

**The Lived Experience of Mothering a Young Child  
with Severe Multiple Disability**

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## **Attestation of Authorship**

I hereby declare that this submission is my own work and that, to the best of my knowledge and belief, it contains no material previously published or written by another person (except where explicitly defined in the acknowledgements), nor material which to a substantial extent has been submitted for the award of any other degree or diploma of a university or other institution of higher learning.”

Signed:

A handwritten signature in black ink, appearing to read 'Atopia'.

Dated:

5.10.2015

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This study received ethical approval from the Auckland University of Technology Ethics Committee (Appendix A) on the 17<sup>th</sup> of September 2013 (13/197) and for the amended study criteria (Appendix B and Appendix C) on the 29<sup>th</sup> January 2014, and 29<sup>th</sup> of May 2015.

## Abstract

In the last two decades improvements in neonatal intensive care have resulted in an increase in survival rates for low birth weight babies. This increase in survival has resulted in a net increase in children living with severe disabilities and mothers who live with the burden of caring for them (Bowen, Gibson, & Hand, 2002). Mothering is a widely practiced social role; yet, little is known about the lived experiences of mothers with significant challenges, such as mothering a young child with severe multiple disability. This study exposes the unique and individual experiences of four women as they experience the everydayness of mothering, and how they come to terms with the demands of mothering a child with severe disability.

This research uses the philosophical perspectives of hermeneutic phenomenology, drawing on the works of van Manen (1990) and Martin Heidegger (1959, 1971, 2000, 2010) to come to understand the essence of 'being a mother'. The participants recruited were 'mothering' a child aged three to seven years with a physical disability coupled with at least one other significant disability of cognitive, behavioural or sensory origin. Semi-structured interviews of 60-90 minutes duration were conducted with participants. Interviews were taped and transcripts were worked into discrete stories of incidents and perceptions of mothering which were checked for accuracy by the mothers. Themes were identified through hermeneutic interpretation, with thematic statements isolated using selective highlighting. Commonalities in texts and themes from the participants were identified.

The stories revealed the mothers' deep and intense transition within mothering. The 'being a mother' of a young child with severe multiple disability is a mothering journey that starts at the same point as 'mothers of typically developing children' in conception; yet veers off on an altered path as the mothers experience being visible, being challenged and being acquiescent. The findings show that mothering a young child with severe multiple disability encompasses interconnected 'being', and that the transition experienced in mothering is not sequential. Rather, a mother can exist in multiple realities at any moment; shifting back and forth in the context of 'being a mother'. The findings also recognise the duality of burden and joy experienced in mothering. Being a mother is a constant; a role that will only cease in death. Coming

to acquiescence, in the lived experience of mothering a young child with severe multiple disability, a mother comes to recognise the 'joy' in spite of the burden, despite the unique journey, and towards acceptance in her own version of 'being a mother'.

The results of this research provide insights that will inform the development of partnerships between professionals and mothers of children with severe multiple disability, thus promoting working together. It highlights the struggles and intensity within the occupation of mothering in its everydayness, and how mothers evolve and endure.

## **The Fourth of December: Insights Into Losing My Body**

*Warm water beads and runs down taut skin.*

*My eyes well up. A blink and hot tears run down swollen cheeks.*

*I am alone.*

*My uneasy hands cup my round belly and he kicks back (like he knows).*

*Time fades. I realise I feel sick. Hunger? Or my body failing me again?*

*Small fuzzy images, static and day time television do little to distract me from time.*

*A knock. And I smile at the thought of human interaction.*

*My smile is short lived as wheels squeal on linoleum. More pills and BP. And another unfamiliar face.*

*Deep breaths as I attempt to be calm. Rapid beats burst underneath a tight cuff.*

*Her face confirms it, as my body fails me. Again.*

*I hear his familiar footsteps and relief overwhelms me; tears flood my eyes.*

*He bear hugs me as I furiously rub ineffective hands over my face to hide the evidence.*

*He seems so happy. A huge lump envelops my throat.*

*My heart races as I try to articulate that our son will be born today. The fourth of December.*

*Lying uncomfortably I stare up at faded ceiling tiles and bright lights as they flash by.*

*Suddenly I hear the harsh yet melodic cacophony of my midwife's mixed accent. I finally feel a sense of ease (it is short lived).*

*People, many people, and a bright room that for some reason stirs thoughts of experimentation.*

*I start to feel sick, and see pixie dust (which is not a good sign). Then large caring brown eyes come into focus.*

*Her hands rest comfortably on my knees as a needle forces its way between my vertebra. I cease to breathe.*

*I have never been so still.*

*A blue fabric sheet forces me to take a leave of absence from my body; as does the strange numbness that has now spread down to render me in stillness.*

*An element of unease is released as I comprehend it has worked.*

*Tugging, pulling, shoving and pressure overcome my torso.*

*I look to him for reassurance; but I see an expression not previously known to me.*

*Worry. No. Fear!*

*The sounds of machines bleeping resonate in me, and I feel like vomiting.*

*I can hear someone trying to reassure me, and warmth as more medication enters my blood stream.*

*And then a forced yet faint cry? More crying, and this time, louder than previously noted.*

*My boy. Our boy.*

*Our precious baby boy.*

# Chapter One – Introduction and Context of the Study

## Introduction

*- New mothers enter the world of parenting feeling much like Alice in Wonderland. They are stunned by the overlap of their emotions – joy, fear, guilt, all playing out at the same time in disharmony.*

*- Motherhood is a process. Learn to love the process. (Rosenberg, 2003, p. VII, 2)*

There are growing numbers of children living with severe multiple disability in New Zealand and Australia, due in part to improved survival rates of babies returning home from care in neonatal units (Bowen, Gibson, & Hand, 2002). The care needs of these children are extensive and to achieve optimal therapeutic outcomes for these children and their families, occupational therapists need to form relationships with the mothers of young children with severe multiple disability; however as professionals, occupational therapists know very little about the lives of these women, in particular, the experience of mothering these children. This is, in part, due to mothering being so ever present within society that it has become ordinary, rarely thought of, and somewhat matter of fact. It is possible that this lack of knowledge jeopardises the health and education outcomes for children with special needs, and the well-being of their mothers.

For over a decade I worked as a paediatric occupational therapist in a school for children with special needs in Auckland, Aotearoa, New Zealand. During this time I developed many relationships with the mothers of the students with whom I worked. I also became a mother in 2007 and it profoundly changed my life and how I experienced everything in the world. Being a mother made the world a much scarier place for me, in which I was concerned about many things; including my ability to be a good mother. Mothering is so ever present; few would deny the overwhelming contribution mothering makes to society. I suggest this is true nowhere more so than in the mothering of a young child with severe multiple disability, a phenomenon in which a distinct void exists in understanding.

Within this chapter I will provide clarification on the purpose of this research, and what my intentions and expectations were in conducting such research. I will also provide a background context and a concise overview of my assumptions of this phenomenon prior to engaging in this research. This chapter will present the methodology in brief and overview the thesis structure.

Early in 2013, a teaching colleague of mine expressed concern regarding the 'sadness' expressed by a number of our students' mothers. Together we questioned whether school processes were contributing to this sadness and postulated that vital insights into the day-to-day mothering of a child with severe multiple disability were lacking. Could the language of our documentation and the expectations of the school be incongruent with the needs of the families of these children? Was the transition from pre-school to school the biggest stressor? Perhaps our expectations for their child did not match their expectations? What was lost in translation? Potentially the cause of the sadness may have been from placing our procedural, (information seeking and sharing) needs ahead of the students' mothers. It has been identified that: "in many instances, parents and professionals may well have widely differing values and priorities that must be articulated for a reasonable resolution to occur" (Guralnick, 2001, p. 535).

There is growing awareness that the number of babies being born with severe multiple disability throughout the developed world is increasing (Anderson, 2009; Bowen et al., 2002; Carpenter, Cockbill, Egerton, & English, 2010), due in part to improved intensive neonatal care and increased survival rates for infants with extremely low birth weight (Bowen et al., 2002). Health and educational professionals are working to develop systems to improve outcomes for this population of children. Within occupational therapy, best practice philosophy is firmly established around collaboration with families and family-centered care (Dunn, 2011). Many other health and education providers throughout the developed world have also embraced family-centered care (Ahmann, 1994; Guralnick, 2000; Hostler, 1991; Law et al., 1998; Raghavendra, Murchland, Bently, Wake-Dyster, & Lyons, 2007) and shaped their service provision to recognise the philosophy of 'optimal child development' while emphasising parents as the experts of their child's needs and focusing specifically on the uniqueness of the individual families (James & Chard, 2010).

Therapists working within education in Aotearoa New Zealand are required to meet 'Specialist Service Standards' governed by the Ministry of Education (2006/2013) from which family-centered care is the overarching principle. Thus, for two decades literature has identified the importance of family-centered care in achieving optimal outcomes for children with special needs and, more recently, governmental policy has been established to ensure such care is adhered to. Despite this evolution in health and education thinking and practices, professionals continue to work with these children and families with a large chunk of the puzzle missing, pieces like co-adaptation, occupation and co-occupation which have recently been identified as central to optimising the potential of children with disabilities (Price & Miner Stephenson, 2009; Zemke & Clark, 1996).

