what her oxygen stats are”.

She wasn’t conducive with life

When Melanie is 3 months old it became necessary to transfer her to a major hospital in Melbourne due to medical complications. Following is the story told in Sandra’s words:

She had this very rare condition of chylothorax where her lungs would collapse and the lung cavity would fill up with this lymphatic fluid. ... So she was going blue and virtually drowning. ... I took a big black garbage bag full of oxygen tubes and God knows what, nasal-gastric tubes and stuff and I jumped on a plane. They aspirated her too. I jumped on a plane and flew to Melbourne with her. But

that didn't faze me at all (laughs). Like now I think, "Oh my God what did I do? How did I ever do it?"

She was admitted. ... They put a chest drain [in] and put a drip in her head 'cause they couldn't get any veins anywhere. And I remember they decided that her chromosomal abnormality was just so severe she wasn't conducive with life and that she was going to die. ... The geneticist in Melbourne, after I'd been there a couple of days, told me that she wasn't going to really get over this situation with her lungs filling up and that I had to get my husband down straight away.

So they took the chest drain out, took the drip out and virtually just left her to die, and she was going to go blue and drown virtually over the next few days, because the geneticist had said that from her chromosomal picture that she wasn't, yeah, she just wouldn't be conducive with living. ... We said to them, "Can you give her something please; we don't want her to suffer". They said no. So they were just going to let her sit there for 3 days and drown, literally. We then went home and cried all night.

Anyway after a couple of days she was still pink (laughs) and bottle feeding by this stage, because they'd taken the drip out and we'd go home every night. We stayed in the hospital like on the third night, thinking that something would happen overnight. We got up the next morning; she was still pink, not blue. Finally one of the thoracic guys came around and said, "It was nothing we did ... but something has happened and the chylothorax has resolved itself". And it was like we felt she'd had a reprieve. ... Then the geneticist waltzed in and said to us, "Oh well it mightn't have been this time but next episode that'll be it". So Chris nearly punched him (laughs) but he got out of the way quick enough (laughs).

Melanie is inscribed by her genetic makeup and by the dominant medical discourse of expert knowledge/authority. Melanie's abnormalities presented in such a manner that the medical professionals, in Sandra's (re)telling and her language, did not consider her "conducive to life". Sandra constructs and positions the medical experts through their privileged knowledge and authority as having determined her daughter's future, her death. The application of a Foucauldian 'clinical gaze' upon Melanie asserts that "the condition of the individual body is defined in relation to general categories of knowledge about *bodies*" (May, 1992, p. 591). Moreover, even though Melanie did not die, Sandra and Chris were assured that medical expertise and knowledge would prevail next time. While Sandra felt the reprieve of life for her child, she perceives herself as positioned within a hierarchical structure which determines scientific knowledge as accurate, science as the truth.

It is “patient subjectivity” which “determine[s] compliance with treatment and thereby maintain[s] the dominance of medical discourse” (Mitchell, 1996, p. 203). Despite Sandra’s positioning as nurse she takes up a patient subjectivity with her compliance with medical diagnosis and intervention. She clearly expresses her subjectivity as nurse and accepts the hierarchical structure inherent in medical discourse:

Traditionally nurses are like on the lower end of the scale. And if a doctor says something, that’s law, that’s what happens. But it was Chris [who] was the one that was objective and would say to me, “But did you ask him why or did you say that, or did your say this”? And I wouldn’t because we’re so [subservient]. In a lot of cases it was a disadvantage having any medical knowledge because I didn’t, being a nurse especially, I didn’t ever question any of their decisions.

While Chris is positioned outside the medical discourse he is more able to resist the positioning of patient subjectivity suggested by Mitchell (1996). Sandra feels this subservience particularly strongly when they were in Melbourne; “*I just guess I was resolved to the fact that this geneticist knew what he was talking about*”. As Chris’ family try to resist expert knowledge, Sandra remains positioned within the medical discourse where experts have the requisite knowledge:

When we were in Melbourne and they said to us [that] they were going to take all her drips and drains out, she’ll die by the weekend, Chris’ family are all saying, “What are you listening to them for? Why do you believe them”? I said, “Well they’ve told us what’s going to happen”. They said, “No, it won’t happen, we’ll pray, we’ll do this, we’ll do that”. I was a bit sort of angry with all of them you know. What do you know? The doctors have told us this is what’s going to happen. Prepare yourselves.

Sandra’s subjectivity as nurse is strongly engrained with/in the medical discourse and she states simply, “*I just believed everything they told me*”. Through her storying Sandra highlights her subject position as nurse which informs the way she experiences medical spaces and dominant medical discourse of the scientific expert. However as Melanie gets older, Sandra’s positionings shift and change and she becomes more instrumental in determining Melanie’s medical care.

Defying all the odds

Melanie’s chromosomal abnormality is extremely rare. Sandra reports that apparently no identical case had previously been recorded anywhere in the world despite searching

genetic databases. At one stage, medical specialists thought Melanie would not live past 12 months, and when Melanie is 13 months Sandra and Chris wonder what to do next. Sandra describes Melanie and their life story as one where “*we felt like we were cheating death, defying all the odds and we were winning. It was a medical achievement*”. The family is highly visible in much of Sandra’s (re)tellings. Their story, as (re)told by Sandra, is a story of resistance to the medical domination of knowledge. It is also the story of a baby Sandra believes was considered and inscribed as “*a medical situation*” through medical discourse, rather than as a baby:

We felt like we’d sort of beaten them all. You know, we spent the first couple of years defying everybody. Feeling like we’d won the challenge, that we’d defied all the odds; we, meaning Melanie and us. And I realised how, of little importance what medical diagnosis really is and how it didn’t matter even if we had her for 3 months. That their whole attitude was that she was a medical situation. She wasn’t a baby and she wasn’t a person and she wasn’t a human being. She was just a medical situation and if what they predicted, like they all tried to predict, all her life they tried to predict what would happen with her. This will happen, and it never did, or most of the time it never did.

Melanie lived to 11½ years of age.

➤ **Therese’s story: *We had this gorgeous baby***

Therese is a primary school teacher working in Deira and Kimberley is her first child. Therese was 30 when she had Kimberley and explains it took 5 years for her to fall pregnant. She reports it as a “*really exciting time because we had been trying and everybody seemed rapt*”.

Therese’s storying of the time spent in hospitals forms the majority of our first interview. Her narrative is not told in a chronological or temporal framework as she moves through time fluidly attempting to describe her experiences with Kimberley’s medical complications and medical spaces and discourses. She moves backwards and forwards, and to the present, to explore her rememberings. Therese’s storying provides a frame for her positioning with/in medical spaces. Many stories are told by Therese, yet, unfortunately, they are not able to be included here with the colour and the detail of Therese’s (re)tellings. Within the (con)text of this thesis I have had to shorten Therese’s

storying. The images I present are brief, fleeting, in some ways an artificial telling of the events as told by Therese.

Therese experiences an “*excellent pregnancy*” until the last week when she begins rapidly losing weight. She is induced on a Saturday, however labour does not commence and the following day Therese undergoes an emergency caesarean, due to concerns about the foetal heartbeat. She describes drifting in and out of consciousness for the next 2 days because of her reaction to the general anaesthetic. During this time Therese recalls hearing her mother commenting on Kimberley’s size (5 pound) and asking if the paediatrician is happy. Her husband Simon replies, “*Yes, except that her anus and vagina look like they’re one opening*”. Therese tells me that this memory is very clear; “*I can remember very distinctly hearing that, but not being able to open my eyes or open my mouth to ask any questions*”.

By Monday it has been discovered that Kimberley’s vagina and anus have a fine membrane between them and that the membrane would possibly increase as Kimberley got older. Therese continues:

So by Wednesday I was feeling quite good about life. ... I was sort of up and about and walking backwards and forwards to the nursery ... we were having problems trying to get Kimberley feeding. I had heaps of milk so I was down [in the nursery] expressing a fair bit of the time and because I really enjoy people I wasn’t going to sit in my room by myself. They put me in a single room because of the caeser and the problems I’ve had with trying to come out of it and all of that, they thought I really needed rest.

Therese actively chooses not to stay in allocated space of a single room, a room chosen for her by the experts, as she says “*they put me in a single room*”. Like Sandra, no choice is provided and Therese is separated because of her response to the anaesthetic, yet Therese consciously resists being positioned in a separate space. As there were concerns regarding Kimberley’s size as well as problems with latching onto the breast and a weak sucking mechanism, she was consequently tube fed every 2 to 3 hours and carefully monitored.

On the following Wednesday the paediatrician announced that he would like to do a chromosome test, to which Therese replies, “*do whatever you like, that’s fine, not a problem*”. She tells me that she did not think anything of this request, and no

information was provided to her as to the reason why the testing was to take place. In her storying Therese literally moves from this section of the story concerning the chromosomal testing to speaking of another aspect of Kimberley's birth. Therese effectively breaks her storying into segments, emphasizing both her decision not to worry and thereby changes the focus and also the temporal framework in which her storying takes place.

We had so many people visit; I mean it was just amazing. ... They were aware I guess that we'd been trying to have kids ... everybody was just over the moon that we had this gorgeous baby. And she was. She was just like a doll. Her head was actually in proportion to her body. You know how most babies have big boofheads, she didn't and she was just so beautiful, 'cause she was only little. ... She actually fitted into Cabbage Patch doll clothes when she was born. So she just looked gorgeous. And lots and lots of people visited, and people from the church.

Therese lays the foundation for the next part of her storying as she presents Kimberley as visually beautiful. An aspect of 'the gaze' is present in her storying, as she describes the way Kimberley looks and appears. Foucault (1973) states that "the gaze" is "the act of seeing" (p. ix). The gaze is applied in multiple ways through socio-cultural discourses. A social presence and the valuing of 'image' is present in the way Kimberley is 'seen', and this manifests itself in the way in which Therese describes and inscribes Kimberley. Therese tells of the number of people visiting and in so doing, allows an opportunity for her social networks to be made visible, and introduces her involvement with the church.

This is really major problem stuff

A week after Kimberley's birth and 3 days after the request for chromosomal testing the paediatrician asks Therese when Simon will be up to visit. Therese continues:

To me it was just passing conversation, it was nothing at all. Anyway Simon arrived. ... And about 2 minutes after Simon arrived in the room the paediatrician was at the door and said, "I want to talk to the pair of you together". ... I thought, "Well there's something wrong here", but I had no idea it was going to be something major, major. I thought maybe we were looking at surgery for an anus and vagina or something like that. ... Or I thought maybe he was going to be talking to me about the feeding thing. ... He was just wonderful. He actually told us that the preliminary results of Kimberley's chromosome tests had come back and that there was a problem. And we went, "Yeah". And he said, "But they're not too sure exactly what's wrong". And we went, "Oh, ok, fine". So he then sat and explained all about chromosomes. ... Then he said that they believed that one of Kimberley's chromosomes was ringed. And he talked about Turner syndrome.

He talked about the fact that when Kimberley was first born he thought she had Cri de Chat because of her cat-like cry, but it wasn't that. He said, "This is really major problem stuff". We were both just totally stunned I guess, because here was this gorgeous little girl who we thought was just perfect, and we were being told that she wasn't perfect at all. That there was something major wrong.

The following Monday Therese and Simon are informed that the chromosomal abnormality is a "translocation 5-13 ring 5". Therese tells me that they asked whether there was another name for it as they had heard of Down syndrome and Turner syndrome and knew that chromosomal abnormalities were named. She also expressed a desire to meet other families whose children had similar chromosomal abnormalities as Kimberley. The need for identification, to identify and inscribe Kimberley as part of a group is brought to the fore. While the individual's experience is traditionally highlighted in the illness narrative, Hydén (1997) suggests that the illness narrative can become "a collective experience" (p. 59). In a similar way to the illness narrative, the disability story can also become a "collective experience". Therese's request to meet other families with comparable experiences can be seen as desiring to be part of this collective identity. "Illness [disability] is removed from the private sphere and becomes a part of an all-encompassing, political and social narrative and context" (Hydén, 1997, p. 59). Also present in Therese's storying is the need to receive information, and to talk with other parents who have experienced having a child with this particular chromosomal picture.

Therese tells me that the following week is "tough" as they have to tell everyone there is something wrong with Kimberley. While the segment is about the telling of friends, it also underpins the social construction of disability as inherent tragedy; the social norms and contexts that are expected with childbirth are displaced with the telling of Kimberley's abnormality. Therese says the continual retelling was good because they had to examine how they felt about Kimberley, and about abnormality:

It was good in a way because it made me really examine how I felt about Kimberley. And we were having to do it all the time. ... We'd be saying, "It'll be fine. You know, she's still gorgeous. Look, she's a lovely baby. Look at the way she smiles". It really made us examine how we felt about her because we were having to do that to try and help other people come to terms with Kimberley. I kept saying to them, "You thought she was gorgeous last week. She's still the same girl. She hasn't changed. There's something wrong, but she's still that same girl that you thought was gorgeous last week". And I think that was really good for us. ... I really felt it helped us and Simon feels that it really helped him too ... I

guess the fact that we didn't know for a week was probably good. And the fact that we had so many visitors in that first week was probably good too, because they knew Kimberley before she had a chromosomal abnormality (laughs) in their eyes. And it was the same kid.

Therese's storying brings to the fore the value placed on the 'normal', the perfect child. The label of abnormality can be seen to challenge the way others perceive Kimberley, the way in which she becomes 'Other'. Kimberley is now different from the group, not of the norm, and thereby is 'Othered' in being named as having an abnormality. Therese's use of visual images, as she asks others to "look" and says, "in their eyes", draws attention to the powerful impact of the 'observing' and 'social' gaze, of how we are seen and read, and importantly, how Kimberley is now seen and read by society. A social gaze is applied to Kimberley; so that while she is the same baby, "she hasn't changed", she is no longer the same; she has an abnormality and is 'Other' to 'normal'. Therese's emphasis on the visual gaze highlights that "bodies are not simply seen, they are also read, and read through categories which place them in a hierarchy of bodies" (Hughes, 1999, p. 163). Therese continues to describe/inscribe, and speak into existence, Kimberley as gorgeous, a lovely baby. This segment of Therese's storying reinforces the previous narrative and Melissa's desire to have had a day with her baby, as a baby first.

As further exploration takes place it is discovered that there is no other child identified in the world as having the same genetic makeup as Kimberley. Like Sandra in the previous story, Therese has entered a motherhood of uncertainties:

He [the professor doing work with genetics] had no news for us. None. Well lots of news but no good news. Told us there was no other child recorded anywhere in the world with Kimberley's genetic abnormality. ... So all our questions of what's going to happen? We want to talk to a family. All of that were just lost because there was nobody else (laughs). So we asked him what it meant, this ring 5, and he'd actually himself had had a lot of dealings with three ring 13 babies and Kimberley's translocation was 5-13 so there was a slight tie-up we thought, sort of. But those three ring 13 babies, the oldest had lived to be 7 months old. The youngest had died within 2 hours of birth. So major deformities, major intellectual impairment they believed, you know I mean it's very hard to judge intellectual impairment on a baby I think, but no recognition of anybody, none of that. We, we (pauses) I think we were really shocked then because Kimberley was just so alive to us, you know she smiled at you and looked at you. But he told us then that we were to take her home and enjoy her because he believed that we were very lucky to have had her this long. And she was four weeks [old].

So he really gave us no hope, which was really tough at the time, but the best thing he could have said to us. It may not be for others but we were really pleased even at the time that he'd been that honest and that harsh.

The news that there is no other child recorded as having a similar chromosomal makeup means Therese and Simon fall outside a collective experience of disability. Therese words indicate their felt isolation; *“all our questions of what’s going happen? We want to talk to a family. All of that were just lost because there was nobody else”*.

When Kimberley is 5 weeks old her paediatrician believes she has a heart murmur and Therese explains how they travelled to and from Brisbane, *“like a bloody yo-yo”* trying to determine the cause. By the time Kimberley is 10 months old the specialists in Brisbane had decided they needed to perform a catheter study to determine what was happening with her heart. This is unsuccessful and an operation is arranged for the next day. Again, they are unable to determine the cause of Kimberley’s heart condition.

Therese explains that *“it all more or less went on from there. We had more catheter theatres and they discovered then that she had multiple VSDs. ... Over a hundred holes”*. However the holes in Kimberley’s heart *“intertwine and weave”*, and Therese explains, *“they’ve had to always put patches rather than sew anything with her hole. So yeah it sort of um, it got worse from then I guess, not better”*. Therese shares one of many stories:

One particular catheter theatre she, she went up and you tend to get a bit blasé. ... You know with catheter it’s a general anaesthetic; you’re sticking something in your heart. You know that’s really a major thing. But compared to heart surgery it’s nothing and you do get blasé and we were getting blasé. Kimberley went up to catheter theatre, [the specialist] came back down, gowned, he had his mask off his face though and said, “Come with me”. She was in ICU. ... She’d gone into heart block. Her heart had stopped, the whole works. They’d had to pace her so she was actually on a pacemaker. And she was in ICU.

Knowing my child

An important aspect of Therese’s storying is in the difference between two medical spaces, two hospitals, named in this thesis as the Cameron Memorial Hospital and the Cooke Bay General Hospital. In 1992, when Kimberley is 5 years old, she went to

Cameron Memorial Hospital to have surgery for a patch on her heart. However due to difficulty coming off the ventilator after surgery Kimberley is transferred to Cooke Bay General Hospital. Therese describes her perception of the Cooke Bay General Hospital:

I guess they're [staff at Cooke Bay General Hospital] used to dealing with people in trauma situations, right? People who can't control themselves, people who are hysterical because their kid's just been in a car accident or fallen off a bike or seriously ill. They're not used to parents who live with life and death everyday.

Therese positions herself as a parent used to facing the struggle of life and death; the length of Kimberley's life is an unknown. Mothering Kimberley is transient; there is constant and ongoing knowledge that it could end at any unknown point in time. Therese constructs the spaces of the two hospitals differently. To Therese, Cameron Memorial is a hospital space where chronic heart and lung conditions are the norm, one where parents are used to the life and death struggle of their children. She does not perceive this to be the situation at the Cooke Bay General Hospital, as to her, it is more for emergency situations and acute incidences. In the discursive site of the hospital system the individual spaces are organised with/in their own structure. Therese reads these spaces as different and the impact she feels from these two hospitals is displayed in the stories she (re)tells.

The way in which Therese is positioned differently as mother by the medical staff at the two hospitals comes to the fore in her (re)tellings. She explains how she is very involved with Kimberley's care while at Cameron Memorial Hospital:

At Cameron Memorial the parents were encouraged to assist in any way you possibly can. So it was very much, "Do you want to bag?" Or "What would you like to do?" And like at one stage we had to put Kimberley back on the ventilator ... and I actually took the ventilator tube out. They just involved you. You know, it's your child and they were involving you in part of it.

The difference between the hospital spaces is in the way her parental knowledge is accepted:

The difference was the acceptance of our, (pauses) of our ability to know our child; the acceptance that we were intelligent enough to be able to understand what they were saying to us. The acceptance of the fact that we are Kimberley's parents and therefore whatever they do is actually our decision, not theirs.

Therese also addresses a political issue as she speaks of the two hospital spaces:

What's been happening politically is that the Cooke Bay General Hospital for years have been trying to get children with heart problems based [there], and Cameron Memorial hospital have been fighting to keep them there. ... The

parent's group have been fighting very hard to keep them at Cameron Memorial because you're treated totally differently. And that was so obvious, just from the times we were transferred.

It is the treatment of the parents that raises the political agenda. Parents resist the dominant discourse of individual hospital spaces and collectively strive to have their children cared for by the staff at the hospital they perceive as valuing their parental and “nurturance-based knowledge” (Landsman, 1998, p. 9). As a collective group they take up power relations with the bureaucratic systems of the hospital.

When Kimberley is transferred to the Cooke Bay General Hospital in 1992 Therese tells me that the intensivist (“*a doctor specialising in intensive care*”) from Cameron Memorial came and spoke to the doctors in ICU at the Cooke Bay General Hospital, and explained their needs: “*These parents need to know what's going on. They need to be told*”. However, this is not to be the case. Therese relates a number of incidences where she is not informed, where no explanations are given for the procedures being performed on Kimberley. As is evident in Therese’s storying professionals, positioned as expert and dominant, “can and do encourage/discourage patient’s input” (Fisher, 1991, p. 177).

Therese eventually is unable to cope with the staff at Cooke Bay General Hospital any longer, “*I'm sick of being treated like an imbecile. I do not have a brain according to them. I don't know my daughter according to them*”. Therese turns to a family friend, a medical specialist in the system at Cooke Bay, and it is after this that she feels that she is treated “*like [I'm] a human being*”. She says, “*everybody's attitude had changed it was just amazing. It was, 'Is there anything you want to know? Do you want to ask me anything?'*” It took intervention from a specialist inside the medical structure/hierarchy to make changes. Therese takes agency to locate a mechanism to resist the passivity expected of her. The unequal power structure is challenged as Therese calls on those with higher authority. Yet Therese cannot accomplish this change in the way she is positioned by the medical staff by herself, the boundaries are redefined only through the intervention of one who could be considered part of the boundary keeping.

Therese and Simon were told at this stage that there is nothing more that could be done for Kimberley, “*it was going to be a toss up between her heart or her lungs or her*

chromosomal abnormality, what was going to kill her first". ... She was on oxygen full-time. We accepted that and we thought *"yeah, ok, we just live and see what happens"*. Further medical interventions occur, yet I leave the story in this temporal frame. Kimberley's story is an ongoing one, not complete at the time of the interviews. Indeed medical stories abound in the Therese's (re)tellings and, with the constraints of the thesis, cannot be explicated.

➤ **Susan's story: *Just one of those things***

The morning I first met Susan and her 8 year old daughter Laura was overcast with intermittent light rain falling. Susan's two-storey house is located on a hill in a quiet cul-de-sac in one of the outer suburbs of Deira. I made my way up the side of the house to the entrance where Susan greeted me at the door. Once upstairs I was introduced to Laura who was lying on the floor of the lounge room propped up on a pillow watching cable television, tiny glasses on her face. The television set was situated low in a cabinet at her eye-level. Susan and I sat on the floor beside Laura while Susan attempted to find a television station Laura wanted to watch – watch Laura demonstrated through her expressive body language and waving her arms. Softball was settled on. Having satisfied Laura we commenced our interview.

Susan explains that she works within the medical profession in a paramedical capacity with limited experience in obstetrics or paediatrics, while her husband Keith is a specialist practitioner in a medical field. After completing her sporting career playing at National level, Susan decided that she was ready to have a family and fell pregnant immediately. During an ultrasound done by friends in the medical field Susan discovers she is pregnant with twins:

My friend Jane, she's found one little 'tadpole' and did the measurement and it was like 7 weeks. And then she was sort of scanning around and I was watching her face and her whole face changed and I thought, "Oh my god, what's going on here?" She said, "There's another one". I went, "Yes! That's great" (laughs). She's going, "Aren't you worried? How do you feel"? "It's great ... I'm happy to have twins but just don't find any more" (laughs).

Susan's friend expresses a concern about a twin pregnancy, to which Susan replies she is *"happy to have twins"* and displays no sense of worry or concern in her response,

“it’s great”. During this ultrasound a radiologist enters the room and after noting the twin pregnancy raises the possibility of abnormality:

He said, “Aren’t you worried?” And I said, “Why?” And he said, “Don’t you know there’s such a great increase of abnormality, abnormality with twins?” That was right in the very beginning, and I said, “No. But that’s just one of those things; a lot of times it works out well.”

Again, Susan’s response to the question about being worried about a twin pregnancy suggests she is not aware of the increased risk of abnormality with twin pregnancies. In Susan’s (re)telling, she replies in the negative when the radiologist asks her directly if she is conscious of the increased risk with a twin pregnancy.

In this part of Susan’s narrative she states her belief that the possibility of abnormality is a part of life, *“one of those things”*, while retaining a discourse of hope as she comments that a twin pregnancy can also *“work out well”*. This discourse of hope sets up a tension, for Susan suggests her pregnancy could end *“well”*, that is, both twins would be non-disabled. From the outset of her pregnancy, Susan has an opportunity to begin to (re)construct a subjectivity of motherhood which takes up the possibility of having a child named with a disability. Susan takes up a position of acceptance of potential abnormality. It is a position that permeates the rest of her narratives – not only her narrative of pregnancy, and NICU, but also the many narratives she (re)tells.

Susan continues, telling me of a good pregnancy, with normal scans until she was *“23 or 24 weeks”* pregnant. Around that time she says she started becoming uncomfortable with her size and began to experience some difficulty breathing. She says, *“my belly was huge and when it’s your first pregnancy you think, it’s because I’m having twins”*. She constructs her changing body as normal within her expectations of a twin pregnancy. Susan’s mother felt that Susan’s increase in size was outside normal expectations and as it was almost time for her next appointment with her obstetrician they rang him. An immediate ultrasound was advised.

That’s when the saga started

The following section highlights Susan’s recall of events after her visit to the obstetrician and is taken directly from the transcript of our first interview. Susan’s voice

is (re)presented here in a longer quote to preserve her storying about the events which then transpired:

It was my girlfriend who had to do it [the ultrasound]. She just started crying and she's going, "This is terrible". There was actually a twin-to-twin transfer, which is a fairly unusual thing. It's not unheard of, it's not that uncommon, but it's not really common either. It only happens in identical twins, where they share the same placenta. What happens is that for some strange reason the placenta starts shunting blood away from one of the twins, which they call the donor twin, and shunts blood towards the other twin, which is the recipient twin. And so as a consequence one stops growing basically ... and that's what the problem was ... this baby, which is Hannah, was floating around in this humongous swimming pool of fluid. ... That's why my belly was so big. Now the outcome is very poor, very poor.

I just went straight over to the obstetrician, got put into hospital straight away and was given a number of options. One of those was to euthanise Laura, to cut the cord. [The second one was] to divide the placenta, which was, um, they didn't really know how successful that would be. Or to have amnio-reduction which was the latest medical technique in this situation. Thank goodness one of the foetal medicine specialists had just come back from a conference in the States in May talking about exactly the same thing, and they'd done five at that time where they actually drain the fluid from the big baby. But you have to do it quite frequently because there's a lot [of fluid] there and it just keeps re-collecting because the donor-recipient thing doesn't change ... anyway we decided to go ahead with that.

I was in hospital then for the duration, and just kept having the second daily ultrasounds to check on the progress and once a week they were draining off like 2 or 3 litres. It was really good because Laura was actually starting to grow and both babies were coping alright, although Laura was already a bit behind the 8-ball. She was still smaller than the other one.

Susan is presented with three options, and demonstrates her knowledge of the medical discourse in which she is made subject. She appears comfortable in her knowledge and understandings of the language of medical discourse as procedures are discussed. She expresses no uncertainty as she speaks in medical jargon. She acknowledges her belief in her choice of treatment as being the correct one to have made, in her statement that the progress was good, and that the babies were “*coping alright*”. While most of the storying is from Susan’s perspective, she includes her husband in the decision-making process in this segment, when she states, “*we decided to go ahead*”. Although silenced throughout most of Susan’s storying he is present, but Susan appears to have chosen to tell her story, from her perspective.

The decision to go ahead with amnio-reduction is chosen because Susan considered it, as a procedure, to be the least invasive. Regarding the first choice offered to her of euthanasia, Susan says, *“I could never have made that decision”*. Despite knowing there was a high possibility of disability if the babies survived, Susan explains to me, *“I just wanted them to live. I didn’t ever have, and I’ve never, ever have had, a problem with looking after a disabled child.”* These statements demonstrate a continuance from her earlier comments that disability is part of life and again illustrate her acceptance of the risk of abnormality. Susan’s clear and positive statements regarding caring for a child named with a disability suggests she does not situate disability predominantly as a negative construct, as tragedy. For Susan, her babies’ survival is more important than the possibility of disability and Susan is prepared to (re)construct her subjectivity of motherhood accordingly. Like Sandra, there is a prioritising of personhood over disability in both these mothers’ stories of their children.

At 29 weeks gestation Susan’s membranes start to break down due to the ongoing amnio-reduction procedure, and she goes into *“prem”* labour. Susan describes how the babies were monitored and the emotion that she was feeling:

The next day was really scary because I had the monitors, the CTG monitors, stuck on both babies the whole time. ... And Hannah was coping. Like I knew what was going on because you can see the heart rate line. ... Laura, Laura was really struggling. ... I said to them, “Look, when do we get to the stage when this kid’s better off out than in?”

Susan’s ability to read the CTG (cardiotocograph) monitors induces a sense of fear, as she is able to clearly see how her babies are coping and is acutely aware of the difficulties Laura is experiencing in utero. Susan’s subjectivity as a paramedical professional enables her to question professional decision-making.

An emergency caesarean section is performed and Susan tells me *“there was like a 70% chance, plus, that both babies would die”*. Continuing her story Susan again shows her awareness and acceptance of the complications of her pregnancy:

I said, “I’ll have an epidural. At least I can get a chance to see them”; because I knew they were alive then. And so we did that and they took Hannah out first, the big baby. And she actually cried, which was amazing, this 990 grams little tiny thing. ... Picked her up, wrapped her all up and they brought her over to me and she goes, “Wee, wee” (laughs). “Oh she’s crying, my God”. Because she was moderately stable I got to sort of say hello to her for about 2 seconds. ... And then they took Laura out. Flat as a tack ... I didn’t get a chance. I saw this little sort of

floppy thing sailing past, 675 grams. They just used the ventilator straight away. Whisked off to the back and basically that's when the saga started.

Susan describes the “*saga*” as an ongoing one in which Laura spends the next 8 months in NICU, followed by a further 4 months in ICU:

It just goes on and on and on. Sometimes it's, you know, days and weeks apart. Sometimes it's like hours apart. I mean I've sat there and watched my kid being resuscitated on a number of occasions and you wonder whether she would come out the other side.

The decision of the parents

Susan continues her story describing a “*roller-coaster ride of sickness*” as Laura remains hospitalised in NICU and ICU. Her description of a roller coaster ride is a familiar metaphor (see McGrath, 2001) and provides a vivid image of the ups and downs, the elations and fears, of the medical spaces she and Laura inhabit. She describes in detail the hour-by-hour changes that occur and the ongoing battle to save Laura's life. However, an important part of Susan's storying of her time in NICU is linked to ‘hidden’ opinions regarding Laura's outcome.

Prior to being moved out of NICU and into ICU, Laura is provided with a handpicked nursing team for her care. Susan explains:

They actually had to put a special nursing team on with Laura because the doctors and us were aware that there were some nursing staff there that had their own ideas about what Laura's outcome should be.

Susan explains this knowledge is provided through a friend working in NICU who tells her “*there are some nurses here that all they would have to do is to just to ignore her alarm for 3 minutes and she's gone*”.

It is already obvious to Susan that Laura will “*be left impaired*”. Results of neurological testing have shown that Laura has cerebral palsy; so as Susan declares, “*there was no doubt*” of her future impairment. However, she questions the right of some of the nursing staff to make decisions regarding Laura's ultimate outcome:

[It's] not their decision to make, whether we can cope with that or not. I'd already said to them, “That's not a problem for me. I can deal with that”. I'm a fairly strong person, but I don't want someone else making that decision for me. It's going to be me [and] it's going to be Keith that will decide that. But we just

knew, both of us knew, that there were nursing staff in there would have, at the drop of a hat, made that decision for me.

As Susan has stated since she was first aware the probability of disability of her child was high, she accepted and was prepared to mother a child named with a disability:

If there was a choice between looking after a child who is disabled or getting it off my hands, there is no question about that. I rather have the child and give her the chance.

Susan points out that the nursing staff were aware of the amount of times Laura had been resuscitated and suggests perhaps they began to question; “*what are they doing this for? Wouldn't it be better off to not do this*”?

Susan's positioning of some of the nurses in NICU indicate a tension between her own wishes and her perceptions of the nurses' beliefs regarding what can be considered a 'successful' outcome; ethical, moral and value judgements are brought to the fore in Susan's storying. Susan considers Laura's life, regardless of degree of impairment, a positive outcome. Nurses' perceptions of the infant's "personhood" and ability to form "meaningful relationships" can affect their opinion of treatment options (Becker & Grunwald, 2000, p. 66). Disability as tragedy is the taken-for-granted social construct reflected perhaps in the nurses' perception of "personhood". The concept of personhood is in tension with disability particularly as it relates to intensive medical intervention of a baby named with disabilities.

Nurses have traditionally been subjugated to the higher power and authority of the doctor and nursing remains "less powerful than medicine" (Hardy, 1998, p. 69), yet as Susan emphasises, nurses have the primary responsibility for care, and are the ones constantly in NICU. Susan positions doctors and nurses in the following manner:

All [doctors] do is give you the facts and say what do you think? She's going to have this disability, and that disability and whatever, and then it's really up to us. Some of the nursing staff didn't feel that way. And they're the ones, believe me, the people who have got the most control in that unit are the nursing staff, not the doctors. The nursing staff have a humongous amount of power in those intensive care units with babies. Because they're, not only are they the primary carers of the children in intensive care as a one-on-one, they're the interface between the parents and the child. They transfer everything. You very rarely speak to the neonatal specialists. Very rarely. You may occasionally see their registrars, the trainee doctors, and they were good. They were supportive and everything. But it's the nursing staff who really have the hands on, and even in a crisis. They're there when the alarms go off.

Susan presents a different reading of power/knowledge/authority in the telling of her story. In her construction, she demonstrates that the boundaries holding medical professionals in traditional hierarchical places blur. The dominant position of doctors positioned at the top of the power structure is silenced; they pass on their knowledge and expertise for parents to make decisions. However, for Susan, those traditionally lower in the hierarchy also hold power. Nurses are now read and positioned as having their own source of power; a power that can determine Laura's outcome. Susan believes nurses' work in NICU is stressful and consequently gives *"them the feelings of having more power than they really should have"*.

The question of medical ethical decision-making is ongoing as technological and scientific advances mean more aggressive treatment is available to sustain life. Becker and Grunwald (2000) note that ethical principles in NICU "derive from a long history of scholarly effort to determine the basis of morality" (p. 59). They continue by citing Duff (1987) who terms these principles "distant ethics" and states that they "are based on religious, philosophical, scientific and legal analysis" and further, "they represent attempts to establish universal rules for moral action" (p. 59). However as Susan's story demonstrates, and Becker and Grunwald assert, ethical decision-making is "profoundly personal" (p. 59).

On numerous occasions during our first interview Susan reiterates her belief that the decision to continue fighting for a child's life, regardless of level of disability as an outcome, should be the parent's decision, *"I think that should be the decision of the parents who have the children, who do the caring, and not somebody else"*. Susan is not alone in this belief. A study was carried out by Saigal et al. (1999) where 203 doctors and nurses working in NICU, 264 teenagers and 275 parents were questioned regarding their perceptions of living in five different states of health; nearly normal to severely disabled. Results show that parents are more accepting of severely disabled states of health than are health care providers. They suggest the consistency and correlation of response between teenagers and parents supports the position that "parents are the most appropriate agents when making decisions on behalf of their infants in the neonatal intensive care unit" (p. 6). This study supports Susan's belief that the decision to intervene should be the parents', those who will be responsible for caring for the child in the future.

Susan perceives her voicing of the power of nurses to make life and death decisions to be “*controversial*” as the dominant lay beliefs are that professionals will do “*the right thing*”:

So that would be quite controversial, something like that to put that in a book and I think it would shock a few people in that field; that a parent has actually verbalised that, because most parents don't. Most parents have absolute blind faith that these people are professionals and they're going to do the right thing. Well that's not necessarily the case (pauses). They might think they're doing the right thing but it's really it's the parents' decision.

A recent study showed a discrepancy between health professionals and parental beliefs regarding ethical decisions in NICU. Parents are more likely to be in favour of intervention irrespective of gestational weight or condition (Streiner, Saigal, Burrows, Stoskopf & Rosenbaum, 2001). Susan's storying accentuates a similar tension between the ethical and moral decision-making regarding intervention for infants like Laura. Susan, like parents in the above study, favour intervention regardless of infant condition, whereas this is not necessarily the case for health professionals.

Susan speaks of the power differences between medical professionals and laypersons and believes most parents have a “*blind faith*” in the professionals within medical discourse. The binary professional/lay posits the professional as expert, particularly as the NICU is a public space, and one not familiar to the parents. Susan shares her story of one of the meetings she attended involving a number of medical professionals caring for Laura, and tells that she disagreed with many things being said:

I find it quite frightening that we sat in that meeting, and Keith and I would look at each other, “That's bullshit, that's bullshit”. What would happen to a family who didn't have the medical background that we did, or the confidence that we did in that sort of environment, which is pretty scary? What would they say? Next time she arrests, don't resuscitate her?

As Susan expresses her concern for other parents, she also highlights the bounded and discursive spaces of the medical environment. It is because she is with/in the system that she feels confident to challenge medical knowledge and professional expertise. Her multiple subjectivities provide an opportunity for agency in resisting dominant discourses.

Through the interview process Susan is able to speak into existence the hidden agenda she believes exists for infants who are long term in NICU spaces. Susan's belief is

supported by Raines (1999) who cites a study by Berseth, Kenny and Durand (1984) that “found that NICU nurses were more reluctant to resuscitate certain high-risk infancies, [and] more ready to favour passive and active euthanasia” (p. 35). Perhaps the difference between nurses’ perceptions of desired outcomes could relate to Hardy’s (1998) comments that nurses do the “emotional and subjective work of caring”, while doctors/professionals work with the “scientific and rational work of diagnosis” (p. 70). The above studies point to the difference in health professionals’ attitudes to active intervention particularly when outcomes were considered unfavourable, that is, the child would have impairments, thereby taking up the dominant discourse of disability as tragedy.