As an occupational therapist I have a deeply ingrained ontological position that human beings are essentially 'occupational beings':

Occupation, that is, purposeful activity, is a central aspect of the human experience ... essential for survival, provides the mechanism for people to exercise and develop innate capacities of a biological, social and cultural nature, to adapt to environmental changes, and to flourish as individuals. (Wilcock, 1993, p. 17)

Occupational therapists are drawn to research within the qualitative vein; developed from social and behavioural scientists concerned with understanding what it is to be human from a holistic, unique and dynamic perspective (Burns & Grove, 1997). As an occupational therapist I am explicitly client centred and I desire understanding within human experiences from an occupational position. A qualitative research paradigm was chosen for this research project as it encompasses what it means to be human, how one experiences phenomena, real people, real life experiences, and uncovers the complexities of life (Smythe & Giddings, 2007). Furthermore, qualitative research has the ability to improve clinical practice, afford humans empathy, and change us and how we see the world.

## **Purpose**

This research study is invested in the occupation of mothering; the day to day engagement that mothers have with their children with severe multiple disability, the fun times and the not so fun times of mothering, the trials and the tribulations and the meaningful experiences that shape a mother. Drawing on the works of van Manen

(1990) and Martin Heidegger (1959, 1971, 2000, 2010), a hermeneutic phenomenological perspective is brought to bear on **‘the lived experience of mothering a child with severe multiple disability’**. The study aims to obtain and present an interpretation that will allow discussion to emerge to benefit mothers of children with severe multiple disability, by providing insights to the relationships professionals have with these women, children and their families. I believe these insights into the meaning experienced by mothers of children with severe disability will challenge the thinking of health and education practitioners regarding their work practices. It is upon this reflection and thinking that change can occur at practitioner level, and improve health and education practices with regard to providing information, expectations of care, establishing relationships and therapeutic use of self. This research is emergent, and will identify a phenomenon which is so vital, yet invisible.

Professionals working within health and education systems are discovering that their established methods of care are falling short; they are unsuitable, and at times ineffective for this vulnerable population of young children (Bagnato, 2005; Bagnato et al., 2004; Carpenter et al., 2010; Piggot, Paterson, & Hocking, 2002; Raghavendra et al., 2007); yet, in many instances professionals are placed in situations in which they have great influence. It stands to reason that health and education professionals could gain valuable information from the lived experiences of mothers of children with severe multiple disability. Our daily reality exists among interactions with other people and these interactions shape us. We meet, shake hands, converse with the mothers of children we work with. Our appearance, gestures, movements and spoken word have at times significant impact, sometimes good, sometimes bad. Increasing awareness of the involvedness that these mothers contend with on a daily basis with their children could lead to the development of collaborative partnerships with mothers, and improved well-being for families and children with severe multiple disability. Knowing more will assist health and education professionals achieve better working relationships and outcomes for all parties. If we are to provide quality health and education for young children with severe multiple disability in Aotearoa New Zealand, we cannot hope to achieve this without first understanding this experience from the perspectives of their mothers.

## **Expectations**

This research project investigates human engagement on multiple levels. As a researcher I engaged with mothers of children with severe multiple disability to gain knowledge of their experiences. An aim of hermeneutic phenomenology is to go beyond 'what I already know' of the phenomenon and immerse myself in the richness that can come with inquiring from those living the reality. The focus is to understand fundamentally what it is to 'be' the mother of a young child with severe multiple disability in its everydayness. What was required prior to investigating this phenomenon and immersing myself in that experience was to understand my own presuppositions, so as not to allow them to cloud my interpretations or force the data during this research process.

The question of knowledge always refers us back to our world, to our lives, to who we are, and to what makes us write, read, and talk together. . . it is what stands iconically behind the words, the speaking and the language . . . the problem is that our common sense, pre understandings, our suppositions, assumptions, and the existing bodies of scientific knowledge, predispose us to interpret the nature of the phenomenon before we have even come to grips with the significance of the phenomenological question. (van Manen, 1990, p. 46)

To assist with gaining insights into my assumptions, I engaged in a presuppositions interview. It was an interesting experience to articulate my thoughts on this phenomenon, the words I chose to express and the stories that came to mind. It was evident in this process as to what had brought me to become interested in this phenomenon; being a mother. What was also a driving force was that I was at a point in my career as an occupational therapist that I was questioning a number of prominent theoretical perspectives and work practices influencing the ways in which therapy was being delivered to young children with severe disability in my own work environment. From my years of experience with children with severe multiple disability, I presumed that it was difficult to be a mother of a child with severe multiple disability, that it encompassed a number of challenges such as negotiating the health and educational systems and making a difficult choice of mainstream or special schooling. I held a belief that mothers were very aware of the milestones that their children would not reach, and that this would be evident across their child's lifespan,

which at times would cause them to go back to grief. For mothers of young children with severe multiple disability, I assumed that they would visualise a future with a large child in a large wheelchair and that the child would always be dependent. From my experiences I also assumed that there would be a focus on the child's physical impairment and his or her inability to walk, and that both the mothers and their child would likely face judgment for the disability. I might encounter mothers I perceived as disconnected, understanding that it was hard being in their position each and every day. I understood that mothers advocated fiercely for their children, yet at times could be swayed by professional input, and that this may not necessarily be good for their mothering. The themes I thought may show in this research were: just coping, juggling, being spread too thin, losing it, hope, joy and validation.

When I was asked about what mothering meant to me, I stated that it was about putting your child first, loving constantly (so that your child knows he or she is loved), juggling roles, protecting and encouraging your child to take risks and learn, nurturing and caring. I was therefore potentially at risk in this study of expecting the participants to share the same ideals.

When asked about my own mother and how she mothers, I stated: she is very loving, yet she pushed me to meet my full potential, she would always say 'life's not fair'. I think the reason she would say this was to allow me to seek greater understanding about the world we live in, in that you cannot assume that everyone has the same experience or the same 'deal in life'. There were no certainties. My mother is cuddly, supportive and encouraging, intelligent, with high expectations, and far more patience than I. I am like her in some ways and for this I am so fortunate.

Mothering changed me. It changed my perceptions, actions and reactions. Having a child made me more fearful because it was not about me anymore; I became responsible for another human being. Pregnancy in a way prepared me for this life lesson as my body, became not my body, its sole purpose became growing another human being. This became particularly evident to me in my first pregnancy (and second and final pregnancy) as I suffered from preeclampsia. My body, which was supposed to be growing my baby, struggled and, for medically unknown reasons, was trying very hard to reject my baby. So, I was fighting my body which was trying to fight

my baby and my body was also fighting me. It was a very scary time, and during this fight I was mindful that due to the prematurity of my baby, the poor blood flow to my placenta which caused him growth retardation and my failing body, that I may become the mother of a child with severe disability.

My final thoughts in my presuppositions interview were this: mothering journeys are different; you cannot plan for them to go a particular way, no matter how much you try. You have to ride the roller coaster because you are strapped into that seat, the brakes are off, and the wheels are in motion.

## **Studying ‘The Lived Experience of Mothering a Young Child with Severe Multiple Disability’**

### **What is mothering?**

Mothering is a biological construct, yet the definition of mothering has been broadened to capture the notion of being the primary provider of care and nurturing to a child (Esdaile & Olson, 2004; Francis-Connolly, 2000; R. D. McKay, 2008).

Mothering involves a series of individual activities aimed at caring for a child, that are rooted in time, influenced by culture, social constructs, politics, ethnicity and class (Esdaile & Olson, 2004). Mothering is also a “socially constructed set of activities and relationships involved in nurturing and caring for people” (Forcey, 1994, p. 357). For practical reasons, within this study, a mother was defined broadly as; a female who provides mothering. This classification was intentional. I did not want to exclude adoptive mothers, grandparents or other family members in the mothering role from expressing interest in being potential participants of this research. I did however intend to recruit only women.

The socially constructed notions that influence perceptions of ‘what a mother is’ are described in more depth in chapter two, the literature review, of this thesis. One of the important notions to understand of mothering a young child with severe multiple disability is that it is a journey of ‘coming to terms’, and altering expectations:

We expect everything to be perfect, because what’s what we think we are entitled to. There’s a lot of pressure on women to be successful in every way. I feel like there’s a real danger if we strive towards a non-existent ideal of having these perfect children. What do we do if they’re not perfect? We can’t just

decide they're not worthy, and discard them – Rachel Callander, (mother of Evie who was born with a rare chromosomal condition). (Casinader, 2015, p. 16)

### **What is severe multiple disability?**

Statistics New Zealand (2013) defined disability as:

any self-perceived limitation in activity resulting from a long-term condition or health problem; lasting longer or expected to last longer than six months or more and not completely eliminated by an assistive device.

The word severe is used within disability research to identify extreme or profound disability. For the purposes of this research the definition of severe disability is that it causes great limitations and an inability to participate fully in all areas of daily life, in that it causes restraint and is deemed serious in manner.

For the purposes of this research project the definition of severe multiple disability is; a significant physical disability-inability to mobilise independently coupled with either a cognitive, sensory or behavioural disability.