Medical spaces and the mothers’ storying

Narratives of knowledge, power, control and ethics are evidenced in the stories (re)presented as the mothers sought to make sense of past events in their present day retellings. The mothers’ narratives did not typically display a negativity to the medical care received as this care impacted positively on their child’s survival, but rather to the particular subject positionings available to them in medical discursive sites. The women’s storying highlights the “constitutive force of discourse and the means by which it inscribes the body and emotions of the constituted subject” (Davies, 1992, pp. 55-56). The stories (re)told took place with/in medical space/s and discourse; a medical discourse that Fawcett (1998) contends is a site of “privileged knowledge” (p. 270). Even though two of the women were able to call on a medical subjectivity through their professional positioning in medical discourse, they experienced the construct of privileged knowledge by medical experts in the care and medical intervention of their babies. Caring systems as constituted in medical spaces such as NICU and ICU are “constructed in a culture of knowledge, and scientific and technical interests” (Clear, 1999a, p. 2). Medical knowledge claims espoused by medical specialists and nurses can be constituted as privileged and dominant and more likely to be considered “legitimate” (Fawcett, 1998, p. 270).

The mothers' narratives spoke to the birth of their children, the subsequent medical labelling and naming of impairment/abnormality inscribed on their baby immediately, or soon after birth and of medical spaces in which they were positioned. As their babies' bodies are inscribed, the mothers bear "witness to the power which inscribed [them]" (Fox, 1993, p. 108), that is, the dominant medical and scientific discourse which enables professionals to inscribe bodies. Fawcett (1998) positions the dominance of the medical model as a "way to understand and respond to disability" (p. 270). The subsequent labelling/naming of impairment/abnormality has been highlighted along with its association with the hegemonic socio-cultural beliefs of disability as negative and tragedy. The stories demonstrate the way in which the mothers took up and/or resisted these dominant discourses, and how particular story lines became their own (Davies, 1992).

Through the narratives portrayed above, "hierarchies of power" (Becker & Grunwald, 2000, p. 62) which exist in the NICU have been pointed out, with medical specialists positioned at the top. However aspects of caring in the discourse of nursing plays a role in the possibility of disrupting the traditional concepts of power, as (re)presented in Susan's story. The NICU and ICU spaces exist within their own social structure and that "shapes the activities and decisions that occur within it" (Becker & Grunwald, 2000, p. 61). The mothers who were involved with NICU and ICU enter the discursive sites with multiple subjectivities, and become subject within the discursive spaces. They come with "varying frames of reference based on different levels of knowledge about the relevant issues, and with different amounts of experience" (Becker & Grunwald, 2000, p. 61). However, subject positions taken up in medical discourses by the women prior to entry as mother, are subject to shifts and changes.

While recipients of care (I locate mothers whose children are recipients of care in this 'category' standing in for their children) are positioned traditionally as passive receivers of medical knowledge and expertise (Hardy, 1998) this positioning does not necessarily remain constant. While three of the mothers demonstrated an initial passivity, they became active in reconstructing their subjectivity and positionings over a temporal frame. As Weedon (1997) points out:

Although the subject in poststructuralism is socially constructed in discursive practices, she none the less exists as a thinking, feeling subject and social agent,

capable of resistance and innovations produced out of the clash between contradictory subject positions and practices. She is also a subject able to reflect upon the discursive relations which constitute her and the society in which she lives, and able to choose from the options available. (p. 121)

The boundaries between professional/lay are gradually being disrupted, blurred and challenged as the “postmodern society” gives rise to the “well-informed patient” (Gray, 1999, p. 2). Ready internet access to journals such as the British Medical Journal, and other electronic sources means that parents who previously had limited or no medical knowledge can locate information pertinent to their own experiences, thereby disrupting the boundary of professionally held knowledge (Fox, 1993; Gray, 1999; Hardy, 1998). An increase in access to information “fuels the reduction of medical authority as the fountain of all official knowledge about illness” (Bury, 2001, p. 268). As suggested by Hardy (2000, p. 68) “‘reskilled’ lay people” are now able to challenge medical decision-making and knowledge.

Chapter 8

It's a whole new world to the parents too

(Sandra): mothering and public spaces

It is also necessary to explore the agency of mothers of disabled children and to examine how they may accept, reject, or reconstruct cultural representations of reproduction, medical science, and technology through their own experiences of mothering a child with disabilities. (Landsman, 1998, p. 6)

Medical spaces and the place of mother

In the previous chapter the stories of four mothers who spent time in NICU and ICU were explored. Issues of positioning, power, and knowledge were brought to the fore in this discussion delving into the way these four mothers were positioned, and what subject positions they took up/resisted in response to these new medical spaces. This chapter continues the exploration of medical discourse focussing on the collective experiences of the mothers as opposed to the solo dances, the individual stories as (re)presented in chapter 7. Voices of other mothers who were constituted in medical discourse are choreographed in/to the group dance adding further dimensions and experiences of the discursive practices in medical spaces. The chapter demonstrates the multiple spaces in which medical discourse is played out; the public spaces of hospitals and private spaces which have become medicalised. Additionally the more traditional and commonly experienced medical professional/lay binary, the interaction between doctor and patient with/in the consultative process, is examined.

The narrative is considered to be “one of the main forms through which we perceive, experience and judge our action and the course and value of our lives” (Hydén, 1997, p. 49). As evidenced in the preceding chapter mothers used the narrative to speak into existence their experiences in medical discourse. While Hydén (1997) focuses on illness narratives, there are similarities to the narratives of illness and disability as told by the mothers. Hydén suggests that chronic illness (and disability) “can be experienced as a

more or less external event that has intruded upon an ongoing life process” (p. 53). This indeed bears similarity with the narratives of mothers. Hydén continues:

Depicting illness in the form of narratives is a way of conceptualizing illness events and illness symptoms by bringing them together within a biographical context. By weaving the threads of illness events into the fabric of our personal lives, physical symptoms are transformed into aspects of our lives, and diagnoses and prognoses attain meaning within the framework of personal life. (p. 53)

Illness narratives have a number of functions: “to construct an illness experience, to reconstruct life history, to make disease and illness understandable, and to collectivise the illness experience” (Hydén, 1997, p. 64). The narratives of multiple medical spaces are part of the mothers’ narratives; they form an integral part of their life story, particularly as mother. They were usually the first story told to me highlighting the medical inscription on their lives, and that of their families, and the impact of that medical inscription on their motherhood subjectivity and positioning as ‘good mother’.

Parental stress in NICU is considered to be due to the changes occurring in the parenting role (Young Seideman et al., 1997). Mothers are unable to assume their position as parent in this medical space (McGrath, 2001). Raines (1999) coins the phrase “suspended mothering” as a construct with/in the NICU environment and perhaps comes closest to explaining the change in the way women are positioned as mother in the discursive medical site. She notes the diminished maternal responsibilities which occur in NICU. Raines suggests that for mothers, there is a “perceived lack of involvement in the care of and decision making for her infant” (p. 38). Mothering is replaced by professional caregivers; experts who now know (better) and are able to inscribe the baby with/in a medical discourse. According to Fox (1993) “professional caring is imbued by discourses on expertise” (p. 117). This medical expertise is the dominant practice in medical spaces and one outside the realm of motherhood subjectivity. Mothering/hood is in a state of suspension as becoming/being mother is subsumed by the medical care needs of her baby. The spaces of NICU and ICU play their role in structuring the discursive interactions between mother and infant, and continue the existing relations of power between professional and lay.

Lupton and Fenwick’s (2001) study of 31 mothers who had infants in NICU revealed that mothers and nurses’ discourses on what makes a ‘good mother’ in the context of NICU had some similarities. However there were also important differences. Evidence

of relations of power were noted between mothers and nurses over the handling and treatment of the babies. Women looked to construct themselves as mother in the NICU environment, whereas nurses focused more on teaching the mother about the child's medical condition and as such, became the 'expert'. In this study the mothers also became lay 'expert' over time.

The dominant discourse of motherhood where a mother is positioned as primary caregiver has been dis/placed, and being mother now takes place in a public space instead of the typical private space of home, resulting in the women taking up a position of dis/placed mother/hood/ing. NICU and ICU exist "in isolation to other family life events" (McGrath, 2001, p. 75). This medical space is often "foreign" to families and consequently "they are at the mercy of health care providers to manoeuvre this hugely technical environment" (McGrath, 2001, p. 79). Within these foreign spaces however, mothers (and at times fathers) take up particular subject positions as discursive spaces and their interactions with/in them, attain a temporal familiarity. As evidenced in the previous chapter the women are able to reconstruct themselves as localised experts of medical knowledge specifically in relation to their child, thereby positioning themselves in the medical space as experts in a particular area of knowledge. Mothers continue to take up their subjectivity as mother and position themselves as experts concerning their child (Lupton & Fenwick, 2001).

Sandra comments on the way she felt the intensive medical intervention interfered with her mothering of Melanie. Her patterns of desire (Davies, 1992) to mother was suppressed by the more powerful medical discourse which claimed authority over Sandra's subjectivity of motherhood:

You don't get a chance to love your baby and treat it like a baby because too many other horrible things are going on. And that's the most important thing. You might only have this baby for a month, why not have a lovely time with it instead of just being so stressed and (pauses) because there's something dreadfully wrong with it you're not allowed to nourish and nurture and cherish this baby.

Sandra's comments reveal the position of suspended mothering in which she is encased. Her ability to love and nurture Melanie is disrupted by the necessity of medical intervention; the spaces of mother dis/placed. In response to my question on what prevented her being allowed to cherish Melanie, Sandra replied:

All the medical intervention and the therapy and the this, and the that, and you've got to virtually, because it's new. It's a whole new world to the parents too. The mother and father are just drawn into this whirlwind of hospitals and specialists and treatments and therapists. You don't know how to deal with that. I mean it takes a lot for a woman to say, "Stop it all, I just want to take this baby home and love it to death and have a lovely time with it". Because you're told this baby needs this, this baby needs that, so that over-rides everything else.

Sandra demonstrates multiple subjectivities as she positions herself as mother, rather than nurse, in this segment. Although familiar with medical spaces, the discursive site of medical power/knowledge, Sandra positions herself, and is positioned as, mother, and as lay without power. There appears to be no choice as she says, "you've got to virtually". Sandra perceives that she is "drawn" into a medical discourse where claims to knowledge structure the "new world". The geographical spaces of medical discourse are brought to the fore in Sandra's words highlighting the public spaces in which being mother now occurs. Sandra's words display a tension, as it is medical expertise and intervention which provides Melanie with the chance of life, while at the same time denying Sandra's desire to simply "take her baby home".

She's still alive (Therese): 'coping' in NICU and ICU spaces

The current literature on the relationship between the NICU experience and parents retains an overpowering emphasis on stresses/stressors and coping (Shields-Poe & Pinelli, 1997; Young Seideman et al., 1997). Literature which has as its focus the meaning-making processes parents draw on to understand the new and usually unexpected time in NICU is scarce. Affleck and Tennen declare "the documentation of distress and disintegration during newborn intensive care and other childbearing and childrearing crisis is an all too familiar research endeavour" (1993, p. 147). A study by Younger, Kendall and Pickler (1997) examined the correlation of mastery over stress through examining the factors that could lead to ongoing stress or personal growth. They state "mastery was conceptualized as a response to difficult circumstances in which competency, control, and dominion have been gained over the experience of stress" (p. 30). It has been suggested that focusing on "the nature of the cognitive appraisal and meaning that each parent gives to the situation" (Lau & Morse, 2001, p. 44) provides a greater understanding of the way in which mothers cope with an infant in

NICU. Parents made use of a variety of coping strategies at differing stages of their experiences in NICU and ICU including emotion-focused and problem-focused, while simultaneously accessing supportive networks (Lau & Morse, 2001, p. 44).

Although I did not specifically ask mothers about coping strategies during this period of their life story, mothers (re)told stories that provided insight into how they coped with the time spent in NICU and ICU:

I think you must go into some mechanism that you, I mean when things are really bad and they're very ill, you're so worried about them, you just go from hour to hour or day to day. And then when they come good and they're ok for awhile you relax a bit and try and get back into as near normality as you can, I guess. (Sandra)

Oh, it was horrible. I don't know to this day. I think it's, there was like, "Oh my God it's happening again". It's all still like a blur. I can't remember how many times it happened. You just take the focus off yourself ... just an absolute sick feeling in the pit of your stomach, just waiting ... and both of us [husband] just kind of grabbed onto anything that was good. (Susan)

If you keep dwelling on the negativeness of it, I think you end up being negative and then you don't cope very well. When [the specialist] said ... to me, "How can you be so jovial"? I looked at him and I said, "But she's still alive". And I think that's probably one reason why we do get through it because we look for the good. Yeah OK, this kid's on death's door, but she's still alive. (Therese)

As these comments demonstrate, the experiences in NICU and ICU are not stable or static, but ever changing. Therefore coping techniques are not static, but shift according to the situation and events taking place (Lau & Morse, 2001). Both Susan and Therese speak of the need to hold on to the positives they could find in their individual situations. Sandra and Susan also comment on the embodiment of the experience in the medical environment.

Therese (re)tells a conversation between herself and her husband prior to the birth of Kimberley when we were talking about coping. In this segment she speaks to a religious discourse and shows its impact on her subjectivity as mother:

When we were driving back from visiting the doctor Simon, totally out of the blue, said to me, "How do you think we would cope if we had a disabled child"? And I said to him, "Don't be stupid, we're not going to have a disabled child". And he said, "I need to know how we'd cope if we had a disabled child". And I just kept saying to him, "Simon I don't want to discuss this because there's nothing wrong with this baby. You're just overreacting because I'm losing weight. There's nothing wrong. None of the scans have shown anything, I've had

so many of them it's not funny. There is nothing wrong with this baby". And he said, "Yeah, but what would we do"? And it went on ... it ended up that I just finally said to him, "Oh for God's sake we'll cope". You know, anything to shut him up. ... "There's no way that if we were given a disabled child we couldn't cope ... because we'd only be given a disabled child if we could cope. And if God gave us a disabled child well then I believe He gave that child to us for a reason and that reason was that He knew that we would cope. Don't talk about it anymore, that's it. Right?"

Therese tells me this conversation between Simon and herself resonated clearly in both their minds as they dealt with the news of Kimberley's chromosomal abnormality. They had already made a decision to "cope" with a child named with disabilities. As Therese explains, this decision was made "*when we were both very rational, when there was no other stress on us. ... We decided that because we said we'd cope then, that we didn't have a choice, we had to cope*". Therese's religious positioning shows through in her storying; the child would be "given" by God and that they would be chosen only if God thought they could cope.

Affleck and Tennen (1993) suggest three pathways to meaning-making in the NICU. These are discovering a purpose, interpreting benefits or gains, and making comforting comparisons. The mothers whose children were in NICU and ICU described a number of these pathways in their narrative on these particular medical spaces. Therese found a religious purpose for having been 'given' Kimberley and talked of the benefits of having Kimberley prior to her first surgery at 10 months of age, "*we decided that if she went then, well we certainly were already, we thought, better people for having her*". In their narratives, Susan and Sandra did not speak of an active search for meaning. The birth of their child named with disabilities was chance, a part of life. A search for meaning is common, but not universal and a "sizeable proportion of parents ... write it off to chance" (Affleck & Tennen, 1993, p. 138). Mothers used a variety of methods to develop meaning from their experience as they (re)constructed motherhood away from their taken-for-granted motherhood subjectivity. Therese and Melissa both provided examples of using "comforting comparisons (Affleck & Tennen, 1993, p. 137). Therese states "*this kid's on death's door, but she's still alive*" and similarly Susan says "*I've got one child that's unscathed and the other child is still alive and she's gorgeous*". Melissa comments on how John was a "*big baby*" compared to the other premature babies around him and explains that was "*comforting*" to her. The multiplicity of

responses shows that just as “there is no right or wrong way of coping, there are many responses to a situation” (Sydnor-Greenberg & Dokken, 2000, p. 186).

You don't have as much control as you think you do (Liza): a discourse of professionalism

Entry into medical spaces can engender a sense of loss of control and a sense of powerlessness as discourses of professionalism and expertise are privileged in the dominant medical space. Liza speaks of her feeling of loss of power as mother during her daughter Lily's illness and hospitalisation. At 18 months of age Lily became extremely ill over a period of 4 days, eventually being diagnosed as having “*myotonic encephalopathy*”, a rare syndrome discovered and named approximately 20 years ago. Liza explains that Lily “*went from a walking, running, competently physical child, to not even being able to support herself*”. Liza explains her loss of control as mother:

You lose control in the fact that you can't do anything ... You can't stop it. How do you stop it? How do you fix it, like you can fix a cut knee? You can put a bandaid on it. And there's no way for us to put a bandaid on it. That's pretty scary. You realise that as parents you really don't have as much control as you think you do when you're having a baby. ... The things that you expect that you would be able to do for your child you couldn't do. You're just unable to because it just didn't work. Didn't matter how much you [held] her or prayed for her or anything. It didn't change (pauses). That's pretty hard I think, and she had no say in any of that either. I mean you just didn't have any say.

In the ICU mothers are expected to surrender their child's care to the professional (Balling & McCubbin, 2001). Liza's motherhood expectation that she would be able to care for and protect her child has been taken away; her role as mother is diminished. This is evidenced in Liza's resultant sense of loss of control which can be demoralising (Affleck & Tennen, 1993). A Foucauldian analysis of power suggests “power is not merely a product of certain situations, but is ever present and operates in everyday ‘micropractices’. Accordingly, power and knowledge shift and change according to context” (Fawcett, 1998, p. 266). Motherhood knowledge and power as mother is therefore seen to be fluid, and in Liza's example has shifted dramatically in the new situation in which she finds herself positioned. She initially takes up a subject position

in medical discourse which she perceives denies her control as mother. Liza is positioned similarly to the mothers in the previous chapter when they entered the discursive spaces of NICU.

Some of the mothers commented on the difficulty of watching procedures which caused their babies/children pain. Despite the knowledge that the intervention was for the benefit of the child, the visual impact of physically inscribing the body stressed the duality and tension between the caring and nurturing of motherhood, and the medical discourse of treatment. The impact of this type of intervention has stayed with some mothers as they (re)tell the stories of painful treatments many years after the event (the years the treatment took place have been identified):

They kept testing his blood, which was a horrible thing to watch them doing, trying to find a vein and then draw out blood and want me to hold him (Melissa, 1995)

I had to learn to give injections ... and I cried for 3 months (laughs) giving her injections. We had to give up to, I guess at some stages it was about six a day.... It's just a horrible thing. I found it extremely traumatic to have to put a needle into my child. (Liza, 1986)

She used to get all those needles and I use to have to sometimes stand there and look ... [she's] only 6 months old, Valmae, it is very hard. Poor little bugger's yelling and screaming and you've got to cop it. There's no drips, no nothing in those days.... I used to cry sometimes when I used to see them giving her needles. I mean three times a day, sometimes more. (Norah, 1959)

As Liza succinctly contends, “*I think it's incredibly hard for any mother to have to do something she knows is hurting her child*”. Liza's statement draws on her perception of a collective identity of motherhood as she ‘speaks’ for “*any*” mother. She highlights a social construct, an accepted way of being and feeling as mother; part of the role of mother as protector of her child. By contrast, Sandra's storying in the previous chapter displays the way in which she took over the medical care of Melanie because she did not want anyone to hurt Melanie; her dual position as nurse and mother enabling her to resist the tensions in being caregiver and the desire not to hurt her child.

The mothers attempt to take up the subject position of ‘good mother’ even though their children are in medical spaces, and even though they have relinquished, to different extents, their position as primary caregiver. They maintain a discourse of motherhood despite not being able to take on their taken-for-granted nurturing position. They spent

time just being with their children. Being involved provides parents with “a sense of control over their situation and their child’s recovery” and because of this involvement, they “feel more like parents despite the strange environment” (Sydnor-Greenberg & Dokken, 2000, p. 189). Taking part in the child’s care allows the mother to “feel useful” and it “stimulates a *perception* of greater personal control” (Lau & Morse, 2001, p. 45, emphasis added). While the perception of control is present, it is not necessarily stable or equal and at times dependent on those holding power, the medical expert, to determine the degree of control available.

Time spent in NICU and ICU is a disruption to the temporality of typical family life and daily interactions (Affleck & Tennen, 1993). A study by Bialoskurski, Cox and Wiggins (2002) notes that mothers are altruistic and often put themselves second continuing to take up the subject position ‘good mother’ in the public space of hospital. Mothers went to extraordinary lengths to be with their children in hospital spaces, yet many still had other children at home, and other family members. The temporal reordering of their lives pivoted around the child in hospital during this period, as expressed by these mothers:

[Melanie] spent so much of her first 18 months, I really think that was the majority of time in hospital and I used to come home after the 10:00 feed at night ... and go back in about 6:00 in the morning. So I lived in at my sister-in-law’s on her lounge room floor for a few months. (Sandra)

I can tell you this from my point of view because I’ve put my life on hold to be with Laura and I was with her every day in the nursery and so I lived through every minute, every half hour, every hour of the saga. (Susan)

I would get up in the morning with Adam [son] and we would be over there [hospital] by 7:00am. We would go for lunch at 1:00 to 2:00. And then we’d go back to ICU. Mum and dad would come at 6:00 and bring tea. They’d take Adam over to the room. They’d feed him. I’d go [there] at 7:00 [pm] and walk him straight back with me and we’d sit there till 10:00 maybe 11:00, sometimes 12:00, and then go back to the room. And then we’d get up the next morning at 6:00 and we’d do it all over again. And there were times when Adam said to me, “I don’t want to be here anymore. I want to go to Auntie Anne”, and I would ring Auntie Anne and say, “Come and get him”, and she would take until he said, “I don’t want to be here, I want to be back with Mummy.” Then he would come back. But I did it every day for 5 months. (Therese)

As Sandra says simply, “I used to sit with her in the hospital month after month. I’d always wanted her close to me”. The impact of illness and time spent in medical spaces

effects what Hydén (1997) calls one of “the fundamental aspects of life”, and that is “its extension in time, its temporality” (pp. 52-53).

Fathers were not always silent in the mothers’ storyings about time spent in hospital; however most of the mothers’ narratives focused on their own perceptions, feelings, and embodiment of their storying. In the previous chapter, Sandra makes her husband visible in her story about his reading of the monitors, and in their story about Melanie not being “*conducive to life*”. Melissa and Therese also highlight aspects of their husband’s involvement in their previous storying. Therese points out that Simon has “*never, ever had any time on long service leave that wasn’t attached to a hospital*”. However, Susan speaks of her perceptions over the year she spent in NICU and ICU that it is usually the mothers who are the ones most involved in the spaces of the hospital, who “*bear the brunt*”:

What happens is you have to go your separate ways and it’s usually the mother who deals with all the crisis that are happening here [NICU]. The father goes off and earns the money and carries on his life as normal and pays all the bills. But he’s 100% protected from what’s going on in the nursery.

Susan goes on later in her storying to position her husband Keith as being “*trapped*” in his job and not being able to be at the hospital very often (he worked away). Melissa tells of the complex arrangements they made for her husband to be able to spend time at the hospital after work, as he could no longer receive leave from his employment. The parents are caught in the traditional gendering of subject positions as mother and father, with the father as breadwinner, and mother as carer. This does not negate the role or involvement the father had with/in NICU and ICU, rather it demonstrates the way gendered subject positions are taken up with/in socially constructed and dominant expectations, and how hegemonic practices sustain the power relations involved.

One of the stories (re)told by Therese represents non-hegemonic practices of typical gendering patterns, and disrupts the male/female positioning in childcare. This particular incident occurred when Kimberley first came home from hospital and had to be bottle-fed every 3 hours. Therese explains:

[It] took me an hour to express and then because Kimberley was so weak, it took her an hour to feed. So I’d express then I’d feed her, then I’d clean up and sterilise the bottles, and I’d go back to bed for forty minutes and then get up again. So Simon decided this was ludicrous (laughs), so he and I would both get up. I would express while he fed her, then we’d both go back to bed and we’d have like two

hours sleep. And then we'd get up again. So that went on for eight months, three hours, day and night (laughs). ... Later on down the track 'cause when she first got on to the breast, which she did do after eight months, she sort of looked at me as if to say "Well who the bloody hell are you? Why are you feeding me? Where's my father? (laughs)"

***It's a massive support network (Susan)/It's not a friendly place (Melissa):
differing perspectives on support***

Not only is having a baby in NICU considered a stressful event in itself (Doering, Dracup & Moser, 1999; McGrath, 2001), the spaces in which the event occurs are also considered stressful (Ward, 2001). Melissa describes the NICU as a space of noise and emotion where *"babies cried all the time and you're not allowed to pick them up and it's really, it's really sad and it's stressful"*. She further goes on to report her NICU experience as *"draining"*. Susan has difficulty speaking NICU into existence as a place, telling me it *"is hard to describe"*. It is the emotive embodiment of being in NICU that comes to the fore in her attempt to portray the medical space, *"it goes from being a really happy place to being an incredibly sad place over a short period of time"*. As she explains, *"there's some really nice outcomes and there's some really, really sad, really sad times"*.

Even though Susan is familiar with NICU through the work she did, she explains that she was placed in a wheelchair by one of her friends prior to her caesarean and taken to see the NICU. She therefore explores the space of NICU from outside her professional subjectivity:

You go in there as a mother and you look at it in a different light and you think, "Right that's where my babies are going to be and they're going to be in one of those boxes, and they're going to be very sick, and I know that. I'm going to be coming in here a lot". So it's pretty amazing.

Susan's thoughts emphasize the way in which her subjectivities are fluid and changing as she speaks of seeing a familiar site and space in *"a different light"*. Susan takes up multiple subjectivities in speaking of herself in the spaces of NICU.

Continuing to depict the spaces of the NICU Susan describes the impact on her parents, who are in their late 70s:

It was scary for them. Especially [for] my poor dad when he'd come into the unit. And he felt really scared that he was going to bump into things. ... They didn't stay in there for long periods because they just felt scared in there.

It's not a very welcoming environment because you only have eyes for the little baby, but there's another sick baby right beside it, and there's another sick baby with the alarms going off there, and another there, and their heads would be like, "Oh God, what's that? Oh what's wrong with that little one?" And it was, yeah, it is very intimidating I would think if you don't understand what's happening.

Susan also considers how the NICU space could present to parents new to NICU:

They [other parents] would feel intimidated in an environment like that. There's alarms going off, there's doctors with white coats, there's all sorts of serious things happening and it's very intimidating.

Again, Susan highlights her multiple subjectivities and positionings. NICU is a familiar space to her, yet for other parents Susan believes that the interaction within that space could be intimidating.

Susan describes NICU several times as being "*intimidating*". However hospital spaces can also be read as representing and reflecting social and cultural changes over time. The organisation of spaces within NICU "is not merely a place in which social interaction occurs, it *structures* such interaction" (Freund, 2001, p. 694). Medical discourse as socially constructed is not static; socio-cultural changes, medical and technological advances and mass communication have impacted on the way the spaces of medicine are perceived by different individuals over time and this in turn affects the power/knowledge interactions within that space.

In describing the NICU environment Melissa uses the powerful and gendered discourse of the workplace as a metaphor. She likens her daily forays into NICU to going to work, "*it becomes almost like, going there every day is like going to work almost.*" In developing this narrative Melissa enlists a hierarchical structure as metaphor where she is positioned, and positions herself, as an employee moving into a workspace, another environment. A public space in which she as mother is positioned differently to her previous motherhood experiences. The care of John is a public event (in the workplace), and out of Melissa's control (she is an employee, not the "*boss*"). Yet, despite her positioning within this metaphor Melissa also shows a temporal progression of moving from her felt sense of loss of control to resisting a passive positioning of helplessness

and lack of knowledge, as she gradually gains control of John's care in the public space of medical discourse. However, it is not only the doctors or specialists that Melissa positions as "boss". As she explains, "*it was a bit like waking up in the morning and wondering if your boss was going to be in a good mood. You'd get to the hospital; you'd wonder who was on duty (laughs)*". Melissa equates the nursing staff with her image of work and the boss, and in doing so positions them with authority over herself. The language of power is signified in the words Melissa chooses. Of interest is the image of power ascribed by Melissa to the nursing staff and this is similar to Susan's storying. However, Melissa and Susan's storying on their perceptions of a nurses' power is strikingly different to the storying of Sandra, who is a nurse. For Sandra, the positioning of herself as nurse brings to the fore the power/knowledge of the doctor/nurse binary, where the doctor holds the dominant position.

Social support is considered one of the key factors in reducing stress in NICU. Susan and Melissa differ in their perceptions of the helpfulness of other mothers in NICU. Susan felt her greatest support was from other mothers:

You get lots of support, heaps and stacks of support from the other mothers. Heaps. Like it's this massive support network.

Susan believes that it is only someone who is experiencing, or has experienced a similar event who can understand and be supportive. The following segment highlights the use of the illness narrative as a form of framing her experience as part of a collective identity:

They're [mothers] really the only people that understand what it's like. What you're actually going through. The hour-by-hour business we live, and the weird thing is it's almost compounded because when you get to know each other very well you live through the other babies crisis as well because you're all sitting together in this little sort of intensive care unit.

In particular Susan (re)tells a story where she is positioned by another (grand)mother as mother, positioning her as one who does not, indeed cannot, give up on her child. A societal surveillance is brought to bear speaking to the dominant social discourse of motherhood. Unfortunately I cannot begin to reproduce the emotive (re)telling of this particular story.

They [the mothers] were wonderful. It was amazing. I think it was the second time Laura had one of her major crisis. ... I could not physically even get myself to go in and see her. I saw her and I walked out and I was just devastated. And I don't even know who this lady was, she must have been the grandmother of another

child ... and she patted me on the head and she said, "Don't you give up on your daughter. If you give up on her she's got nothing" (pause and commences to cry.) She was right. She was right (pauses). Even after all these years it's still really hard to talk about some of the things. (Susan)

On the other hand, Melissa explains she felt NICU was a space she inhabited by herself, one in which she felt she was on her own and where she did not receive support from other mothers:

None of the mothers really talked because everybody was kind of in their own state of trauma because their child was in intensive care. Some of them were waiting on operations, some of them are finding out different things all the time. So people don't really talk. It's not a friendly place.

Sandra believes the nurses did not know how to cope with Melanie's abnormality. "*The [nursing] staff just couldn't, didn't know how to cope with the situation, so they wouldn't come into the room*". Sandra is isolated through Melanie's abnormality by the medical staff. Susan's perception of most of the nurses differs to Sandra's story and perhaps in that difference is the dualism of illness versus abnormality. Susan explains:

The nurses do really cute things, like when you come in the morning they'd have her lying on her tummy with her head turned to the side and her legs sort of bent up ... and there's this tiny little bum ... and written across it in biro was, 'Hi mum have a happy day', right across her bum. And they'd write letters from the kids too, and I've kept nearly all of them.

There appears to be a difference in the way illness and disability are perceived from the stories of Sandra and Susan. Referring to the illness/disability binary Hardy (1998, p. 42) puts forward the suggestion that "'health' can take on a moral element which makes it difficult for those with disabilities to present in a positive light". In Susan's story, the longer Laura was in NICU and ICU, and the more obvious it became that she would have severe disabilities, she believes that the perceptions of some nurses changed. Sandra perceives the nurses were unable to cope with abnormality. The negative social construct of disability is present in their storying; an ill child can be treated, cured, whereas disability presents as a threat to the medical discourse of cure. The medical model as employed by professionals, can be constructed as a deficit model; a model "that focuses on correcting weaknesses (illness)" (Clear, 1999a, p. 6) and impairment/abnormality cannot be cured threatening the very construct of the medical model.

Blurring the boundaries – home care

Home is about privacy, security and identity. It embodies the self, both in the sense that it is the concrete extension of the self and in that it contains and shelters the self in its ultimate form of the body. (Twigg, 1999, pp. 397-398)

For many of the mothers whose children were medically inscribed through NICU and ICU, the inscription continued once the mothers left the public hospital space and re/turned to the private spaces of their home. As some of the children continued to need ongoing medical and technical care, the home became medicalised, technicalised. A disruption of boundaries occurs as the public discursive site of hospital moves to the private spaces of home. In contemporary Western society there is a divide between public and private spaces (Freund, 2001; Twigg, 1999). However there is fluidity in boundaries when the private and intimate space of home also becomes a medical space and spatial reordering occurs within the home (Twigg, 1999). The medical or clinical gaze is considered a variant of Foucault's gaze which is "conceptualised as an act of 'discipline' or power, a way of defining and regulating subjects" and refers to the "ways in which the objects of medical knowledge and practices have been viewed and understood" (Heaton, 1999, p. 769). As the boundaries between public/private medical spaces shift and merge the medical gaze extends into the private sphere of the home. Heaton (1999) refers to this as the "vicarious authority of the medical gaze" (p. 771). While the mothers' care of their infant remains under the medical gaze, they continue to be made subject within a medical discourse. At the same time, they appropriate the medical expertise offered by medical discourse to ensure the well-being of their child bringing into tension the binary public/private. The subject positions the mothers desire to take up as part of their motherhood subjectivity intersect with a surveillance gaze adding a further tension in professional/lay knowledge. While desiring to mother her child, the woman is subject to professional surveillance which in/forms her mothering experience.

Susan finally brought Laura home after almost 12 months in NICU and ICU. They were required to do a course in paediatric resuscitation before going home and the hospital supplied the necessary equipment for Laura to remain monitored at home at no cost to the parents. Susan portrays the blurred boundaries between public/private:

We took her home to a house that was set up like a casualty ward. She was fully monitored on a heart monitor and that, the information from that monitor was downloaded via modem to the Children's Hospital and they checked it out.

Susan had her sister living with them by this time and between them they were able to monitor and care for Laura, as well as continue the caring for Hannah. Susan's husband worked long hours and part of his job involved commuting:

My sister was with me the whole time and we did 24-hour shifts. Jenny was a night owl so she stayed with her through most of the night. I was with her during the day. And we were just so tuned to the sound of the monitor. And most times when it went off it was nothing. But you couldn't not go and check. So, yeah, we survived through that.

[Laura] would have been on the chirometrics monitor, which is the more high powered one that actually had sort of ECG leads, she would have been on that, I'd say about 3 months ... till they were confident to put her on the little Grasby monitor and she would have been on that for at least another 3 to 4 months. And then it really comes down to the parents having the confidence I think to take them off that. 'Cause that's pretty scary and I'm sure other parents that have had children that are monitored would feel the same way.

Diane experiences a similar disruption of the public/private binary in medical care. Her son Peter is born 13 weeks premature and spends 3 months in NICU. What was once the responsibility of the discursive site of NICU, that is, the intensive care of Peter, moves to the private space of her home. Diane and her husband were required to do a resuscitation course before taking Peter home. As well, they had to learn to give Peter, Neulin (a heart stimulant). Diane explains "we used to put that in by a syringe into the side of the mouth so he could sort of suck on it a little bit and take it down". However, Diane tells me that things did not go smoothly the first night:

Now the night we got home – it was such a glorious event – I was giving Peter his Neulin, he sucked as I was putting it in. He choked, he couldn't breathe; I had to resuscitate him. Brian just panicked because, as I said, he hadn't been there [NICU] a lot of times. When I went through resuscitating him, it was like I was witnessing myself doing it because it was just an automatic reaction.

In her storying Diane explains that she took an apnoea mattress home to monitor Peter's breathing, as he would occasionally stop breathing. Diane explains:

We opted to take an apnoea mattress home with us. Now the apnoea mattress was, there was a little monitor attached to Peter for his breathing, to monitor his breathing. It was like a li-low bed, it was just a blow up bed that he laid on. And if he stopped breathing the alarm was supposed to go off. ... For the next few weeks we lived on nerve's edge because the alarm kept going off because the damn

mattress kept going down. We would think that we had to resuscitate our child all the time. It was just horrific. In the end we had to make the decision to get rid of it and just deal with the situation.

Oftentimes control is thought to be regained once the child comes home from hospital (Affleck & Tennen, 1993). A study conducted by Abendroth, Moser, Dracup and Doering (1999) found that using an apnoea mattress initially increased emotional distress which resolved itself over time. Diane and Brian however did not find this emotional resolution due to problems they encountered with the mattress and made a decision not to continue using the mattress.

What does that really mean? (Melissa): The need for information

The women whose stories concerned medical spaces often indicated their need and desire for information particularly in NICU and ICU settings where they perceived a loss of control and power. Indeed studies have suggested that the need for accurate information and communication with the medical professionals is an essential part of maternal well-being (Balling & McCubbin, 2001; Bialoskurski et al., 2002). The mothers expressed various perspectives on asking for and receiving information, oftentimes dependent on how they were positioned, or positioned themselves within the medical environment. It has been suggested that “the uncertainty of lay knowledge compared to the coherence of medical expertise compounds the inequalities of power between them” (Hardy, 1998, p. 70).

Diane emphasises the difficulty in her lack of knowledge – “*we were very naïve at that stage too and we didn’t ... know what to ask. I didn’t know what to expect, I didn’t know what I should ask*”. Melissa talks of “*throwaway remarks*” made by medical professionals and expresses the difficulty for her, in not knowing how the numerous pieces of information affected John:

Everything they tell you, you think: “Ok what does that really mean? What does it mean to [John]?. ... You’re really trying to get a hold on what (pauses) it will do to John.

Norah, whose daughter Cheryl developed meningitis at 6 months of age in 1959, highlights the different expectations of her era and the clear duality of professional/lay knowledge:

All I know is it's [meningitis] like a brain disease or something that affects the brain, but no, they didn't tell me anything. Not in those days they didn't, probably now.

Norah's words demonstrate the subject position she has taken up in the professional/lay binary discursively constituted in medical discourse. She appears to be a passive receiver of expert knowledge, however acknowledges that with shifts in medical discourse over time the way recipients of care (or their parents) are positioned are changed:

It's different now. They'll [doctors] sit down or they'll tell you everything about it. But as I said in those days, no. Well, I don't know whether they knew a hell of a lot about meningitis in those days.