The reason for choosing to research mothering of young children with severe multiple disability was due mainly to my interest in working with these children in the education setting in which I worked at the time of starting this research project, the children primarily had cerebral palsy (CP), and were classified as 'severe' by a Gross Motor Function Classification Scale (GMFCS) rating, of which they were all at the top two levels of the GMFCS Level IV or V (Palisano, Rosenbaum, Bartlett, & Livingston, 2007). The GMFCS is a five level classification system, with specific age ranges, that is based on self-initiated movement, with the distinctions between levels based on the child's functional limitations and the necessity to use devices and assistive equipment (Palisano et al., 2007). A level V defines the child with cerebral palsy (CP) with limitations in all areas of motor function, and the child has no means of independent movement (unless they master self-mobility in a power chair). The GMFCS was established to create an improved system of classifying the extent of the disability rather than stating the CP is mild, moderate or severe. However, these descriptions are still employed even with the GMFCS being used widely in this population of children with disability.

## **The New Zealand Context**

The New Zealand Disability Survey (Statistics New Zealand, 2014), noted there are 95,000 children from newborn to 14 years old living with disability, with most occurring before or during birth. The severity of the disability was not identified.

There are two streams of health funding that a child with disability might be eligible to receive services from; the national insurance agency, Accident Compensation Corporation (ACC) or Ministry of Health (MOH). If the cause of the child's severe multiple disability is a birth injury or accidental injury, and the claim is accepted by ACC, the child will receive his or her funding via this organisation. If the child's severe multiple disability was not related to injury or accident the MOH will provide for the child's health care needs. In this study, two of the young children were under ACC and two under MOH funding.

The MOH and ACC see that a child with severe multiple disability is provided with regular input from a paediatrician, child development services (occupational therapy, physiotherapy, speech and language therapy), and supply of support based on regular needs assessments. This includes provision of necessary equipment and in home support.

Within the education sector, from five years up to age 21, children with severe multiple disability are eligible to apply for the Ongoing Renewable Resource Scheme, which is funding allocated to the child to provide a component of specialist teaching programming, teacher aide support, and therapy provision at school. Under five years of age, they would receive educational support from Group Special Education, who have an early intervention service with access to early intervention teachers, education support workers, speech language therapists and child psychologists.

## **Summary and Overview of the Thesis**

***The essence of Dasein lies in its existence. . . The essence of this being lies in its to be. The whatness of this being must be understood in terms of its being insofar as one can speak of it at all. (Heidegger, 2010, p. 41)***

This chapter has briefly outlined what this research study will investigate and why it is important to explore 'the lived experience of mothering a young child with severe

multiple disability'. This chapter has given a brief overview of the methodology of this research, the reasons I was compelled to carry out this study, and introduced me as the researcher. The two key notions of 'mothering' and 'severe multiple disability' have been defined and some New Zealand contextual information has been shared.

In the following chapter, literature is presented that gives an overview of the current understanding of this phenomenon. 'Mothering' is deeply investigated from a social perspective down to the intensity of experience in mothering a young child with severe multiple disability. Being a mother and doing mothering are explored to give insights into this complex transformative process. As very little research exists on the experience of mothering a young child with severe multiple disability, I drew on a wide range of literature that gave insights into mothering with challenges.

Chapter three will focus on the methodology and philosophical underpinnings, which includes fundamental Heideggerian notions of importance for this study. This chapter also covers the methods undertaken in this research project; ethical considerations, inclusion criteria, recruitment, data gathering and analysis. The mothers and children involved in this study are also introduced in this chapter.

The next three chapters, four to six, present the findings of the research. These chapters contain my interpretations of the narratives gained in exchanges with the mothers of children with severe multiple disability. Chapter four describes the mothers' awareness of being visible and the limitations of a public and physical world mothering a child with severe multiple disability. Chapter five details the challenges of social isolation, and burdensome nature of mothering, as well as the disturbing nature of severe disability and its influence on mothering. Chapter six illustrates the importance of coming to terms with being a mother of a young child with severe multiple disability and the necessity of support and the power in relationships. Key Heideggerian notions are scattered throughout these chapters to assist in interpretations and enhance these findings.

The final chapter in this thesis pulls all of the findings together to discuss and understand the meaning in the lived experience of mothering a young child with severe multiple disability. The findings are viewed, enmeshed in the philosophical underpinnings and discussed in relation to occupational science. This discussion

chapter also outlines the strengths and limitations of the research study and the implications of its findings for mothers of children with severe multiple disability and health and education professionals. It is hoped that this phenomenon of 'the lived experience of mothering a young child with severe multiple disability' will be better understood and regarded.

## Chapter Two – Literature Review

*Beyond the changes to your inner landscape, as a new mother you will also have to deal with the peculiarities of our society and our time in history, both of which further impact your development as a mother. (Stern, Bruschiweiler-Stern, & Freeland, 1998, p. 17)*

### **Introduction**

This chapter explores literature pertaining to what is known about mothering and current literature relating to the experience of mothering a young child with severe multiple disability. It will provide the reader with insights into the co-occupational nature of mothering and the context of mothering a child with severe multiple disability. The information presented will guide the reader into and along this journey in the pursuit of gaining insights into this little known phenomenon; ‘the experience of mothering a young child with severe multiple disability’.

### **Search Methods**

The literature search was carried out using two primary databases, EBSCO Health and ProQuest Central. I also used Google Scholar and SCOPUS. The key search terms included ‘mother\*’ or ‘parent\*’ and ‘child\*’ or ‘young child\*’ and ‘disabilit\*’. At times the search included ‘lived experienc\*’. Terms excluded from the search were autism and mother with disability. The search terms were defined further by adding in ‘sever\* disability\*’ or ‘profound’, or ‘multiple\* disability\*’. When pertinent articles were obtained I used the databases to search for related articles to the one I had just sourced. Articles of interest were scrutinised based on how many times they had been cited. Reference lists were used to find other sources of information for the topic. I also used journal site search engines, such as on the Journal of Occupational Science website, with the aforementioned key search terms which yielded good results. A number of reference books, autobiographies, poetry, magazines and articles already known to the researcher were also integrated into the literature review.

### **Social Meanings of Mothering**

Mothering is a life role that throughout time has been marginalised and rarely considered worthy of research; however in the last few decades there has been a shift

in recognition of its vital importance (Francis-Connolly, 2000). The Oxford dictionary defines mother as simply the “female parent” (*Mother*, 1930/1981). Within the literature, extending from autobiographical pieces, magazines and opinion pieces, to various research designs, mothering is described as what is done by women to nurture and care for their child(ren) (Francis-Connolly, 1998). Mothering is described as being the most important occupational role for a woman (Esdaile & Olson, 2004), a nurturing responsibility (Esdaile, Farrell, & Olson, 2004; Stern et al., 1998) and an intricate phenomenon (Francis-Connolly, 2000) that is socially constructed, culturally defined and time bound (Esdaile & Olson, 2004; Phoenix, Woollett, & Lloyd, 1991). Mothering is “the bedrock of our society: instilling social values in new generations of members” (Larson, 2000, p. 250). More recently there has been acknowledgement that the role of mothering has also been carried out by others, those who are not necessarily female; mothering can be performed by a grandparent, a father, an adoptive parent (Larson, 2000). However, for the purposes of this study I, like Esdaile and Olson (2004), “recognize and honor the fact that even now, and certainly through most of history, women have been the mothers” (p. x).

It is important to understand that in the modern western world, the ideal mother, and mothering expectations have set both unrealistic and forced social ideals and responsibilities against which mothers are measured. Mothering should, in a sense, come naturally. Mothers should be attentive and presently available to provide for their children, and mothers should mother selflessly (Malacrida, 2009). Society further challenges mothers with the ideals of prescribed conditions for the best pregnancy, the optimal healthy baby and infant, the latest research and best practices for mothering (Esdaile et al., 2004).

Throughout history women have been in receipt of the message that the most critical social role a woman can engage in is mothering (Brydon, 2009). It is a socioeconomic construct which perpetuates this myth of ‘ideal mothering’ and has evolved throughout time; seen time and time over in television, film and print media:

Western cultural messages define mothering, not fathering or parenting, as the performance of nurture. Specifically, mothering is an all-consuming act of binding oneself to the everyday nurture of the physical, mental and emotional

lives of children to the exclusion of that same nature of oneself. (Brydon, 2009, p. 133)

Mothers not only hold the position of being the primary provider of care giving and nurturing, they have historically also been held accountable for providing a child's moral development and mental health alongside their overall well-being (Malacrida, 2009; Read, 2000). In the post war years, increasing emphasis was placed on the future mental health of a child being entirely answerable on the early relationship that was developed with their mother (Read, 2000). It is difficult to come to being a mother when there is such a high set of expectations within the role.

Motherhood is a social role that carries a significant moral weight . . . despite the normative belief that motherhood is a natural set of practices common to all 'proper' or 'real' women motherhood, like other aspects of femininity, is a set of behaviours, attitudes and actions that is learned and reproduced by social actors. (Malacrida, 2009, p. 102)

It is important to have this back ground information as this view of mothering influences the thoughts and actions of many mothers, and the ways in which they engage in mothering. The life role of mothering has the influence of shaping women's self-identity (Horne, Corr, & Earle, 2005) and mothering can come to have both positive and negative effects on the mother's mental and physical well-being (Farber, 2004).