Norah positions the professional as the one with power, knowledge and authority yet suggests the fluidity in the subject positions available as discourses shift.

Spaces which are controlled by medical professionals provoke feelings of powerlessness (Case, 2000) and are evidenced in the mothers' remembering. Melissa and Diane both perceive a connection between knowledge, information and power. Diane says "*maybe I felt I could control it in some way if I knew. I don't know*". Melissa is very clear in linking professional knowledge to power and control:

A lot of the time when you do have consultation time with them you haven't got all these questions to hand. But that, that's what's scary and in a lot of ways you immediately think, "Oh right I need to go and be a nurse or a doctor so I'm never in this position again". You think, "I don't want to be this powerless again".

Susan, Sandra and Liza have medical backgrounds when they enter the medical discourse. Susan explains she found this medical knowledge useful, but also "*scarier*" and compares her and her husband's knowledge to her perception of a lay person's knowledge:

I think there's a lot of things you can be blissfully ignorant about and they can just sort of go over the top of your head ... Whereas Keith and I could look at Laura's charts. We could listen to what they were saying on ward rounds and knew exactly what they were talking about. ... Most people listening to medical jargon wouldn't have understood what they were talking about.

Liza also considers her medical knowledge in her positioning as mother, noting the stress which impacts on gaining information. Like Melissa, she finds it difficult to have all her questions on hand in the time frame allocated by medical specialists:

[The specialist] would speak to us and then we'd go away. And then I'd have another question for him. I couldn't think of everything at the time. Or I'd forget something that he told me. And I think that's just the stress that you're under.

However, Liza also examines the provision of information in the subjective self as professional when she considers the way the specialist would go “over the same ground several times”:

It's probably something as professionals we need to think about. Often you think, "I've already said that, why don't they remember?" ... But yeah, when you've got that kind of stress that you're living with and the shock of it, you don't remember.

Liza continues to move between subjectivities as she narrates her memories of her time in hospital moving between her positioning as professional with medical knowledge and the emotive embodiment and positioning as mother of a sick child. In Liza's storying, information is not always readily provided by all professionals:

I found that it was part of the devastation of the experience of having a child acutely sick and go into hospital is that (pauses) the not knowing meant that you were making uninformed decisions. Like [the specialist] was very good, but still when you went to have your ultrasounds and things like that, people would just take the child and do it and get information and you wouldn't know what was going on.

Sandra explores the movement between her multiple positionings when she speaks of the early months in NICU. She speaks of the rounds done by the doctors and speaks into existence her positioning as passive subject, as mother and as nurse and her positioning as subordinate to the doctors: “I would sit and wait my time and try not to ask any stupid questions”, and further she would “just do what I was told”. She explains:

I think there are attitudes amongst, naturally amongst people where they'd expect you to be professional about things, or ask pertinent questions. So then I didn't want to sound stupid so I wouldn't ask the most basic questions.

Sandra's storying portrays the power/knowledge of medical discourse and the conflict between her need for information and the tension between her multiple subjectivities and positioning as subordinate. In the following segment Sandra displays the tension between mother and nurse:

I remember in particular when Melanie was a tiny baby, and we were in the children's ward and there were a couple of mums there who had children and they didn't understand about their medical condition. ... They would ask, over and over again. They would ask the same questions and I always felt like they were tying up the doctor's time, even though that's what they [the doctors] were there for and that's what they should have been doing. ... I always felt like their time was precious, the doctor's time was precious. ... 'cause I'd been on rounds for years, you know we're always tied to time and it was very busy and so much to do, that unless I had anything really important to say I wouldn't say anything ... In hindsight I should have just been as demanding as everybody else, but that's not in my nature.

Melissa also comments on making demands on the professionals' time – “*the people who do know haven't got the time for you to be running up to them all the time asking*”. She positions her desire for information as less important in the NICU space than that of the time available from the professionals, according them a higher status and reinforcing the hierarchical positioning in the medical site. Sandra observes that the interview and subsequent transcript provide her with a mechanism to reflexively think on her time in NICU. She comments on the importance of her personality in taking up multiple positionings:

Reading through that transcript so much of it comes from the nature of the person too. I mean you can be an assertive, aggressive sort of person, and you would always probably come across in any situation like that. Whereas I'm quite passive and I'm a pacifist and I like to keep the peace and I think that's how I handled every situation. Trying not to ruffle feathers, step on feet, overstate my mark. Finding that niche where I was both the mother and the professional.

I don't think people thought you had any knowledge (Kathy): professional/lay knowledge

Despite research advocating the participation of mothers in the caregiving process in the discursive site of medicine and the building of professional/parent relationships (Bialoskurski et al., 2002; McGrath, 2001; Sweeney, 1997), mothers often spoke of the difficulties they faced with issues surrounding the professional medical relationship. Clear (1999a) states “our formal caring systems, private and public, our professional activity in human service generally is constructed in a culture of knowledge, and scientific and technical interests” (p. 2). This discourse of medical culture sets up a binary of professional/parent, where the professional is accorded dominant status. For

example: Therese comments on the way she was positioned differently in professional relations in two hospital spaces, yet these hospitals exist within a similar medical discourse and hierarchical structure. Susan speaks of the power of nurses particularly in relation to decision-making regarding the continued care of her baby. Sandra initially takes up subjectivity as nurse and does not question the medical decisions made on behalf of Melanie. The professionals held the formal expertise and knowledge in the medical discourse.

At least eight mothers spoke of their interrelationships with doctors (GPs) and/or other medical specialists as being fraught with difficulty. Power relations and subject positions available within discourses affected how mothers perceived the medical professional/lay interaction. After deinstitutionalisation doctors “who had little experience or training in the special needs of patients with developmental disabilities were thrust into the role of providing care” (Doostan & Wilkes, 1999, p. 93). Further, Doostan and Wilkes (1999) propose that parents and caregivers perceive doctors to be insensitive to people with disabilities, and unwilling to care for them. Some of the women spoke of the difficulties they experienced with some doctors and/or medical specialists:

Some people [specialists] haven't even got the time. I met a few that said, "I don't know why you're even bothering worrying about it ... because he's got so many other disabilities, why are you worrying about it. It's a waste of time". (Michelle)

I hate going to doctors. ... To get a doctor who really, who you felt was interested in you and Belinda, interested in Belinda, cause I think a lot of them just palmed her off. "Oh, there's not much we can do about this kid, why bother"? ... A lot of them are not really bothered with people with problems. (Patti)

People named with disabilities, and their caregivers, constitute a group who are unaccustomed to satisfactory care and treatment (Doostan & Wilkes, 1999). Further, Doostan and Wilkes (1999) contend that the difficulties the recipients of care present in terms of communication, cognition, additional resources and time, among others, place them as a “frustrating” group for physicians.

Other mothers told of the struggles they had to have their nurturing and lay knowledge accepted while they were in spaces regulated through medical discourse. Mothers “occupy a lower status than professionals, and have minimum practical recognition of the validity and usefulness of their expertise and experience” (Case, 2000, p. 275). As

Kathy so clearly states “not being of a medical background and whatever, again I don’t think people thought you had any knowledge”. The women’s stories resonate with the professional denial of their knowledge of their child, and tell of feeling powerless in the professional/lay binary:

We went to Brisbane again when [Belinda] was 4 and they did more tests on her ... She had one test and they’d given her a dose of something and she’d go straight to sleep and they did the test and the next day they were going to do the scan. I said, “What are you going to do”? And they said, “Oh we’re going to inject her with Valium”. I said, “Valium doesn’t agree with her”. “Oh this will be alright”. There were about 6 people holding this little 4 year old down, to hold her still to get the injection into her arm. And it just had the reverse effect on her. She just went berserk. (Patti)

We fought with the doctors because I had said to them, “You are not going to be able to get Alex to eat. I know that for a fact. When he’s in hospital he won’t eat for anyone else”. And the doctor said to me, “He’s alright, our nurses know what they’re doing. They’ll be able to feed him”. I just let it go. He thought he knew everything. So then when we get to hospital ... the nurses can’t feed him. They tried to put a tube down his nose, he fights them; they knock him out, put a tube down his nose and he pulls it out. And so I wasn’t as dumb as the doctor thought I was. (Kathy)

I said, “What are you doing”? And he said, “Oh we need to anaesthetise her to keep her still”. I said, “No you can give her an injection”, and he thought that would upset her. I said, “She has 5 injections a day. She’s ready for the injection, she understands that she’s going to have it”. He went, “Oh ok”. And then he walked out. Then the consultant anaesthetist comes through and they literally took her out of my arms and they held her down. She was a screaming mess by this time I might add, this 2 year old child, held her down and put this mask on her head and she eventually sedated. But I was like, I was in the room and I couldn’t do anything and it pulls at me to this day. (Liza)

Liza expresses to me that she did not have “the strength” to be able to act on her knowledge of her child, that is, Lily was ready to receive an injection. During the interview Liza quietly expresses how the memory has lingered and continues to “pull” at her and suggests what she should have done: “I didn’t have the strength to say stop it. I should have held her and just said, “No piss off”. But I didn’t”. Hardy (1999) notes that professionals “patrol the boundaries of their work” (p. 69) with the mothers oftentimes silenced or ignored to preserve the professional/lay boundaries. Additionally “the uncertainty of lay knowledge compared to the coherence of medical expertise compounds the inequalities of power between them” (Hardy, 1999, p. 70). It is to these inequalities that mothers speak.

Therese and Michelle highlight in their storying their perceptions of a dominant discourse of doctoring. They establish a power structure displaying a viewpoint where doctors are positioned and valued highly by society. Traditionally, medical knowledge was based on years of training and remained in the hands of the doctor while the public was excluded from this knowledge (Gray, 1999). Yet, both Therese and Michelle argue against this standpoint:

I think some people look at doctors and think they're Gods. I look at them and think they're a person doing their job ... they're a human being first and they don't know everything. And they know they don't know everything. And if they're willing to let me know that they don't know everything, well then that to me is a sign of a bloody good doctor. (Therese)

I used to put doctors up on pedestals but now they're just human and I really appreciate when a doctor tells me that he doesn't now, or he's unsure, rather than give me all this blab that I know is just a load of rot. (Michelle)

Sandra and Michelle speak to a fluidity in the boundary between medical/lay knowledge and expertise as they resist the passive position they originally were subjected to and take an active role in the care of their children:

I'd only go to GPs if I needed an antibiotic ... for a chest infection. Because with Craig and all his different things and that, I felt more comfortable going to [the paediatrician] who had his background and knew him quite well. (Michelle)

It got to the point where you went to doctors only if you absolutely needed some antibiotics. I'd go to family GPs that asked me what I thought she needed and they were fine, 'cause I knew what worked and what didn't. But it's a strange situation. ... We'd arrive and they say, "Ok, what's the problem"? And she'd be in a wheelchair and obviously couldn't speak and they'd sort of look at me. (Sandra)

Sandra and Michelle demonstrate their shifting positionings in the doctor/lay binary. They have become knowledgeable about their own children and take on decision-making. For children with rare chromosomal abnormalities, such as Melanie or Kimberley, or with rare disorders such as Lily, mothers become highly knowledgeable and disrupt the traditional medical boundaries. Landsman (1998) found in her study of non-disabled mothers whose children are named with a disability that “the countering of expert knowledge with nurturance-based knowledge and action reasserts the status of real motherhood” (p. 9).

The clinical gaze (Fox, 1993; Foucault, 1973) gives rise to the objectification of the body as it is inscribed into parts. The medical/clinical gaze divides and inscribes the body into segments belonging in different spaces. Professionals are responsible for their part of the body. The body is no longer a whole entity, it has become decontextualised and medicalised. Susan explains the way in which Laura's body was inscribed, segmented and fragmented into pieces:

She had a paediatrician who was overseeing her and she was monitored. ... He arranged for consults with neurologists, chest physicians, the gastro people regards feeding, orthopaedic people. You name it, everybody, eye specialists. So here was the paediatrician and branched off were all these super specialists that only looked after one bit. And they were pre-occupied with their bit. And so really when it comes down to a child with multiple disabilities they get divided up into their parts and they stop being a whole person. And that's what Laura was like.

Sandra also reflects on the early years when she perceives Melanie was not considered a whole person, rather she was seen as a "medical problem" whose body was inscribed and fragmented:

There was nobody up here [Deira] that was really interested in her as a whole ... she had kidney problems, lung problems, heart problems – she had holes in her heart and valve, a leaking valve ... brain problems, and they thought she was blind for about 6 months ... We didn't know how much she was hearing.

Both Susan and Sandra see their child as a person primarily, like their other children, and desire the medical gaze to see and care for them as such:

We found over the years that you go to all different sorts of specialists and they're so intent on their own area, but we see the child as a whole, like your other children, with needs and wants and things. (Sandra)

We want someone who's going to be holistic. Just, yeah, treat her like you'd treat Hannah. You don't divide her up into bits. Why do we divide Laura up into bits? (Susan)

Medical discourse is divided into areas of expertise, each designed to treat and 'cure' or rehabilitate a particular part of the body. Tensions exist in the different subject positions taken up by doctor and mother, each seemingly in tension with the other.

Positioning within medical spaces

Constructs of power can be seen with/in the medical spaces that mothers inhabited, either during time spent in NICU and ICU, at home, or in their interactions in medical spaces such as doctor's offices. As pointed out by Case (2000), "parents frequently experience powerlessness in professionally-controlled settings" (p. 274). These medical spaces have their own hierarchy and way of being within those spaces based on the institutionalised knowledge of medical discourse. Space has power, "for it emphasizes that people and objects interact in space and there could be laws of behaviour which govern these interactions" (Sack, 1993). Traditionally doctors and specialists have the knowledge and expertise based on years of training, and parents are positioned as lay, and unknowing.

In a poststructural reading, "power is never absolutely held – it is constantly the object of resistance" (Fox, 1993, p. 20). Some mothers take up claims of authority and authenticity (Fox, 1993) as they became knowledgeable over time about their own child. Fox states that the "postmodern position on health asks some questions which focus upon the creation of knowledgeability about illness and health" (p. 20). For the women in this research their claim to knowledge and authority is based in part on their motherhood subjectivity and how they position themselves within medical discourse, as well as experience gained over time. The women's stories as a collective experience show how illness and disability "is removed from the private sphere and becomes a part of an all-encompassing political and social narrative and context. Through the narrative the illness experience becomes a collective experience" (Hydén, 1997, p. 59). As the women's knowledge increased they took up multiple responses as they resisted, worked within or rejected the hegemonic belief structure of the professional as all knowing.

Chapter 9

Put into a category (Sandra): adding a therapy discourse

I do remember [Melanie] ... being assessed by a therapist one day and she told me all things that Melanie couldn't do. I remember turning to her and saying, "Can't you give me a list of all the things she can do?" (Sandra)

Slotted in there (Sandra): finding the label to inscribe the body

In chapters 7 and 8, I examined the discursive spaces of NICU and ICU, as well as the medicalisation of the private spaces of the home. The women whose stories in/formed those chapters were intimately involved with/in a professional discourse of expertise as their children required intensive medical intervention. Stories of interactions with/in the professional/lay binary were also noted, particularly in the discursive site of the medical consultation. However, in their narratives mothers also spoke of another aspect of the medicalisation of their children, that is, the discourse of therapy. With the exception of Norah and Patti, all the other mothers in the study spoke of involvement with formal therapy services in some capacity; physiotherapy, occupational therapy, and to a lesser degree speech and language therapy. This chapter continues the discussion of the 'medical' gaze, but from the viewpoint of a therapy discourse.

A qualitative study was conducted by Stainton and Besser (1998) to determine the positive impacts on families who had children with intellectual impairments. Although the study was aimed at locating the positives in families' lives "negative interaction with professionals was raised by every family unit" (p. 66). Stainton and Besser's study found physicians were the most commonly mentioned professionals with whom negative interactions occurred. However, the women in my study not only nominated specialist doctors and general practitioners as those with whom they had experienced negative interactions, but also therapists and teachers (including principals). Stainton and Besser suggest that the responses from their study lent "support for the social

constructionist theories of disability and the ‘disabling’ effects of professional responses” (p. 67). The responses from professionals arise from the medical model of disability as deficit and provide the basis for knowledge and expertise which in/forms their practice/s. As maintained by G. Williams (1996) “the medical model that informs traditional approaches to disability takes the biological reality of impairment as its fundamental starting point” (p. 196). Disability is located in the individual, inscribed on the body by experts, and the social is silenced.

Like medical practitioners, therapists form a group of professionals imbued with specific training, credentialing and organisational structures. Within therapy discourse, professional expertise has held sway, and utilising poststructuralist theorising(s) offers a way of “dismantling conceptions of the natural and ‘correct’ hegemony of the particular group that has traditionally held unquestioned power” (Davies, 1996, p. 17). Parton (1994) draws on Foucault’s work on Governmentality by stating that it “draws attention to the range of mechanisms whereby different groups and forms of knowledge regulate, and thereby construct and constitute, the lives of individuals, families and the community” (p. 12). Further, according to Parson (1994), Foucault proposes that when medicine became a new discipline it “instituted a regime of power exercised through disciplinary mechanisms and the stipulation of norms for human behaviour” (p. 14). Established ‘norms’ of human behaviour thus become the measure by which children named with disabilities are made subject to the disciplinary gaze (Mitchell, 1996). In the mothers’ storying which follows, aspects of the disciplinary gaze are brought into play as they explore their positioning with/in a therapy discourse.

Many mothers spoke of the categorisation of their children that took place in the discursive realm of therapy through the processes of examination and placement into milestones of ‘normal’ development. Sandra talks of the therapist’s need to categorise Melanie in/to a space, a place where Melanie ‘fits’ within/against the norms of typical childhood development. Sandra uses the metaphor of a “*pigeonhole*” in which to place Melanie:

The whole focus was on her inabilities. They [therapists] had to categorise them and I remember thinking after 6 or 8 months how happy I was because finally she had been put into a pigeonhole of having low tone. So there were three groups; either low tone, normal tone or high tone. Melanie had been classified as low tone. Oh beauty. She’s finally got a pigeonhole.

The notion of a “*pigeonhole*” speaks not only to a need to categorise; it also speaks to bounded spaces. One definition of a pigeonhole is “to give a definite place to in some orderly system” (The Pocket Macquarie Dictionary, 1997, p. 785). The “*pigeonhole*” into which Melanie is placed represents a space in an ordered system – that of ‘tone’ based on placement which intersects with the ‘norm’ of childhood development. Bound up in Sandra’s speech is an example of discreet categories which are constituted through a disciplinary gaze. Disorderly bodies are placed into an “orderly system”. The notion of pigeonholing is also used by Christensen, (1992) when she suggests, “a process of ‘pigeonholing’ is used to match clients with the appropriate standard programs” (p. 10). Melanie’s categorisation enables her to be positioned within a particular and “appropriate” therapy program.

Sandra comments on the therapists’ need to ascertain what levels Melanie is achieving, in order to slot her into the timeline of typical childhood development:

From my experience they [therapists] have to slot the child into a timeline. They’re at this stage in their development of their gross motor and this stage of their development of their fine motor. ... They’re put into a category and slotted in there and that’s where they’re at and it’s always outlined in their inabilities. What they can’t do, because all their milestones are taken on what they are achieving. And in Melanie’s case she wasn’t achieving very much.

According to Sandra she perceives an emphasis on inability which is woven into a discourse of negativity; what Melanie could not do, could not achieve, of the places Melanie had not yet reached. Melanie is framed and inscribed by and through her inabilities, and these inabilities are socially constructed within medical and societal constructs of what constitutes ‘normal’. The Foucauldian concept of governmentality “highlights the centrality of ‘the body’ and how it is disciplined, inscribed and subjected to the power/knowledge of ‘experts’ within the realms of governance” (Mitchell, 1996, p. 202). Professionals come to the field with the dominant social construct of disability which is embodied in the medical model of disability and deficit (Murray, 2000).

While Sandra is aware of the therapists’ need to determine Melanie’s inabilities, “*because they’re trying to direct the children in the right way to achieve their milestones*”, she also perceives herself as being realistic in her own assessment of Melanie’s abilities when she states; “*I think I knew all along she had grave limitations*”. In her narrative Sandra locates herself with/in a collectivity of mothers

whose children are positioned and categorised at similar levels to Melanie and declares: “*some kids are never going to achieve them [milestones]*”. Mothers continue to be made “acutely aware of the standard developmental milestones for ‘normal’ children. Their children are measured by their delays and deficiencies” (Landsman, 1999, p. 12). Barnes, Mercer and Shakespeare (1999) assert that “interpretations of ‘able-bodied’ normality in terms of body shape and capacities become intertwined with moral and social values” (p. 64). They continue by stating, “‘able-bodied’ and healthy ‘normality’ is equated with virtuousness” (p. 64). A tension is set up between inability, impairment and ‘normality’.

There appears to be a disjunction/tension with how the mothers view their children and how the children are positioned through the extended medical/clinical gaze of therapy. Additionally, children’s needs as determined by professionals “can also be regarded as a statement of fact, rather than as an interpretation which privileges a particular knowledge framework” (Fawcett, 1998, p. 270); a framework based in medical discourse. With/in a therapy discourse there is a taken-for-granted and standardised set of milestones to achieve, and professionals work towards achieving as close to the ‘norm’ as possible, working to maximise the child’s potential. While the mothers take on the work of therapy, their belief is that the child is their child first and foremost, and each achievement their child makes is one to be celebrated. While working within the therapy discourse, they do not position their child in milestones; rather they focus on the individual and personal achievements of their child. In their (re)tellings many of the mothers in this study appear to accept their child’s (in)abilities, their child’s space and place outside the category ‘normal’, and whilst continuing therapy also accept where their child is positioned in terms of ‘the norm’. The tensions the mothers experience between the push for therapy interventions and their own celebration and acceptance of ability, “leads to professional interventions contributing to, rather than alleviating, the stress and difficulties faced by families” (Stainton & Besser, 1998, p. 68). A tension between their positioning as mother and the subject position as para-professional is brought to the fore as they take on the therapy programs devised by the professionals.

You've been knocked off your block (Julia): attempting to celebrate the positives

Both Therese and Sandra highlight a discourse of negativity that permeates their experiences with individual therapists. Their storying of this negative discourse referred in particular, but not exclusively, to their experiences with therapists from Children's Health:

It was always so depressing going to ... the occupational therapist, the speech therapist, and the physio, because they would outline how badly Melanie was situated and almost give you no hope. It was all very negative, nothing very positive. (Sandra)

I'd go in, I'd be really excited you know, "Kimberley held this in her hand today, isn't that wonderful"? "Oh yes, but she should have been doing that by the time she was 2 weeks old". ... Every time I wanted to celebrate something there was that negativeness coming in about the fact that yes, but she wasn't up to a normal child. Well I didn't care. I was just glad she was doing what she was doing. (Therese)

Despite the temporal context of Sandra and Therese's storying taking place 10 years ago, it seems the stories have not changed significantly over time. Robyn, whose daughter Natasha is 4 years old, and attending Children's Health says:

I was telling this [therapist] what Natasha was doing at home, what she was able to do. And this woman had just turned around to me, "No Natasha couldn't do anything like that". Basically made me out to be a liar. That I didn't know anything my child was doing.

As acknowledged by Tomlinson (1993) professionals "claim expert knowledge and profess to know better than others what is wrong with their clients" (p. 79). Robyn's lay knowledge is silenced in the power/knowledge of the expert's disciplinary gaze. Decisions which are made by the therapists are based on their expert knowledge and involve "value-judgments and power-relations" (Barton & Oliver, 1992, p. 74); judgements that place expert knowledge over lay knowledge, where mothers are not considered expert (Clear, 1999a).

Julia speaks of the discourse of negativity she is currently experiencing at Children's Health. Her son Andrew is 3 years old, and she notes, *it's just like real negative. You go in there singing their praises; you come back feeling like you've been knocked off your block*". At another point in the interview Julia states:

Everybody always wants to pick up on the bad stuff ... they send [mother's] home with all this bad stuff and telling them they've got to try harder, they've got to keep doing this, they've got to keep doing that. But making them feel really negative by the time they've left. Making them feel, oh well, what's the point, kind of thing?

This segment of Julia's storying shows how she believes herself positioned in a therapy discourse in the request/demand to "try harder". Sandra also speaks of her perception that she is positioned by professionals into a situation where she has no choice but to engage in therapy programs; "they're working on emotionally blackmailing you really, because they give you the programs and tell you that you have to do them so many times a day or a week or whatever". Therese speaks of a discourse of guilt when she says:

The therapists put such a guilt trip on you that it was (pauses) they made you feel that if you didn't exercise Kimberley to do these 8 sessions every day that it was your fault that she wouldn't walk.

For Therese, the guilt is placed on her. She feels positioned by the therapists as the one who is to blame for not carrying out therapy programs. Therese, as mother, is at "fault". Diane describes the program she was requested to do with her son as "extremely overwhelming to begin with", and she asks, "how the hell were we going to fit all this in? I had to spend my whole day doing therapy". Sandra portrays herself as "being absolutely consumed by it". There appears to be a continuation of the surveillance gaze as the medical discourse, through therapy practices, enters the private spaces of the home. Taking up the subject position the mothers perceive available within the therapy discourse – they are expected to perform the therapy to achieve the best for their child – intersects with the taking up of the position of 'good mother' as one who does all they can for their child. Their motherhood subjectivity is complicit in how they position themselves.

Discursive therapy practises "fabricate 'health' and 'illness' and patient subjectivity which determine compliance with treatment and thereby maintain the dominance of medical discourse" (Mitchell, 1996. p. 203). Julia's words and those of Therese and Sandra, invoke a sense of being positioned within a therapy discourse as responsible for the outcome of therapy programs. This in turn ensures compliance in following through therapy programs.

Julia's words also demonstrate her perception of belonging to a 'group' of women, non-disabled mothers who have children named with disabilities, a sense of a collective identity, when she says "I've talked to so many mothers who have that [negativity] from *Children's Health*". Julia gives credibility to her (re)telling by positioning herself within a collectivity of mothers who have been similarly positioned in a therapy discourse. Julia speaks to what it is she perceives mothers need:

Mums need the full on, "You're doing great. You're doing really, really well. Just keep it up". ... I don't think they understand just how much a mother needs to hear positive input coming from the outside world.

Additionally, Julia's words bring to the fore societal negativity surrounding disability from "*the outside world*" as she calls on the need, the desire, to hear "*positive input*". There is a binary visible in Julia's words when she speaks of "*the outside world*". This outside world is one of taken-for-granted normalcy with its developmental milestones, and therapists represent the professional expertise, the holders of knowledge, needed to reach these milestones of normal development. As posited by Murray (2000), "professionals, by the very nature of their status, are thought to hold knowledge particular to their profession, which non-professionals do not have easy access to" (p. 692). However, Walther (2002) has argued that "it is the parents who know their children best" (p. 9).

Mothers can also be seen to be beholden to the therapy discourse as a discourse of hope.

Kathy speaks of the hope of attaining normalcy through therapy programs:

You do the therapy because you believe if you do all the things that you're shown to do with him, you think, "If I do all this I'm going to get him to be able to do all the things that the other kids do". You know, that's why you put the splints on and the callipers and everything else. And the more therapy you can do, the better his chance is. ... Then the years go by and you realise that it's not going to work out the way you planned.

Michelle expresses similar sentiments:

Therapy was very hard. ... You sort of channelled everything into Craig because you wanted him to roll over, walk, talk, do all these things. ... You had people coming into your house, helping with the therapy. Because I thought, the more we did on Craig he would get up, and sit up and roll and walk and do all these things. But it didn't happen.

Both of these mothers began therapy with a discourse of hope; that the time and effort they put into working with their children would allow their children to "*do all the things*

that the other kids do” (Kathy). They access therapy in order to get closer to the ‘norm’ of society showing the paradox of desiring the norm, while accepting their children.

You just get the exceptional ones along the way (Kathy)

Many of the mothers also commented on individual therapists who they perceive as positive and supportive. Julia praises the speech therapist at Early Intervention who offers “*so much encouragement*”. Robyn tells how the therapists at Early Intervention have “*all been fantastic*” and have taught her skills she did not have – “*I would never have known about the Makaton [a form of signing] without the speech therapist*”. Kathy, whose son Alex is 21, highlights how it is the individual nature and personality of therapists which impacts on how the professional-client relationship evolves: “*You just get the exceptional ones along the way. ... Some people are just a little bit more gifted or talented with it. Some aren’t really interested. They sort of throw him in the too hard basket*”. Elise expresses the importance of having positive people working with her and David when she explains, “*the positive people, they draw you on and they make things seem possible. The negative ones really sit you back (pauses). They say it’s not possible*”. Elise says that the negative attitudes that she perceived some professionals held were “*the hardest to deal with*”, the people “*who didn’t lead you on, who saw all the problems and not the positive things*”.

Michelle and Kathy comment on specific individuals who they remember working with their children. Kathy draws attention to the difference in individual therapist’s attitudes towards Alex. One therapist was willing to be flexible in her professional knowledge:

I can remember back when Alex was only small, there was a therapist at the hospital who was so fantastic with Alex and she didn’t do things by the books. If you rolled him over the ball this way, he should do that, but Alex didn’t. So she used to do him the opposite way and she’d get more reaction and things out of him than the others.

However, Kathy also comments on those therapists who she believes found it difficult to work with Alex:

You’d get others, because Alex was so severely disabled, looking at their watches thinking, “How are we going to fill in this time”? ... So we blow bubbles for an hour to pass the time away.

Michelle expresses her resistance to the domination of professional knowledge, power and expertise when she says:

Therapists ... went along with what usually works with people, and we kept finding with Craig that it was usually the opposite. And a lot of the times it was only because we put our foot down and said, "We want to try this" they did at least try. ... We found things did work. There might be some things that didn't either, but at least they gave it a try. (Michelle)

Both Michelle and Kathy speak to the temporal nature of therapy services:

After awhile you get to know the therapists and they've been with you for awhile. But you didn't really have any therapists for any length of time too. That's the trouble; people just came and [went] through Craig's life all the time. There's no continuity there. (Michelle)

I used to take Alex out to the Base Hospital and he had some physios who would try their best, but of course they were on 3 monthly rotations there (Kathy)

It's part of our lives (Liza): normalising therapy

One of the issues raised by most of the mothers in the study was the amount of time involved in therapy programs in their daily lives. Being mother "often becomes intertwined with the therapy and programming for the child" (Clear, 1999a, p. 5), at times becoming all consuming. Therese states:

We had to do this therapy program six times a day and the therapy program, if I did every thing it said, it would take me 1 hour and 40 minutes to do it. Now if I'm doing that 6 times a day, when do I eat, sleep cook?

Diane comments on the disruption to her life by saying, "you're thinking, My God. My life is going to have to stop for me to fit this in". The concept of "normalisation" as addressed in Bury's (2001, p. 272) work on illness narratives is relevant to the mothers' narrative on therapy. Relating the concept from the illness narrative to the context of the therapy discourse, this particular construct of 'normalisation' refers to incorporating therapy into a (re)constructed lifestyle. Therese speaks of how the therapists at early intervention show her how to make the program part of her daily life:

When you go to change her nappy that's when you stretch her hamstrings and we do this 3 times ... and when she's sitting down watching television and you're sitting down with her this is what you do. It wasn't we're going to do a therapy program, it's we're going to play.

Similarly, other mothers comment on how therapy became part of their life and incorporated into their daily routines.

What I tried to do was just include the program in your normal daily activities. Instead of taking out a special time to do a program, just to include it in some of the things you were doing. (Michelle)

I do it 24 hours a day. It's part of our lives. Even now it's part of our lives. It's part of how we speak to Lily. That's what I've done is just blended it into our lives and I think that's what can be done a lot of the times if people understand the basics ... it can be part of what you're doing. (Liza)

It's a matter of learning to cope, well learning to deal with it and saying, "I can't stop my life for this. I need to incorporate it into my life". So that's what we did with a lot of his therapy, or that's what I did with a lot of his therapy. I made it into everyday activities that we did. (Diane)

Kathy states that therapy was something that she did all day long and demonstrates how therapy became a normal part of her day:

Actually you'd probably do therapy all day long, but you don't realise it. ... Overall there'd be hours in the day gone, because you'd do arm exercises, leg exercises, rolling. Every time you'd change them you'd put their legs up and swing their little hips from side to side, put arm bands on them to keep their arms out, and try to sit them up. So there were hours gone in the day. But you look back now and you sort of think nothing of it because it's an automatic thing you do, and you sort of get yourself into a routine as well.

While Sandra did not believe she was shown how to incorporate therapy into her daily life and work, she attempts to take up the concept of normalisation as described by Bury (2001) when she explains:

I used to try and get into a routine of doing her hip stretches when I was changing her nappy and things like that. ... It was never of part of yeah, the regular home life. It was always an extra.

The results of a study carried out by Case (2000) suggest that mothers "want to play a direct part in their child's treatment and to be involved in therapy" (p. 282). Many mothers spoke of their lack of knowledge regarding working with their child in the initial years and their dependence on experts for guidance. They appear to have taken up a therapy discourse which influences their daily lives and to have "acquired the views and concepts of the specialists and therapists" (Walther, 2002, p. 10). While these mothers took up the subject position of being highly involved in therapy initially, over time some mothers resisted the way in which they were positioned in a therapy

discourse. Thomson (1994) proposes that while medical discourse and the medicalisation of the body has a role “it easily slips into paternalism, echoes stereotypes of dependence, and/or reinforces the sick role” (p. 2). Michelle spoke of the guilt she felt by choosing not to do therapy programs:

We had all these programs and that thrown at us that we had to do with him. ... And I used to feel so guilty if I didn't get it done. I used to get so upset.

The subject positions available to mothers within the therapy discourse create contradictions and tensions with their other subjectivities, particularly that of mother.

You have to love the child first (Liza)

Some mothers resisted the discourse of negativity that they perceived to be part of the therapy discourse in which they were positioned. Sandra began to “question” what was being done and made choices to involve Melanie more in family life. Therese explains how she became more “confident” in her ability to handle Kimberley and did not worry so much about fitting the entire therapy program into her daily routine. Robyn told the paediatrician there was “no way in hell” she was going back to Children’s Health, and was placed in a different program. Each of these mothers demonstrates an ability to move and resist the boundaries of discursive therapy practices. Sandra points out the tension between therapy to achieve ‘normal’ milestones and her love and acceptance of Melanie in the following quote:

I guess that's the whole name of their game really. They're assessing children at levels and trying to improve them. But it got very depressing for awhile, 'cause she wasn't doing anything (laughs) and yet I thought she was gorgeous (laughs).

Therese notes the importance of loving her child and how it took time for her to place the value of love over and above therapy:

It took me a fairly long period of time to come to terms with the fact that the most important thing to give her was love and everything else would follow.

She also comments on other parents who voice their concerns about not exercising their child and tells how she now is able to say to them, “have you loved your child today? Yes. Well that's the most important thing. If you give your child nothing else but love,

that's the most important thing". But as she reports, "it's all very well to say that almost 13 years down the track".

Similarly Liza, a therapist working with children named with disabilities, emphasises the importance of love. The interview process provides an opportunity for Liza to explore therapy, and the tensions which co-exist in the professional/lay and professional/mother binary. Liza displays her subjectivity as therapist rather than that of mother when she says:

I was so concerned with Lily and getting her walking and making sure she was sitting correctly and doing all these things, which were really good because I'm sure that that's made a difference, I forgot to have fun with her, to laugh and to just to play around, and to tease her and things like that. ... I just think that's one of the most important things, to come from being a [therapist] and giving advice, to being a parent, is that more than any other thing that child is yours to be part of your family and having fun is an important part of that. And being loved, you know. All that other stuff will come and it's hard work to fit everything in, but I think before you do any programs or anything like that you should have fun and have some family time, some loving time. That's more important than anything else.

Liza's words highlight Walther's (2002) comment that "the orientation towards therapy has increased to such an extent that the children very often do not know what it means to play" (p. 9). Liza's multiple positioning as inside the discourse of professionalism, and outside the world of 'normal', enables her to speak of the dualism involved and to speak to a discourse of love not present in a professional disciplinary discourse. Similarly, Sandra discloses how she worried more about Melanie's therapy than her play:

I would beat my breasts because I hadn't done 30 minutes every day and here's this happy, healthy child sitting there enjoying being crawled all over by her sisters and I'm worried about her being taken away and therapy being done.

Liza's story picks up a discourse of love arising from her motherhood subjectivity in opposition to mother as para-therapist. In her positioning as therapist she voices what mothers speak of, that is, the tension between professional therapists' expectations and that of being mother. When Liza and I spoke of the need to love the child, to be the mother, Liza comments from multiple perspectives, mother and therapist:

The professionals don't understand that. We [professionals] don't reinforce that. 'Cause it wasn't until I had Lily that I looked back and I thought, "How could I

have said to these parents you need to do this, that and the other thing as a home program”? Do you know what I mean? To us [professionals] it’s quite easy, but we’re not living that life. When you live the life you realise (pauses). So it’s a bit different. Yeah you do, you have to love the child first.

Liza’s subjectivity of mother impacts on her positioning as therapist and becomes part of her professional subjectivity: “*If I talk to parents and they sometimes say, “Oh, I don’t have time. I say “that’s fine ... just go and have some fun. Don’t worry about it”.* Liza positions herself as part of a group, suggesting a collective (professional) identity when she speaks about her subjectivity as professional in her use of the pronouns ‘we’ and ‘us’ in this segment.

Sandra also calls on her positioning in a collective group of professionals, as nurse, in the following segment. She points out the faith and belief in the knowledge of the therapist as professional and expert, and of what might be possible by following professional advice.

The attitude of a lot of professionals, and I’m one, is that if you don’t do it then you’re not giving your child the best they can have. And I personally believe that for a long time you believe that if you do everything you’re told by professionals that by the end of a year, or 3 years, or 5 years your child will catch up, be normal.

Also visible in Sandra’s speaking is the underlying construct of ‘good mother’. That to be a good mother is to do all that you can otherwise “*you’re not giving your child the best*”. To make your child ‘normal’ constitutes the child named with a disability as ‘Other’; it is the mother’s responsibility to make all attempts for the child to be ‘normal’. In order to achieve this, the construct of ‘good mother’ privileges expert knowledge in the binary professional/lay knowledge.

Mothers with children of different ages also felt this tension between motherhood and therapy. Sandra tells how she would meet mothers with older children who “*poo-hooed*” therapists and says she would think “*how game are they to not take that advice*”? However, in later years Sandra came to see these women as being strong in their defiance:

Then I realised what strength they had, in my future years, because they had questioned a lot of the practices and really just looked at the child and what the child’s needs were and what the needs were of the family.

Sandra's words speak to the agency of women who resist dominant assumptions of professional as expert who knows best, and expert imbued with knowledge and power. Other mothers' resistance to hegemonic belief structures and practices provide Sandra with a different story line to take up as her own.

As an older mother, Michelle speaks from the earlier perspective that Sandra mentions. Michelle expresses how "upset" she would be because she was not "getting all these things done that were supposed to be done". Then she says she realised; "that wasn't my role. I was there to be his mother and care for him". The discourse of motherhood, as a "significant, primary and vital role" (Clear, 1999a, p. 5) is rarely acknowledged by therapists. The way women are positioned as mother is also commented on by Walther (2002) who acknowledges the tensions expressed by the above mothers; "the fact that they are first of all parents and as such have a completely different job than the specialists is in real danger of getting lost due to the therapy orientation" (p. 9). Michelle echoes these thoughts as she tells how she takes up her positioning as mother:

It dawned on me one day that my role was to be his mother. Not to be his therapist or anything like that. To be his mother. To care for his needs in that area first and then if there was time for the other things sure. They were important, but the most important thing was that I was his mother. That I wasn't just using him as a thing that you just did all these things with. That I loved him and cared for him.

Michelle's words speak to the resistance of bodily inscription of the medical discourse, that Craig is not "a thing" to do "things" on. The disciplinary power imbued within medical and therapy discourse determines "the ways in which bodies are understood, monitored and regulated" (Barnes et al., 1999, p. 63).

The above mothers' storyings demonstrate the tensions which exist in the professional/lay and professional/mother binaries within a therapy discourse. While desiring to 'do the best' for their children through their motherhood subjectivity, mothers typically turned initially to expert knowledge. However, the mothers' stories also highlight their perceived intrusiveness of therapy programs into their daily lives and how they became consumed as they were made subject in a therapy discourse. This chapter has used poststructural theorising(s) to investigate the possibility of looking at individual's "patterns of embodied desire, both as they are shaped by those discourses and as they are capable of re-shaping or re-constituting bodies and desire through imagining other possibilities" (Davies, 1996, pp. 12-13). The mothers whose words

in/form this chapter show how they were shaped through a medical/therapy discourse and how they reconstituted/(re)constructed themselves to take up story lines as mothers over the subject positioning as para-therapist. Intervention “is all about supporting the parents with their worries and efforts for their children” (Walther, 2002, p. 10). It is the parent’s view of the child which should be foremost and the specialists’ viewpoint “incomparably unimportant” with the parents having the “right to choose the support” (Walther, 2002, p. 10). Positioning the mother as the one with knowledge of her child helps to decentre the traditional notion of professional knowledge as dominant and opens a way for mothers to enter new spaces with/in a therapy discourse.

SECTION FOUR

**EDUCATION SPACES AND
MOTHERS' DESIRES**

Chapter 10

The (discordant) dance of education

Based upon a medical model of individual pathological defectiveness, the discursive practices of special education proceed from essentialising views of normality and abnormality. As such they produce powerful discourses that establish hierarchies of those who are included in regular social life and those who are dispersed to the margins and beyond. At the centre of these discourses are particular forms of knowledge that construct the world. (Slee & Allan, 2001, p. 179)

The language(s) of education: special, regular and inclusive

After narratives of medical diagnosis of disability, the most commonly (re)told stories were of mothers' involvement and interaction with/in the discursive sites of education. I continue with the temporal organising structure of the thesis and commence with the experiences of mothers of the oldest children in the study and continue through to those whose children are just entering the education system. Effectively I begin with narratives of education of the early 1960s and continue the education 'story' until the year 2000 at the completion of the interviews. As pointed out by Lye (1997) "discourse is a material practice; the human is rooted in historicity" and further that "historicity implies that what we conceive of as history is tentative, situated, contingent" (p. 3). The (re)telling of the mothers' education stories from oldest child to the youngest to help to establish a sense of the history of education for some children named with disabilities in the Deira region. Additionally it provides an opportunity to explore the fluidity with/in an educational discourse, particularly in relation to special education. Bearing in mind Kitchin's (1998) argument that "life and society are not solely constituted in time and history but are also situated, contextualized and reproduced in space" (p. 344) the construct of spatiality is investigated throughout the entirety of this section.

Section 4 investigates the spaces of education as words such as 'mainstreaming', 'integration' and 'inclusion' were being spoken frequently (and oftentimes contentiously) into existence. Research on issues surrounding the discourse of inclusion

tends to focus on how much integration is taking place, that is, how much time students (named with a disability) spend in regular education settings (Allan, 1996). Whilst in the mid 1990s Allan (1996) contended that integration was the dominant discourse in special education, the word 'inclusion' is now widely used. Inclusion could be considered the dominant discourse within the field of education/special education, "replacing 'integration' as the preferred term within the literature, policy statements and general discourse on the education of young disabled people" (Swain & Cook, 2001, p. 185). However words as language-in-use are "not regarded as transparently reflecting meaning" but "continually creating it" (Fawcett, 1998, p. 266). Fawcett (1998) continues, "words do not exist objectively, but take their meaning in relation to how they are positioned in particular contexts" (p. 266). As such it is useful to use poststructural theorising(s) to examine how words and categories "construct and inscribe disability, normalisation and spaces of otherness" (Baker, 1999, p. 100). Baker (1999) also contends that the "world/subject fissure is maintained with the difference being that 'the subject' has become decentred by the prerogatives of language-as-world to inscribe 'subject'-ivity" (p. 100). The student is made subject and inscribed as disabled and positioned by language-in-use in educational discourse. Education Queensland documents refer to the educational provisions for students with 'disabilities', inscribing the students as disabled.

Coexisting with the development of inclusive education has been an ongoing development of linguistic frames in which to situate the discourse of inclusive education. Historically, educational terminology for children named with a disability echoed with the words of mainstreaming, integration, and inclusion as they were spoken into existence to describe the interplay between the spaces of regular and special education, as well as parents, students and multiple professionals. The words continue to be used interchangeably both in the research literature, and by the mothers in this study. It has been proposed that the word 'inclusion' will be used in "different ways, just as they have done for decades with words such as integration [and] mainstreaming" (Mittler, 1995, p. 5). Arguably, the slipperiness of these words as language-in-use creates dilemmas in understanding underlying philosophies, or as Slee (2001) succinctly notes; "the absence of a language for inclusive education that stipulates its vocabulary and grammar increases the risk for political misappropriation" (p. 167).

Positioning education and its social role

The role of education in the social construction of disability is accentuated through the mothers' narratives. Disability theorists state that "the special education system is a key element in the creation and perpetuation of the social oppression of disabled people" (Barnes et al., 1999, p. 104). The spaces of special education can be considered to be "organised and written to perpetuate disablist practices" (Kitchin, 1998, p. 347). Drawing on the work of Foucault, Cuff et al. (1998) propose that "discourses create (or produce) their objects"; for example the student named with a disability, who "can only exist through, is only thinkable in terms of, the discourse that has grown up, and out of, these organisational and occupational restructurings" (p. 277). The geographical spaces occupied by students stigmatise as surely as the label/category of disability itself, or in Sibley's (1999) words, "stereotypes of place compound the stereotype of the group" (p. 141), emphasising the relevance of adding a spatial critique to the analysis of educational discursive practices. The children are made subject in multiple discourses, social, educational and geographical, and the interactions of multiple discourses collude to continue taken-for-granted assumptions of the common-sense place of disability in educational spaces.

As education, and the schools which in/form the discursive site/s, can be seen as a "reflection of larger society" (Friend & Cook, 1992, p. 11), it is necessary to investigate how discursive practices of education serve to maintain the dominance of an ablest discourse. Since the early 1990s there has emerged an expanding body of literature which focuses on how "the production of space is linked to the production of identities" (J. Morgan, 2000, p. 279). As a discursive site where children with disabilities are made subject and 'Other', education takes on a dominant role in the production of a "disabled identity" (Lawson, 2001, p. 213). The spatiality existing in educational discourse can be linked to the ongoing creation and sustenance of disability and segregation within the discursive site of education. Consequently, the spatiality of education will be considered throughout this section. Institutions or structures such as schools "make certain discourses powerful and make others not hearable as of any value, yet structures are dependent on being spoken into existence through the discourses that legitimate their existence" (Davies, 1996, p. 16). Regular education can be seen as the powerful or

dominant discourse that marginalises those students inhabiting the geographic spaces of special education discourses. Slee and Allan (2001) suggest that schooling is a “significant force for disablement” and that schools are “cartographic police” (p. 178) controlling/patrolling the boundaries of their discursive field. Further, they suggest that “exclusion proceeds through deep structural and broad cultural mechanisms to invigilate a shifting spectrum of diversity” (Slee & Allan, 2001, p. 178).

Education is considered to be involved in “power relationships and the privileging of certain forms of knowledge” (J. Morgan, 2000, p. 274). The power relations inherent in education/special education will be examined in this section taking into consideration the privileging of discourse of professionalism. Continuing to explore spatial issues J. Morgan (2000) contends that “spaces are organised to keep a whole range of ‘others’ ‘in their place’ and can be seen as texts that convey to certain groups that they are ‘out of place’” (p. 279). Sack (1993) also comments that “territorial rules about what is in or out of place pervade and structure lives” (p. 1). As will be evidenced in the mothers’ stories which follow in both chapters 10 and 11, who is ‘in’ and ‘out’ of places and spaces of education come to the fore in many of their narratives. Students are ‘Othered’ with/in education and it is to, and of, these spaces that many mothers speak.

The spaces of education

In the next two chapters I focus on the discursive field of educational practices as expounded by mothers in this study. Drawing on poststructural theorising(s) to analyse the discursive site of education I consider “what power relations they [the discursive site of education] produce and reproduce, where there are resistances and where we might look for weak points more open to challenge and transformation” (Weedon, 1987, p. 136). In keeping with poststructural theorising(s) issues of knowledge/authority, language and the taking up of particular story lines are brought to the fore in this section. Within traditionally hegemonic assumptions which constitute the binary of education/special education, students named with disabilities are labelled, categorised and made subject. Through individual mothers’ storyings, shifts in the boundaries of

educational discourse are made visible as mothers take up multiple positionings, and resistance to dominant discourses becomes not only desired, but possible.

By linking education practice to dance, one can envisage similar disruptions in taken-for-granted assumptions. Drawing on a specific mode of dance, that of ballet, certain assumptions/expectations are formed influencing conceptions of what constitutes acceptableness in ballet performances. However, there are possible points of rupture with/in the traditional romantic/classical renderings of ballet and the possibilities of neo-classical, postmodern and experimental works are choreographed into existence in/to the movement spaces usually occupied by traditional ballet technique. Choreographers use, or disrupt the vocabulary of ballet to create/speak into existence new forms and shapes of movement. For example, traditional classical ballet story lines, such as *Swan Lake*, have been disrupted and represented in alternate formats as neo-classical dance, modern dance, and even performed with an all male corps de ballet dancing *'en pointe'*.

In chapter 10, I introduce the spaces and language of educational discourse continuing the use of temporality to structure my engagement with the mothers' narratives. In this chapter my focus is on those mothers whose children were predominantly excluded/segregated from what I shall refer to as 'regular' education. It has been noted, "places have histories and people have biographies which they articulate through stories or narrative" (Popay, Williams, Thomas & Gatrell, 1998, p. 636) and it is to these narratives that I turn in the following section to investigate the history as experienced, remembered and (re)told by the mothers. I commence with the stories of Norah and Patti, two women whose children are the oldest in this study. Norah and Patti's stories are made visible within a socio-cultural context/era which has a history of segregated education (Slee, 1999). Historically, "educational provision has been dominated by an ideology of 'special educational needs' and a segregated education system" (Barnes et al., 1999, p. 104). The impact of this segregated education system, as shown through the mothers' storying, emphasises the argument that "geographic place and space affect everyone" (Sack, 1993, p. 1). As noted by a number of writers, "regular education was never meant for all comers" (Slee & Allan, 2001, p. 186; see also Christensen, 1992) and this taken-for granted assumption that children named with a disability were considered to be outside and 'Other' to 'regular' education will be evidenced in the

following narratives. Following Norah and Patti's stories, I (re)present the narratives of those mothers who, together with their children, were just beginning to enter the contentious spaces of 'integration' or 'mainstreaming' with/in 'regular' education.

Bringing in the soloists: voices and the mothers' stories of education

Places have different histories and the history, and the present, of a neighbourhood or locality will mean different things to individual people who have their own temporal and historical associations with the area. (Popay et al., 1998, p. 636)

The multiplicity of the mothers' voices and experiences of educational spaces choreograph a sequence, building step upon step, to form a multifaceted dance. These are the mothers' solos, their stories, and because of that they contain the mothers' biases. These are the stories they chose to (re)tell to me, the willing listener. These are the dances they perform from their memories; the steps deriving from/out of the way they remember, the way they perceive the events which have occurred. The steps indelibly imprinted in their (re)tellings.

I continue with my deliberate choice to include as much of the mothers' storying as possible, both in terms of me '(re)telling' their story and in using the women's verbatim words from the transcripts to speak their experiences in/to this thesis; to tell their 'own' story. I follow the sentiments of Pugach (2001) who states, "one of the primary characteristics of contemporary, postmodern qualitative research is the commitment to bring to the surface stories of those whose voices have not been heard, those who have been oppressed or disenfranchised in schools" (p. 443). My work continues this commitment to add the rarely heard voices of mothers (who have children named with a disability) to the academic educational literature. Through my (re)tellings of the mothers' stories I attend to what Pugach suggests, that is, the text is "recognized as a vehicle" which serves to disrupt my single voice (re)presenting the mothers' narratives, their "reality" (p. 444).

Some of the mothers in my study believe that the decision as to which educational space their child attends/inhabits should be theirs to make, while others defer to the (perceived) higher knowledge, power and authority of the various professionals engaged within education. Other mothers, with older children, simply had no choice as their child fell outside both the Education Department's role and charity-run organisations at the specific point in history when their child was school age; further marginalised in an already marginalised group. Their stories will be analysed in terms of spatiality and the play of language and power and how mothers and children are variously positioned and become subject. The professional/parent relationship is explored within the constructs of subject and power/authority. "Geographies of resistance" (J. Morgan, 2000, p. 283) speak to the mothers' shifting positions as they are made subject with/in educational spaces.

☞ Norah's story: *They had schools for, like, backward kids*

Norah tells me there were no schools in Riverside (a small rural town close to Deira) specifically for children named with disabilities when Cheryl commenced school in 1963. Her storying takes place in the frame of an era where no educational services for children with intellectual impairments existed in the small rural town where they lived. The disability discourse of the time was one of social exclusion (Krauss & Seltzer, 1993). Dalrymple was a small rural school located near where Norah and her family lived and Norah sent Cheryl to this school with her sisters and brother when she turned 5 years old. I use the (re)presentational device of a play to (re)tell Norah's narrative on education. Norah and Jan (re)construct their memories of educational discourse in 1963 and display the meaning it had for them as well as for Cheryl.

They had schools for, like, backward kids

- Jan: There was no support until the sub-normal school. They opened the school
- Norah: Oh yes. Mrs uh, was it Mrs. Crawford? Who come out?
- Jan: Oh someone came out and they took her off to school. She used to go to that Dalrymple primary school with us

Norah: With these, but you know, I mean she used to go to sleep, or walk around the yard. She'd take off, you know. She'd walk down the road and I'd have to tear after her.

Valmae: How did the school react?

Norah: [pauses] She just sat there or went to sleep or walked home

Valmae: They didn't have a problem with her being there?

Norah: No, no. Actually she was no problem [speaking to Jan] was she? I mean she wasn't naughty or anything like that. No, no, no, no.

Jan: As long as we were there with her

Norah: Somebody that she knew, you know? The principal took her when she was five, but as I say she didn't stay there that long. Then they took her, you know they took her in town. They had schools for like backward kids.

Valmae: When did you realise that there were going to be the learning problems? [pauses]

Norah: I don't know. [Turns and asks Jan] Do you know? I suppose when we sent her to school and she'd come home and these would do their homework

Jan: But right from the start we knew. We really were told she was, 'cause we had to have all these toys

Norah: Oh yeah

Jan: So obviously they must have thought she's not going to be a normal child

Norah: I can still remember Dr. Jones saying: 'Treat her as a normal baby'. Well I mean to say, you'd have to be a little bit naïve if you didn't know she wasn't going to be the full, you know, baby like normal baby, like these.

Valmae: What did happen at school?

Norah: Well

Jan: I don't think it was long after that

Norah: [cuts in] That they took her in there eh? Yeah, she just went down to Dalrymple primary. Would it be 12 months? No. Would it? I can't remember now. But it was just to go with the kids and mix with them instead of being home with me all the time.

Valmae: When the charity school came, what happened?

Norah: Well they took her in there. They used to come out, pick her up in the taxi

Valmae: How did you get that service?

Norah: I don't know

Jan: I can remember when Mr. Bryce wasn't it?

Norah: That's right. Bill Bryce and his wife, because their girl, one of the girls, yeah, Marlene [pauses]

Valmae: What sort of things did she do at school, can you remember?

Jan: I don't think they did much at all [laughs]

Norah: I don't think so

Jan: Not learning wise

Norah: No

Jan: I really think it was to get the kids away from their parents

Valmae: To give the parents a break? So it's like respite?

Norah: Yeah that's right

Valmae: So it wasn't really set up for their education, it was more – so that's what you think?

Norah: [Valmae and Norah talking at the same time] No, because I don't think they could learn really. I mean

Jan: [cuts in] Not back then

Norah: No, no. Now they probably would

Jan: They just used to take them places

Cheryl's educational opportunities appear to have been limited by the spatial, temporal and family circumstances in which she lived. She was accepted into the local school perhaps because her siblings were present and as Norah perceived, because Cheryl exhibited no behavioural problems – she was “*no problem*”, “*not naughty*”. Cheryl was

allowed at the school, her behaviour socially acceptable. A disciplinary gaze is applied to Cheryl's behaviour to determine if her behaviour is acceptable to the norms of society. Norah comments that if Cheryl was not able to attend the local school she would have been "*home with me all the time*" indicating that there were no other educational opportunities available to Cheryl that Norah was aware of. Norah's storying also displays an awareness of the need for Cheryl to mix with other children and school presented an opportunity for that to occur.

Norah and Jan's (re)construction also highlights the fluidity of the social construct of disability as they point out the changing expectations of what a person with a disability is 'capable' of learning. Norah states that when Cheryl attended the local primary school, she "*just sat there or went to sleep or walked home*". While Cheryl is 'accepted' into the educational space of a regular school, she is positioned as one who cannot learn. As Norah continues her storying she speaks to her perception of the teacher's lack of expectation of Cheryl's ability to learn:

He's not teaching her, he's just, "She's retarded, push them out". Instead of him making her sit down and giving her a little bit of paper or putting something on the corner of her board and say, "Cheryl that's for you, now you try and write it". Don't you think so? Well I do. I do. But he didn't, see.

Norah is aware of lost opportunities for Cheryl as she continues later:

I think if she had have had a teacher when she first went to school and made her sit down there instead of going to sleep or something like that. I think that she would have been able to read a line you know. But it's too late now. (pauses) She'll get by.

Although Cheryl attended the local primary school, there was no expectation of her to learn, or a belief in her ability to do so, suggesting a taken-for-granted assumption about intellectual impairment, rather than Cheryl's abilities.

Education within the charity system, from Norah and Jan's storying, appears to have provided an opportunity for respite for the parents and leisure activities for the child. Norah and Jan perceived Cheryl did not do much at the charity school; as Jan says, "not learning wise". There appears to be a disjunction between what a school is expected to provide in terms of an education, and what the charity school was providing according to Norah and Jan's (re)tellings. Cheryl's participation in the charity school came about through other parents who had children who were named with disabilities. According to

Norah and Jan, parents in Riverside were instrumental in starting the charity school there and approached Norah with a request to allow Cheryl to attend thus becoming one of the original students. It was often the case that educational services for children with disabilities were established through the advocacy of parents seeking an education for their children. At the time of the interviews, Cheryl continues her link with the charity organisation attending daily and participating in multiple leisure activities.

A special school for ‘subnormals’

Patti’s narrative which follows serves to further situate the educational opportunities available for children with disabilities in the 1960s and early 1970s in Deira. As Deira is the major town in the region, services are more readily accessible for Patti than they were for Norah, living in Riverside, a small rural town. An article from ‘Viewpoint’¹ published in 1969, records that in 1960 a public meeting was called in Deira, and a decision was made to establish a “special school for subnormals” (p. 4) to be run by a charity organisation. The State Government gave 1½ acres of Crown land in trust for the establishment of the school which was “largely composed of swamp” (p. 4) and local council members and other contractors voluntarily filled the land.

In the early 1960s the school officially opened with two classrooms and 7 students. Of interest is the use of language to describe children named with disabilities; they are “subnormals”; “less than or inferior to the normal” (The Pocket Macquarie Dictionary, 1989, p. 1029). A binary normal/subnormal is clearly established and spoken into existence. Also of note is the land ‘given’ to the charity organisation – swamp land; land not valued for building. Disability is placed in the margins of geographical terrains, in spaces not considered inhabitable. Prior to the opening of this school, known as Rosslea, some students named with disabilities received no education. Patti’s story on education reflects the places and spaces students named with disabilities can be educated.

¹ I have made a deliberate decision to use a pseudonym for the name of this magazine as well as some identifying dates and years. Confidentiality for all participants takes precedence over referencing this material. The name of the paper is available from the writer on request.

☞ Patti's story: *My child is not like those children*

At 18 months of age, Belinda contracted a viral illness, resulting in what Patti says the neurologist in Brisbane diagnosed as “*simple epilepsy*”. They were told “*she'll grow out of it in 18 months*”. Patti explains that medication never fully controlled the epilepsy:

She just seemed to get worse ... that has been the pattern of her life, that's she's never been fully controlled with this epilepsy. She's never outgrown it. It's certainly got worse and it's caused mental retardation. She's never really developed mentally much beyond that age.

Life for Patti became ‘*full on*’. Belinda did not sleep during the day and was always “*on the run, on the go*”. Life, as Patti says, “*was very busy when you had four children including one who took a lot of care*”. Patti also reports that her husband did not believe in helping in the household portraying distinct gender roles within the family structure. Patti was positioned by her family, and was also complicit in taking up a subject position as being responsible for the children and the household; taking up this traditionally gendered and familiar story line as her own.

When Belinda is 4 years old, the family drives to Brisbane (a trip which takes almost two days) for further testing. This time they were informed that Belinda had “*encephalitis. She got a bug from that bowel inflammation. It ended up infecting the brain*”. Patti says they were told “*she won't grow out of it, she'll be epileptic for the rest of her life, and she will have this mental retardation problem*”.

In 1971 Patti begins to look at the educational options available to Belinda. This is where Norah and Patti's stories diverge considerably. Patti's storying about educational availability for Belinda takes place 8 years after Norah's story. The educational opportunities that are available to Belinda in Deira did not exist in Riverside when Cheryl commenced her education. According to Patti's storying the Education Department operated an Opportunity school, which catered for children who fell within specific IQ parameters. Patti states “*if your IQ was a certain level you went into Special School [the Opportunity school]. If you were below that, then you were at the charity school*”. According to Baker (1999) “the formation of education systems of inclusion/exclusion [is] around notions of ability and intelligence” (p. 99) and this

concur with Patti's memories concerning IQ levels and student placement. It is into this dichotomy that education in Deira is shaped and remembered; the categorisation of students with intellectual impairments into different levels influencing the spaces they could inhabit in the discursive spaces of education. If unable to attend a regular school, the opportunity school was available for a specified IQ range of intellectual ability; otherwise students could perhaps attend the charity school, Rosslea.

Patti explains her thoughts about which school Belinda would be able to attend; "*I thought that she would go there [to Rosslea] for awhile. I thought my child is not like those children [at Rosslea]. My child would at least go to the Opportunity School*". Patti is working within a strong socio-cultural discourse that categorises children, and determines levels of social acceptance as well as acceptance in educational facilities. While Patti is aware that Belinda is not able to attend a 'regular' school and has an intellectual impairment, she attempts to place Belinda with/in a group more acceptable to her, and her perception of what may be more socially acceptable. This sets up a tension for Patti as she tries to resist being positioned in a disability discourse, and desires to remain as close to societal acceptance as possible. It is important for Patti that Belinda attends the Opportunity School, to not be "*one of those children*" who goes to Rosslea.

Within Patti's construct of disability she establishes a hierarchy based on the way she understands disability; for her it is better for Belinda to attend the Opportunity School than go to Rosslea. Patti applies a societal gaze on how others (dominant society) see not only Belinda, but also herself. Patti also brings into play her motherhood subjectivity and her positioning as being responsible for her child. Patti's perspective emphasises the contention of various writers who critique the school's role in the social construction of disability, the perpetuation of a disablist discourse and the application of a social gaze which stigmatises a marginalised group, students attending segregated schooling (Barnes et al., 1999; Kitchin, 1998; J. Morgan, 2000; Sibley, 1999).

Nobody wanted her

During her narrative Patti speaks of her father's death in 1977 and mentions that she never told him that Belinda had been "cessated" from Rosslea School. I had not heard the word 'cessated' used before in connection with education and requested clarification. Patti explains that the staff at Rosslea "didn't want her. She was 11. She was not allowed, we were told that they couldn't cope with her at the school, and so she was home". The following poem is taken directly from Patti's interview, using only Patti's words. Its simplicity captures her thoughts and feelings about this particular time in her life as she weaves a present meeting into her past.

Cessated

*Life -
Life was pretty hard.
Life was pretty stressful for us all.*

*I guess
when Belinda was home fulltime
there was just
no light
at the end of the tunnel.*

She was home for 12 years.

*A few weeks ago
they said there was this lady
coming up from the charity school.
They were having morning tea.
I said,
"I don't want to meet that lady".*

*But anyway
I sat beside her
and she said, "I don't think I know you".
And I said, "Oh yes, we met many years ago,"
I said, "It wasn't a very happy meeting".*

*At the time
I couldn't remember why
it wasn't a happy meeting.
After I came home
I thought,
"That's why it wasn't"*

*She was the lady
who said
they didn't want Belinda
at the charity school
anymore.*

She was home for 12 years.

Life was pretty hard.

Patti tells me that the cessation of services for Belinda happened several times and continues by explaining how she never felt secure in whatever service Belinda was receiving because “*it was like an axe threatened over you*”; how “*all of a sudden they were going to chop [the service] off and say, ‘We don’t want your daughter any more. Take her home’*”. As she poignantly says; “*nobody wanted her. Nobody knew what to do*”. Patti says to me, “*it’s a terrible feeling when nobody wants your child*”. Patti speaks to a discourse of motherhood; Patti has a child unwanted by anyone else.

From the age of 11 years, and for the following 12 years, Belinda lived at home full time. In the early years after Belinda’s ‘cessation’ from Rosslea there were limited services available for Patti to access, either respite services for herself, or activities for Belinda; “*there wasn’t very much at the time*”. The lack of all types of support available to Patti and Belinda permeates Patti’s storying:

I didn’t have any support from anybody and wherever I went Belinda was with me. I had to take Belinda with me. I had nowhere to leave her. Nobody wanted her. Nobody wanted to even know us ... just didn’t want to have anything to do with her at all, do with us at all, and I felt that if Belinda didn’t have me to look after her, who did she have?

Patti was unable to receive respite afforded through Belinda’s attendance at school heightening her position as mother and primary caregiver, although this gradually eased over time as respite and leisure services became more readily available. What is foregrounded through much of Patti’s storying is a discourse of isolation. Many times through the interviews Patti stated that Belinda “*didn’t fit the mould*” of disability categories, which emphasises the inability to essentialise disability as a homogenous category.

Disrupting (special) education boundaries

Patti also tells me of parents who desired more than the segregated educational practices she experienced with Belinda. This was at a time when integration was only just coming into the social consciousness of the parents in Deira and they were working to resist the segregated spaces in which their children were located educationally. Patti speaks about other mothers from the same temporal frame in education discourse:

They weren't happy with their children being branded. They weren't happy with them being segregated. They felt they should be mixed in the mainstream. There was one mother who used to take her child to Blue River School and the child couldn't fit in and he used to spend all his time sitting on the steps of the school.

Elise and Michelle are two such mothers whose desire was that their children be “mixed” with non-disabled children. Elise and Michelle’s narratives on education take place in a spatial and temporal framework of change and illustrate the fluidity of the boundaries surrounding educational places and spaces. Their narratives recount the gradual involvement of the Education Department in educating children named with disabilities within clearly defined and measurable intellectual and physical criteria. At times, Elise and Michelle take up and demonstrate points of resistance to the dominant discourse of education.

✎ Elise’s story: *Among normal kids*

Elise’s narratives on her experience with education provide a framework in which to situate the development of inclusive education in Deira. In Elise’s storying there are points where she actively resists dominant and accepted segregated practices and other times where she is passive in her acceptance of segregated spaces and practices. She is multiply positioned taking up various subjectivities as she (re)tells her story. In recounting her experiences, the changes she speaks of build upon the stories already provided by Norah and Patti. The boundaries of segregated spaces are shown to be fluid as parents and professionals create a new and sometimes discordant dance of educational practices.

To recap, Elise's son David was born in 1972 and was her fifth child. It was "hinted" at birth that David could have Down syndrome, and this was confirmed at his 6 week check-up. Elise explains that his development closely paralleled the milestones she was familiar with from her previous mothering experience and because of her nurturing knowledge she considered his enrolment in a (non-disabled) kindergarten a viable proposition. However, in Elise's storying it appears that professionals do not give her perceptions of David's ability to attend a regular kindergarten credence:

I said to the paediatrician, I remember this vividly saying when he was 1 [year old], "Well, perhaps I should find a kindergarten that he will attend and enrol him". And he said, "I think you might be getting ahead of yourself here. He may never be able to attend a normal kindergarten". You know, this is the sort of stuff that I dealt with constantly from this fellow. ... Things like that you know, I feel quite bitter, not bitter, resentful, that he, probably unwittingly, he felt like he was doing the right thing. But here was a child who was achieving quite well, yet he still felt he had to put the brakes on. No, this won't happen, your child won't attend – he did attend a normal kindergarten (laughs).

Elise's mothering knowledge and desires do not appear to be heard or valued. She perceives negativeness in the response she receives from her paediatrician and there is no suggestion from the paediatrician as to how she might achieve her goal. She acknowledges that the paediatrician possibly believed "he was doing the right thing" yet this points to the accepted positioning of disability as outside 'normal'. Also in evidence is the perceived power of the professional in the medical consultation. David's achievements do not appear to be considered; his disability inscribes his future placement, the spaces he is expected to inhabit, and Elise as mother, is positioned as unrealistic.

At the point in time when Elise was desirous of an inclusive kindergarten placement she was not aware of any other children named with disabilities attending public day care or kindergarten facilities in Deira. She was not sure if private kindergartens had children with disabilities enrolled, but David was the first child with a disability to attend Deira Community Kindergarten in 1975 through the support of counsellor from a charity organisation who "gave encouragement that David could attend a normal kindy and paved the way". While receiving negative feedback from one professional, another supported Elise and her desires for David.

Elise explains her desire for David “to be in a normal kindy”:

To me he was among normal kids. This was long before integration was ever thought about. It was like, well, why shouldn't he be with normal children, he can do normal things. If he had been, um (pauses) had a high level of disability I probably wouldn't have seen that, but this was a mobile child, who could climb, who at that stage was starting to talk, who was functioning in this world like most other children except that he was hyperactive and couldn't talk. He could only talk a little bit.

Elise demonstrates a resistance to the dominant discourse of segregated education. Elise refuses to remain positioned by the paediatrician and actively seeks “integration” for David achieving his placement as the first child named with a disability to be integrated into a State run kindergarten in Deira. Elise questions segregated placements that were taken-for-granted for children with Down syndrome and works to break the bounded spaces in which children were placed and educated.

The attitude and support of the teacher at the kindergarten is emphasised in Elise’s storying:

There were other children with disability, not necessarily Down syndrome who followed David, not necessarily the next year ... So it probably paved the way for other placements because that placement was successful, because there were a lot of nervous people around. When it's not been done before it takes a teacher to really step out in faith a bit to say, “Ok, I'll take this on”.

It is Fulcher (1989) who asserts that “teachers matter” (p. 274) and without the agreement and support of the kindergarten teacher David would possibly not have been able to attend the kindergarten. However Elise also draws attention to how she supported David during this time:

I, by the same token, spent a bit of the time at the kindy in support. Well there was always the mother roster thing. ... But if there was an outing for instance, because David would just leave the group and go and do his own thing, I always accompanied the group as an extra mother. ... There was a need for me to be at the kindy.

Elise makes no mention of any other supports put in place for David’s integration. There is no talk of a teacher aide being employed to support David’s placement and as David’s mother, Elise provides this service, demonstrating her positioning as ‘good mother’ who is actively involved as part of her motherhood subjectivity.

A forward-thinking teacher

David entered a regular preschool as well as Rosslea, the charity school. Elise explains that David was a “borderline case” (of interest is the spatial reference) in terms of his ascertained IQ, and could have gone to either Rosslea or to the Opportunity School, run by the Education Department. Elise speaks of “a forward-thinking teacher” when she describes David’s placement in Year 1:

He actually at one stage had part-time placement with grade 1’s until we had this forward-thinking teacher who thought the only place for a child with a disability was in her special school [Rosslea], and couldn’t possibly cooperate with the State school so he could carry on with music and movement and his PE [physical education]. That’s all dumped. We couldn’t possibly fit them around his program at Rosslea, so they had to go.

Elise elaborates in her second interview when commenting on the transcript of the first interview:

I note here [in the transcript] I underlined it, a forward thinking teacher. And I was being really sarcastic when I said that (laughs) ... It was the time when David was in, jointly in a special facility and had an opportunity to go to a normal facility and she was agin’ it. And I know it was new stuff at the time, but she made it impossible for it to go on ... But she belonged to the [charity] mentality.

David’s educational opportunities are placed in a temporal framework of the beginning of integration of students named with disabilities in/to regular classroom spaces when Elise says “it was new stuff at the time”. While a teacher in the regular State system was prepared to move the boundaries, the teacher in the special system was not. Boundary keeping continued the divide, the binary of regular and special education, keeping David firmly in his place; professionals policing their discursive boundaries (Slee & Allan, 2001). While Elise earlier demonstrated resistance to her paediatrician’s negative attitude, she made a choice not to do so this time. Elise indicates that even though she felt the teacher “was being unreasonable”, she was not prepared “to rock the boat”. Elise adds “it was a well known fact that if you rocked the boat, you could be asked to leave the school, and you would have no schooling” (Patti’s story is exemplary of this point). Resistance becomes difficult where Elise is made subject and relations of power impact powerfully on the ability to choose/resist particular discourses. Without the charity school, there was no other educational option for David and little choice for Elise.

The kinds of doors that get open

David moved to Greenhill High SEU at age 15. While Elise says that the SEU functioned as a separate Unit within the school and “*not a lot of integration took place, except in the grounds and for some kids in sport and a few subjects*”, Elise comments that what she remembers most is “*David’s pride about being in tandem with Greenhill High*”. Elise states that for David there was pride in being “*able to wear the school uniform. To say ‘I go to Greenhill High’*” and further “*the fact that he attended a normal school, he was seen as normal*”. The space that David inhabits demonstrates Kitchin’s (1998) assertion that “we live and interact in spaces that are ascribed meaning and convey meaning” (p. 349). Meaning is implied in the educational spaces students attend; going to a regular school inscribes David differently than attending a Special School. Elise tells me how being at Greenhill “*opened doors*” for David. The metaphor of opening doors takes on geographic positioning and spatiality in the discourse of education. It highlights the separateness of David’s special educational placement and positions it as one that takes place behind walls, and therefore not visible. A boundary exists and is one that can be seen to have no openings; the doors did not open for David until he moved to the ‘normal’ school, Greenhill High.

In the segment which follows, Elise’s thoughts and beliefs on the value of David’s education taking place in a SEU at a regular High School as opposed to a Special School are brought to the fore. I quote her response at length as she covers a number of issues which spotlight the spatiality of educational discourse and its relationship to a discourse of normalcy:

The IEP type program was far more geared to normality in High School than it would have been in the special ed. of that era. I’m not saying of today’s era (pauses). If I think of the things David did when he was at Rosslea compared with the High School and the vision that Rosslea had ... It’s about, probably a lot’s about vision. About where David would be when he left school. Through the charity school system they have a tunnel vision to the workshop. ... Whereas when you’re in a normal High School, what’s everyone in normal high school do? They go and work; they have recreation. They do all the things that everybody does. ... So, those are the kinds of doors that are there to be opened, or at least for you to access.

If David had stayed in the [charity school] system at the age of 16 they would have shunted him off to the workshop and everything would have been geared along there and we wouldn’t have been thinking about independent living skills ...