### **Being a Mother**

Mothering is regarded within society as being very special; yet very little understanding has been established that captures insights into the everyday mothering experience (Francis-Connolly, 2000). Esdaile and Olson's (2004) publication about the complexities of mothering, revealed that although mothers will experience mothering in very unique and diverse ways, commonalities exist; such as a mother's need for support, facing social expectations in mothering, mothering lasting a lifetime, and that mothering has a profound impact on one's life. An online webpage designed to support mothers in their journeys of mothering, openly requests mother's to contribute to the body of knowledge available to viewers. One mother (Julie) shared the following narrative of her insights into being a mother:

What is most amazing to me about being a mother is how often the role changes. Being the mother of an infant is not at all the same as being the mother of a toddler. And being the mother of a first-grader is nothing like being the mother of a middle-schooler. Just when you think you have the role down, it changes suddenly, sometimes with no warning. What this has meant for me is that I am constantly growing and changing, challenging myself to new ways of thinking and being. It's as if my children are constantly shaping me, adjusting me, testing me, just as I shape, adjust, and test them. Our family is so dynamic as we press and pull on each other. There is no time for stagnancy. Sometimes it feels as if there is no time to breathe. And then, suddenly, there is time to breathe, just for a second. And so you breathe. You take it all in. You admire everyone's present state of life. And then you dive down again, into the rush of life, change, challenge. I never understood how exhilarating the ride would be – and how I would be so constantly changed by the whole experience. *Julie, mother of 3* (Murdock, 2012)

This perspective into the constant challenges, shaping and reshaping of mothering shows the dynamic nature of the mothering journey.

Being a mother starts at conception when women realise they are about to start a journey of immense change. Stern et al. (1998), in a guide to motherhood experience, stated that mothering will have a the profound influence on a woman's way of thinking:

A woman develops a mindset fundamentally different from the one she held before, and enters a realm of experience not known to non-mothers. No matter what a woman's previous motives, vulnerabilities, and emotional reactions, when she becomes a mother, she will, for a time, operate from an entirely new mindset. (p. 5)

As the mother of two children I would have to concur that this is entirely true. Stern, a psychiatrist, is adamant that this change in thinking does not occur at that exact moment in time when a child is born. It is a gradual accumulation that begins to take place before child birth and notably during pregnancy (Stern et al., 1998). In the time from conception to birth, a woman will experience an emotional and physical journey (Andricksen, 2009). For most, finding out about being pregnant is an extremely joyous time, as thoughts stir about planning a future with a new baby, and planning for motherhood (Emerson, 2007; Woodfield, 2009). In the nine months before a baby is

born a mother will fantasise about her perfect baby, engage in imagining dreams of what her baby will be like, and how she will engage in mothering (Raab, 1999; Stern et al., 1998). “In a sense, there are three pregnancies going on simultaneously: the physical fetus growing in your womb, the motherhood mindset developing in your psyche, and the imagined baby taking shape in your mind” (Stern et al., 1998, p. 32). Stern et al. (1998) noted, however, that although the physical nature of pregnancy can greatly influence a woman’s preparation for motherhood, it is not imperative, as women who adopt are also able to develop a mothering mindset without this experience. The birth of one’s baby can feel like the climax to many long months of waiting, preparing and hoping. However, the birth of the baby is just really part of the beginning to the journey of mothering (Leach, 1977/1985). How a mother transitions within mothering once the baby has arrived is dependent on many variables which have been investigated in a number of studies.

In a synthesis of nine qualitative studies related to the transition to motherhood, Nelson (2003) used Noblit and Hare’s meta-ethnographic comparative method of synthesising qualitative studies to identify two processes, five thematic categories and 13 underlying themes. Nelson argued that maternal transition ultimately requires *Engagement* which enables *Growth and Transformation*. Areas of disruption in the transition are; *Commitments, Daily life, Relationships*, the notion of *Self (facing the past, facing oneself, and coming to feel like a mum)* and *Work (the search for balance)*.

Earlier research of the transition into motherhood had identified similar themes. For instance, Barclay, Everitt, Rogan, Schmied and Wyllie’s (1997) grounded theory of early motherhood, developed using focus groups with 55 first time Australian mothers, encompassed wanting to be left alone to handle things their own way; a sense of giving everything to meet all the physical, mental and emotional demands of mothering an infant; loss of roles and of social life and sense of self; developing skills and confidence in mothering and caring for their babies. Like others, the researchers concluded that “the experience of becoming a mother is developmental and appears to follow a chronology related to increasing maternal confidence and experience” (Barclay et al., 1997, p. 726). Importantly, in the context of my study, the nature of the baby and his or her maturation were identified as influential dimensions of women’s transition to motherhood. More recent studies have continued to emphasise the

mothers' needs to develop competence and confidence with their mothering and a sense of control; that mothers tend to lean heavily on their partners or others for support; and what Darvill, Skiron and Farrand (2010) referred to as an '*altering self-concept*' which begins early in their pregnancies.

Quantitative evidence paints a somewhat different picture. An Australian questionnaire-based, before-after (during pregnancy and four months postpartum) study of 71 first-time mothers' transition to parenthood indicated that mostly the participants' expectations of what it would be like to be a mother were matched or were exceeded by parenting experiences (Harwood, McLean, & Durkin, 2007). However, where parenting experiences were lower than expectations, there was greater depressive symptomatology and poorer adjustment measurements. Such findings suggest that mothering does not come without sacrifice or cost.

Research from late last century also addressed the issue of return to work for women in Western societies. As infants get older, many mothers were reported to negotiate either returning to work, with renewed commitment to income earning or return to work on a part time basis. Some mothers potentially re-evaluate expectations for success in the workplace or career progression or they may choose to disengage completely from the workforce (Barlow & Cairns, 1997).

The transition to mothering/motherhood and being a mother captures a significant period of change and adjustment which is an important area of research, as it involves both the health and welfare of the mother and infant, and the stability of a family (Nelson, 2003). Another focus within literature relating to mothering as a transformative process is the importance of connecting 'what people do' to 'who they become'. For mothers, the occupation of mothering (the doing) comes to shape their identity (Horne et al., 2005). "Roles and responsibilities are components of our self identity because, to the extent, we identify with our roles ... we see ourselves reflected in the attitudes and actions of others towards us" (Horne et al., 2005, p. 177). Role identity is a very personal and private internalised understanding; the same role does not equate to the same role identity. However, due to the fact that roles are socially influenced,

we and others share fundamental expectations of what it means to be in a given role relationship . . . our public and personal identities are suffused with our roles . . . we come to see ourselves, judge our behavior, and assign worth to ourselves in terms of our own understanding of the roles we inhabit. (Kielhofner, 1995b, p. 71)

Difficulties can arise when role expectations are not met, when roles are lost that previously held value, or when restrictions or demands are placed on roles which make it difficult for these roles (or work) to be carried out (Kielhofner, 1995b). So, what does the research literature tell us about the doing of mothering?

### **Doing Mothering**

Multiple cultural, social, personal and internal factors will influence how a mother experiences mothering. Mothering has been identified as an occupation that influences self identity, which encompasses a deeply transformative process for women; it is socially influenced and necessitates constant change. The process of becoming a mother starts at conception and lasts the length of a mother's lifetime. From that moment, and for every moment after, a mother will always be a mother; she will not cease to being a mother until the day she dies. Doing mothering requires a set of "behaviours, attitudes and actions" that are learnt, produced and reproduced to provide care, protection, nurturance and teaching to a child (Malacrida, 2009, p. 102).

In early childhood, mothering relationships are extremely important as the child learns from the communicative relationship with his or her mother. "Synchronous, coordinated parent-child interactions, characterized by reciprocity and contingency, also contribute to cognitive and social-emotional outcomes for children" (Gartstein, Crawford, & Robertson, 2008, p. 11). The interplay of affective states and relatedness between parents and infants has been well researched, alongside early communication in infants stemming from the interactions with its mother (Feldman, 2007). Feldman (2007) alluded to the importance of reciprocal interactions:

Synchrony describes the intricate 'dance' that occurs during short, intense, playful interactions; builds on familiarity with the partner's behavioural repertoire and interaction rhythms; and depicts the underlying temporal structure of highly aroused moments of interpersonal exchange that are clearly separated from the stream of daily life. (p. 329)

These reciprocal interactions urge the mother to continue to interact with her child and as the child grows and learns the parent/mother will adapt and intensify or challenge her child in the interactions (Gartstein et al., 2008).

Doing mothering, and the implications of social engagement and reciprocity in relating to one another with regards to a child's development, was intimately investigated by Doris Pierce, an occupational therapist who became fascinated with the notion of play with her infant daughter in the early 1990s (Pierce & Marshall, 2004). This fascination with play became the topic of her thesis, in which she coined the term 'co-occupation', "the way in which two individuals occupational patterns can require and be shaped by each other" (Pierce & Marshall, 2004, p. 75).

Co-occupation is a dyadic interplay between the occupations of the mother and those of the infant... Thus, the mother's occupations require and affect the child's occupations. Co-occupations can be face-to-face in peek-a-boo play. They can also occur in alternations linked only in time and space, such as the daily pattern of the toddler carrying toys from the toy box all over the house and the mother returning them to the toy box at the end of the day. (Pierce, 2000, p. 297)

Within occupational science an occupation is deemed to be a richer and more fulfilling experience if it involves a shared encounter or give-and-take between two individuals (Olson, 2004; Zemke & Clark, 1996). The co-occupational nature of mothering changes over time as a child grows and mothering evolves in to a different set of daily activities based on the child's developmental process. Conversely, "co-occupation is an integral piece of a child's occupational development . . . co-occupations are central to providing opportunities and optimizing potentials of children" (Price & Miner Stephenson, 2009, p. 180). Maternal work is therefore engrained in co-occupation to meet the changing developmental needs of the child.