It was just a totally different concept of education. ... Expectations also (pauses). I think when you're in a more normal environment there are expectations people have of what people do, of how people behave.

The ability to travel to school via a normal bus instead of being picked up by the school's thing that has a label on it. There's a lot of stuff about labelling and if you to a school that's got a label, you get a label. You carry it for the rest of your life.

It's about making friends. David meets kids in the supermarket that he went to school with and says hello. It's just a different environment to be in. It just equips you better for life. And if you know lots of people it must have had an impact on your, how you see yourself in the world and who you are in this community, if you're one of them, or if you're not one of them.

Those are the kinds of doors that get open just by being in a normal environment. They're there to be opened.

Elise cites numerous ways the doors have opened for David. These openings form a connection, a bridge, from the world of disability to the 'Other' world of normalcy, providing a blurring of the clearly defined boundaries that Elise sees as created through and by the discourse of special education.

Elise comments on vision and the difference between special education and regular education. She speaks of how being in a regular high school brings to the fore what it is that "everyone" does and how it is they behave. "Everyone" is representative of the lack of a word to describe those who are considered to be 'normal' emphasising the unmarked category of 'normal'. The 'normal' do not need to be defined, existing already as dominant. She notes the impact on how the future is envisaged by being with and doing what "everyone" does. She brings into the dance of education the ability to dream, to think beyond accepted moves towards the "workshop" and the "tunnel" that seeks to keep David in his place, and lead him to where he should go. Throughout this segment of Elise's narrative her words resonate with bounded spaces, the geography of disability in education.

Elise speaks of labelling and the long-term implications of naming. Through the naming of schools, places, and types of transport, David too is named and labelled; inscribed as 'Other'. Elise talks of the friends David has made through Greenhill High, who are now the people in the community, and importantly brings into the spotlight how David sees himself. She speaks powerfully into existence not only the binary of abled/disabled

when she says, “*if you’re one of them, or if you’re not one of them*”, but also of being marginalised and made subject as ‘Other’.

➤ **Michelle’s story: *They allowed him into the classroom***

Michelle and Craig enter the spaces of education at a time when the Department of Education took over the responsibility of the education of all students. Michelle indicates that Craig would not have received any form of education if the Department of Education has not taken on this role. Michelle acknowledges that she never expected Craig to attend Rosslea; “*Craig wouldn’t have even got into Rosslea ... because he was incontinent. ... He would have been home with me*”. Michelle’s narrative shares a consistency with the stories already (re)told by Norah and Patti, and demonstrate agreement with the article in Deira Times. With the Education Department taking over the education of all students, Craig was able to attend an early intervention centre and then moved on, and in/to the Education Department’s Special School.

The Special School however was one all children with disabilities attended together, regardless of disability – a homogenous grouping because/of disability. Michelle says that there were “*just all different levels all in together*”. Not long after Craig started at the special school Michelle tells of a parent who established a parent group in Deira and how she became involved in this parent group. She explains the parent group’s role had two functions; one was as a means for parents to come together, and the second was to tackle issues which arose with the Education Department. She says that they “*achieved a lot in that time*”. When asked to expand on this comment, Michelle goes back to explain the evolvement of SEUs in Deira:

Craig was at the Special School and they then started up the Units at the different State schools and the kids with the higher abilities, they went out into the Units and all the kids with multiple disabilities were kept at Special School. ... I went along to a parent meeting that we had with the Education Department and they had this proposal of this ‘you beaut’ Special School that they were going to build and all this, this wonderful thing, and the parents more or less told them what they could do with it.

Michelle makes noticeable a tension existing between what the Education Department saw as appropriate educational placement, and what parents wanted for their children.

The beginnings of integration in Deira come to the fore in Michelle's (re)tellings. Parents did not want their children in segregated Special Schools, and parents took up a geography of resistance (J. Morgan, 2000) as they refused to accept the separate spaces of the Special School.

Michelle explains the change she observed in Craig once students went to the SEUs and the Special School became a placement for children with severe multiple disabilities:

Craig became like just a zombie because there was no stimulation. He had gone from getting heaps and heaps of stimulation because there were so many different levels of kids in the Special School to them all [students with severe disabilities] just being placed together.

The negative impact that Michelle could see in Craig's behaviour as well as her involvement in the parent group gave Michelle the "encouragement" to say that she wanted Craig "out into a Unit too". She notes: "I started that process. It wasn't easy because he was the first with multiple disabilities to go into a Unit". Through the support obtained because of other parents, Michelle begins to resist Craig's positioning in educational discourse and geographical space. A geographical and temporal movement of place is associated with disability, segregation, and education. Michelle wanted Craig out of Special School and in to a SEU. The spatial metaphors of place exist in the 'out' and 'in' of Michelle's narrative resonating with the spatial discourse as established by writers such as Sack (1993) and Kitchin (1998). Spatial boundaries segregating the discursive fields of education/special education begin to blur, yet the discourses of professionalism controlling those boundaries were more stable.

While SEUs were seen during Michelle's experience of education as a way to move beyond the segregation of Special Schools, it can also be proposed that the SEUs simply create the illusion of being part of a regular school. Slee and Allan (2001) term the existence of SEUs "co-location" (p. 176) and define co-location as "the growing practice of re-locating a special school inside the grounds of a regular school and encouraging some shared activity" (p. 187). Co-location can be read as the model in many SEUs that have been built on the grounds of regular schools in Deira. While the geographic spaces of special schools have shifted, the segregated and bounded practices often continue through the structures of SEUs which maintain a special education discourse. The binary of education/special education remains in tension.

Michelle perceives the move to an SEU came with the opportunity for Craig to attend a regular classroom as well as being spatially located in the Unit. She says being able to go to the regular classroom “*was part of it*”. However time in the regular classroom was not a taken-for-granted and Michelle explains that the special education teachers “*were reluctant*” for Craig to go to regular classrooms. Because a teacher aide was sent with Craig each time he went to the classroom he “*didn’t go very much*”. She also says that the initial expectations of the special education teachers were of how “*difficult*” it would be for Craig to go to the classroom. However Michelle explains:

In the end they realised they didn’t need as much aide hours as they thought they needed. Craig used to go over to the classroom without even an aide, the kids would just come and get him, take him over to the classroom.

The notion of shared activity mentioned by Slee and Allan (2001) between SEUs and regular schools is visible in Michelle’s story as she tells how Craig moved between the two spaces.

When considering the spatiality of disability in education I concur with Allan (1996) who contends that the place a student occupies has significance in claims of whether a student is considered included. “Physical proximity” is “cited as evidence of integration” (Allan, 1996, p. 225). Yet the closeness of the spaces is not always and only a measure of inclusive practices, as demonstrated in Michelle’s story. Temporality, used as a measure of inclusion, defers the meaning of inclusion to the length of time students are educated/spend in the regular classroom. Constructs of spatiality and temporality constitute the discourse of integration and as such require further examination of their roles in the multifarious interplay of meaning. However, being in the same space as non-disabled students does not guarantee that segregative practices will not occur.

During our conversation about education, I ask Michelle if her request for Craig to spend time in the regular classroom was part of the beginning of the push for integration:

Michelle: Yes it was. Very much so. That was a very strong push for it. Eventually the Special School was completely closed down.

Valmae: So where did the parents get their information or their understanding of what was happening?

Michelle: I think where it all came from was with their other children; they were out there, so why shouldn't the child with a disability have the opportunities? And I think they'd learnt a lot from the parents that had had their children at the Special School previous to that. There was a Special School run by the Education Department. ... And the one-on-one that their children had got, had got them academically quite far, but the social interaction was not there, so that when they went to get a job it was no good to them because they didn't now how to deal with people.

In Michelle's (re)telling parents desire the same opportunities for their child labelled as disabled as their other children are able to access. Part of the same opportunity meant attending the same schools as their other children. As Michelle said to me towards the end of our interview, "*one of the things I regret is that Craig never ever went to the same school as his sisters*". Michelle also argues that socialisation skills are important for participation in society, and felt these skills were not available to Craig in a segregated Special School.

Michelle highlights the benefits she perceives being available to Craig through attending a regular classroom as well as the SEU:

He just got the stimulation. He didn't actually even need to be doing what they were doing. Just being amongst them and the activity was enough to stimulate him. And then it was quite good because then he'd go back to the Unit and he'd get one-on-one. He'd get his therapy and stuff like that, and feeling and all that type of thing dealt with.

A continuum of services appropriate to what Michelle believes relevant to Craig allows him to move between the spaces of education. While Michelle acknowledges the benefits of time in the regular classroom, she also values the benefits of more intensive time in the SEU. However she goes on to explain that she did not believe the regular teachers included Craig when she says they "*didn't include him. That was definite. They didn't really include him in what they were doing. But they allowed him into the classroom and he got lots from it. And the kids were great with him*". As such it can be seen that "segregation is not always a question of physical location" (Slee, 1999, p. 123). There also exists an issue of 'belonging' to the spaces of the regular classrooms; teachers "*allowed*" Craig into their classes, suggesting that he did not belong there. He was from the SEU, 'Other' to regular educational spaces.

Michelle explains that she found the transition from primary school to High school difficult because of the teachers' attitudes; "*it was very hard to get through to high*

school teachers that Craig didn't need to achieve academically. That his achieving socially was what he was there for. And that he's developing as a person by doing that". She also notes that "they're very rigid and set in their ideas". I ask Michelle to explain the differences that she found between High School and primary school:

Michelle: The difference between primary and high school was a big change. In primary school it worked so well. It doesn't work as well once you get into high school

Valmae: Why is that?

Michelle: Just going back and forwards to the classroom because they aren't in the same classroom and even the teachers, just coming to terms with that Craig only needed to be in the classroom to get the stimulation. He didn't need to be actually doing anything. ... Achieving in the area of just socialising and stuff like that. So it was very difficult to get that through. And in the end I had to come to terms with that Craig was happy. Because at least he was still getting, there was still plenty of stimulation. Kids were still always around [in the SEU] and everything in the playground and also there was higher level kids in and out of the Unit the whole time. So he was getting plenty of stimulation. So I had to come to terms with that he was happy.

For Michelle the stimulation and the opportunity to be amongst Craig's peers in a regular classroom is a valued educational outcome, however she viewed teachers as seeing only academic achievement as an outcome. The tension between achieving what is recognised as acceptable 'educational' outcomes can be a barrier to achieving successful inclusive curricula and social outcomes. This begs the questions, what are acceptable educational outcomes, and further, who decides? While Michelle perceives Craig's socialisation a valued outcome, Michelle positions teachers as desiring only academic outcomes. This tension remains unresolved for Michelle as Craig is returned to the spaces of the SEU in his High School setting.

What you thought best for your child

Michelle elaborates on the role of the parent support group in which she was involved and her response demonstrates the increasing desire parents had for the integration of their children. Her story is played out in a temporal frame which displays the beginnings of integration in the Deira region. Michelle tells of parents' involvement in issues of education:

Michelle: It was mainly making sure that education kept running in the way that we wanted it to go.

Valmae: Which was?

Michelle: Which parents wanted was integration. Whether it was fully integrated or just, I think parents were really happy with even just having integration as being on site. So that you could have the choice. You could just be in the Unit if you wanted that, you could be partially integrated if you wanted that, you could be fully integrated if you wanted that. Just to have that choice. That you could have what you thought was best for your child.

Valmae: So if the parents wanted a continuum did that happen?

Michelle: No. Just because doors were opened in certain areas for certain people, it didn't automatically flow on. That was one thing I did notice. Although like Craig being accepted in, did open doors in that people realised it wasn't as difficult as they thought it was going to be. So that did open doors and let other people in. But it never happened all the time. Just because you achieved something for one person didn't mean that it would automatically carry on to the next. The next person could have a battle to achieve the same.

Michelle's (re)telling raises the notion of choice, and that parents want the moral 'right' of choice in determining their child's educational placement. Choice of placement can be seen to be of particular import to parents yet this does not seem to be realised within educational policy documents. Michelle points out that parents want what they believe is the best option for their child, and this implies there need to be an acknowledgement of parental knowledge and expertise. Not all parents desire inclusive placements, just as not all parents want their child in an SEU or Special School. In Michelle's narrative she suggests that parents strive for a continuum of educational options from placement in a Special School through to inclusive placements in a regular classroom.

There is a lack of consistency in achieving desired inclusive placements. This raises questions regarding the underlying philosophy of education and its connection to disability and special education. Michelle explains that just because one person achieves an inclusive setting, there was no automatic flow on for another person seeking the same option. Like Elise, Michelle uses the metaphor of "doors" signifying the boundaries of special education requiring doors to be opened to allow students access to 'regular' education spaces.

The agency of parents

As evidenced in the above narratives, the charity school catered for many children named with disabilities who were receiving no educational services from the Education Department. However there were those who fell outside even these boundaries. As Patti's story demonstrates, there were children, like her daughter Belinda, who were not accepted at either the Education Department's Opportunity School or the charity school. Patti believes that at that point in time in educational discourse "*no-one wanted to know you*". Michelle's story also acknowledges the lack of education for some children.

Patti and Elise explain to me their understandings of how the charity school came into being. Elise believes it came about because of parents who saw "*a perceived need for education for their children*". Interestingly in an article from the 'Deira Times'² in September 1983, celebrating 20 years since the opening of the charity school, the Administrator of the organisation had the following to say; "At that time [1963], the Education Department did not consider sub-normal children, as they were called then, to be educable" (p. 19). However, parents believed their children able to be educated and resisted dominant professional knowledge and expertise to establish their own schools for their children. The agency of parents is expanded further by Elise and Patti:

[The charity school] was started by a group of parents ... whose children had no schooling, couldn't be accepted anywhere ... [they] obviously had decided not to put them into institutions. ... It was in Brisbane. ... by this group of about a dozen parents, I think, who wanted a school for their children. So they got together, formed a committee, raised some money and employed a teacher. (Elise)

It [the charity school] started in Brisbane and then a group of parents here [Deira] got together ... they had nothing for their children then and they started up the Rosslea School here. (Patti)

Norah and Patti's stories also speak to their knowledge of the role of parents in the formation of schools for children considered ineligible to attend 'regular' schools. Their knowledge is based on their experiences and observations and as such their construction is outside the realms of professional classification and knowledge. Their perceptions inform their memories and stories of education.

² Similarly, the name of this newspaper is a pseudonym and is therefore not referenced. The article is available on request from the writer.

According to the article from the Deira Times, “intellectually handicapped” children were often taught at home by their parents either individually or as a group of parents who held activities “under homes or in church halls” (p. 19). Education can be considered to be disabling, as it is unable to accommodate a diverse range of students (Christensen, 1992), and this is particularly noticeable in the 1960s and 1970s when some of the mothers in the study had school-age children. In Norah and Patti’s storying they express how the Education Department of that particular timeframe catered for a ‘normal’ intellectual range of students in Deira, and those who fell outside were marginalised into Special/Opportunity Schools or charity schools, or no services at all. Special education for students “retained the assumptions of the medical model” and therefore “functioned to provide a separate segregated system to contain those who, because of their physical, emotional and intellectual characteristics, did not fit the regular system” (Christensen, 1992, p. 7). However, Elise and Michelle’s storyings bring into play agency, resistance and fluid boundaries in the discursive field of education.

The above mothers’ narratives of educational spaces provide a glimpse of the way children with disabilities were, and I propose, continue to be, made subject in the discourse of special education. The same article from the Deira Times mentions that some children “never left their home in their entire life time, and others were put into institutions for the mentally disturbed” (p. 19). Norah and Patti entered the education system in this era; their children segregated, labelled and invisible in the discourse of education. In their experience disability is effectively silenced in its separate spaces. It is currently asserted that “separation from mainstream society keeps disabled people hidden, thus out of public consciousness” (Gordon & Rosenblum, 2001, p. 12). Spatiality comes into the education discourse as education is divided into separate spaces for those named as outside ‘normal’ and placed in separate spaces. The social gaze is brought into play as disability is “hidden” from society.

However, as witnessed in Elise and Michelle’s stories, “individuals and groups can reshape discourses, invent new ways of speaking that both reflect desire and may open up possibilities of new forms of inner/outer being and new patterns of desire” (Davies, 1996, p. 16). Elise and Michelle continued to speak into being the possibilities of more inclusive education for their children; they speak to their desire for their children be part

of the regular school space. With/in the spaces created between regular and special education there arise points of resistance. Weedon (1997) states, “where there is a space between the position of subject offered by a discourse and individual interest, a resistance to that subject position is produced” (p. 109). Norah and Patti did not appear to be accorded spaces for resistance perhaps because the structural organisation of educational spaces and the controlled boundaries of professional and institutional discourses precluded the opportunity or choice. There did not appear to be a space to resist their subject positioning in the discourse of education. Elise and Michelle both gave examples of when and how they took up agency and resisted the positions in which they were made subject in the discursive practices of education. At times, they actively sought to disrupt common assumptions of education/special education and as such opened up possibilities for points of rupture to bring into play “patterns of desire” for more inclusive spaces with/in education (Davies, 1996).

Chapter 11

Changing educational spaces: towards inclusive schooling

Special education is exclusionary and oppressive. There is no place for special education in an inclusive society. I have come to dance on the grave of special education. (Oliver, 2000, ¶ 5)

Inclusive education is about all students. Inclusion is an aspiration for a democratic education and, as such, the project of inclusion addresses the experiences of all students at school. (Slee, 2001, p. 168)

Seeking inclusive education: disrupting boundaries of ‘special’ and ‘regular’ education

Chapter 11 begins by drawing on the stories of those mothers whose children are currently with/in, or have just left, the education system, as well as the narratives of mothers whose children were attending early intervention programs at the time of the study. Many of the mothers’ narratives display their desire for inclusion or inclusive education. As such, these narratives of desire build on the stories already (re)told in chapter 10 highlighting the gradual changes with/in the discursive practices of education from segregation to more inclusive educational opportunities.

Education and the geographical spaces of disability are brought sharply into the spotlight in this chapter. The mothers’ performances abound with spatial motifs and metaphors as they speak of their memories and perceptions of educational places. The spaces students inhabit are important to consider in the analysis as the manner in which educational spaces are organised “constructs bodies and offers bodily possibilities and constraints” (Freund, 2001, p. 697). The bodies of students inscribed as disabled are “experienced and ‘lived-in’ differently in various socio-material environments and material cultures” (Freund, 2001, p. 697). Spaces of education are representative of broader socio-cultural binaries. Slee (1999) asks; “where do teachers, and others, get

their ideas about disability?”, and suggests that “typically they get them at a distance. Typically they get them from non-disabled people, from experts, from specialists” (p. 123). I contend that educational spaces also need to be examined through poststructural frames, because as Kitchin (1998) notes:

Society is socio-spatially organised to sustain hegemonic power within a nested set of social relationship at varying social scales. If we are to understand disability and the experiences of disabled people we must deconstruct landscapes of power and exclusion, and the geographies of domination and resistance. (p. 347)

The landscapes of power and exclusion that this chapter focuses on are the binary spaces of regular education/special education. This chapter also spotlights the points of resistance some of the mothers made visible through their narratives of educational discourse and practice. However, while many of the mothers who took part in this study work/ed towards resisting segregative discursive practices, these particular mothers in this study cannot be read as representing the views of all mothers. My analysis of the mothers in the study showed that many of their narratives spoke to their desire for inclusion, an inclusive education, and as such stories of geographical resistance of places of exclusion and segregation come to the fore in this textual performance. Mothers whose children were just entering the geographical spaces of education did not always hold strongly developed views on inclusive education and their stories are (re)presented later in this chapter.

Throughout their narratives of education the women fluctuated in their use of words such as ‘mainstreaming’, ‘integration’ and ‘inclusion’. The word ‘inclusion’ is considered problematic, as it “has been used to refer to unconditional access by some while it refers to a sliding scale of partial participation for others” (Slee, 1999, p. 175). I question “what is ‘inclusion’?”, and find no simple answer. What is its meaning and to whom does it apply? Further, who decides meaning when language-in-use is deferred, slippery and polysemous? Within the disability and special education literature is a lack of an agreed and universal definition for the word ‘inclusion’ (see Baker, 1999; Bines, 2000; Slee, 2000; Slee & Allan, 2001; Swain & Cook, 2001; Ware, 2002). Thousand and Villa, (1999) state that “the practice of welcoming, valuing, and supporting the diverse learning needs of all students in shared general education environments is referred to as inclusive education, inclusive schooling, or inclusion” (p. 73). Inclusion in this definition can therefore be considered to be the same as inclusive schooling or

inclusive education. The Centre for Studies on Inclusive Education [CSIE] in the UK offer a broader socio-cultural meaning of inclusion as “enabling pupils to participate in the life and work of mainstream institutions to the best of their abilities, whatever their needs” (CSIE, section 2, ¶ 2), while they define inclusive education as meaning “disabled and non-disabled children and young people learning together in ordinary pre-school provision, schools, colleges and universities, with appropriate networks of support” (CSIE, section 2, ¶ 1). Both of these definitions suggest inclusion, or inclusive schooling/education means the placement of students named with disabilities in regular classrooms, where they are valued and supported members of the class. It is this meaning that the mothers in this chapter speak of when they use words such as ‘mainstreaming’, ‘integration’ and ‘inclusion’.

I question whether the shifting philosophical underpinnings of terminology are reflected in the changing language used to situate students in educational discourse in Education Queensland policy documents. After all, a “change of name is not necessarily a change of policy” (Swain & Cook, 2001, p. 205). Davies (1996) points out:

The imposition of another discourse, however powerful, does not automatically rule out the old. Old discourses exist amongst/with the new. Ways of knowing and desiring overlay each other, bump into each other, inform each other. Like the palimpsest of writings on an old parchment, where the old was partially rubbed out and the new overlaid on the old, the old can still be seen and shapes, at least in part, how we see the new. (p. 17)

The language employed in policy documents serves to describe, define and inscribe students; their bodies then placed into pre/in/scribed spaces. Under the newer discourse of inclusion come the variants of inclusive schooling, inclusive education, and inclusive curriculum. These discourses are written over the top of previous policies, the same players controlling the meanings and implementation of new discourses. Education Queensland refers to inclusive curriculum and inclusive schooling in its policy documents (DOEM, 1998) but does not use the word ‘inclusion’. To reiterate from the opening chapter of this thesis, inclusive schooling in the Queensland context means that “schools will include and value students through the provisions of a range of flexible curriculum options that allow access and participation and which ensure that educational outcomes are maximised” (DOEM, CS-05, 1998, p. 3). With the continued provision of segregated special schools and SEUs, referred to by Loxley and Thomas (1997) as “systemic dualism”, and with the construct of ‘clustering’ students who have

similar educational needs (notably intellectual impairment and physical impairment) in specific schools (DOEM, *EPSD*, 1998, p. 6) it is difficult to determine any similarity with the above definitions of inclusive schooling/education. In effect students named with disabilities can be located in segregative schools or SEUs and be involved in inclusive schooling. The question remains, with whom, and how are they included? In contrast, the Tasmanian education policy document clearly stipulates an attempt at inclusion and inclusive schooling which appears to be in line with the earlier definitions: inclusion “implies providing for all students within the educational program of the regular school” while inclusive schooling is defined as “attempting to provide for all students, including those with disabilities in regular school” (Moss, 2002, p. 233).

The multiple existence of educational discourses are in tension with the multiplicity of desires of those intensively involved – policy-makers, professionals, parents, and students. Inclusive education needs to “deconstruct traditional forms of knowledge lurking behind ... inclusion programmes in Australia” (Slee & Allan, 2001, p. 175). Simply changing names and spaces does not ensure inclusive practices. One method Slee and Allan (2001) suggest of achieving this deconstruction is to support “hitherto silenced or marginalised voices to enter and lead the conversation about educational exclusion and inclusion” (p. 176). In this chapter I (re)present the normally “silenced or marginalised” voices of mothers who move in the spaces of education, choreographing dances for their children which oftentimes disrupt the assumptive expectations of education. I commence with Liza, whose daughter has just left school and move chronologically to mothers whose children were attending early intervention settings at the time of the last interview.

Mothers’ narratives on education

☞ Liza’s story: *You have to pick your fights*

Liza comments to me in our first interview that “*you have to pick your fights*”. When asked to expand she explains that the fights she referred to were mainly within the discursive site of education. As Liza’s daughter, Lily, was in Year 10 at High School

when our first interview took place, much of Liza's storying revolved around specific situations she had recently encountered with the Catholic High School in which Lily was enrolled. However it is to Liza's beliefs about, and experiences in, education that I now turn. Liza does not provide a chronological narrative on Lily's education, rather she presents her beliefs of what education is and could be, choosing to relate various incidences arising out of the spaces education inhabits to explore her beliefs. As education takes place in various sites particularly when it is applied to children named with disabilities, education can be seen as one of geographic isolation as segregated educational practices can be instituted, and institutionalised.

I started by asking Liza to "tell me about education" and her immediate response (after laughing and saying, "*the can of worms*") highlights her belief in inclusion:

I think the main thing [is], I have a strong belief in mainstream education, in inclusion, and I've been fortunate to have had Lily and to work with some people who believe that and do it well, so I've seen it work. So as much as it's an ideal, I know it can work.

Liza speaks of inclusive education as an "*ideal*", not as her perceived concept of the dominant discourse of education; her words suggesting that it is an ideal perhaps unable to be realised. Liza raises the issue that inherent in successful inclusion practices is the need for a belief from the teachers in inclusion, a belief that children named with disabilities can be a member of the 'mainstream' or regular class.

Liza does not know where her desire for inclusion came from and says "*it's just always been there*". Yet Liza then goes on to question whether her belief came from her early "*denial*" that Lily had an intellectual impairment. Liza explains she used to state that Lily had a learning disability; "*I stated it as a learning disability because I saw it quite differently*". Labelling and naming of disability has a profound effect on how a person is seen, the gaze that is cast upon them by others making them subject, in this particular case, by teachers and also by Liza: "*See to me a learning disability, and I think what this meant to other people, was that she could learn. She just had a difficulty in learning*". When I ask if this was part of labelling, Liza responds "*yes ... because if you said she had an intellectual impairment, that meant she wouldn't learn (pauses) well she would probably learn some things but there would be a definite halt to some things*". The interview provided Liza with an opportunity to reflect on her thoughts

regarding her long standing denial of the label of intellectual impairment and said, “*I don’t know if it was denial (pauses) but I couldn’t say the words*”. Language is used to speak into existence the disability and place Lily into the category of ‘Other’. By stating that Lily had a learning difficulty meant to Liza, that there was nothing “*wrong with [Lily]*” and therefore “*she would just go to school with the other kids*”. Liza notes, “*I never had a desire for her to be in any sort of special school*”. Here Liza clearly speaks to her belief in inclusion as being in a ‘regular’ classroom “*with the other kids*” and away from a special school.

During Lily’s primary education she was dual-enrolled in a State primary school, as well as an SEU which was on site. Lily, however, attended only the regular classrooms. Liza considers this dual enrolment was “*so they had numbers for aide time*”, that is, funding would be available for teacher aide support. Liza explains, “*I specifically said that she would not be part of the Unit. Not go back to the Unit or have time out in the Unit or anything like that*”. Liza’s attitude and desire for an inclusive education is clearly stipulated and she positions herself with power and authority as parent to make the choice of an inclusive education.

Liza reiterates many times throughout her narrative the importance of an inclusive education for Lily. However she also points out the active role she played in order for the inclusion to happen:

It was important [to me] that she was seen as another kid in the class and generally that happened, but it happened because I was there all the time, and because I had expectations and I would lead the meetings and the IEP.

By the time Lily reaches Year 6 Liza transferred her to the Catholic Education system due to difficulties being experienced with reducing teacher aide time and increasing inconsistencies in her programming by teachers in the State system. Liza states that maintaining Lily’s inclusive status was also beginning to become difficult. She reports that while the SEU staff members were generally supportive of Lily being included, there were also tensions of which she was aware:

They may have talked behind my back and not been so supportive but they knew me well enough not to even broach that [returning to the SEU]. I think they were pretty supportive but there were things they wanted to do. See I was very keen on her learning typing and that was fine, but I just found the teacher who was supporting her from the Unit was not someone who believed that she could be educated and do these things. She would say it, but she never believed it; in her

actions and in some of the things she said, it just grated. And Lily could even see that. [The teacher] would always see the disability first.

A tension between professional/parent is evidenced in Liza's comments, yet Liza positions herself as able to make decisions, as one who takes agency and resists professional expertise. She actively rejects the spaces of the SEU and the subject position she has taken up in the discourse of education is clearly stated. Yet despite Liza's positioning, (special) teachers' attitudes impact significantly on the way Lily is positioned in educational discourse and made subject as one without ability in the learning of skills. While Liza expresses clear learning objectives for Lily (e.g. learning to type), her power and authority is in tension with the professional implementing the program.

It is not only the attitudes of the special education teachers that impact on how Lily is positioned within the school. Liza expands on her perception of the importance of teachers' attitudes in the regular sector:

Some [teachers] were great and some were not so great, and I think it just comes back to that basic innate things that people decide whether these kids are worth it, or not worth it. There were some teachers that thought they shouldn't have to have these kids in the class and there were other teachers that were just fine. Those were the teachers that would automatically have expectations, and they're teachers that Lily would rise to the occasion.

Liza's words bring to the fore the dominant negative constructs of disability which may be taken up by some teachers, reflecting Slee's (1999) comment that teachers get their ideas about disability from non-disabled people. Some teachers' 'knowledge' of disability is informed by discursive practices of ablism impacting on their attitude to children named with a disability being included in 'their' classes.

Teachers' attitudes have a bearing on successful inclusion practices (Mastropieri & Scruggs, 2001). Murray (2000), the mother of a child named with a disability and an academic, comments:

A major impediment to a child's inclusion in the class and, therefore, the school, were the fears and anxieties of the teacher concerned. Such fears and anxieties, although perhaps understandable, are allowed to dominate in a system which does not value all children equally. (p. 695)

Similarly, the notion of worth, of a person's value of being lesser if they are named as having a disability, particularly an intellectual impairment, is intrinsic to Liza's

storying. Not only is there a clear binary of regular/special visible in education discourse when Liza speaks of teachers “*having*” Lily “*in*” the class, the spatiality of disability, and its landscapes of inclusion are also contained in her words. The words inscribe Lily as being ‘Other’ and being allowed in/to a regular classroom. Lily is positioned outside of ‘regular’ in the language used. Discursive and physical spaces of special education influence the attitudes of ‘regular’ teachers, and also of special education teachers; attitudes which are informed by socio-cultural constructs.

While acknowledging an inclusive education “*is work*” for the teachers Liza counters by stating:

[Lily] should have the same opportunities to learn as the others. It might take more work for her to have those same opportunities, and it might take more money and more time, but she should still be allowed to have them.

Liza continues by asserting her belief that it is the professionals within the discursive site of education that do not “*believe that these kids should be just part of the mainstream*”. She says that “*it’s easier to put them away somewhere and it’s fine to have them in for a classroom period for 20 or 40 minutes with an aide, because they [the classroom teachers] still have no responsibility for that child*”. Liza again raises the geography of disability as it is enacted in the discursive site of education. “*These kids*” have an(O)ther space to go to for their education, they are positioned as excluded and marginalised both geographically and educationally. The regular teacher is positioned as having no “*responsibility*” for “*these kids*” as they ‘belong’ in another, separate, space with their own teachers and consequent discourse of professionalism, knowledge and expertise.

From Liza’s perspective, the professional discourse in which a teacher is positioned means knowledges inherent in the discourse enable the teacher to develop strategies to teach and adapt programs to meet Lily’s needs. Liza asserts that “*all you’re asking is for that person [the teacher] to do their job*”, yet teachers say to her “*but I have no training in disability*”. Liza responds:

No but you are trained as a teacher and I am not. You are trained to teach. Surely all of the children in your classroom are not at the same level. You make allowances and you give extra work for gifted and talented kids. All I’m asking is that you do that automatically for this child who’s a little bit more out on that line.

According to Mastropieri and Scruggs (2001) successful inclusion does not simply require add on strategies; rather the teacher needs to commence with effective teaching skills, skills which are part of the expertise of education professionals.

Alongside Liza's belief in inclusion is her belief that Lily should be with her peers, and to Liza, Lily's peers are the children in "a normal classroom". Further Liza stipulates; that Lily's "peers are not a group of kids with disability. Nobody's peer is that. Our peers are a range of people across all sorts of races, backgrounds, trades, professions". Liza's belief that Lily should be in a regular classroom with her peers subsequently influenced her choice of High School. The Catholic High School eventually chosen was based on its published Mission Statement which stated that "they supported children and their individual abilities and encouraged them to achieve at their ability level, and they were valued". During the interview Liza reflects on the Mission Statement and how the stated goals of achievement of individual ability did not seem apply to Lily:

They [the teachers] just didn't want to do it. And I mean that sounds hard on them, and they say, "Yes but I wanted to, but I didn't have aide time, and but this, and but that", but in the end (pauses) she was not valued and that was the bottom line.

Liza felt that the school did not embrace the "fundamentals" – that Lily be "a valued member in the school, being valued for herself and her abilities and the belief that she had a right to be educated, and she could be. And that she had goals, and they were achievable goals".

In our final interview Liza reflects on her experiences of inclusive education in the Catholic High School and comments:

Liza: It could have been so easy really. Anyway, who knows, it wasn't meant to be was it, really? You can't change things (pauses). I don't know. I don't understand it. It's just so much easier, or supposed to be, when they get older, but it isn't, it's harder.

Valmae: The inclusion?

Liza: Yeah, yeah. And I can see that, like the gap is huge and all that, but it's such an opportunity to look at your basic fundamentals. ... To look at differences and embrace them. It's such an opportunity. But they, they won't move out of that comfort circle. It's just pushing them over the line and they don't want to do it. They want to talk about it, but they cannot model it.

Again there is the metaphor of spaces which the professionals with/in education inhabit. Liza speaks of a “*comfort circle*” suggesting an enclosed space that could not be breached, and of being “*pushed over the line*”. Both metaphors bring into play the boundaries separating regular and special education and the dance of education which is contained within each; a circle to stay in, a line not to be crossed. And each side of the binary continues to dance to the edges of their own spaces.

In her narratives on her experiences with/in education Liza also shares positive experiences with high school teachers who were willing and able to include Lily:

The drama teacher just did it. And that's frustrating 'cause you've got it sitting there in the palm of your hand. It works, look at it, watch it, but they don't want to see it.

There was a guy that came over from another school for a short stint ... the lesson was dissecting a chicken wing to see how it was working. ... Lily went into the classroom ... she wasn't going to school that often and he just said “Hi Lily. Do you know what this lesson is about”? She said, “No”. She didn't have a book, so he lent her his book and just made it really simple and said, “Have fun”. She talked about that for weeks. It was so easy. It was so easy. He just treated her like a normal person. He treated her with respect. He didn't make her feel like she was nuisance when she appeared at the door ... and he had an expectation that she would learn something from that day, and she did. It was easy, and he'd never seen her before.

These two episodes demonstrate Liza's earlier point (as well as Fulcher, 1989; Mastropieri & Scruggs, 2001; Slee, 1999) that teachers' attitudes towards/about students named with disabilities impact dramatically on the students' education and placement in regular classrooms.

By our third and final interview Lily had finished High School earlier than what had initially been planned. Lily contracted a viral infection at the beginning of the 2000 school year and had a relapse of her medical condition (detailed in chapter 6) resulting in prolonged time away from school. Yet it was the tensions and difficulties which Lily experienced at school, which eventually caused Lily to experience a “conversion disorder”. This subsequently led to the decision to finish schooling early.

Liza's storying of the difficulty she experienced in achieving successful inclusion for Lily during her secondary years in education may not be unique. The number of students named with disabilities drops when entering secondary educational spaces. The

EPSD (DOEM, 1998) provides a table of figures presenting the placement of students currently identified and receiving special education services. Intellectual impairment constitutes the highest number (although conflated with students with autistic spectrum disorder) at 7065 in 1997. The numbers of students with disabilities attending regular secondary schools drop in all disability categories. Nine per cent of all students across all disability categories receive their education in regular secondary school settings compared to 36% in primary schools (p. 9).

☞ **Sandra's story: *Like one of the kids***

Sandra commences her storying of education with Melanie's attendance at early intervention at a State preschool just after she turns 3 years old:

That [early intervention] was a really weird situation because I really didn't know what to expect. Things sort of came to me gradually that now I think, "Why did I ever put up with those situations". For a start, the kids with special needs started ½ an hour after the regular kids and finished ½ an hour before the regular kids finished ... but they weren't included in the regular program. It was a separate program. And in those days we were focussed with [therapy]. We needed them to be having all this constant therapy so that they were maintaining their range of movements, and that was important.

Sandra's words echoes my questioning of the geography of disability in early intervention, the separate places and spaces inhabited by early intervention and preschool which I (re)presented in the beginning of this thesis. While I was being told in my positioning as teacher aide, that we were providing integration, what was visible to Sandra as mother, was the division and segregation between the preschool and the early intervention group. Sandra highlights the tension she perceived between the need to provide a therapy program, yet also provide a program which included the 'group' of children attending early intervention with the rest of the preschool.

Of particular interest to me is Sandra's comment concerning the difference in arrival and departure times. My memories from working in this early intervention group was that children with special needs were not allocated the same amount of time, including teacher aide support, at school as the preschool children, hence the difference in start and finish times. However unbeknown to me, this was a concern for two of the mothers

from this group who spoke with me during the research process. Both of their narratives of education point to a lack of knowledge concerning the ‘why’ of the difference in times between the two groups. They both perceived their children as being hidden from other mothers. As Sandra says, *“I don’t know that any of the parents ever knew that there were children with special needs in that group, which just absolutely horrified me”*.

The discourse of professionalism can be seen to influence Sandra’s passive acceptance of a situation with which she did not feel comfortable.