The idea that mothering changes as children develop is supported by Francis-Connolly's (2000) research which compared two stages of mothering. A group of 20 mothers of preschool children (aged 1 to 5 years) participated in this study. Two themes emerged from the preschool mothers. The first, *immersion in motherhood*,

revealed the endless demands of mothering young children and feelings of being overwhelmed, and unprepared for the intensity in mothering. Mothering as an *enfolded activity* was the second theme and describes the combined caretaking in mothering, which encompasses the daily care tasks alongside, nurturing, play and teaching. This research reinforces the understanding of the occupational and co-occupational nature of mothering, the need for adaptability and change in mothering, and the socially held belief that mothering is a nurturing and selfless role.

Play was emphasised by Pierce (2000) with 18 mother-infant dyads to understand management of the home as a developmental play space for infants and toddlers (aged 1 to 18 months). Results showed that much of the mother's thinking about play revolved around play objects, and the mothers adapted to the needs of their child as they grew and their needs changed. New toys were a necessity to engage their child, in order to juggle other role priorities and task completion. Play changed as the infants became more mobile and sought their own play objects around the home, requiring the mothers to react, adapt and structure environments in a play friendly set up. The mothers actively safety proofed the home, demonstrated protective play practices and engaged in teaching with their children. At times, positioning their children in a variety of positioning devices was necessary for providing a safe space away from siblings, and to allow the mothers to engage in household tasks. The spatial tie between mother, child and environment, and the continuous reconstruction of mothering work and routines to match the changing needs of the child was highlighted. "Habits, activities of daily living, tool use, activity analysis, and function are all spatially constructed, and all of our actions are spatial in their embodiment" (Pierce, 2000, p. 297). This research introduces another element influencing the doing of mothering; the consideration of the physical environment and its influence on performance. The physical environment can both enable and limit the ability of mother or child to engage in occupational choices, tasks or activities (Kielhofner, 1995a; Polatajko et al., 2007).

Much of the literature that has been covered thus far points to the psychological and behavioural process of mothering; however, mothering is, by its nature, a very physically demanding role. Doing mothering, particularly with an infant, toddler or young child places considerable physical demands on a mother, yet has received very little interest in literature or research (Sanders & Morse, 2005). One small qualitative

study explored the choices nine mothers of young children make when lifting their children. The overall conclusion was that mothers did not consider their back care when lifting their children; what was foremost in their minds was choosing methods that would most benefit their children (Griffiin & Price, 2000). These research findings are congruent with the previously mentioned ideals of mothering, and the necessity of being a mother who mothers selflessly. A research study conducted in Aotearoa New Zealand by McKay (2008) with 25 mothers investigated the nature of lifting practices in mothering to identify risk factors linked to musculoskeletal disorders. Results were statistically significant with ratings on physical stress associated with 50 childcare tasks. The most common musculoskeletal complaint was lower back pain, followed by pain in the neck, shoulder and upper back regions. The study concluded that the physical demand of mothering creates a notable number of risk factors for mothers engaging in the everyday demands of mothering. These studies also point to a mother's need to take care of herself in the occupation of mothering, perhaps to mother somewhat less selflessly, at least enough as to not place oneself in harm's way.

The intensity and physically demanding nature of mothering has also been identified in research that investigates mothers with a physical disability (Araujo, 2012; Farber, 2004; Grue & Tafjord Laerum, 2002; Malacrida, 2009; E. A. McKay, 2004; Pischke, 1993; Prilleltensky, 2003, 2004; Thomas, 1997). Mothers with significant physical disabilities have been discouraged to engage in the role of mothering by family members (Thomas, 1997) and medical professionals, with many women made to demonstrate their abilities and competence to physically manage the demands of mothering (Prilleltensky, 2003). One such account by Pischke (1993) detailed a physician using her own 8 month old infant as a test, to see if the spinal cord injured patient could effectively manage the daily needs and necessities of a real life infant. The group of health professionals then made attempts to convince the patient to give her child up for adoption or place her child in foster care. Pischke, refused to give her child up, and she went on to successfully raise four children.

Doing mothering places many stressors on a mother and a term that seems to be quite prevalent in the literature is the documented 'burden' associated with doing mothering (Arendell, 2000; Jackson & Mannix, 2004). Burden is defined in the Collins

online dictionary as meaning something that is “carried, a load, something that is exacting, oppressive, or difficult to bear, onerous” (“burden”, n.d.). Mothering, in all its complexity, can be seen to be a contradicting mix of emotions and states of being. “Mothering can confer both maternal power and an immense burden of responsibility” (Oberman & Josselson, 1996, p. 344). When mothers describe failures in acting responsibly in their mothering, they often express feelings of guilt, fear and failing as a mother (Elvin-Nowak, 1999). Guilt and stress in mothering was further identified in relation to working mothers trying to juggle the demands of mothering, their individual needs, family needs and workplace demands (Guendouzi, 2006). The notion of shame as an associated burden of mothering, as described by mothers, has also been frequently reported in the literature: “guilt involves fear of punishment, stemming from feelings of having done something wrong, while shame focuses on the role of the self in relation to others, or a violation of group norms” (Sutherland, 2010, p. 311). Guilt and shame often result from mothers doing mothering under constant public scrutiny, which has formed these ideals about being a ‘good mother’ (Jackson & Mannix, 2004; Seagram & Daniluk, 2002) and producing the ‘perfect’ child.

What is the experience of mothering when you do not have the perfect child, but one with a severe disability? For the most part, little is really known about this phenomenon. Much of the literature on the occupation of mothering focuses on transitioning into motherhood, the becoming of a mother or on the marital dyad (Francis-Connolly, 1998; Horne et al., 2005). A few studies have investigated quality of life or wellness of mothers (Davis & Gavidia-Payne, 2009; Eker & Handan Tazun, 2004; Leung & Li-Tsang, 2003; Mackey & Goddard, 2006), and the phenomenon of mothering being a lifelong role or occupation (Francis-Connolly, 2004; Graungaard, Andersen, & Skov, 2011; Kilic, Gencdogan, Bag, & Arican, 2013; Kim, Greenberg, Seltzer, & Krauss, 2003). From the literature that has been reviewed, and from what will follow in this thesis, the experience of mothering a child with severe multiple disability encompasses the same notions expressed by ‘other mothers’. What mothers of children with disabilities experience however, is ‘mothering intensified’.

## **Mothering Intensely**

Read (2000) postulated that the caring of children with disability is predominantly carried out by mothers. A significant body of literature on mothering a child with disability has focused specifically on the negative aspects and burden (Voysey Paun, 2006) associated with phenomena such as coping (Graungaard et al., 2011; Heiman, 2002; Minnes, Perry, & Weiss, 2014; Paster, Brandwein, & Walsh, 2009), grief and chronic sorrow (Bruce & Schultz, 2002; Kearney & Griffin, 2001; Patrick-Ott & Ladd, 2010; Scornaienchi, 2003) and stress (Heaman, 1995; Miller, Gordon, Daniele, & Diller, 1992; Noojin & Wallander, 1997; Wallander & Noojin, 1995).

The experience of stigma was also recognised in the literature regarding disability (Alvarez McHatton & Correa, 2005; Barg, Armstrong, Hetz, & Latimer, 2010; S. E. Green, 2002, 2003, 2007) and the issue of public perception, scrutiny and reactions to children with disabilities and their families. Stigma has most notably been defined and analysed by Goffman (1963) who defined stigma as referring to “those attributes that signal difference in relation to an assumed norm and are usually negatively appraised” (Craig & Scambler, 2006, p. 1116). Mothering a child with cerebral palsy has given S. E. Green (2002, 2003) first hand experiences into stigma and discrimination; she is a well respected and cited author on the subject:

I carried into this experience awareness that Amanda would likely be devalued and discriminated against because of the stigma associated with her diagnosis. I also carried an intense, almost unbearable fear that this stigmatized status would result in a life of rejection, mistreatment, social isolation and loneliness for my daughter. (2003, p. 1362)

Stigma is not only experienced by the child or person with disability. It is also experienced by those close to the individual with the disability. In her mixed methods study which surveyed 81 mothers of children with chronic disabilities (cerebral palsy, down syndrome, spina bifida, autism, muscular dystrophy, non specific developmental delay and neurological injury) in Florida, USA, S. E. Green (2003) found that perceived stigma increases the subjective burden mothers perceive in their mothering tasks. Stigma was also found to directly influence the interactions that the children with disabilities had with peers. Limitations noted within this study were the small

catchment of participants, being one localised area of the United States of America. The researcher also noted the young age of the children in the study with a mean of 5 years. The high degree of children with cerebral palsy (31%) could also have potentially influenced the data, as other research has shown children with cerebral palsy generally tend to have fewer peer interactions.

Research and literature exploring the phenomenon of children with disabilities is shifting away from such pre-conceived pessimistic notions toward revealing the relationships mothers have with their disabled children (Landsman, 2005; McKeever & Miller, 2004), the nature of everyday activities (Kellegrew, 2000; Woodgate, Edwards, & Ripat, 2012), play (Pierce, 2000), informal support (Lindblad, Holritz-Rasmussen, & Sandman, 2007) and being supported by professionals (Davis & Gavidia-Payne, 2009; Sloper & Turner, 1992). Research and literature has identified the difficulties inherent in managing the societal influences and demands on the role of mothering or parenting a child with disabilities (Graungaard et al., 2011; S. E. Green, 2007; Leiter, 2004; Ryan & Runswick-Cole, 2008).

It is important to note that a large body of disability research has focused on specific diagnoses, particularly autism (Ekas, Lickenbrock, & Whitman, 2010; Hayes & Watson, 2013; Kasari, Gulsrud, Wong, Kwon, & Locke, 2010; Lee, Harrington, Louie, & Newschaffer, 2008). Mothering/parenting a child with intellectual disability (Broberg, 2011; Kilic et al., 2013; Mackey & Goddard, 2006), Down syndrome (Pillay, Girdler, Collins, & Leonard, 2012; Stoneman, 2007), Duchenne's muscular dystrophy (Dreyer, Steffensen, & Pedersen, 2010; Samson et al., 2009) Rett syndrome (Lim, Downs, Li, Bao, & Leonard, 2013), spina bifida (Black Mosen, 1999), brain injury (du Toit, Coetzee, & Beeton, 2013) and cerebral palsy (Eker & Handan Tazun, 2004; Glasscock, 2000; S. E. Green, 2002; Meeham, 2005) is also evident from literature searches. As I am seeking the experience of mothering a young child with severe multiple disability, I have sought research and literature that fits within the specifics of this specialised group.

As previously stated, research has mainly focussed on the mothering of a child with a particular disability, such as cerebral palsy, and the mothers perspectives on therapy interventions (Case-Smith & Nastro, 1993), experiencing worry (Black Mosen, 1999),

the role of spirituality and religion in mothering a child (Pillay et al., 2012), mothers as activists (Llewellyn, Thompson, & Whybrow, 2004), and specific theories for adaptation (Moore, 2005). I was able to source only limited research that sought the everydayness and meaningful experience of the occupation of mothering. Even less research has considered the lived experience of mothering a child with severe multiple disability (Case-Smith & Nastro, 1993; Esdaile & Olson, 2004; Glasscock, 2000; Llewellyn et al., 2004; Moore, 2005; Read, 2000). Because of their direct relevance, studies of mothering young children with severe disabilities are reported in some detail below, although none were located in Aotearoa, New Zealand.

One phenomenological study investigated the lived experience of mothering a child with cerebral palsy aged 1 to 5 years (Glasscock, 2000). Thirteen of the 15 participants were African American; the remaining two participants were Caucasian. Four clustered themes were generated. *Caregiver burden*; addressed the nature of caring for a child with cerebral palsy. *Family/social support*; highlighted the assistance that was received from family, friends, partners, medical professionals and social services. *Women's/mothers' roles*; the mothers in this study shared experiences of managing multiple roles, mothering other children, being a wife and home maker. *Socioeconomics*; the mothers spoke about not being able to work and the loss of income, and maybe working in the future, if they were able. In this study all the mothers identified significant caregiving stressors. Mothering was described as hard, time consuming and it necessitated support. Despite the reports of stressors, all the mothers identified that caring for their children with cerebral palsy was a positive role and they all reported enjoying mothering.

In a similar phenomenological study carried out by Meeham (2005), with five mothers of young children (3 years to 6 years in age) with hemiparesis, six themes emerged: *Mother's way to know*; described the women's experiences and instinctive knowing that something was not right with their child. *Being blown away*; came from the descriptions given by the mothers detailing when they were told of their child's diagnosis. Their children were not the perfect babies they had imagined or expected. *Gradual awakening of an unknown future*; referred to the gradual realisation of the impact of their child's disability and that the effects would be lifelong; the mothers worried about societal attitudes towards their child and being judged for physical

appearance. *Fiercely advocating for my child*; referred to actively becoming involved in the system, gathering information, making informed decisions, and speaking up for their children. *Living in the Middle*; portrayed information that the mothers shared about not fitting in with the mothers of typically developing children, nor fitting into the world of mothers of children with severe disability, despite trying to find support groups and other mothers like them. *A heart filled with joy and sorrow*; encompassed the sadness and mourning for the child that was or could have been as described by the mothers. This theme was particularly pertinent at definitive points of child development and the mothers found themselves comparing their children to their typically developing peers. However, they also described such joy from mothering their children with hemiparesis, using terminology such as; he's our hero, he's fearless, the most amazing child. The mothers also referred to themselves as being changed by the experience of having a child with disability; one stated she had new perspective about life, *'just everything changed'*. A few commonalities exist between the previous study by Glasscock (2000) and Meeham (2005) as both identified the mothers seeking support and the importance of mothering with support. They also identified burdens in mothering and the expressed joy in the experience and positive nature of mothering a child with special needs. There are limitations within this study regarding the small group of participants who were all middle class, well educated American women and described the experience of mothering children with a very specific diagnosis of physical disability.

It is interesting in Meeham's (2005) research that the mothers described their children using 'super' statements, and attributing them with bravery, courage and being somehow remarkable. Similar sentiments are shared by mothers of children with disabilities in a book written and photographed by Callander (2014). Rachel Callander was the mother of a little girl, Evie, who was born with a rare chromosomal condition. Callander described the process of readjustment of her dreams for her family, and a new appreciation for living each moment of each day. She described the stress, the heartache, and the gratitude for the short time she had with her daughter. Evie's parents believed she felt and responded to the environment in very unique ways, almost like she had an electromagnetic sensitivity, they called these Evie's super powers. Evie's parents came to realise that she was teaching them and others around

her profound things. She was tough, brave, she evoked deep love and pure joy. After Evie passed away, Callender invited mothers of other New Zealand children with similar conditions to share their insights.

“She has made us more caring and a lot stronger. We take a day at a time and appreciate each one” (Kelly – Honor’s mother, p. 148).

“He has taught us a very important life lesson; that we’re not all the same and we don’t have to be” (Bianca – Kaden’s mother, p. 152).

Along the way you meet people who have coped. It makes you stronger and helps you to see what you have in front of you rather than seeing the ‘imperfect child’. I started to see Amira for who she was. It changed me. She gives me so much strength. I now can face the lessons I need to learn. Bring it on! (Grace – Amira’s mother, p. 164).

Literature and research by S. E. Green (2002) shares the same emotions to her mothering journey. S. E. Green was diagnosed with preeclampsia and her baby was born two months prematurely with severe cerebral palsy.

The road we travel is full of twists and turns and has many blind alleys. We must continually reimagine what lies ahead and are constantly, and quite often pleasantly, surprised by what we find around the bend. The journey down this path has been a personally transforming experience for me in some surprising ways. It seems to have opened up some areas of my soul that would otherwise lie dormant. (S. E. Green, 2002, p. 24)

As previously discussed in other research findings, S. E. Green (2002) identified with the loss of the imagined perfect child, and an imagined reality:

There is a profound sense of irony in this sense of loss, however. Unlike other interpersonal losses, the object of the loss has not left or even changed. The child you have always loved is still with you and needs your care and attention. Only the imagined narrative of his or her life is changed. (p. 22)

Eventually, she emphasised parents’ need to come to adapt their “master narrative” and accommodate to the realness of their child and their disability (S. E. Green, 2002, p.22). The experience of caring for her child with severe disability changed her by opening *areas of her soul*, and she felt compelled to share her journey in the form of

poetry that describes insights into her child's disability and how she experiences mothering her daughter.

### **Worlds Apart**

In dream time, I am my child – or she is me.  
I feel the rock hard muscles in my arms and legs.  
I sit held fast by metal bars and nylon straps.  
I'm braced against the spasms that will stiffen limbs.  
I also know the sadness that my presence sometimes brings,  
    and feel the need to squelch the hidden source form which it springs.  
I wonder,  
In her dreams can she be me?  
Does she then know the freedom of unbounded moves through space  
    and can she see the look of need upon another's face?  
Among my deepest hopes is that this maybe so.  
For in the daylight hours,  
    each other's worlds we cannot know.

(S. E. Green, 2002, p. 27)

S. E. Green (2002) arranged her poetry and insights into 'mothering Amanda' under three of the five stages in the model of adjustment to the presence of a child with a disability, proposed by Seligman and Darling (1997/2007). In this model the authors propose that a family transition from: *Anomie (postpartum or post diagnosis); meaninglessness/powerlessness, to seekership (infancy); searching for support, to normalisation (childhood); integration of the child into a family/community life, a return to seekership (adolescence); planning for impending adulthood necessitates a move back to searching for support, and then a return to normalisation (adulthood)* (Seligman & Darling, 1997/2007). It is proposed within this model that most families of children with disabilities will achieve normalisation. However there are barriers that can prevent this:

Unmet financial, service, social support, or counselling needs, perceived stigma, and extreme caregiving demands due to the severity of the disability. Where these barriers are insurmountable, families may become socially isolated or, alternatively, enmeshed in the insular world of others who are wise to the experience of disability. (S. E. Green, 2002, p. 23)

The above theory highlights commonalities of the aforementioned research in the seeking and need for support, alongside the importance of mothers changing their master narrative. The relevance and impact of unmet needs (financial and social), stigma and isolation were also emphasised.