In those days I still felt like I didn’t have the knowledge or the experience of what was best for Melanie and I was looking to people in the field who had obviously worked with children with special needs for years and years and know what the best thing was for them. You’re constantly told that this was the best thing to do.

Sandra’s positioning is visible through her lack of knowledge in the system; she is positioned, and positions herself, as requiring professional expertise. Within this acceptance is the taking up of the position of ‘good mother’ who is responsible for doing the best for her child. While accepting the discourse of professionalism at the time, Sandra is able to reflect on and share her concerns about the program during the interview process.

After 2 years of early intervention, Sandra requests that Melanie attend a regular State preschool. By sharing Melanie’s funding with the funding received by another student named with a disability, a full time aide position is available for both students to access a regular preschool full-time. Sandra comments that this was *“the best year Melanie had in the State system because she was supported just in the regular preschool”*. She adds that Melanie was treated by the teacher *“like one of the kids”* while allowances were made for toileting and other basic needs. The importance of attending the physical spaces of the regular preschool, and being treated as a child with individual needs, rather than as a child named with a disability comes to the fore in Sandra’s words.

Sandra then goes on to talk about her desire and subsequent struggle to achieve an inclusive education for Melanie from Year 1 onwards:

The first she’d [Melanie] ever been segregated from anything was when she went into the school system and that really didn’t sit comfortably with me”.

Like Liza, Sandra defines an inclusive education as one in which Melanie is considered a member of a regular classroom. Sandra explains that previously she *“had seen the [SEU] run ... as it was meant to be, with all the children out in the classrooms as much as possible and the resources all going out”*. Yet, Sandra tells me that with a change in teacher-in-charge of the SEU, the SEU gravitated back towards what Sandra perceived a more traditional model to be; one of children named with disabilities staying in the SEU except for short periods of time in the regular classrooms. This is reminiscent of Slee and Allan’s (2001) concept of co-location whereby the SEU is located on the grounds of the regular school, with some shared activities occurring.

Sandra explains that her desire for an inclusive education came simply from the fact that Melanie was part of the family; *“we had always treated Melanie as just part of the family. She wasn’t any different”*. It is this acceptance of Melanie that influences Sandra’s belief in including Melanie in the regular school:

I don’t even know how we came about how we felt we wanted Melanie included. I think she just, because she’s a part of our family, that the way we are we just always treated her like a normal, healthy baby. Not even that. That’s a strange sort of way of even describing any child, but just part of the family, just one of our daughters.

Sandra’s words reiterate Michelle’s’ earlier comment that parents desired that their child named with a disability have the same opportunities as their other children. Speaking specially about State schools, Sandra’s queries, *“I still can’t fathom why the State system has so much trouble coming to grips with having children with special needs in a regular classroom”*. It is the State system which Sandra *“battled against ... for the next 3 years”*. Sandra notes that there were teachers *“willing to have Melanie in the regular classroom because they believed that’s where her place was”*, yet there was little support from the system to achieve these goals. Sandra believes that at times the staff members at the SEU were actively obstructing Melanie’s inclusion in various ways. The tensions in blurring geographical boundaries are visible in Sandra’s narrative as special educators strive to preserve control over their area of expertise. In Sandra’s storying it can be seen that there were regular teachers willing to shift taken-for-granted educational boundaries and include Melanie. Yet the geographical and educational boundaries appeared in Sandra’s storying to be firmly held in place with Melanie located with/in special education.

Even though Melanie is enrolled into the SEU, Sandra believes that Melanie would be in the classroom for as much time as possible, “*in consultation with the teacher and the powers that be*”. Of importance is that the time Melanie would spend in a regular classroom was dependent on the professionals within the system. Sandra lacks power and authority to make decisions regarding placement and length of time in different settings and in these professionals spaces resistance is difficult. The power held by professionals over parents is suggested by Sandra when she refers to them as “*the powers that be*”. In Year 1 Melanie receives “*a token ½ hour every morning in the classroom*” signalling a discrepancy between Sandra’s understanding of as much time as possible and what seems to be ‘tokenism’ of ½ hour per day.

When speaking of the SEU, Sandra makes this comment, and in so doing reaffirms the sentiments of Liza:

None of them [children name with disabilities] were getting the opportunity to be with regular kids and learn regular behaviours and it was all just so horrible. Lumping them all together. I mean if they all had the same or similar disability and there was something to be gained from even working with them altogether for ½ an hour or something, well, well and good. But these were kids, maybe a dozen kids with a most diverse range, some of them with no physical abnormalities, but intellectual abnormalities. It was just awful. I just couldn’t bear to see her in there. Couldn’t bear to see any of them in there.

Both Liza and Sandra disagree with the policy of “*lumping*” students together in an SEU because they form an essential group of students named with disabilities; the range of impairment among the children is diverse and oftentimes the only commonality is being named as having a disability. Sandra questions how the students were to learn regular behaviours and goes on to tell how Melanie learns to produce a high-pitched squeal from another child in the SEU. Yet this grouping, the concept of clustering, based on disability continues in Education Queensland’s policy documents.

Sandra does not simply accept what is offered for Melanie’s education:

I think we always knew what we wanted for Melanie, but until situations came up where it wasn’t happening, [then] you had to realise the situation wasn’t happening, and then rectify it. So like once she started school and she started being excluded, that was foreign to us, because as a toddler, or as a preschool child, she’d always been included in everything we had done. So we’d come up to new situations where we’d, I guess have to step back and think, “Well hang on, I don’t like what’s happening here”. Then you’d have to gain the confidence to know that, yes I do want it to happen differently and then make that assertion.

Sandra positions herself as an active agent resisting the dominant discourse of special educational spaces and programs on offer. The experiences of exclusion of Melanie from regular education acts as catalyst for Sandra and Chris (her husband) to interrogate their belief structure about the construct of disability, and to resist being positioned as passive recipients of professional knowledge and authority.

As a point of resistance to Melanie's segregated education Sandra negotiates with the teacher-in-charge of the SEU, the principal and the Year 2 teacher to place Melanie in a regular classroom. Sandra speaks highly of the Year 2 teacher:

The teacher actually took a lot on because she had Melanie a lot of the time, she was in there a good part of the day unsupported. So she had buddies that would help her do things or she would just participate in group activities, and it was a good year. Melanie enjoyed it and (pauses) sort of adapted quite well to it.

I think it was a huge responsibility on the teacher because I felt she wasn't getting the support she was supposed to be getting. At that stage they were supposed to have 2 hours a week release time to access learning support teachers and all sorts of things. She didn't get any of that, she did it all her own.

In asking why the teacher did not get the support she was allocated Sandra tells me she believes there was a lot of "dissent" among the staff at the school:

I don't know where it was actually coming from but they weren't happy that one of the children with special needs was being mainstreamed. Actually there were 3 children at that stage being mainstreamed. ... They weren't happy that the children with high support needs were in the mainstream classrooms.

Sandra explains that as she was part of a regional parent group she was aware that regular class placement was an option (supposedly) available for Melanie:

I was on the regional parent group that met with the Regional Director, State Education, once a term with all our concerns of different situations and what was happening. ... He reiterated time and time again that there was a whole range of options available and that anybody could fit in wherever.

Sandra's belief, in/formed by her meetings with the Regional Director, is that "anybody", any child named with a disability, could be placed "anywhere", in a regular or special educational setting. Yet, so far in her narrative this does not appear to be the situation for Melanie and the "whole range of options" available are not visible in her storying. While retaining her own belief in inclusive education/schooling, Sandra also recognised that other mothers felt and believed differently and says, "there's obviously

people who do believe that [the SEU is] the best place for their children. And that's what the options are. You have the option of a special school, or mainstream, or anywhere in between". Sandra's belief is that when the Regional Director states that a range of options are available, this implies real choice for the parent to determine where their child attends school.

When Melanie is in Year 3 Sandra begins to explore placement options at the Catholic Primary School, however she is uncertain whether Melanie will be enrolled because of her severe impairments. Sandra describes the principal of the Catholic school as “*very supportive, totally supportive*” and the following year Melanie changes schools. Sandra reports that Melanie “*was a different child*”:

I didn't realise that she was so unwell or unhappy until we went to [the Catholic school] into grade 4. ... She just fell into it so beautifully and she started sleeping better and eating and growing. She was just so happy.

Sandra expands on the differences she perceives between the two education systems and the impact professionals' beliefs and attitudes have on the possibilities for inclusive education for children with disabilities. I quote at length Sandra's thoughts:

[The teacher at the Catholic School] was an experienced teacher [but] she had no experience with children with special needs. Nobody really did have any experience with teaching a child with Melanie's needs and they actually kept a journal that year, the teacher and the teacher aide. The first day was like, "Wow, we survived the first day", sort of thing. But the whole attitude was different. It was very obstructive in the State school where we were because the person who ran the Special Ed Unit at the time believed the children were far better off getting constant care in the Unit, even though a lot of their time, most of their time was taken up with feeding and toileting.

They [teachers at the SEU] focussed on things like trying to get Melanie to hold a spoon to feed herself. Now she never, she could do it occasionally, but in later years that wasn't important. We didn't even care. She could finger feed. She could eat to survive and hold a cup to survive. I mean whether she could use a spoon or not was irrelevant ... the focus was so different. ... At [the Catholic school] where they'd never done IEPs before we just sat around and had a dream session of what our dreams were and things like that, so it came more from the holistic view of what we really wanted Melanie to be able to achieve and how we could break it right down to where we are.

It's sort of hard to even draw parallels between the two systems and yet I'm sure it was just right down to the convictions of the principal and the actual teacher, and obviously the support. If we had more support in the State system, even in aide hours and things, although I don't think that would have made any difference honestly.

Education is seen by Sandra to be two entities, a binary, a regular education system and a special education system. While Sandra speaks of the issue of increased funding resources in terms of support, it remains her belief that successful inclusive practices come from the convictions of those intimately involved, in particular the principal of the school and the teachers. This echoes Liza's stories of teachers who were willing able to include Lily, and those teachers who believed she did not belong in regular school spaces, further illustrating Fulcher's (1989) statement that teachers matter. From Sandra's position, education is more than 'academics':

In the whole scheme of things I couldn't care less if she never held a pencil or could sign her name, or (pauses) could write numbers or anything like that. The main thing was that she was happy and content being a part of the scene and feeling in herself that she contributed.

For the 2½ years Melanie attended the Catholic school until her death in 1999, Sandra reports that Melanie "was deliriously happy".

☞ Therese's story: *She needs to live in the real world*

Like Sandra, Therese commences her storying on education with early intervention and follows a similar storyline noting especially the time differences between the preschool children and the children attending early intervention:

For us to have to arrive ½ hour after the other children, so that we wouldn't come into contact with the other parents and then have to pick them up early so that we didn't come into contact with other parents, it was like (pauses) our kids weren't worth being seen. And that was really hard. Or we don't want those regular parents to know that we have these sorts of children here.

I find it interesting that both Sandra and Therese remember the difference in start and finishing times of preschool so vividly. The separateness and spatial marginalisation they felt of their children being separated, as well as their perception of being excluded from other parents has impacted highly on their memories of early intervention. The reasons for the times, from my memory, are not what Sandra and Therese perceived. They read this difference as making their children, and themselves, invisible to the regular preschool parents. The espoused integration is also silenced in Therese's (re)tellings. Segregation still exists in a supposedly included, integrated, environment.

Despite the early intervention program being located and run within a regular preschool space, boundaries are kept in place ensuring the maintenance of the regular/special binary.

Therese then comments on the different situation she encountered at the regular State preschool that Kimberley attended, saying *“it was wonderful”*. Kimberley *“was never treated any differently”* from the non-disabled children and she was *“part of the class”*.

Therese relates an incident which occurred while Kimberley was in preschool:

I had a parent come up to me about week four, said to me, “I need to speak to you”. I thought, “Oh my God, here we go. It’s been wonderful so far. This is it. This is the bomb”. I said to her, “Yes, what is it?”, and she said, “I was talking to my son last night and he’s been prattling on about this little girl at preschool, how gorgeous she is and her name’s Kimberley, but she’s really tiny, mum. ... So when I came this morning I said to him, ‘Which one is she?’, and he pointed her out ... I just about died because he hadn’t mentioned the [medical equipment] or the wheelchair or the fact that she couldn’t speak. And I obviously now have to re-evaluate all my thinking about people with disabilities”.

Interesting is the little boy’s gaze. The visual, the gaze, which is so important in our socio-cultural construct to name, label, define and categorise people, has not yet impacted on the way he constructs his world and the people who inhabit it. His gaze highlights how we choose what to ‘see’ as important when we gaze/look, on/at people. He chooses not to see the wheelchair, the medical equipment, not to hear the speech(lessness). He sees and positions Kimberley as gorgeous and tiny. His gaze rests on what could be read as the positives of Kimberley, Kimberley as a person. A person complete with wheelchair, medical equipment and lack of speech.

I ask Therese, “where did the inclusion come from, the desire for Kimberley to be part of the regular school”? Therese responds similarly to Sandra:

I really believed that Kimberley had to live in the world and I had never, ever, ever, ever, ever hidden Kimberley. I went to the shops she came with me. I went to church she came with me. We went out to dinner she came with us. ... We have always treated her as part of the family. ... And so I really believe she needs to live in the real world and that was why I wanted her to be integrated.

The binary abled/disabled is perpetuated in the way we speak, constantly speaking disability as ‘Other’ into existence. Therese speaks of living *“in the world”* implying there is a different, an (O)ther world, for those named disabled; a world of invisibility, of being hidden from society’s gaze. *“In the world”* is the dominant space, the world as

read by the majority. As Therese emphatically stresses, she has never “*hidden*” Kimberley. Therese’s actions demonstrate a resistance to keeping Kimberley away from the public gaze, as Kimberley is made visible in the world in which Therese lives. This ‘Othering’ takes place with/in the spaces of education as well as in the surrounding social milieux. At the end of the above quote Therese once again speaks of “*the real world*”, the world which exists in the dominant discourse of ‘normality’ and speaks to an ablest society. Through ‘Othering’ two worlds are created each existing as the other is spoken into being.

At the end of the preschool year Therese attends a meeting to determine where Kimberley will attend school. As Kimberley has multiple impairments, a placement meeting is required, whereas this is not a prerequisite for non-disabled children. It is not a given as to which space she will attend, although it is usually expected and accepted that because of her severe and multiple impairments, her typical placement is the SEU. However, as Therese recounts her story I find myself surprised at what eventuated at the placement meeting:

Therese: We had a placement meeting. We weren’t given an option. We were told that Kimberley was not welcome in the Unit.

Valmae: Not welcome in the Unit?

Therese: Not welcome in the Unit. They refused to have her (pauses). That’s a turn up for the books, isn’t it Valmae? (laughs)

Valmae: Yeah

Therese: Yeah. They didn’t want the responsibility.

Valmae: The [medical issues]?

Therese: Yeah, so nothing to do with anything else. It wasn’t because they were thinking of Kimberley’s best interests and wanted her integrated (laughs), nothing to do with it. They didn’t want to have to cope with her [medical issues]. And that was it. So we weren’t given a choice. We were told ... she has to go into the mainstream. But she won’t get much aide time. So that’s the situation.

Therese explains from that subject position it became her responsibility to determine how Kimberley would be able to access mainstream education. Because of her medical needs Kimberley required a full-time teacher aide which is not typically provided by Education Queensland. Through meetings with Ministers from “*Health and*

Education”, Therese is able to access 5 hours per week aide time from the Health Department and 10 hours per week from the Education Department with an additional 5 hours coming from RDO time (Rostered Days Off). This means Kimberley is able to attend school for 20 hours per week – only when totally supported by a teacher aide. Therese calls on her subjectivity as teacher when she reflects on the time Kimberley is able to attend school:

Well, it was a statement that the Education Department made and I felt, fair enough, because Kimberley’s [medical needs] really were up and down and she can’t alter [them] herself. And I guess, as a teacher, I felt it was unfair to expect a teacher to have Kimberley in the class and having to keep one eye on her and her [medical equipment] and one eye on the other 29 kids. So I felt comfortable with that decision as long as she was going to get enough aide time to be there.

Therese tells me of the ‘politics’ which were played out in the spaces of regular/special education, and tells similar stories as Sandra regarding boundary keeping, despite the boundaries being reversed; in this situation Kimberley is excluded from the SEU. Therese explains how relevant information is not passed on to her; of not having access to toys and equipment through the Toy Library which comes to the SEU; and not being able to access the computer in the SEU. No support is provided from the SEU to the regular classroom teacher, even though time is allocated through education policy for such support to occur. She speaks of having to “fight” to be on the interview panel for the appointment of Kimberley’s teacher aide, necessary because of Kimberley’s severe medical condition and the possible life and death situations which could occur. Therese’s narrative of education was replete with stories of opposition from the staff at the SEU. Therese asserts that it is because she is positioned multiply as teacher and as a parent highly involved in education matters, as one who ‘knows’ the system that she has been able to fight within it.

Therese (re)tells how Kimberley’s inclusion is at one stage, feted as an example of successful inclusion:

The Minister of Education came up and he’d come out to the school and he’d come into Kimberley’s room, because this was the way inclusion should be. This was an example of inclusion working. And it’s working because of the support.

However 2 months later Therese reports on an IEP meeting which she describes as an “attack”, stating it was “scary”, “horrific” and “disgusting”. During this particular

IEP meeting Therese and her husband Simon, are “*attacked because we wouldn’t have Kimberley in the Unit*”. This about-turn in placement apparently is because aide time is to be reduced lessening the hours that Kimberley could attend school. However neither Therese nor Simon want the option of an SEU placement for Kimberley and indicate they would fight for aide time. Therese explains that Simon became angry at the IEP meeting and had to leave to attend work before the meeting finishes:

Simon said, “Well I’m going to have to go now, but I’m telling you now, over my dead body will Kimberley go into the Special Ed. Unit”. And he [the principal] said, “We want what’s best for her”. And Simon said, “That is fucking bullshit. You want what’s best for you. Therese and I want what’s best for Kimberley”. And with that he walked out.

Evidenced in this segment is a disparity and open conflict between what Simon and Therese want for Kimberley and what the professionals see as appropriate. The parent’s desire for inclusion clashes with the professional’s desire to place Kimberley into SEU spaces – a desire which, in Therese’s narrative, appears to be based on economic imperatives as opposed to best educational outcomes. Simon states clearly that he believes that the professionals care more about what will benefit the school rather than Kimberley.

While Kimberley’s inclusive placement was positioned previously as a successful model of inclusive education, resources and a discourse of professionalism combine to constitute placement in the SEU as now the preferred placement option for Kimberley. Besides Therese and Simon, there were 15 professionals involved in that particular IEP meeting. A “discourse of persuasion” (Fulcher, 1989, p. 27) was pervasive in Therese’s complete (re)telling, as various professionals attempted to coerce Therese and Simon, restating their belief that the Unit is now deemed to be the best placement option for Kimberley. Therese notes at that time children in the SEU “*were lucky if they were out of the Unit for half an hour a day*”. She goes on to say, “*there was no way I was doing that to her*”. At the end of the IEP meeting Therese says to the principal:

I’ve listened to what you’re saying but I’m telling you it’s not on for Kimberley and you can’t accept that decision. And let’s face it, it’s my decision where Kimberley goes, not yours. And if you won’t provide that service for her, well then she won’t be here.

At the end of our second interview in December of 1999, Therese tells me how she eventually became “*sick of this fighting ... to get aide time every 3 months*”, and had decided to move Kimberley to a Catholic school. At this Catholic school Therese and Simon had been asked and had decided that Kimberley would attend a regular classroom fulltime on Monday, Wednesday and Friday, and Tuesday and Thursday up until lunchtime. A significant increase in teacher aide support was made available increasing Kimberley’s opportunities to access and participate in schooling. Reminiscent of Sandra’s storying, Therese also speaks of the difference in professional attitudes between the two education systems. In our last interview in July 2000, I inquired about Kimberley’s attendance at the Catholic school. Therese responds:

She loves it. ... There’s no comparison, none. I can’t believe it (laughs). ... We don’t fight for things. ... Things are done for Kimberley without us requesting them. And if we request them, it’s, “Of course”, not, “Oh we’ll have to think about that”. It’s just (pauses) it’s amazing. I, I just can’t believe it. And it’s not just Kimberley, like the other kids at the school are treated exactly the same. Because I teach there, you know, you could think, “Oh it’s because she’s a teacher”, but it’s not. All the kids with special needs there are treated exactly the same way. So it’s fantastic.

The attitudes of the adults is, nothing is a drama. If there’s a problem it’s not insurmountable, it’s “How are we going to solve the problem”? So that’s really nice.

In the following segment Therese speaks of education as being more than just the academics and acknowledges the acceptance of the Year 7 teacher at the Catholic school:

The teacher’s wonderful. She expects Kimberley to be a 13 year old. She accepts the fact that Kimberley being immersed in what she’s teaching the class is a valued educational outcome. She’s not expecting that Kimberley has to write something to prove that she has knowledge. She’s just accepting of Kimberley as Kimberley, which is great.

Therese comments on the teacher’s acceptance of Kimberley’s immersion in the classroom as a valued educational outcome. Therese is able to look at educational outcomes both from her positioning as mother and also as teacher.

Like the stories (re)told previously, Therese’s story of education is an ongoing one; one which extends beyond the reach of this thesis. I do not know how Therese and Kimberley have gone on to experience the spaces of High School. I do not know if the

inclusive education achieved through Kimberley's primary years has continued. The mothers' stories dance outside the confines of this text.

For Liza, Sandra and Therese inclusion appears to mean complete placement in a regular classroom and they all worked towards achieving this ultimate goal for their children.

☞ **Serena's story: *To be amongst a normal environment***

Serena's narrative on education originates from her storying about the support group for autism that she was instrumental in establishing in Deira. She explains how the Education Department organised for "*a speaker on autism*" to speak to teachers, therapists and parents of children named with autism and of her attendance at that meeting. Serena recalls the speaker saying, "*they need other children around them to give them that normalcy, to show them how to be normal kids*". Serena remembers also being told:

The best thing for him, for his communication was to listen to other children speaking, was to communicate with other kids, was to see the other kids and how they did things on their behaviour; to learn from them.

Serena points out how she "*made significant inclusion like decisions*". Prior to this meeting Jason was attending a regular day-care centre 2 mornings per week and a regular preschool 1 morning a week. Jason was also attending an early intervention centre for 2 afternoons, and Serena reflects that "*there were only other children there with disabilities – no other children there, normal children*". Serena adds, "*I didn't want him just going to [early intervention]*".

Serena explains that part of the reasoning behind enrolling Jason in a regular day-care centre and the preschool is because she "*felt that the more that he was included the quicker that he would change. The quicker that he would get better, because he was going to be amongst a normal environment, normal kids*". Serena has already noted the advantages for Jason in attending regular settings in her previous comments concerning Jason's communication. While it might be read that Serena is denying Jason's autism in

her statement “*he would get better*”, Serena explains further that Jason would learn from the other children:

Even though it was very difficult for Jason to learn from other kids because he never took any notice, but if we could pattern behaviours with him by having a teacher aide explain it and go through it with him step-by-step. ... The more he was amongst them, the quicker he'd learn. That's what information I got. ... He didn't follow them; he had to be told how to follow them.

Serena also calls on her motherhood experiences with her other two children to demonstrate how being with peers would help Jason:

I felt there was real proof with that thing about other kids helping him, because I had two children – Jessie who was pulling Jason along and making him do things that I couldn't make Jason do. I also had James who was pushing him along. James would be going in leaps and bounds along in his development and Jason would have to be catching up to him basically.

By positioning Jason with ‘normal’ children Serena seeks to increase Jason’s skills in communication and behaviour.

Serena’s experiences with the Education Department have a different focus than the previous mothers. She perceives that autism was “*a new threshold*” within education and therefore people within the Education Department were “*compassionate*” and “*understanding*”:

They [Education Department] knew that they had to do something about it [autism] because they were going to get more of these kids. They had kids out there who weren't diagnosed, and the fact that there were going to be more kids going to be diagnosed. ... So they were realising that these kids were out there and [they were] going to need help with them.

The *EPSD* (DOEM, 1998) supports Serena’s storying that there were/are students named with autistic spectrum disorder already in the school system, but undiagnosed: “Currently there are 753 students who have been ascertained as having educational needs arising from autistic spectrum disorder. It is estimated there could be approximately 2100 students with autistic spectrum disorder within the education system” (pp. 9 – 10).

It is the knowledge that autism is largely unknown within the education system in Deira that spurs Serena into forming the Deira Autism Support Group, rather than a need for the emotional support often offered by parent support groups. Serena saw the

establishment of such a group as a vehicle for developing an awareness of autism within the discourse of education and affecting the professionals working within that discourse:

The reason I wanted to have the group too, from what the woman [at the meeting] was saying, [was] unless we're a group and we are a bigger number, because autism's not known out there, we would not get the support from the Education Department. We would not get the education that these children need. We would not get the teacher aide time or anything because it's not recognised, and the teachers also would not get the information that they need and the resources that they need, or the Autistic Association come up if we weren't recognised as a group up here.

Further, Serena explains Jason's future education is part of the reason she established the support group:

If my child's going to be educated, is going to need some sort of education, and be accepted in the school system, because I don't want him in a little Unit that's stuck out there, on his own, without being part of normal schooling.

Interestingly Serena brings into play the spatial references which abound when speaking of education/special education and disability; she did not want Jason to be in a place, a space geographically and metaphorically "stuck out there". She perceives that being "out there" is not "part of normal schooling", thereby accentuating the boundaries and landscapes of exclusion which exist in the binary education/special education.

The interrelationship of Serena and my lives is revealed in the next part of Serena's narrative on education. Serena moves on in her storying to talk about Jason's inclusion in a regular in Year 1 classroom. I was the special education teacher in the SEU attached to the regular school at the time, and I embraced inclusive education principles. However my experiences in the SEU were fraught with difficulties as I attempted to break the boundaries between the regular and special spaces. Teachers within the regular setting opposed my attempts to change the spatial arrangement of children named with disabilities, resisting efforts to have students with disabilities included into the clearly defined spaces of their classrooms. Serena notes, "I remember the struggle you had with the teachers of having kids included, and Jason was one of them". She adds that some (but not all) of the other students had more severe impairments which increased the difficulty of achieving inclusive placements.

However Serena believes that the ethos and acceptance of that particular school community towards including children named with disabilities has changed over time:

It's amazing now compared to then, how far it's [inclusion] gone. It's almost like, "What was the issue all about really? Why was there the problem"? These kids should be accepted, because they can work out programs for them, which is best for those kids. ... And it's a really caring community, the school.

As in Liza's story, Serena also suggests that regular teachers are able to adapt programs to cater for children named with disabilities within the regular classroom. Serena explores the time children spend in a regular classroom and like mothers in the previous stories, Serena draws upon the metaphor of space as she continues speaking to the binary of regular/special education:

It might be some time out of the classroom but it might be most of the time in the classroom. But don't put them out first. Bring them in. Work it round the kids being in there, then look at how best to have them in or out of the classroom. Don't automatically assume that they've got to be out. And that's what's happened. Now all the kids are in [at this school], except for the time that they go out for their program, which is better for them.

The language of "out" and "in" confers status upon the children; those who belong are described as being 'in', and those who by being named disabled are 'out'. Speaking of the regular classroom as being "in" gives voice to its dominant position in the discursive site of education. Serena also speaks to the dominant practice of placing students named with disabilities into SEU spaces as first option. Even though the SEU is on site, situated on the same grounds as the regular school it still bears the stigma of being "out". Regular classrooms are situated as the norm, and the SEU is outside this space. The geography of separate and named spaces continues the dualism of regular and special education.

It is proposed that "space is socially produced to exclude disabled people" (Kitchin, 1998, p. 345). Kitchin (1998) also uses the words 'in' and 'out' to explain how space is socially produced, as too does Sack (1993) when he notes that "in or out of place refers to territorial control as constitutive of social relations and power" (p. 2). The language Serena chooses in describing the spaces of education echoes those of Kitchin and Sack, and highlights the social production of disability and power relations within the discursive site of education. Serena continues the spatial metaphor as she goes on to reflect on how much non-disabled children have benefited from having children at the school:

The kids have learnt so much from it, from having that care that they have for other children. Not being afraid of them. There's kids in wheelchairs ... they're

just like one of the other kids. Everybody's different. They see that everybody's different. If adults put them into a separate box, well then the kids are going to. Then the kids fear them, they think, "Well what's wrong with them? I don't know how to treat them. I don't know how to say hello to them. I don't know how to talk to them".

The metaphor of a box that Serena speaks of is powerful. It speaks to spaces and boundaries of education, and of a greater socio-cultural discourse. A box can be read as something that encloses and contains, a space with given boundaries. Yet too a box can be opened and that which is in be allowed out. Serena perceives that by removing the 'box' the lack of knowledge about disability in education can be replaced by new/different knowledges, that the fear can be removed, and that the children's gaze will see disability differently.

Serena continues to speak to the shifting discourses of education that have been developed by the previous mothers' narratives yet she attributes part of the shift to societal changes:

My attitude when I first heard about kids with disabilities [was] that they were going to be in normal schools, because society was going that way anyway. I went into [education] at a level where it was changing. Where society was changing, yet I was still hearing a lot of horror stories. ... I was going to latch onto the positive and just keep on seeing Jason in mainstream school. ... To me society had changed before Jason was diagnosed.

Serena acknowledges the "horror stories" about segregated education but actively chooses to resist this narrative, instead taking up a discourse of positiveness concerning Jason's education. However, by our last interview in 2000, funding for teacher aide support has been reduced, impacting on the programs available to Jason. Following is an excerpt from our conversation:

Valmae: What support does he get in the classroom now with aide time?

Serena: *I think it's only like 3 hours a week. I think it's been reduced dramatically.*

Valmae: On level 6? [The highest allocated level for funding and resources]

Serena: *Yeah, 3 to 4 hours per week.*

Valmae: It's gone from 10 hours?

Serena: Yeah, yeah. It's gone right down (pauses). So he's out of the classroom a bit more with the SEU teacher. Yeah. And he should be getting more in that classroom. ... But with [this particular teacher] he does need that more support.

With reduced teacher aide time, support to both Jason and his classroom teacher is compromised and this lack of support has limited the amount of time Jason is in the regular classroom. Jason's educational opportunities are changed because of reduced funding to support him in the classroom, not because the SEU is the best place for him to achieve. Decreased funding hinders Jason's educational opportunities in a regular classroom. Funding can be seen to influence the spatial arrangement of students who are 'Other'. It is not a given that students named with disabilities will receive their education in a regular classroom, or school. The level of funding allocated to supply teacher aides to support students in the classroom appears to remain of paramount import in the inclusivity of education in Queensland.

☞ Susan's story: *Given the option*

Susan does not speak in detail about Laura's education. In our first interview in June, 1999, I learn that Laura is in regular Year 2 classroom and ask Susan why she chose an inclusive education for Laura. Susan explains that Laura "*went through a preschool system where she was totally with disabled children and it was very non-stimulating*". Laura's physical impairments mean she is dependent on her seating position to see what is happening around her to receive stimulation. Susan believes that many times in the preschool Laura was placed where she could not see or interact with those around her. Susan says of the segregated preschool, "*she might as well be in her room on her own*". Having observed Laura interacting with her sister and friends, Susan feels that Laura reacts to the stimulation provided by having non-disabled children around her:

Laura was far more responsive when she had abled-bodied children running around all in front of her. ... She's so much more alert and interested if they're including her, than if they're all stuck in a line in these chairs and can't interact with each other, and that's the way it was set up.

Laura's experiences at preschool influence Susan's decision to request an inclusive schooling placement.

Laura has similar medical requirements as Kimberley and also requires a full-time teacher aide to attend school. Susan (re)tells how she is presented with options for Laura's educational placement:

We were basically given the option. How do you want to do it? Obviously if she's put in the Unit then she can go to school full-time and be in the Unit, or you can opt for inclusion and take whatever aide hours are allocated and that's your lot, but she'll be in the classroom with the other kids.

Susan makes the decision to place Laura in a regular classroom despite a reduction in time spent she is able to spend at school. Susan explains:

Laura's really more a child that needs quality short time, one-to-one to know that her safety's ok. I think integrating her with an aide is the way to do that, even if it means she went for less time.

Laura attends school for 20 hours per week, the amount of time that she has a full time teacher aide allocated for her, and this means that she has 1 full day at home, 2 half days and 2 full days at school. In Susan's storying there appears to be no discussion of a continuum of placement options.

In our interview in December of 1999 Susan talks about teacher aide support and tells me how "they're always threatening to cut it back" and how this was "threatened" a "few month's back". However she tell how both Therese and herself had their paediatricians write letters to Education Queensland on the basis of their children's safety because of their high medical needs and thus were able to continue with the allocated aide hours. On my return in July 2000 however, I am informed that the funding for aide time for Laura has been cut right back, "like everybody's":

We've agreed to do part time in the Special Ed. Unit, in the support unit. But she gets farmed off for music ... and [the aide] doesn't necessarily have to be with her then. So we give the mornings with [the aide] ... and try and make that mostly classroom time I think so she can help Laura with just involvement in the classroom and then the afternoons tend to be more in the support room and on the computer and stuff.

Laura's day is now split between the classroom and the SEU; "prior to the funding cut it was with [the aide] in the classroom, but we can't do that anymore". While ideally needing one-to-one support even to be in the Unit this has been reduced and Susan notes that "many, many letters" have been written regarding "compromising [Laura's safety] and making it a lot harder for the teachers at school too". As she says "there's been a few letters gone back and forth to the Education Department about that and how it's

incredibly unfair to actually cut aide time to these children [with high medical needs]”. When I ask about the outcome of the correspondence, Susan replies in words that many mothers in the study have used in connection with inclusion and education; *“nothing has changed as yet. I think it’s an ongoing battle”*.

Susan’s narrative has shown how funding issues have gradually eroded her desire and the initial achievement of an inclusive education for Laura. The choice she was given when she first enrolled Laura has been taken away. Susan is positioned as now not having choice, or of a choice that is not one she preferred and stated at the beginning of her narrative. Once again the relationship of teacher aide support and placement options comes to the fore. In the beginning of Susan’s storying educational placement was an either/or option, again situating education in its geographical distribution. As financial support diminishes for human resources, particularly teacher aide time, so too do inclusive education opportunities and Laura is returned to the spaces of SEU. Inclusive education is Susan’s place of choice, yet is denied through economic restructuring.

The narratives of the above women demonstrate a desire for inclusive education for their children. They espouse a variety of inclusion positions ranging from total inclusion in/to a regular classroom, through to partial placement in educational spaces designed to meet the particular and individual needs of their child. Other mothers told of their struggles to have their children moved from total segregative practices to being geographically located in the same physical spaces of regular education, but not necessarily in the same classroom. In their collective storying there is a sense of the historicity of educational development of inclusion, the continuum that is purportedly available for students named with disabilities (although this is not an *a priori* given) and the resistance and advocacy of the mothers in battling for educational change. However, as was illustrated, the educational placement options available to the children continue to have incredibly strong links to the provision of human resources, rather than to systemic changes in schooling, or the students’ education needs.

Disabled schools for them (Julia): entering the discourse of education

A chapter in the recent book, *Exceptional lives: Special education in today's schools* by Turnbull, Turnbull, Shank and Leal (1999) outlines four phases of inclusion in the area of school reform in the US. In particular, they draw attention to what they term “first-generation inclusion” whereby students named with disabilities were ‘simply’ moved into regular classrooms in their local school as an add-on attempt at including all students in regular schooling. The add-on attempt at inclusion can be clearly witnessed in the stories of the above mothers whereby their children were at times placed/located in regular classrooms, albeit often after considerable struggles with the powerful machinations of educational bureaucracy. Educational professionals ‘allowed’ some children named with disabilities ‘in/to’ regular classrooms and oftentimes this was named as ‘inclusion’.

Turnbull et al. (1999) further propose that a “second-generation inclusion” is the current status of inclusive education, which has at its basis school-based reform and systemic-wide changes in the school system. Education Queensland policy documents suggest that inclusive schooling means schools will value and include *all* students by providing flexible curriculum options that will allow students named with disabilities access and participation (DOEM, 1998). While Turnbull et al. (1999) contend that special education is not a place it is an educational service, they expand by stating that in second-generation inclusion students should begin their schooling in the general curriculum. The following narratives on education are from women whose children were in early intervention programs in 1999 and 2000 when the interviews took place. At the time they were at the beginning of their interactions with the discourse of education. It is questionable from the following women’s storyings, whether their children will automatically be geographically placed in the general curriculum as espoused by Turnbull et al., or whether they will continue to be caught up in the apparently divisive and discursive boundaries of regular education/special education as allowed for in Education Queensland policy documents.

The stories of Oranea, Robyn, Melissa and Julia are shorter and more exploratory than those which went before; these mothers are only just beginning to learn the movements

of the dance of education. Indeed, the system into which they have entered is a changing discursive site to the education discourse mothers with older children entered and experienced. Social and political changes impact on how the system is experienced; how mothers are therefore constituted, as well as how they position themselves with/in the spaces. They enter at different points in the dance, in time. The rhythms change and the dance alters, but are the steps the same? Do the discourses that constitute regular education/special education remain constant? How will these mothers now entering the discursive site of education go on to experience educational spaces after the textual end of this thesis?

☞ **Oranea's story: *Just to be himself***

At the time Oranea and my first interview took place in June 1999, Oranea's 5 year old son, Michael, is attending a special education preschool as well as a cluster group designed specifically for children named with autism. Oranea speaks from her expert knowledge as mother and knower of Michael; one who understands who Michael is, and how he behaves. Inclusion was not of importance to Oranea at the time of speaking with her and she explains why she prefers Michael attending the cluster group where she believes Michael learns best:

I'm very protective of him and with other children maybe, because I know him, he doesn't work well when there's so many children around him. It's too much for him and then he starts to run away or keep himself in the corner. But with where he's going [the cluster group], it's a small amount of children [and] that makes him more comfortable to do what needs doing. Just to be himself.