The extreme nature of caring for a child with severe disability and the impact of barriers has been embodied by Ian Brown, a Canadian journalist and author, who received acclaim for his book 'The boy in the Moon' which details the life of his son, Walker, born with a very rare genetic disorder. Although not a mother, Brown's insights into his son and his disability are of value and can be given consideration for this body of research. Brown highlighted some interesting insights into the nature of caring for a child with severe disability and some overarching societal insights. Overall, he expressed that having a child with severe disability is exhausting; it will strain relationships, can ruin a marriage, will influence your financial situation, cause sleep deprivation and is extremely isolating (*CBC radio one*, 2009, November 4; *watchmojo.com*, 2009, December 15). A number of the barriers that his family faced are barriers identified in Seligman and Darling's (1997/2007) model of adjustment.

Similar notions of the experience of mothering a child with disability were researched by Barbosa, Chaud and Gomes (2008). Five Brazilian mothers of children aged 6 to 17 years, were asked "What does it mean, for you, to have a disabled child?" The data revealed five thematic categories describing the grief, helplessness and at times rejection of the infant. A mother shared her guilt the fragility of her child and the disability that destroyed "the dream of the ideal infant" (Barbosa et al., 2008, p. 49) in this quote:

...she was born with a heart condition... There was a night... that she had some crises and I..., I thought a lot..., who knows, if she died..., then our problems would be over [tears]... I was feeling very guilty..., I was feeling very..., like a... very bad person... (Barbosa et al., 2008, p. 49)

This study illustrated realisation from the mothers of being in a world of stigma, shame, rejection, experiencing isolation, and distancing themselves from society, which has been noted in previous studies. The mothers described seeking information about their child's disability, and emotional turmoil from professional's attitudes

towards them and their child. This incongruity was also a theme shown in research by Barbosa et al (2008). Searching for support was a similar notion shared across the multiple studies outlined. In realising their love for their child, the mothers also came to realise the fragility of their child and the potentially temporal nature of mothering them. One participant said “I dread that one day God may take my child...You know, some nights I don’t even sleep” (Barbosa et al., 2008, p. 50). This study concluded that mothers overcome sadness and grief, and through their own growth as mothers, their families successes and achievements they come to feel joy and happiness, and see their child with disability as being a lever for these accomplishments.

There are limitations noted to this study, it was a small study with only five participants, and from a localised area in Brazil, with vastly different cultural practices and perspectives. The children with disability in this study were also wide ranging in terms of age, and it was not possible to determine the severity of the children’s disabilities. Nonetheless, this research identified key categories that have been established in other studies of the phenomenon of mothering a child with disability. In particular, it stressed the need for professionals to be aware of the emotional needs of mothers and to assist them in understanding their experiences of mothering and finding their way to ‘being-there-with-their-child’.

## **Conclusion**

***“Normal is whatever I am, and whoever you are” (Cosgrove, 1978/2002, p. 25).***

Mothering is an extremely complex and evolving psychological experience for any woman and how one ‘mothers’ is influenced socially, culturally, spatially and historically. There is an expectation that when a woman conceives a baby that she should adhere and conform to a specific ‘normality’ of being the perfect mother. During pregnancy a woman will also idealise in her mind her imagined ‘perfect baby’. From the literature, it is evident that all mothers will encounter these truths. Furthermore, the literature notes that mothers will experience a change in mindset, altered life roles/identity, a change in self concept, adjustment, transformation, growth. This occurs throughout the lifetime of mothering, from conception, to birth,

until her death. Throughout mothering, a mother will encounter the burden of mothering. There will be guilt, shame, stigma, financial costs, sleep deprivation, loss (of time, of control, and roles, an imagined life) it will be isolating, exhausting, overwhelming, and demanding (physically, mentally and emotionally). Doing mothering in its everydayness requires a mother to nurture, care, play and teach. For a mother to be successful and able to carry out mothering she needs support, to create a positive role identity and to actively seek information and advocate for her child. Mothering a child with severe multiple disability includes all of these experiences. What is evident in literature about the experience of mothering a child with severe disability is mothering in change, where it is necessary to transition and evolve, yet be present as their child makes little or no developmental gains. The doing of mothering for a child with severe disability denotes caring, whilst the disability enforces restrictions in play, teaching and nurturing. The experience of mothering a child with severe disability is mothering intensified, where the burden is heavier, and the everydayness has forced restrictions and limitations, for the length of the relationship with the disability and the child. Yet, mothering a child with disability with its intensity brings extremes in growth and understanding a unique relationship with their child and a vastly different perspective on life and their own sense of 'normal', despite the slightly altered path on which they journey.

## Chapter Three - Research Methodology

*To do research is always to question the way we experience the world, to want to know the world in which we live as human beings. And since to know the world is profoundly to be in the world in a certain way, the act of researching – questioning – theorizing is the intentional act of attaching ourselves to the world, to become more fully part of it, or better, to become the world. (van Manen, 1990, p. 5)*

### Introduction

This chapter describes and justifies the hermeneutic phenomenological methodology used, guided by Heidegger's phenomenological philosophy and van Manen, to carry out this research project. It then details the research methods used and shows how they are congruent with the methodology and its interpretivist underpinnings.

### Philosophical Underpinnings

This research was carried out using hermeneutic phenomenological methodology, and was guided by the writings of Heidegger (1959, 1971, 2000, 2010) and van Manen (1990). Phenomenology was chosen to explore the lived experience of mothering a young child with severe multiple disability, whilst the hermeneutic phenomenological approach provided the researcher a means to interpret the participants' stories, language used and the meanings behind the text. Hermeneutic inquiring can, in essence, expose somewhat hidden meanings and intent in text (Crotty, 1998). The importance of language is centralised within hermeneutic phenomenology; "language is both the medium and product of human culture" (Allen, 1995, p. 176). van Manen (1990) likens phenomenological inquiry to that of an:

artistic endeavor, a creative attempt to somehow capture a certain phenomenon of life in a linguistic description that is both holistic and analytical, evocative and precise, unique and universal, powerful and sensitive... determined by questioning the essential nature of a lived experience: a certain way of being in the world. (p. 39)

I engaged the participants in this study in conversational-type interviews aimed at evoking the participants' accounts of particular moments in going about their day as

mothers. I used ontological language to name the thematic notions arising from my analysis of these mothers' stories, as a way of conveying the lived experience of things.

Phenomenology is about gaining a depth of understanding and the meaning of experiences as they occur in the everydayness (van Manen, 1990). "It is based in the belief that those who have experienced a phenomenon are the most knowledgeable about that phenomenon" (Stanley & Nayar, 2014, p. 8). Therefore, in this study, I invited the mothers to recount particular moments and events of going about their mothering. Hermeneutic phenomenology, informed by Heidegger's philosophy, is centred around *being* or *being there*; that one is always experiencing things within a context and understands that *being* is experienced within time. People are shaped by their world and every person's experience is unique to him or her (Burns & Grove, 1997). "Phenomenology requires us to stick with the things that appear in experience, and learn to see them in such a way that they show up as they really are" (Wrathall, 2005, p. 9). In other words, in this study, I aim to show a trueness of mothering a young child with severe multiple disability as it is in its everydayness for the mothers in this study, and its very being in the world.

Phenomenology is particularly useful when the phenomenon of interest is understood as existing; yet, the essence of experiencing the phenomenon is taken for granted, covered over in some way and not discussed. Phenomenological research "explores the humanness of a being in the world" (Morse, 1991, p. 55).

Hermeneutics guides the methods to interpret text in a way that the author may become enlightened to the phenomenon (van Manen, 1990). Heidegger's concept of hermeneutics was that he did not merely want to re-experience a person's lived experience; he wanted to gain the "power to grasp one's own possibilities for being in the world in certain ways. To interpret a text is to come to understand the possibilities of being revealed by the text" (van Manen, 1990, p. 180). Hermeneutics recognises that I come to this phenomenon having previous knowledge and experiences of my own which will shape and influence how I come to interpret and understand these mothering experiences (van Manen, 1990). My presuppositions and my history are within me; however, I stay true to the text and open to the meanings within them. By listening to stories about the lived experience of these mothers, my own horizons of

understanding are broadened, deepened and my history altered. Next I explore, in more detail, why I selected phenomenology for this study.

### **Why Phenomenology?**

In line with Heidegger's ontological philosophy, I assumed that phenomena may exist yet be hidden in some way. Further, that people can come to know phenomena through their everyday experiences; that is, the lived 'being' of that phenomenon may announce itself in lived experiences. In accord, "the only possible route to Being is through a being which has an understanding of Being" (Large, 2008, p. 115). In other words, the phenomenon of mothering a child with severe multiple disability can only be experienced by living and mothering a child with severe multiple disability. As a novice hermeneutic phenomenologist I am concerned with interpreting the experiences of mothers, mothering young children with severe multiple disability, through their stories of lived moments and events, and getting as close as possible understanding the possibilities revealed in the data from these mothers' experiences.