Oranea's nurturance knowledge is given priority in this segment. It is important to Oranea that Michael is in an educational placement where he feels comfortable and is therefore able to achieve in the program offered. In her understanding of who Michael is, she allows him to be "*himself*" and gives her perceptions of his needs precedence.

When I ask if she would like him to learn to mix with other children Oranea replies:

Oh yes, yes. But at this time, for me, I think that this time it's very important for him to learn better safely, in an environment that suits him to learn. Otherwise he'll spend all his time trying to run away and won't concentrate on why he's there.

Oranea portrays the spaces special education inhabits as safe, a place where Michael has the opportunity to learn. In doing so, she positions regular educational places as not providing an environment able to cater to Michael's needs. It has been acknowledged that there is a "parental reluctance to forsake the protective environment of a special school" (MacLeod, 2001, p. 191). Regular educational spaces are positioned in opposition to the safer places of special education. Oranea hints at the problematic surrounding inclusive schooling, namely that maintenance of the existing school system does not equate with the role of an inclusive school in providing safe learning environments for all students.

It is during this first interview that Oranea explains she is "*told to enrol him in a normal preschool*" by the teachers at the special education early intervention unit for the upcoming school term. When I returned for our second interview 6 months later, I ask Oranea how this placement has gone, and how she felt about being "*told*" to enrol Michael. She explains that as she did not know her way around the education system she was happy to be advised on the next step to take. Oranea accepts the expert knowledge of the professionals within the field even though she had previously stated her concerns to me regarding Michael's ability to learn in a large group of children. Oranea is positioned as lay and passively accepts the information and advice provided to her. The bureaucracy establishes its supremacy and power through the discourse of professional knowledge.

Oranea says how she is "*a little bit scared*" as she did not know "*whether the preschool would accept him as he was*". Oranea is aware that Michael has to be "*accepted*" by the 'normal' preschool personnel, it is not taken as a given. Michael is 'Other' and Oranea expresses concern that he will not be accepted in a regular school. This concern possibly arises from her common-sense knowledge as a non-disabled person who has been part of an ablest society. Oranea notes that "*he needs a little bit more than the other children. I mean he does things differently*". As it eventuates the preschool teacher "*has worked with autistic children as well, so she understand Michael's needs*" and Oranea reports on the success of the program.

For the 2000 school year Michael is enrolled in an SEU which is co-located with/in a regular primary school. Oranea explains that Michael will be integrated "*for a couple of*

hours to mix with the normal, you know, the other classes". Remembering Oranea's concerns about Michael being able to mix with other students I ask her where she would like the mixing with the regular classes to go. She responds, *"I think I'm comfortable for him to mix with regular classes providing that someone is there to help him when he needs it"*. The need for adequate human resources for successful 'inclusion' to occur is again brought to the fore in Oranea's words, and gives additional weight to the discourses of the previous mothers.

☞ Robyn's story: *First day at school*

Natasha is 4½ years old in June 1999. At the time of the interview, Natasha has no medical diagnosis, no label by which to name her. Natasha shows signs of delay in the areas of communication and mobility; she has no verbal communication skills and has begun to walk in the past year. Robyn explains that Natasha attends both an early intervention unit, as well as a regular day care centre. Two different services support Natasha at the day care centre and Robyn points out she acts as *"the middle man"* between the two services. When I ask how she feels about that she responds:

Oh that doesn't worry me because then I'm not left out. At one point there they were interacting with each other and I wasn't even knowing what was going on. And that's when I sort of stepped in and said, "Can someone tell me here what's going on"? So now it all goes through me. ... It's all on my head.

Robyn adds *"it was sort of like, this is my child. I'd like to know what's going on"*. Robyn's subjectivity of mother comes to the fore as she takes actively takes control of the events concerning Natasha.

When I ask where Natasha goes after the special education preschool unit, Robyn's answer depicts her uncertainty regarding Natasha's education:

I don't know to tell you the truth. Once she's at a certain age, I don't know. I know that next year she's booked into the actual preschool, so I think because they're next door to each other, I think the preschool actually interacts with the Special Ed. Unit, so that helps them. I don't know what age that is. They haven't actually spoken to me about it. I should have asked by now. But I think once she starts at the preschool that's it. She's at the age where she doesn't have to go back to the actual unit any more. But I'm not 100% sure.

Obvious in Robyn's words is her uncertainty about how the education system works. Again the bureaucracy of education is evident. Her storying is told in terms of what she thinks might happen, not what she knows. Additionally she tells of not being spoken to by the teachers, yet positions herself as responsible and taking the blame for not knowing when she says *"I should have asked"*.

Robyn's initial storying indicates that she has no specific beliefs about placement and is allowing the professionals to guide her. She says, *"I think it will depend on what level she's at when the time comes"* in answer to whether Natasha will attend a regular school or an SEU. However in the following statement it becomes clearer that Robyn would like Natasha to attend a regular school:

See, I'm hoping that somewhere along the line either at preschool they'll actually get her doing more stuff, like working with her with the alphabet and stuff like that so that she is slightly prepared if she does go into grade 1.

Later in the interview Robyn adds, *"I don't know where we'll go from here"*. I ask if she worries about this, if she thinks about the future in terms of Natasha's education, and Robyn replies, *"yeah, yeah, I wonder if she's going to ... go to a normal school"*. Robyn's use of the words *"grade 1"* and later *"normal school"* suggests that she is referring to a regular school placement rather than placement in an SEU.

Robyn goes on to describe what her dreams and her desires were prior to Natasha's birth, and then questions the present. Robyn's words are (re)presented in poetic format, taken directly from her transcript with minimal changes from her verbatim speech:

First day of school

*I've always thought to myself,
"When I have a little girl
it'll be fantastic.*

*First day of school
send her off in her school uniform
with her little bag and lunch box
and all that sort of stuff"*

*I keep wondering to myself
"Will I have the chance
to dress her up in her little school uniform*

*and her little school bag,
with all her books”?*

*I don't know.
I guess it's just
if it happens,
it happens.*

*There's nothing I can do to change it
so I've got to take it as it comes.*

Robyn's words demonstrate a tension between her desire of a regular education for her child and the uncertainty of the future they both now face. Special education does not appear to be considered a part of schooling; it is not present in Robyn's storying as she wonders if Natasha will ever attend 'school' in her uniform with her school bag. In Robyn's storying special education is constituted as a space separate to school.

Robyn appears to passively accept expert advice regarding school placement, as she says, "*there's nothing I can do to change it*". There was no evidence in her interview to suggest Robyn was advised of the possibility of regular school placement and her uncertainty when she talked about where Natasha would go to 'school' supports this view. Her passive attitude, "*if it happens, it happens*", left me wondering who would advocate for Natasha after preschool.

➤ Melissa's story: *They espouse integration*

Melissa's son John is almost 4 years old during our first interview. John attends a special education early intervention group as well as a regular kindergarten. Melissa is actively seeking an inclusive education for John and is planning for him to attend his local Catholic school for preschool in 2001. She explains that she is hoping to follow the path of her friend's daughter Rosie, who has Down syndrome and is included in the classroom at the Catholic school:

Well we're kind of following behind Rosie, because Rosie [goes] to [the Catholic school] and it's going really well so far. And we're hoping that he'll be able to go there.

Melissa speaks of the segregation of children with disabilities if they attend SEUs in the State system, rather than regular schools. She perceives that although the language speaks of inclusive practices this is not the situation:

Although they espouse integration and things like that, in a lot of the schools, the Units don't really don't take children to the class, or there's not much classroom time because there's not the funding, the individual funding to put aides on kids. A lot of the teachers are not really trained to deal with it and to accept children into the class.

Melissa points out that not only are there economic and funding imperatives in supporting students named with disabilities, but that teachers and their attitudes and beliefs about disability also play a role in the acceptance of inclusive education. Melissa's words echo with the sentiments already acknowledged by some of the previous mothers' narratives.

➤ Julia's story: *I didn't know how to do it*

Julia's son Andrew is 3 years old when we have our first and only interview. At 2½ years of age Andrew begins to attend an early intervention unit as long as Julia accompanies him. Julia describes her reaction when she first took Andrew to the unit:

I remember the first day I took him there and I saw the other kids. I just wanted to pick him up and run. I was like, I don't want him to be here. I don't want him to be around all these really disabled children. I don't think it's good for him. I want him to be with normal kids. Then I was like ... now hang on a minute, [it's] not for you, not for what you want him to think. It's for him. He needs to be here to learn so that he can then go and be the normal kid.

This appears to be Julia's first 'visual' experience of a group of children named with disabilities. Andrew's disability is not inscribed on his body as he is diagnosed as having autism, his appearance does not inscribe his body. Julia works through her emotive reaction to determine that this is the best place for Andrew. Within her storying is the desire for Andrew to be with normal children and the belief that by attending the early intervention program now, he may in future be able to be a "normal kid". She explains this below:

This is actually doing it for Andrew and if we keep doing it now, then with any luck, hope, hope, he might get to function with regular kids and just be a regular little boy.

As Julia speaks of her thoughts after Andrew's diagnosis she clearly identifies the able/disabled binary, the dualism of two worlds that exist in society, and highlights education as one of these discursive sites:

I think you're suddenly like, "Oh my God"; you're like you've sort of changed from one world and then into another one. You know like disabled schools for them. And they needed extra help. And all this sort of extra help that we couldn't actually do it for him, and we couldn't just take him to regular services. ... I think it was a bit devastating. ... I haven't got a normal child; I have to go to all these places that you know you really hoped you wouldn't be going into.

Julia constructs disability as moving into another world. Not only is Andrew part of another world, but Julia positions herself firmly in this Other world as well. She has moved into a different space through Andrew. Apparent in Julia's words is a loss of her parenting subjectivity, "*we couldn't actually do it for him*", and as a consequence there begins a new reliance on the discourse of professionalism, of "expertism" (Bines, 2000) and one who knows; an extension of the clinical gaze (Fox, 1993). Also apparent in Julia's words is her readings of the binary of normal/abnormal when she says, "*I haven't got a normal child*". Social and cultural discourses of disability can be seen to impact on Julia's words. The geography of disability and the spaces it inhabits is visible and noticeable in the discourse of negativity attached to disability spaces; "*I have to go to all these places that you know you really hoped you wouldn't be going into*".

An aspect of concern for Julia in her storying was running of a playgroup at early intervention in which both children with disabilities and those without disabilities attended with their mothers. Julia explains that when the group first started "*the women ... understood that there were disability kids there. And there was this caring thing*". However Julia believes that the playgroup has become "*distorted*" as more non-disabled children attended, and the caring for all children has consequently disappeared:

I mean they get so wrapped up in, "Oh isn't my child perfect?" that it doesn't need that much help. They just don't even think. It doesn't even occur to them. You know like in the playground maybe Michael can't get into the swings, but he's standing there wanting to get in and there's a mother with her kid swinging backwards and forwards on the other swing, but she doesn't stop to help your child. ... I really wish there was this sort of common unity of let's all care for each other's children. It doesn't matter what's wrong with them or what's right. Just all care. That really upsets me a lot.

She perceives that as a mother of a child named with a disability she has increased her ability to care for all children regardless of their needs, "*I think when you have a*

disability child yourself you suddenly care about everybody else's children. You just care more because you realise that you can care more". Julia's words resonate with Landsman's (1998) study which found that for mothers "the knowledge gained through the experience of raising a child with particular disabilities becomes so generalized as to affect their attitudes toward all people with disabilities" (p. 10). Julia also positions motherhood as caring reinforcing a stereotypical and dominant subject position of motherhood. Julia looks for a discourse of care in her social construct of motherhood, an inclusive acceptance of all children.

If mothers come here with normal kids they come on the understanding that there are disability kids and they have to put some effort in and maybe they'll learn something, like I have, on what you've got to give to disabled kids. And that's the joy that have in helping them. If they can't walk properly, you help them walk and they love it. I just think they're missing out with that sort of narrow mindedness.

These four mothers have moved on from where I have positioned them with/in this text, and possibly how they are positioned within their motherhood subjectivity and the discursive site of education. The futures they spoke of in these pages will have shifted and moved as they interact with the discursive site of education. New dances will be choreographed on their lives and the stories they have yet to tell about education.

All these professionals (Diane): questioning the professional/parent partnership

The professional/parent relationship is particularly obvious in the discursive practices of (special) education. While parental involvement in a child's education usually diminishes as a child gets older and goes through the school system, this is not necessarily the case for mothers who have children named with disabilities (Murray, 2000). Elise speaks of this continued engagement in education:

If I think back to David's childhood, with the other children in the family while there would have been times when we had to have some direct involvement, I was never as involved in education as I have been in David's.

The women in this study mentioned numerous professionals with whom they have been involved in the discursive site of education. Murray (2000) suggests that there is "a

widely held belief that within education generally and within special education in particular, a partnership between parents and professionals is both desirable for and beneficial to a child's education" (p. 683). The policy document, *EPSD* (DOEM, 1998) also speaks to a partnership between parents and professionals when it states that the "responsibility for achieving the policy goals for the education of students with disabilities is shared by a partnership of schools, parents and the community, district offices and central offices" (p. 4).

The professional/parent relationship and parental involvement can be constituted through such processes such as the Individual Education Plan (IEP). According to Education Queensland's policy document the *EPSD*:

An IEP is negotiated and developed by a team which includes the student (where possible), parents/caregivers, teacher and other significant personnel. The plan documents the agreed learning outcomes for the next six months and the responsibilities of each of the service providers. (DOEM, 1998, p. 7)

Some mothers spoke of their first experiences of the IEP process as "daunting" (e.g. Diane, Sandra) and "intimidating" (Susan). The IEP process, while being one of shared decision-making, has a heavy reliance on professional input:

I didn't know what to expect. I didn't understand why there were so many people there. I thought it was going to be myself and [the teacher aide] and her teacher, and maybe one other person. It was whoa ... there were about 8 or 10 people in there. (Susan)

It's a very daunting experience to be involved in an IEP session. ... The first one we ever had with Melanie, there were 9 people present. Every person who had even looked at Melanie was involved in it, which I thought was absolutely ridiculous. (Sandra)

Kimberley's got a huge team. Kimberley has 2 parents that always attend the IEP meetings, she has the deputy [principal] normally, the teacher, the teacher aide, that's five. She then has the physio, the OT [occupational therapist] and the speech [pathologist], she has the 2 school nurses that come. That's 10. She has the Advisory Visiting Teacher, that's 11. (Therese)

The IEP can be seen to be an area in which parents can be collaboratively involved in decision-making regarding their child's educational program. Susan believes that most professionals involved in Laura's IEP have been "responsive" to her ideas for Laura's program. Likewise Serena comments that feels the IEP process has been a "two way

communication thing” and that she has “*always felt as if I’ve been a part of it*”. Many of the mothers describe how they have taken an active position with/in the IEP process. Serena explains that she did not feel as if she had any problems with the IEP process – “*I don’t think I have. ... If I did, I feel I would be fighting a dead horse, I didn’t feel that it was worth having conflicts with them*”. Tensions and contradictions exist in Serena’s words. She is part of a partnership, a collaboration, yet at the same time Serena displays an awareness of the professionals’ power when she speaks of the possibility of conflict. Serena positions herself as the one who has to avoid conflict, not the professional. While attempting to have a shared decision-making process, a discourse of professionalism operates which raises the spectre of power and authority. In her study of mothers, Read (2000) notes that women “may sense that they need to be very diplomatic and not offend people whom they feel have the power to make crucial decisions in their child’s life” (p. 118).

A clinical discourse is one in which the discourse of professionalism takes centre stage to determine individual student’s particular needs and advise intervention (Gilbert & Low, 1994). Students named with disabilities become objects of the professional gaze (Slee, 1999) and though professionals attempt to involve the parent/s in the IEP process they base their decisions and interventions “on professional knowledge which only they can authorise” (Gilbert & Low, 1994, p. 14). The professional discourse can create a barrier to parental involvement and partnership in the decision-making process and as such power relations become “implicated in the professional expertise of school personnel” (Gilbert & Low, 1994, p. 14). Therese’s narrative (re)presented earlier was exemplary of the power relations inherent in the IEP process. An IEP most typically takes place in the professionals’ domain, utilising their stipulative language and ultimately the professional retains control of available resources (Read, 2000). Additionally, the sheer number of professionals involved in the process can serve to heighten the already unequal power relations through utilising discourses of expertism.

To achieve an effective and efficient partnership between professionals and parent, a discourse of parity needs to exist. Yet many of the above women’s narratives did not suggest parity in the partnership. Indeed the overwhelming ratio of professionals to parent adds to the difficulty in achieving parity or a sense of partnership. The professional(s)/parent relationship is supposedly ‘in the best interests of the child’

which Murray (2000) describes as being a subjective goal. The professionals and parents do not necessarily come to the decision-making process with the same goals for students named with disabilities in mind. Therese, multiply positioned as mother and teacher, states that professionals need to accept that “*parents have the final choice*”. Liza, positioned as mother and therapist, also comments on the different goals and the moral ‘right’ of parents to make the final decision:

As a professional I’m obliged to say [what I think is best] but ... as a mother I don’t feel that it is my role to make it happen no matter what. ... I really believe that it is the parent’s choice. ... I see a lot of professionals actually working people into a position where the professionals made the choice.

Parity occurs when “each person’s contribution to an interaction is equally valued, and each person has equal power in decision making” (Friend & Cook, 1992, p. 6). However, as suggested in many of the above women’s stories, and despite the policy rhetoric of partnership, Case (2000) contends the professional/parent relationship remains one of disparity, with “the professional persisting in the expert role” (p. 287).

A metaphor of “*battle*” is often used to describe the interaction within the discursive spaces of education and this is a constant metaphor used by many of the mothers in the study. Metaphors “represent one of the ways in which many kinds of discourse are structured and powerfully influence how we conceive things” (Sarup, 1993, p. 48). It is interesting to note that the “*battle*”, or the “*fight*”, as it is often described, is frequently used in a discursive site that supposedly values collaboration with parents (DOEM, 1998; Murray, 2000). Mothers variously describe their interactions with education as “*traumatic*” (Diane), “*a battle*” (Sandra and Susan) and “*a fight*” (Liza and Therese). Read (2000) also acknowledges the metaphor of a battle in her study of mothers who have children named with disabilities. She reports that mothers talk of “battle fatigue” (p. 111) and describe how it is “necessary to fight very hard” (p. 50) and of “battles fought and won” (p. 121). The metaphor of a battle is symbolic of two opposing sides, pushing against each other striving to win their own war; sides which do not have the same outcome in mind. As explained by Sarup (1993) “in our society argument is in part structured, understood, performed and talked about in terms of war. There is a position to be established and defended, you can win or lose” (p. 48).

Trying to get maximum funding (Susan): the relationship between resource provision and inclusive education

Many of the mothers in this study spoke of their desire for inclusion in educational spaces – specifically many wanted their child to be considered a valued member of a regular classroom. For Liza, Sandra, Susan, Therese and Melissa, inclusion meant access to and participation in a regular classroom. While some mothers were happy to accept a range of placement options from the SEU to the regular class, others preferred their child to be educated in the spaces of regular education classrooms. Despite the mothers stated preference, one of the themes running through many of the mothers’ narratives is the strong connection between the amount of special education teacher aide time a child named with disabilities receives and the amount of time that child can be ‘placed in’ a regular classroom. For many children the limited time spent in the spaces of a regular classroom – with a teacher aide – determines the totality of their inclusive schooling experience. As evidenced in the previous narratives (particularly Therese, Serena, Sandra and Susan’s stories) physical placement does not necessarily relate to the best educational programs available to students, rather is correlated to the ever-decreasing level of funding available in terms of human resources, in particular teacher aides; the placement in regular spaces diminished accordingly with a decrease in teacher aide support. There appears to be a continual tying of inclusive education to funding issues, rather than educational programs and the individual educational needs of the child.

For some of the previous mothers, their stories demonstrate the integral relationship they perceive between teacher aide support and the ability of their children to access inclusive educational placements. The ascertainment process is used “to recommend the level of specialist educational support needed by students with disabilities. This educational support is provided by or accessed through specialist teaching personnel after the ascertainment process has been initiated” (DOEM, *SM-15*, 1998, p. 3). Part of the ascertainment process takes into consideration the availability of programs; another aspect is that of considering existing resources including human resources. While the level of ascertainment assigned to a child determines support personnel such as Advisory Visiting Teachers, therapists and specialist teacher support, mothers regularly

speak to the resource they view as most important to their child's inclusive opportunities; funding allocated to teacher aide time. Serena highlights this clearly when she says, "*resources meaning the hours of time they are able to be with the child*".

Ascertainment appears to be about "pitched battles for apparently scarce resources" (Slee & Allan, 2001, p. 179; see also Loxley & Thomas, 1997), rather than the determination of support for educational needs. Mothers are intensely aware that resource provision is tied to ascertainment levels, hence the need "*to suck as much funding ... out of the system*" (Susan). Evidenced in the stories (re)told by the mothers, funding is imperative to 'inclusion' and resource allocation to teacher aide time. As such, ascertainment, and its attendant allocation of teacher aide time, is problematic for the students' assigned level and educational placement opportunities.

The relevance of ascertained level becomes increasingly obvious and important when considering the regular classroom as a placement option. Barton and Armstrong (2001) suggest that "settings that are described as being 'provided for' or 'especially for' particular groups hide their role in segregating groups and individuals from ordinary social experience behind a discourse of solicitousness and accommodation" (p. 704). The constitutive power of language can be called on to separate students by providing programs "especially for" them. Inclusion is all too often based on the number of hours a child can be supported by a teacher aide in order to be allowed in to a regular classroom (perhaps better called 'integration'). A child ascertained at level 6 receives the maximum amount of allocated teacher aide time and this applies a perceived pressure on parents to have their child ascertained as requiring the highest level of support. This often means focussing on what the child is not able to do. In Diane's words:

I mean the basis is that to get the level of support that you need you have to almost (pauses) you have to focus in an ascertainment, you have to focus on the negative. On the aspects that they can not do.

Diane's words are highly suggestive of Allan's (1996) argument that "in a climate of resource constraints, distance from the norm has become valued" (p. 223). The medical model with its emphasis on individual pathology and deficit is implicit in the ascertainment process. Through the ascertainment process "the role of the expert professional advising on the pathological defects of the child and the structure of

intervention is reinforced, so too is the marginality of the disabled child” (Slee & Allan, 2001, pp. 179-180).

In(con)clusive schooling/education

Numerous spatial references and metaphors used by many of the mothers in this chapter signal the physical and metaphorical boundaries of the binary regular/special education and the separate spaces inhabited by each. Special education, particularly for children named with an intellectual impairment or multiple impairments, is ‘Other’ to a ‘normal’ or ‘regular’ education. In defining special education it becomes ‘Other’ and is marginalised, and oftentimes hidden from the gaze of regular students, as students are placed in special schools and SEUs. Regular education is spoken into being as the dominant discourse through the naming of special education. In referring to regular schools as mainstream schools, Swain and Cook (2001) propose that “there would be no such thing as mainstream schools in a truly inclusive system (as there would be no special schools – mainstream only having meaning in relation to special)” (pp. 186-187). Sandra alludes to Swain and Cook’s assertion during our conversation on education:

I personally believe, and Chris [husband] and I, we’ve talked about this at length for many years, that there should be no special education. It just should be called education. All education for any child who is assessed at different educational levels ... Special education to me almost makes it like non-education, a different sort of education.

Sandra’s words speak the binary clearly into existence and highlight the slipperiness of language-in-use; how a word such as ‘special’ has multiple meanings dependent on subject positioning within multiple discourses. As language-in-use the word ‘special’ “has certain connotations relating to difference in a negative sense” (Barton & Oliver, 1992, p. 72). Further, the word ‘special’ is seen to be divisive accentuating the binary able/disable as it has been used to “separate and segregate pupils from pupils. An individual identified as being outside of the range of acceptability is thus defined as special” (Baker, 1999, p. 72). Sandra’s words portray the separateness and the invisibility of the dominant discourse of (regular) education in the naming of ‘special’ education. ‘Special’ when used in the construct of education becomes negative.

Women such as Elise and Michelle (chapter 10) demonstrated a resistance to the dominance of segregated special education practice through their efforts to have their children moved from segregated special schools to onsite SEUs. Their resistance to dominant discourse in education is at the “level of the individual subject [and] is the first stage in the production of alternative forms of knowledge, or, where such alternatives already exist, of winning individuals over to these discourses and gradually increasing their social power” (Weedon, 1997, p. 107). Other women such as Sandra, Therese, Serena and Susan continue to resist separate educational spaces as they struggle in their desire to have their children placed in regular classrooms. However, marginal discourses, such as these mothers’ desire and struggle for what they believe to be inclusive education is limited by power relations which exist in dominant discourses and “is governed by the wider context of social interests and power within which challenges to the dominant are made” (Weedon, 1997, p. 107).

As asserted previously in this chapter, language such as ‘mainstreaming’, ‘integration’ and ‘inclusion’ used to describe, inscribe and place students in particular spaces is problematic. As ‘inclusion’ has replaced ‘integration’ in policy and as language-in-use (Swain & Cook, 2001) it must be noted that the applications of new discourses of inclusion do not overwrite the old, each existing with varying degrees of power (Davies, 1996). Despite the many mothers’ narratives reflecting desire for inclusive educational practices, the traditional construct of special education as a separate entity is visible in the silence. The word ‘inclusion’ is not used in Education Queensland policy documents and the use of variants such as inclusive schooling and inclusive curriculum means that inclusion as language-in-use remains problematic for those who are desirous of inclusive education for their children.

SECTION FIVE

LOWERING THE CURTAIN

Chapter 12

The (temporary) end of the textual performance: concluding thoughts

Disability identity is about stories, having the space to tell them, and an audience which will listen. It is also about recognising differences, and isolating the significant attributes and experiences which constitute disability. ... Theory has a part to play in this process. But (metaphorically, if not physiologically), it all starts with having a voice. As Foucault suggests, our task is to speak the truth about ourselves. (Shakespeare, 1996, p. 111)

And then we 'reword' the world, erase the computer screen check the thesaurus, move a paragraph, again and again. ... This 'worded' world never accurately, precisely, completely captures the studied world, yet we persist in trying. (L. Richardson, 2001, p. 35)

Taking up familiar story lines of mother/hood: revisiting the framework

My motivation for embarking on the dance of a PhD candidature was to bring to the fore 'voices' and stories I have argued are rarely heard; those of non-disabled mothers who have children named with disabilities. Their voices are neglected in the theorising by disability theorists and feminists (Corker, 2001; Lloyd, 2001; Morris, 1995, 2001; Sheldon, 1999). Simply put, my original intent when commencing this study was to listen to, explore, and investigate the stories the 15 women of the study had to (re) tell about the living of their lives with children named with disabilities. However, the stories as (re)told and consequently (re)presented could never be relegated to the 'simple'. The women's individual narratives derive from the highly complex interplay of language, power/knowledge, subjectivities and available subject positions taken up and/or resisted through dominant Western discourses of disability, motherhood, society, medicine, and education, to name but a few of the multiplicity of discourses in which the women participate. Because of the range of women and their ages, the stories as (re)told cover a

wide temporal and spatial span situating the women differentially in multiple discourses and providing insights across time.

This concluding chapter provides an opportunity to revisit the dance(s) choreographed from the movements of the mothers, as their stories were stepped out across this textual stage. Within this chapter I present a brief overview of the methodology I employed to discern the steps which eventually became the movements of this text, and I consider the use of poststructural and feminist theorising(s) on the narratives (re)told by the women who participated in this research project. Implications and considerations for the discursive sites of medicine and education are presented, as are thoughts on how the analysis can add to the body of disability and feminist theorising(s).

When I conceived this study I wanted to know: How does each of these women position herself, and/or how are they positioned within multiple discursive sites; what meanings do they give to their life experiences of mothering a child named with a disability; and how do they experience the physical and discursive spaces of disability in an ablest society? Parker et al. (2002) amongst others (e.g. Avery, 1999; P. Ferguson, 2001; Shakespeare, 1996) have called for the stories and voices of parents to be heard in the literature of disability studies, and I propose the results from this thesis contribute to that call. This study provides perspectives not often considered and voices rarely heard and thus adds to the sociology of disability studies, as well as having the potential to inform feminist studies.

I chose qualitative methodology to provide a basis for the study, a mechanism by which to interrogate the interaction between the women's experience of disability (through/because of their children), socio-cultural attitudes and spatial environments. The use of conversational interviews as part of this methodology provided a means for multiple stories to be remembered and (re)told, which were then (re)presented and choreographed to form but partial dances with/in the bounded stage of this thesis. Qualitative research methodology with its focus on personal meaning-making provided a vehicle to investigate how individual women came to (re)construct motherhood when mothering a child considered marginal and 'Other' by dominant motherhood and societal discourses. It provided an opportunity for the women to tell the stories that were important to them, to speak to their individual perceptions and experiences of disability,

motherhood and society. The “narratives of experiences” provided by these women therefore supply “important contributions to the continuing theoretical exploration of disability” (G. Williams, 2001, p. 124).

Previous studies concerning the impact of a child named with a disability on the mother (and/or families) were most typically conducted from the assumptive standpoint of the medical model of disability and were oftentimes quantitative in methodology, their questions predetermined. Studies often focused on stress and coping, denial, grieving, the dysfunctional family – the taking up of a common-sense knowledge of disability as a negative construct. By contrast, privileging the narrative allowed the women to (re)tell “the individual joys, pains, struggles and gains that caregivers typically only describe anecdotally” (Berg-Weber et al., 2001, p. 264). In their narratives the women in the study typically did not isolate the negative impacts of their lives or speak specifically to ‘stress’, ‘acceptance’, or ‘grieving’. Rather they (re)told stories in which the difficult times as well as the positives were interspersed in the living and (re)telling of their lives.

While providing compelling narratives with rich and varied detail, the stories have limited generalisability; they arise from a small sample of women and are context-dependent. Nevertheless the results from this study may be extrapolated to design larger studies. Future studies utilising the conversational interview with a narrative intent can investigate the meaning-making of a diversity of women; mothers from varied ethnic, socio-economic and religious backgrounds. Ideally, studies could also explore those significant others who are part of the family unit – father, siblings and other family members – and who did not form part of the design of this study. Further qualitative research is needed to examine families’ experiences on what constitutes disablement in the multiple discursive sites in which they interact, rather than continue a focus on the taken-for-granted negativity of disability. In particular the stories and ‘voices’ of fathers are seldom heard in the disability literature and would add an additional layer to an understanding of disability and the ways families who have children named with disabilities are discursively constituted.

The application of feminist and poststructuralist theorising(s) provided a mechanism by which issues of subjectivity, power, resistance, authority/knowledge and positioning were brought to bear on the narratives (re)presented. This afforded an opportunity to

investigate particular ways motherhood has been found to be constituted in this research and (re)constructed when the women are marginalised from dominant discourses of motherhood (Landsman, 1998). The story lines the mothers in this study have taken up resonate with the 'typical' story lines of dominant motherhood discourse. The women took up familiar story lines of 'good mother', intensive mothering and mother as primary caregiver. However there were differences between the women in taking up motherhood as full-time or part-time, but not necessarily because of the child named with a disability, rather as a result of the individual women's own socio-cultural belief of what constitutes a 'good' mother. The taken-for-granted discourses of motherhood are bound up in current Western expectations of being mother; motherhood discourses are taken to be 'normal' and natural. Yet the women also (re)construct motherhood discourses to take into account their children who fall outside the norm. Discourses of love, care and responsibility become enmeshed in their story lines. The motherhood the women desire and envisage prior to the birth of their child serves to in/form the way the women position themselves, and the subject positions they choose to take up as mother of a child named with a disability. This positioning as 'good mother' within a typical Western discourse of motherhood permeates the women's narratives and informs the way they position themselves in multiple discursive sites.

While many of the mothers' narratives spoke to various challenges and difficulties encountered in mothering a child named with a disability, motherhood was (re)constructed by nearly all the women in the study as providing both positive experiences and becoming a 'normal' part of their life. Many of the mothers deconstruct the discursive binaries of normal/deviant, able/disabled in their speaking and in the living of their lives. Most questioned what is 'normal', and found spaces for their child and their families; they argue "their children in from the margins" (Read, 2000, p. 120). In their taking up of subjectivity as mother, and choosing their motherhood story lines, their patterns of desire push against and challenge barriers which continue to view disability as 'Other'. Numerous stories spoke to new ways of thinking, new possibilities and imaginings that challenge dominant hegemonic common sense knowledge of what constitutes 'normal'. I contend that many of the women's narratives "supply a perspective on resistance generated within a politics of difference and of lived experience" (Fox, 1993, p. 105). As the women (re)construct their motherhood subjectivity their stories suggest their resistance to the taken-for-granted assumptions of

disability as tragedy. In doing so, they challenge dominant assumptions of motherhood with its attendant construct of the 'perfect' and therefore 'normal' baby/child as being essential for maternal fulfilment.

Exploring (re)constructed motherhood subjectivities "contributes to the knowledge of how motherhood is constructed in various contexts, as well as one of extensive maternal interaction with medical experts, new technologies, and government bureaucracies" (Landsman, 1998, p. 6). In this study motherhood is (re)constructed in the face of commonsense knowledge of disability as tragedy. One of the negatives that all the women spoke to in various degrees came through their interactions in medical discourses, education discourses, with multiple professionals, and in the locating of services and support. While individual women are able to speak of the positives of their child and their life, it is how they are discursively constituted with/in socio-cultural spaces which serve to increase the challenges they face in their daily lives. The mothers' narratives have the potential to add to the politics of a social model of disability, in particular in examining the power relations of professionals in multiple discursive sites and their role in perpetuating disabling barriers for children named with disabilities. Identifying barriers created through relations of power can help to dismantle power relations and create sites of resistance to hegemonic discourses.

The feminist focus I have taken throughout this study allowed the lived experiences of mothering a child named with disabilities to be spoken with/in the narratives the women told of mothering/hood. The study, however, considered one aspect of their lives as mothers; that of mothering and caring for a child named with disabilities. While this aspect has the tendency to become the defining feature of motherhood (A. Richardson & Ritchie, 1989) other aspects of mothering could be explored further in future studies. As the study evolved over the course of the interviews and analysis, it gradually became limited to narratives on medical and educational discourses. The emphasis on medical and educational discourses is consistent with the findings of Nagel and Raxworthy's (1998) New Zealand study of parents with children with visual impairments where similarly, stories of medicine and education predominated. The impact of the availability of residential and leisure services on the lives of the mothers and their children was (re)told to me by some of the mothers, yet did not feature in the thesis. This is an area which requires further exploration. Another area lacking in the current

research and highlighted by the results of this study is how parents conceptualise the future, particularly long-term future planning. How do parents plan for the future? What steps do they take in planning and who provides assistance? What supports do parents require to plan adequately for the various transition points in their life and their child's life? How can professionals best address the needs of parents who often live their lives 'day-to-day', and still be able to offer practical and moral support?

Adding the body: continuing the call for an evolved theory of disability

The power of the name penetrates the flesh and maps out for it a performance. (Butler, 1993, cited in Hughes & Patterson, 1997, p. 333)

The addition of poststructuralist theorising(s) with its attendant emphasis on language, power, discourse, subject, subjectivity and positioning also adds a layer to the body of work at the relatively new intersection of disability and poststructuralist studies established by researchers such as Corker (1998), Crow (1996), Hughes and Patterson (1997) and G. Williams (2001). Poststructuralist theorising(s) has been criticised for its potential for writing the body out of existence (G. Williams, 2001). Furthermore, G. Williams contends that the social model of disability is also complicit in writing out the body with its focus on the social construction of disability and neglecting the body in its theorising(s). This study emphasised that disability is constituted in discourses which have a bio-medical interest in applying clinical, disciplinary and surveillance gazes of/on 'impaired' bodies. Knowledges of/about 'impaired' bodies is "central to their governance and control" (Hughes & Patterson, 1997, p. 332), and this was evidenced in discursive sites such as medicine, therapy and education.

An alternate reading of poststructural theorising(s) is offered by Hughes and Patterson (1997) who state, "post-structuralists" suggest that "somatic sensations themselves are discursively constructed". Further they cite Foucault (1979, 1980) to explain that "impairment is fully cultural and the body is an outcome of social processes" (1997, p. 332). Throughout the thesis my desire was to keep the ('impaired') body visible, to look to how the body is seen, read and inscribed in multiple discourses; to acknowledge the

“social processes” which constitute the ‘impaired’ body and give rise to the social construction of disability. The use of poststructural concerns of power, language, subjectivity and position/ings with the women’s narratives has provided evidence of how professional authority, knowledge and relations of power have been inscribed on the bodies of their children. For as stated by Foucault (1980, p. 39) “power reaches into the very grain of individuals, touches their bodies and inserts itself into their actions and attitudes, their discourses, learning processes and everyday lives” (cited in Hughes & Patterson, 1997, p. 332).

As demonstrated throughout this thesis, non-disabled mothers who have children named with disabilities continuously interact within discursive sites which bio-medically constitute their children with/in individual pathology, and as such these mothers and their children are discursively situated in the theorising of medical sociology. It is problematic to write the ‘impaired’ body out of disability studies as the biological reality of their child’s individual impairment positions non-disabled mothers with/in multiple discourses such as medicine, therapy and education. These discursive sites continue links with the medical pathology of the individualised ‘impaired’ body.

The thesis has shown how the women work with/resist/reject the fluid boundaries and barriers of multiple discourses – the social barriers of disablement and medical/educational barriers of disability as individual pathology. While the existing sociology of disability has a focus on the social model, the analysis arising from the women’s narratives suggest a more fluid theorising is necessary, one which includes the biological impairment as part of the social construct of disability. The dualism of disability/impairment needs to be reworked and decentred to allow a theorising of disability that includes the medical rather than retain the status quo and continuation of the binary. The dualism disability/impairment is inconsistent with the complexity of lived socio-cultural experience: “The nature of disability is not merely the interaction between the person and society, nor is it the impairment itself, but rather a combination of both, varying with context and circumstance” (O’Day & Killeen, 2002, p. 11).

Maintaining ‘the body’ with/in a medical pathology serves to promulgate medical control and power/knowledge over ‘impaired’ bodies, and by association the women who typically care for those ‘bodies’. As the medicalisation and individuation of

impairment impacts in more sites than the discursive realm of medicine – such as educational spaces and social spaces of employment, residential and leisure services – an expanded theory of disability could work to deconstruct the segregative practices which derive from medical pathologising of the ‘impaired’ body. The social model of disability as it currently stands “denies the body an identity of its own and fails to acknowledge the child’s body as an experiencing agent” (Case, 2000, p. 283). The narratives of mothers concerning the embodied experiences of their children in multiple sites, highlights the role of the (‘impaired’) body in determining how the women and their children are positioned as subject. Additionally, through the taking up of story lines of ‘good mother’ the mothers oftentimes become subject to medicalised professional knowledge. A more evolved theorising of impairment within a social model is required to offer non-disabled women who have children named with disabilities alternate spaces in which to resist hegemonic practices of disablement they encounter on behalf of their children. Through such spaces and resistance a more inclusive society may become the ‘norm’ for those currently considered ‘Other’.

The discourse of professionalism and the women’s experiences

A discourse of professionalism dominated and permeated the women’s experiences in multiple discourses in which they are made subject. This thesis considered in particular, the spaces of medicine and education. The professional, disciplinary gaze of these discursive sites places the women’s subjectivity as ‘good mother’ under scrutiny and surveillance. The narratives presented in the body of this thesis reveal how having a child named with a disability increases interactions with a multitude of professionals which typically commence early in the child’s life and usually continue for the child’s lifespan. The relationships between professionals and the women were shown to be constitutive of unequal power relations with mothers oftentimes accorded lower status (Case, 2000; Clear, 1999a; Murray, 2000; Read, 2000). The women do not have “the knowledge, expertise or power to influence decisions, participate in interventions or negotiate the services” (Case, 2000, p. 271). Professionals have power/knowledge in the professional/parent relationship in the discursive sites of medicine and education which perform acts of boundary keeping and dominance of professional discourse. The vested

interests of professionals in maintaining their positioning and the “expertism” which is part of professional subjectivity are examples of power relations (Bines, 2000, p. 24). A discourse of professionalism positions the women as unqualified lay persons in opposition to the multitude of expert professionals (e.g. medical specialists, family doctors, nurses, special education teachers, regular teachers, therapists, guidance officers – to name but a few) with whom the mothers interact. By taking up the subject position of ‘good mother’ they become both subject and object of the disciplinary gaze.

Within medical discourse, many of the women in the study were subjected to the powerful discourses of professionalism as enacted in NICU and ICU spaces. In these spaces the mothers attempted to reconstruct themselves as mother in the light of a dis/placed motherhood and at times, and over time, position themselves as ‘lay’ expert in tension with professional knowledge, resisting being made subject in these spaces. Professional knowledge is determined through a scientific knowledge base not typically available to the lay person, and provides professionals with dominance in the professional/lay relationship. However there was also evidence in the women’s narratives of breaking down knowledge boundaries through the ability to locate relevant medical information and becoming informed and knowledgeable concerning their own child. Professional/parent interaction impacted on the women’s experiences of being mother, and on the taking up of motherhood in the public spaces of NICU. While there is a move to make NICU and ICU more family oriented there remains a need for professionals to be aware of issues concerning the dis/placement of motherhood in NICU, ICU and to enter into a dialogue which supports the taking up of mother in these spaces.

The discursive interactions women in this study encounter with therapy professionals cross dual professional boundaries as therapy moves between medical and the educational sites. There is an overlap in therapy offered in multiple spaces, and the positioning of mother in these discourses. Therapy takes place in traditional medical discourse in public places; however it also moves to the private spaces of home, as well as entering the educational arena. Mothers and their children are subject to a professional gaze in multiple sites through the therapy interventions carried out for/on their child. Many of the mothers position themselves in the discourse of therapy as ‘good mother’, as one who does all they can for their child and are also positioned as

para-professionals, performing physical, speech and occupational therapy in lieu of the (professional) therapist.

The discourse of therapy derives from the medical model and is informed by an emphasis on the 'normal' developmental milestones of the non-disabled child. The 'normal' becomes an embodied way of being that mothers try to achieve for their child as part of their subjectivity of 'good mother'. Yet simultaneously their child is inscribed as 'Other'. As a result of dominant societal construct of what constitutes normalcy, reinforced through medical discourse and health professionals, the women frequently feel compelled to endeavour to 'make' their children 'normal' through intensive therapy. Most of the mothers are positioned/position themselves as reliant on knowledge and authority of the medical model of cure and rehabilitation, particularly in the beginnings of their interactions with professionals. This positioning is oftentimes in tension with their desire of motherhood, the subjectivity of mother they have taken up as their own. While desiring to do all they can for their child as 'good mother', they also desire to love their child as a person first. This was emphasised in particular in the women's narratives on therapy where many spoke to their belief in their role as mother, that is, to love their child first and foremost. The following two quotes are representative of many of the mothers' comments:

I just wanted her to be part of the family and enjoy [her] (Sandra)

More than any other thing that child is yours to be part of your family and having fun is an important part of that, and being loved. (Liza)

Many of the mothers' narratives suggest a need for therapists to realise the mothers' desire that their children be accepted as they are, and for personal attainments to be celebrated, rather than the oftentimes (over)reliance on normal developmental milestones to label and inscribe the bodies of their children. A discursive space exists for the discourse of therapy to move from one of negativity, couched in the language of ablest discourse; a space for agency to celebrate positive achievements. In the professional/lay relationship mothers' nurturance-based knowledge should be acknowledged, positively valued and given credence so that the relationship between therapist and mother can work to meet the needs of the child and the family milieu.

The professional shifts from providing knowledge to a process of active engagement and negotiation with the mother (Murray, 2000).

The “training, attitudes, and behaviour of health professionals” towards people named with disabilities are “all vital because of the important role health professions play in many disabled people’s lives (often with physicians dominant)” (Basnett, 2001, p. 452). Future training of health care professionals should have more emphasis “on understanding the impact of attitudes and the environment on people with disabilities and how that can be disabling” (Basnett, 2001, pp. 462-463). Health care decisions which impact on people named with disabilities are made at a number of levels which may “enable or disable disabled people” (Basnett, 2001, p. 454). These decisions are the result of the taken-for-granted assumptions about disability being applied in the system, assumptions grounded in the medical model of individual pathology and disease as well as an essentialist discourse of disability as tragedy. Without a sociology of impairment, it is possible for the political role of disability as a socio-cultural construct to be neglected leaving health care professionals to continue patrolling their boundaries.

The (in)visibility of special education

Inclusive schooling ... is not about the same voices choreographing new steps for an old educational dance. (Slee, 2000, section 2, ¶ 11)

An unexpected outcome from my analysis of the women’s narratives was the addition of a consideration of the spatiality of disability, which is said to be neglected in disability studies (Imrie, 2000). The numerous metaphors the women chose to speak about their experiences of disability brought spatiality to the fore in my analysis of the stories (re)told. The term spatiality was coined by Soja “to refer to the fact that space is socially produced and interpreted” (J. Morgan, 2000, p. 276). The consideration of a spatiality of disability became particularly relevant in the women’s narratives of the discursive site of education where they frequently described their children as ‘in’ or ‘out’ of educational spaces. It is in reading the socio-cultural landscapes and the spaces inhabited by disability that “we are indoctrinated into perpetuating and reproducing the

meanings and messages that spaces convey” (Kitchin, 1998, p. 350). The consideration of spatiality adds to the body of work located at the intersection of disability and human geography.

Spatiality is implicated in disability studies where “the environment is regarded as the expression of power, a universe of discrimination and oppression within which disability is created” (G. Williams, 1996, p. 195). A political task becomes one of “understanding how resistance to oppressive power relationships can be realised” (J. Morgan, 2000, p. 281). Throughout the women’s narratives multiple points of resistance were evidenced; many of the women took up knowledge in foreign spaces of NICU, ensured their children were visible in public spaces as they lived their ‘normal’ life, advocated and fought for necessary services, and resisted segregated spaces of educational disablement (Slee & Allan, 2001) as they sought inclusive spaces in day care facilities, kindergartens and pre-schools, as well as attempting to achieve inclusive educational placements for their children.

It is suggested that special education is not a place (Turnbull et al., 1999); it is part of a historical change that has occurred in the education of children. However the meanings attached to the name of special education are laden with spatial overtones and societal value judgements:

The use of space, the designation of particular sites for particular purposes, the marking of boundaries, and the erection of frontiers are powerful processes in society and in education system to defining social relations within and between different communities. (Barton & Armstrong, 2001, p. 703)

For all of the mothers in the study, (special) education was (metaphorically, physically and discursively) a space into which their children were placed. Education is mutually constitutive of place and space in the narratives of the mothers. The places and spaces inhabited by special education were different, segregated and exclusionary from educational spaces deemed as ‘regular’. While it can be considered that the binary regular/special education is no longer conducive with/in the current terminology of ‘inclusive schooling’, it is the way the women spoke of education in their narratives. Mothers from Norah through to Julia, covering a temporal frame of 40 years, positioned education as binary, a system in which ‘regular’ education was considered dominant, accepted as the norm, and special was ‘Other’ to regular educational spaces.

The stories of education (re)told by the women help to display the development of educational services for students named with disabilities in and around Deira from the early 1960s. These women's narratives provide a mechanism to reflect on the evolution of educational service provisions for students named with disabilities over that time period. Special education has undergone rapid transformations during the time that the women were involved in the discourse of education. There has been a gradual move from no provision for children named with disabilities to one where educational boundaries are becoming increasingly blurred and where special education traditions are coming to terms with "competing understandings of knowledge and different moral visions of education" (Paul et al., 2001, p. 14). Despite these acknowledged changes a strong perception of education as two separate entities is evident; the women tell their stories of education clearly speaking of separate systems of education.

The discursive binary of regular/special education works to "functionally erase ambiguities of membership" and also "stigmatize one half of the set" (Gordon & Rosenblum, 2001, p. 12). As Gordon and Rosenblum (2001) further assert the "non-stigmatized member of the set can be described as curiously 'absent' while the stigmatised member is quite 'vividly' visible" (p. 13). Disability takes its name from the silence of able, 'normal'. In the same manner special education is named, where education (regular, mainstream, normal) is assumed as the dominant discourse and is prefaced with an adjective only to describe its state of being as separate to a special education discourse. 'Regular' education is taken-for-granted in the education/special education binary and special education is stigmatised and marginalised in education discourse. This binary is further distinguished through the structures which shape the spaces of the discursive practices of special education. According to Davies (1996) "structures are dependent on being spoken into existence through the discourses that legitimate their existence" (p. 16). Special education speaks segregative practices and institutions into existence retaining the 'disabled identity' of students named with a disability.

In the previous chapter I established that definitions of inclusion and inclusive schooling are not universally accepted or agreed upon (e.g. Bines, 2000; Slee, 2000; Ware, 2002). Lombardi & Woodrum, (1999) question whether 'inclusion' is a philosophy, program or placement. Yet these 'slippery' and 'unstable' words form the basis of policy

documents impacting on students named with a disability and their parents/caregivers. Additionally these words and their attendant multiple meanings are reinterpreted and used by the various stakeholders in educational systems. The way in which policy decisions are made and interpreted occurs at the level of “discourse, attitudes, assessment, curriculum, and pedagogy” (Barton & Armstrong, 2001, p. 706) and as was evidenced in some of the mothers’ narratives, different teachers and principals’ attitudes showed both barriers to inclusive schooling and points of resistance to exclusionary practices. A change in terminology from ‘mainstreaming’ to ‘integration’ to the current variant of ‘inclusion’ is not visible in the way mothers use language. The words the women who desired an inclusive education for their children varied, yet the underlying message appeared to be the same – education in a ‘regular’ classroom with non-disabled peers. Many of the women interchanged words of ‘mainstreaming’, ‘integration’ and ‘inclusion’ freely; the meanings of the words not located in ‘academic’ knowledge and theorisings. Their stories were about where and how they desired their children to be positioned in educational spaces, and the progression of the women’s desires for a more inclusive education could be evidenced over the temporal framing of their educational narratives. Most of the women’s desire was for their children to be accepted and valued members of ‘regular’ educational spaces.

An inclusive education is no longer about ‘integration’; a process of putting children named with disabilities into the spaces of a ‘regular’ classroom. Concepts of inclusion where the students named with disabilities are expected to ‘fit’ in/to the school as it currently exists, act in similar ways to integration and are considered to be “assimilationist” (Slee, 2001, p. 170; also Bines, 2000). This construct of ‘inclusion’ was apparent in the stories told by many of the women whose children were in schools at the time of the interviews. Therese and Sandra were two of the women who were able to (eventually) (re)tell ‘inclusion’ stories where they believed their children were valued and accepted as part of the ‘regular’ class. Inclusive education becomes one which is not conditional upon standardised ‘academic’ achievement, but one which accepts and values all students and welcomes the diversity they bring to the classroom.

Inclusion is currently considered a “process involved in making mainstream schools accessible ... in terms of curriculum and teaching, organization, management, the physical environment, ethos and culture” (Swain & Cook, 2001, p. 186). Inclusive

schools are based on philosophy which values and celebrates difference (Swain & Cook, 2001) and moves beyond disability to remove barriers of participation for all students who are disadvantaged in school spaces (Barton & Armstrong, 2001). Proponents of inclusive schooling contend that inclusive schooling involves system wide reform to enable schools to be welcoming of diversity and to cater for the needs of *all* students, those named with disabilities as well as others marginalised in the education system (e.g. D. Ferguson, 1995; Barnes et al., 1999; Barton & Armstrong, 2001; Lawson, 2001; Slee 2001; Swain & Cook, 2001; Turnbull et al., 1999). In the words of Swain and Cook (2001, p. 204) “an inclusive system is explicitly designed to cater for all”.

The narratives presented by the women in the study speak to many barriers, in particular attitudes, discourse, pedagogy and expertism which posits the professionals as experts and shapes unequal power relations. Although policy documents mandate a partnership with parents/caregivers in decision-making, this partnership remains “largely dominated by professional concerns” (Loxley & Thomas, 1997, p. 282). The ascertainment of a specified level for a child named with a disability is a key determinant of educational placement. Education Queensland policy documents do not clearly state the provision of inclusion in a regular classroom as a matter of parental choice. The provision of program options in multiple sites has the effect of creating “the illusion of choice” (Swain & Cook, 2001, p. 203). While there is no ‘real’ choice of placement in educational spaces for mothers/caregivers for mothers whose children are currently in education spaces, their stories demonstrated that often resource issues and the provision of teacher aide support is necessary for their children to access regular classrooms. Resource allocation appears to override educational concerns in many of the narratives on ‘inclusive schooling’. Many of the women in thesis displayed examples of how “resistance to discourses of domination is possible” (St Pierre, 2000, p. 486). Taking up the subjectivity of ‘good mother’ they often fight and advocate for their child, attempting to achieve what they believe best for their children’s education. At various points in time mothers resisted, rejected and challenged the socio-culturally accepted standards and expectations for the education of their children as they sought to have their children accepted in the (regular) spaces of education.

However, there are considerations which need to be taken into account. This study (re)presented the views of a small group of women. Many women/caregivers desire more specialised educational services for their children which they believe will best meet their children's needs, such as Oranea. This choice should not be denied them. This thesis contends that a lack of choice existed for most of the women in this study in determining the educational opportunities/placements for their children. In more recent years the inclusive educational opportunities available to children named with disabilities appear to be continually tied to human resource issues (and lack thereof) rather than to the student's educational needs or outcomes, highly suggestive that system wide reform to meet the diversity of children is still in its infancy. Inclusion must not be about losing the resources needed to meet students' individual and educational needs; it must now move to focus on changing traditional discursive practices of both special education and regular education to begin to dissolve the dualism that appears to be inherent in educational practices and professional(s) attitudes. The spatial metaphors used by the mothers speak clearly to the divisions that are read by the women in educational discourse. However, this study did not take into account the perspectives of educational professionals (both 'regular' and 'special') whose narratives could expand understandings of inclusive practices. Continuing research to determine what is required for successful inclusive schooling is warranted and needs to take into account the perspectives of all stakeholders.

Above all it is necessary for policy-makers to develop stable meanings for the language which is used to inscribe and spatially place the bodies of children named with disabilities. There is a need to decentre 'inclusion' by questioning 'exclusion'. What does exclusion mean in an educational context? How are students excluded, and where does that exclusion take place? Who decides which students are included and who is excluded? On what basis? Education needs to reach the point Slee and Allan (2001) describe when they cite Royal (1999): "Inclusion can only be achieved by 'excitation' (p. 305), that is when inclusion is no longer cited, but has passed spectrally into our language and practices" (p. 181).

This is where it all starts (Elise): the possibility for education

Attitudes, beliefs, and practices that shape the school culture, in turn, influence enduring perceptions about disability among school professionals, students, and their families. (Ware, 2002, p. 152)

I proposed early in chapter 10 that the segregation of students within the discourse of education contributes to the perpetuation of disablist practices in society (Barton & Armstrong, 2001; Kitchin, 1998), and continues to constitute people named with disabilities as ‘Other’ in dominant socio-cultural discourses. The spatial arrangements inherent in educational discourse can be read as reiterating and reinforcing the ‘Otherness’ of students named with disabilities and of adding a discourse of professionalism as professionals preserve their boundaries. The gaze ensures students are medicalised and categorised with/in the institution(alisation) of education. Language-in-use is also constitutive of the marginalisation of students in educational spaces as it reads and inscribes the bodies of those who are named with disabilities and associated ‘levels’. Education has a role to play in formulating and justifying ways of seeing, being and behaving in the world (J. Morgan, 2000). This raises implications for educational ethics and policy. Schooling can be seen as a form of “cultural politics, since schooling always involves an introduction to, preparation for and legitimisation of, certain ways of seeing and behaving in the world” (J. Morgan, 2000, p. 274), a mechanism by which to read the cultural landscape (Kitchin, 1998).

The social and judgemental gaze applied to people named with a disability can be perpetuated through education. Through the naming/labelling of impairment/abnormality of their child, mothers in this study found themselves interacting with/in discursive practices and sites with which they are/were unfamiliar. The spaces students inhabit with/in the discursive field of education needs to be problematised. If the spaces in which students are placed are conceptualised as taken-for-granted then it is to suggest “that current social arrangements that exclude certain groups of people and maintain social hierarchies go unchallenged” (J. Morgan, 2000, p. 285). Education spaces not only reflect the broader, bounded, structure of society and constitute social constructs, it is with/in education that ideas of self worth are developed (Rizvi & Lingard, 1993); ideas of the places in which oneself and ‘Others’ belong. It is

interesting to note that many of the mothers in this study reflected on the potential influence of education to challenge and resist dominant societal attitudes and constructs, reflecting disability theorists' argument concerning the role of education in the preservation of disabling practices.

The storyings as (re)presented by the women in chapters 10 and 11 of this thesis concur with Barton and Armstrong's (2001) suggestion that "educational institutions play a major role in social and cultural reproduction" (p. 693). Arguing further, Barton and Armstrong (2001) state that the "relationship between education and society is both complex and contradictory, providing spaces for alternative ideas and practices" (p. 693). A question I put to most of the mothers was, "do you think society's perception of disability has changed? If so how and why?" Although not typically part of a conclusion, the women's responses to my question are (re)presented here as their answers speak to the future, to the potential for change in society, and in so doing illuminate a path that education can take in breaking down the segregated barriers and spaces currently inherent in the discursive site of education. I will let the voices of the mothers speak to the spaces in/to which education can move to impact on broader societal perceptions of disability.

Diane believes that the history of education "*took over a major role in moulding and making our citizens*". She perceives that schooling "*can educate on more levels than what they're doing to change our society*". Many of the women believe that inclusion has impacted positively in shifting societal boundaries of normal/disabled. Despite narratives which emphasised the struggle and difficulty the women encountered in the discursive spaces of education, they remain positive about the ability of education to bring about change. The women also perceive that non-disabled children have a role in the future in changing societal attitudes. Applying children's learning to spatiality J. Morgan (2000) asserts that "children learn from a very young age that space is both enabling and constraining" (p. 281). Children are inducted into the acceptance of taken-for-granted spaces that separate able/disabled in the education system. Additionally, children learn that spaces have boundaries and "that some people can dominate space to exclude others" (J. Morgan, 2000, p. 282). The women believe that inclusive education provides a mechanism to rework this bordered learning of childhood to impact on future readings of socio-cultural landscapes.

The women whose quotes are (re)presented below depict a broad age range and as such speak to diverse experiences in education as underlined in the education section of the thesis. Yet they speak to a commonality of thoughts about the potential impact of inclusive education on societal acceptance of human diversity. This commonality of stories is representative of L. Richardson's (2001) definition of "collective stories – stories which both resist and alter the accepted norm" (p. 37).

Kathy and Elise highlight the importance of a social gaze in their response, one which derives from the discursive spaces of education. Elise says the changes in society have come about through "*people or children with disabilities being seen, being out there, being taken shopping, not being locked away*". When I ask her how that has come about she responds:

We've got kids going through school, who are in school with kids with disabilities, growing up. And kids are the most impressionable of all. Kids befriend each other, take home attitudes and standards. This is where it all starts, in the education system.

Kathy also notes the difference in attitude between adults and children while exploring how and why society has changed:

It's [disability] more seen. I mean ... they integrate them at school right from an early age. And the thing is, with (pauses) it's not children so much having hassles with people who are disabled, it's what their parent's reactions are. 'Cause kids don't really see anything that different ... especially when they're younger it doesn't seem to worry them as much.

Patti perceives that society appears to be more accepting of people with disabilities:

People are much more accepting. The children are integrated in schools now, so children grow up with people with disabilities right from the word, or from once they start school. If they hadn't exposure to it before that ... it's once they start school, preschool they have children with disabilities with them.

Michelle hopes that "*with children at school ... when they get to be adults the attitude will be quite different because ... it's quite open in the schools*". Additionally, Michelle reasons that social interaction is part of education and she views that as "*a way of getting the community to recognise them and accept them [people named with a disability]*". She says that it is like "*second nature if they're around all the time. ... They just think of them as just being there*". Children with disabilities become part of the dominant discourse disrupting and blurring the dualism of able/disabled.

Susan was quite straight forward when stating the reasons for change in society – *“oh the integration of these children into the classroom situation. And people having made it easier to actually take disabled people out into the community”*. Susan goes on to speak on the value of inclusion:

I think it's better that these children are actually integrated and if it carries on ... these kids that are coming through with these disabled kids are going to be a lot more accepting than what the adults are of disabled people now. So it's very positive.

Therese also was very precise in her response to the question, “is society changing its view of disability”? She immediately stated, *“yes, yeah, very much so. And I think a lot of that's got to do with the fact that kids are now in the schools. Heaps. Heaps I reckon has got to do with that”*. However, Serena positioned education appositionally to the other women, as she perceived it was the evolving attitudes in society that were pushing education to make changes to its policies:

To me it felt like as if there was more acceptance from society of children with disabilities in the schools. It wasn't only the parents with the children with the disabilities that wanted the kids in the class; there were other parents out there. I remember talking to and feeling, not everyone, but a lot of parents also thought that there probably was an advantage having kids in the classrooms.

However, Liza initially answered that she did not think society was changing, *“I think that old view is still there that they should be put away”* and that *“it's too hard for society”*. Later she draws on a discourse of hope and reflects on the potential of education to bring about social change:

I hope it's changing with the children that are coming through inclusion. See the children that have been in Lily's class I hope would not have that attitude and that they would be able to greet somebody with a disability without turning or walking away, or saying, “I don't want to do this”.

I only had the opportunity to have one interview with Julia as she moved from Deira before the second scheduled interview. Towards the end of our interview I asked if there was anything she would like to say to finish. Julia's concluding thoughts provide an opportunity to recap on education's potential ability in speaking into existence an inclusive education system which impacts on the spaces in which children are placed and seen. J. Morgan (2000) contends that “spaces are made in the living of our lives, and since they are always being made, the possibility remains for them to be made differently” (p. 285). It is to this possibility that Julia refers when she speaks of the

promise of inclusion, the breaking down of barriers and boundaries that exist, and of the “*unknowing*” of disability:

I feel that I want special kids to be integrated so much more. I think that is the way to go to stop all the barriers, the social barriers of what's acceptable and what isn't acceptable. It's like the black, the white, the disabled, the whatever. I would like it that they would be all in the same environment at school. I think it's very important that disabled children, and for normal children to be around each other. Then further on down the line you won't get this unknown, because it's just the unknowing. Because you haven't had any knowledge, you haven't had any experience, like coming amongst it [disability] the first time, you don't know do you? I think if people could just keep that integration going then that big barrier-crossing-over sort of thing wouldn't happen so much. People would be talking to mum's with kids who have disabilities and have a lot more understanding, a lot more openness to the situation. They [mothers who have children with disabilities] wouldn't think they were cast out of society because they had a disabled child.

The positioning of mother as different if one has a child named with a disability is clearly seen in Julia’s response. The discourse of motherhood enters the spatiality of disability as one positioned and “*cast out of society*”. Julia blends together the discourse of motherhood, the socially dominant discourses of normalcy, spatiality, education and inclusion as she explores education’s place in the spaces of her life and education’s potential role in (re)constructing spaces which are made differently; spaces where normal constitutes diversity and education is a place for all children.

What a memory (Serena): women speak to the interview process

The women in this study can be read as being imbued with a discourse of love for their child. Through their individual taking up of story lines of ‘good mother’ and ‘doing the best’ they can for their child they have demonstrated the potential to resist, reject and reshape dualisms of able/disabled, normal/deviant in multiple discursive sites and opening up possibilities of an inclusive society where difference *is* normal, for as Patti said to me about contemporary society, “*it’s normal to see people looking different*”. Throughout their narratives the women spoke of personal transformations, meaning-making and (re)constructed motherhood which they believe came about because of their child named with a disability. It is into these (re)imagined spaces of motherhood that new stories can (re)imagine a discourse of disability that becomes ‘normal’. The study

provided a textual space for the women to step out movements of their (re)constructed motherhood; movements resonating with personal meaning-making and transformations. In time and space the individual women spoke to a (re)constructed discourse of disability as they resisted and challenged dominant assumptions of whom and what constitutes 'normal'.

The study not only provided the opportunity for these women's 'voices' and their stories to be heard, it afforded a space for the research process to be of value and meaningful to them (Glesne & Peshkin, 1992). Conversations with my husband (a general practitioner and assistant professor in Family Medicine) called into question the notion of the conversational interview as therapy. As an unintended consequence of providing an opportunity for people whose voices are usually silenced, whose stories are not heard, the interview may have therapeutic value to the participants. Some mothers indicated that a silencing of their voices also occurs in the telling of their life stories in general conversations. Choosing a qualitative methodology which encouraged a narrative (re)telling provided opportunities many mothers had not experienced, that is, a chance to (re)tell their story in detail:

I don't discuss my life in details with friends and that. If it comes up in conversation, some parts of it, yep, but not as detailed as I was with you. (Oranea)

Because of my role that I've had with the support group and also because of the people I've known, there's been quite a few times when I've been asked to actually speak about Kimberley. But nothing like this detail. (Therese)

It's not something we would sit on the beach and talk about, see. You would sit on the beach and talk about good things wouldn't you? Memories and family and friends and times, and that, but its not something that you sit on the beach and talk about it cause it was such a, emotionally devastating time. It's not something you talk through really. ... You don't retell it often, well very rarely. I mean, I would never have retold all of this. (Liza)

Some of the women spoke to their belief that the interview had provided personal benefits and opportunities for internal reflection and this concurs with findings by Berg-Weber et al. (2001) and Cotterill and Letherby (1993):

It's probably been good in that it's provided a reflection and a path, yeah. And it's made me think about where we've come from. (Liza)

Looking back at it, it's really good to really go back, into your life, and where I am now, and understand. You know, looking from a different perspective, different view. (Oranea)

It's been good. It's helped me to go through and just work through some things that maybe I needed to work through, by getting them out and sharing my opinions and sharing my experiences. I mean, I don't know about you, but I feel there's been a definite progress for me as an individual. Each time the interviews have come, we've had the interviews and worked through different things. Yeah, just sitting with it now I just feel a lot more at peace. (Diane)

I felt I needed to put it down I guess. I had something and done something for so long to be able, even if you don't use any of it, I've said it all now and you've made me reflect ... but it's good to talk I think. To have an opportunity to think over how things are and I mean, you've challenged me ... made me really think about things and reflect on things. And that's great. It's all very productive and healing in a lot of ways. (Sandra)

It's been great therapy. It's given a whole picture to, a better picture to what actually happened ... it's allowed me to think more clearly about me, and the future then, and how it might be. (Serena)

Thank you for letting me open up. It's probably done me good to open up. (Patti)

I conclude this thesis with Serena's words as she explores the way in which her experience of mothering a child named with a disability has become part of her subjectivity:

What a memory

*It's more
a re-living
of those experiences
and knowing
how far I've come*

*I have
experienced all that
and I started off
not knowing
what
I was going to experience*

*I can say
there were negatives –
like how I took it onboard*

*and put the pressure on myself
and burdened myself*

*I can take
the positive side
of how I ran with it
and learnt so much*

*I can appreciate
the whole experience
now that
I've lived through it*

*And say
"What a memory"
"What a wonderful thing to have"
To have lived through
and to come out
the other end*

*And say
"That makes me
a whole person"
It's part
of me.*

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Appendix A

A profile of the women participants

A brief and partial profile of each of the women who participated in the study is presented in this appendix. The aim of the profile is to provide additional information on each woman; the names of their husband/partner, number of children and the medical descriptors of their child named with a disability. The demographic information provided comes from what the women choose to tell during their interviews, and therefore some details may be lacking. Chronological details recorded in this brief overview are determined from the date of the first set of interviews held in May and June, 1999. The intention of this profile overview is that it be read like the program notes of a dance performance, as a reminder of who the soloists are, and the physical spaces they inhabited at the time of the first interviews, while realizing that they have since moved in the stories of their lives.

✿ Julia

Julia and her husband Jeffrey have been in Deira for 2 years since moving from overseas. They lived in a rented house near the centre of Deira and have two children. Andrew, their older son, is 3 years old, and had recently been diagnosed with Autistic Spectrum Disorder. Before moving to Deira Julia was a clothes designer and is currently a full time mother. Several months after our first interview Julia and her family left Deira to work and travel around Australia.

✿ Melissa

Melissa and her husband Graeme are also from overseas and moved to Australia in 1993. They moved to Deira in 1995 and now live in a middle-class northern suburb with their three children. John is their youngest child and is 4 years old. He has Down syndrome. Both Melissa and her husband are accountants and Melissa worked until her

first child was born. Although Melissa is not presently working, she is looking to gain employment once John is at school either as an accountant, or perhaps retrain as a special education teacher.

☞ Robyn

Robyn was born in Deira and has lived there all her life. She is a single mother to Natasha who is 4 years old and they live in a rented unit in North Deira. Natasha's father Ian is very involved in her progress and has regular contact with Natasha. Robyn has had a variety of part time employment since Natasha's birth and currently is studying commerce at university. Natasha has communication and mobility delays.

☞ Oranea

Oranea is separated from her husband, Darryl, and moved to Deira from overseas in January this year (1999). She lives in rented accommodation with her three children and Michael, her youngest child, is 5 years old. Oranea is a full time mother, looking to do volunteer work with children once Michael is at school. Michael has autism.

☞ Susan

Susan is married to Keith and they have twin 8 year old girls, Hannah and Laura. They live comfortably in the northern suburbs of Deira in a two-storey house located in a quiet cul-de-sac. Susan currently works full time in a paramedical profession and Keith is a doctor working in a specialty area. They moved to Deira from a capital city in Australia for a lifestyle change and have been in Deira 5 years. Laura has severe cerebral palsy and multiple disabilities.

☞ Serena

Serena was born in Deira and has lived there most of her life. She currently lives in a quiet middle-class outer suburb of Deira with her three children. Jason is her second child and is 9 years old. Serena has been divorced from her husband Kevin since 1998.

She was working full time when the first interview took place but is now in part time employment. Jason was diagnosed with Asperger Syndrome when he was 8 years old, after initially being diagnosed with autism at age 4.

☞ Sandra

Sandra and her husband Chris have lived in Deira since 1984 in the northern suburbs of Deira in a quiet middle-class area. Melanie was their oldest child who died aged 11, before the interviews commenced. Sandra and Chris have two younger children. Sandra works as a mid-wife on a part time basis and Chris runs his own business. Sandra and Melanie were both part of my early experience in special education. Melanie had severe multiple disabilities because of an unnamed chromosomal abnormality.

☞ Therese

Therese has lived in Deira since 1983 and lives in an outer middle-class suburb of Deira with her husband Simon who was born in Deira. They have two children. Kimberley is 13 years old and the older child. Therese stopped working during the early years when Kimberley spent many months in hospital but is currently employed as a primary teacher and Steve is also employed. Kimberley has severe multiple disabilities resulting from her rare chromosomal abnormality. I knew both Therese and Kimberley from early intervention.

☞ Diane

Diane was born in Deira who has spent all of her life in Deira, apart from 12 months spent travelling around Australia. She lives in a middle-class suburb with her husband Brian and their three children. Peter is 13 years old and is their oldest son. Diane and Brian run their own business from their home while Diane also has part time work. Peter has physical impairments from cerebral palsy and uses an electric wheelchair. He has no intellectual impairment or communication difficulties.

☞ Liza

Liza has lived in Australia since 1983 with her husband Tim and they have a home in a quiet street in one of the middle-class northern suburbs of Deira. They moved to Deira in approximately 1987. Their daughter Lily is 16 years old and they have a younger son. Liza is currently employed with Education Queensland as a therapist and works with children who have disabilities. Tim is presently working in a professional capacity. Lily has a rare disorder, which includes intellectual impairment, because of a viral illness she contracted at the age of 18 months.

☞ Kathy

Kathy and her husband Ken have lived in Deira for 11 years and moved there after Ken was seriously injured in a motorbike accident requiring significant rehabilitation. They live in one of Deira's middle-class southern suburbs with two of their children. Alex is 18 years old and is their middle child now living in supported accommodation. Kathy is a full time mother who also works in her husband's business. Alex has cerebral palsy with severe multiple disabilities.

☞ Michelle

Michelle was born in Deira, and is married to Richard. They have four children and live in a middle-class northern beach suburb. Craig, 20 years old, is their second child and lives at home. Two years after Craig was born they lost a son to Sudden Infant Death Syndrome at the age of 7 weeks. Michelle started working part time when Craig commenced preschool and has only just stopped working. Craig has cerebral palsy with severe multiple disabilities:

☞ Elise

Elise has lived in Deira with her husband Paul for 35 years. They have five children and live in a quiet street in a middle-class southern suburb. David is their youngest son and is 26 years old. He lives at home and has support to live partially independently. Elise

has been a full time mother since having children, yet she also ran her own part-time business and worked on many voluntary committees for people with disabilities. Paul is now retired and both are actively involved in support services for adults with disabilities. David has Down syndrome.

☞ Patti

Patti was born in Deira and lives near the centre of Deira in a middle-class area with her husband Vince. They have four children and Belinda is their youngest child. Belinda is 33 years old and is living in supported accommodation not far from the family home. Patti was a fulltime mother who also worked in the family business. Belinda has intellectual impairments, epilepsy and behavioural difficulties because of a viral infection contracted at the age of 18 months.

☞ Norah

Norah has lived all her life in Riverside a small town approximately one hour's drive from Deira. Her husband Joe owned a cane farm and Norah worked in the field with her husband, before working for many years as a barmaid in a local club. Joe died in 1991 and Norah continues to live in the family home with Cheryl who is 41 years old. Norah has four children and Cheryl is her youngest child. Cheryl has intellectual impairment as well as epilepsy resulting from contracting meningitis when she was 6 months old.

Footnote: Norah passed away during the writing of this thesis, and Cheryl currently lives with one of her older sisters.

Appendix B



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ETHICS REVIEW COMMITTEE (Human Ethics Sub-committee) APPROVAL FOR RESEARCH AND TEACHING INVOLVING HUMAN SUBJECTS	
PRINCIPAL INVESTIGATOR	Valmae Anne Ypinazar
SCHOOL	Education
PROJECT TITLE	Mothers' stories of living with a child with disabilities

This project has been allocated Ethics Approval Number **H914** with the following provisos and reservations:

- All subsequent records and correspondence relating to this project must refer to this number.
- The Principal Investigator is to advise the responsible Monitor appointed by the Ethics Review Committee:
 - § periodically of the progress of the project;
 - § when the project is completed or if suspended or prematurely terminated for any reason.
- In compliance with the National Health and Medical Research Council "Statement on Human Experimentation (and Supplementary Notes)" you are required to provide an annual report detailing security of records and compliance with conditions of approval. The report should very briefly summarise progress.

NAME OF RESPONSIBLE MONITOR	Dr Ian Jackson
SCHOOL	Education (Cairns Campus)
[forwarded by E-mail without signature] Tanya Healy Administrative Officer - Ethics/Legal	DATE Thursday, 27 May 1999

cc. **MONITOR:** Dr Ian Jackson
HEAD OF SCHOOL: Associate Professor Robert Gilbert
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