The focus of the research is to obtain a richness and depth of information from the recounted experiences of the participants to reveal previously hidden notions and gain deeper understanding of the phenomenon of mothering a young child with severe multiple disability. I have worked for over 10 years with children with severe multiple disability and formed relationships with many mothers; however my understanding of their everyday lives was lacking. I had many assumptions as to what their lives were potentially like, I had read about the chronic sorrow, the burden of care and grief. What I lacked was a knowing about the meaning of mothering a young child with severe multiple disability and how that phenomenon could improve my ability to form meaningful relationships with mothers to benefit their child and to benefit them in their role as mothers.

My own interpretation is influenced by being a mother to two young children aged five and seven years. It is influenced by my time spent working in the disability and education sectors for the last 15 years, and of the knowledge I have obtained in engaging in post graduate study. My lenses have glanced over the phenomenon of interest in the past; they have however not ever been as up close and focused as they are presently.

## **Fundamental Heideggerian Notions**

Throughout this thesis I have drawn on notions from Heidegger's philosophy. A brief explanation of the key Heideggerian notions is given to assist readers as to why and how they inform this research. Further clarity of these notions are shown through my interpretations of the stories that unfold in this text.

### **Dasein**

Dasein is the knowingness and understanding of one's existence. Heidegger believed only human beings were conscious of their existence and that our existence was an issue for us (Heidegger, 2000). Therefore Dasein is human existence. We all individually have our own Dasein because we all exist in the world in our individual ways. In this study the Dasein of being the mother of a young child with severe multiple disability was explored by inviting mothers of young children with severe multiple disability to tell stories of doing mothering.

### **Being**

Being is the most universal concept;

the fact that we live already in an understanding of being and that the meaning of being is at the same time shrouded in darkness proves the fundamental necessity of retrieving the question of the meaning of 'being'... The indefinability of being does not dispense with the question of its meaning but forces it upon us. (Heidegger, 2010, p. 3)

Being, as Heidegger saw it, was the focus of inquiry. To ask about the 'being' of anything is to question the very nature or meaning of that phenomenon. Being is essentially the ontological term used to describe the method of human science research (van Manen, 1990). Throughout this study, I assumed that the 'being' of being a mother of young child with severe multiple disability was a phenomenon that existed.

### **Being-in-the-World**

Heidegger's perspective was that only human beings were completely open to existing in the world. Therefore being-in-the-world is used to describe how human beings act and are concerned with the world (Heidegger, 2000). This notion played out in the

current study through evoking ‘this’ mother’s primordial stories about being in the moment, in ‘this’ place, doing ‘this’ thing with her child.

## **Methods**

Having shared the theoretical underpinnings of this study and the methodology of hermeneutic phenomenology, the following sections of this chapter will cover the methods that were used to gather and interpret the rich narratives that were gifted by the mothers. Herein lies the “concrete techniques” and the “planned procedures” (Crotty, 1998, p. 6) to procuring the meaning in mothering a young child with severe multiple disability.

## **Ethics**

This research project obtained ethical approval from the Auckland University of Technology Ethics Committee (AUTEC) in May of 2013 (Appendix A). Subsequent approval was also sought to amend information in the original ethics application; in the first instance the approval request was successfully granted to allow SKYPE interviewing (Appendix B), in the second instance approval was granted to expand recruitment to include a named school and other similar organisations (Appendix C).

Participants were given full disclosure about the purpose of this research (both verbal and written). Explanation was provided to participants as to the nature of the interview and questionnaire process; what and how information would be sought, and for what purpose, the implications for them as participants in this study and their right to withdraw from the research at any point if they wished to do so. Signed consent forms (Appendix D) were sought from participants at the beginning of their first interviews and were reconfirmed when receiving and accepting the stories provided for verification. Participants’ self selected pseudonyms and these were used when quoting stories and findings to protect the participants’ identities.

## **Inclusion criteria**

To meet the criteria for inclusion in this study the potential participants needed to be currently in the role of a mother (i.e. a female who provides mothering; not necessarily a biological mother) for a young child aged 3 to 7 years with severe multiple disability. Severe multiple disability was classified as being a significant physical disability; the inability to walk unaided, coupled with at least one other significant disability of

cognitive, behavioural or sensory origin. Inclusion criteria also included the ability to speak and understand the English language in both verbal and written form, as this was the researcher's primary language and would be used to communicate the entire research process and allow interpretation of the text provided by the participants.

At the beginning of the research process I was employed as an occupational therapist in two work settings that provided services to children with severe multiple disability. Thus, to avoid any conflicts of interest and to preserve the therapeutic relationships already in existence and future therapy relationships, potential participants could not be considered for this study if they were in receipt of therapy from a named school offering specialised educational services and Paediatric Rehabilitation Services.

Midway into the study I resigned from my position as an occupational therapist at the specialised school and a variation to the original Ethics approval was accepted by AUTEK (Appendix C) to openly recruit mothers of children with severe multiple disability from this setting under the condition that they had not previously had any relationship with the researcher.

### **Recruitment**

Purposive recruitment was used to identify potential participants for the study. Fifteen special schools and organisations nationally, with predominance within the Auckland region, were contacted for assistance to distribute a flyer outlining the research project to parents (see Appendix E). Six special schools within the Auckland area included the flyer in their weekly newsletters. The flyer was further distributed via email network distribution lists and Face Book pages of music therapy centres, conductive education providers, support organisations such as Parent 2 Parent, The Cerebral Palsy Society and Focus on Potential. Occupational Therapy New Zealand (OTNZ) was also contacted and the researcher successfully applied to its Ethics Panel (Appendix I) for assistance with recruitment and flyer distribution via the members of special interest Google groups.

The flyer invited potential participants to contact the researcher by phone (free phone 0508 number) or email to express their interest. Potential participants who made contact with the researcher were given an explanation of the research process once it was confirmed that they met the participant inclusion and exclusion criteria. The

researcher then confirmed their interest and obtained details from the potential participants as to their communication preferences to either post, email or SMS the research participant information sheet (Appendix F), consent form (Appendix D) and demographic questionnaire (Appendix G). The researcher outlined the process of a stand down period to the potential participants and stated after two weeks contact would be made to establish if they would like to continue as a participant in the study.

The researcher used purposive sampling, and openly sought Māori participants to engage within the research. There was only one participant who identified her ethnicity as being Māori.

Five potential participants were sent information pertaining to the research process and, of those five, four agreed to continue as participants. The researcher continued to actively recruit participants for the study up until October of 2014, a period of 17 months, when it was deemed that willing volunteers had been given reasonable opportunity to indicate interest in participating.

## **Participants**

### **The mothers**

The four participants, aged 35 to 46 years, were all biological mothers of a young child with severe multiple disability. Three mothers identified as being New Zealand European, and one mother was Māori/German. All of the mothers lived in the North Island of New Zealand with two living in Auckland. Two lived in urban areas and two in rural areas of the North Island. The participants were all families of five in total, comprising mother, father, and three children. For three of the participants the child with severe multiple disability was the middle child and for one participant the child with severe multiple disability was the youngest.

### **The young child with severe multiple disability**

The young children with severe multiple disability were also, in spirit, participants of this study as the research question aimed to reveal the experience of mothering them. Mothering may be seen as a co-occupation, as mothering is a caring occupation or the occupation of being a caregiver to a child. Being a caregiver requires two people; each plays their part in whatever activity they may be engaging in. The child's part may be

passive or it may involve interplay with his or her mother; either way, there are two people in that moment of mothering (Olson, 2004). With regard to the children embedded in this research, two of the children with severe multiple disability were five years of age, one was six and one seven. Two were boys and two girls. Three of the children had a diagnosis of cerebral palsy and one a rare neurodegenerative disease. Two of the children attended special schools and two mainstream schools. Two of the children were funded under ACC and the other two by the Ministry of Health. All of the children were born prematurely.

### **Data Gathering**

Participants were invited to fill in a brief demographic form (Appendix G), which outlined their age, occupation, ethnicity, marital status, education, their child's age, disability/diagnostic information, the child's educational history and ages of any additional children.

Semi-structured, face to face interviews, of 60-90 minutes duration were conducted with the four participants. Two interviews were carried out in the participants' homes and two were carried out using an online, real-time communication platform, SKYPE. "SKYPE encourages interviewees who have time and place limitations for face-to-face interviews to participate in research" (Janghorban, Roudsari, & Taghipour, 2014, p. 1) as the participants lived outside of Auckland. Interviews were digitally audiotaped, using two Dictaphones. The interviews were downloaded to a password protected file and the audio files were deleted from the devices. The audio files were supplied to the transcriptionist using a shared cloud storage site, Dropbox. The transcriptionist signed a confidentiality agreement (Appendix H) at the beginning of the research process protecting all information that she would be privy to during transcription work.

The raw transcripts were reworked to draw out coherent narratives/stories (Caelli, 2001) which captured the essence of the participants' experience mothering a young child with severe multiple disability. These narratives were then emailed to the participants for member checking and verification. Two of the participants sent back revised narratives, requesting insertions that gave the reader additional background information and context, and removal of colloquialisms. One mother requested details of a narrative be removed as she was concerned this could reveal the identity of

herself and her child, whilst the other two were happy with the emailed version. Stories of an identifying nature were excluded from print if required. Interviews, transcriptions, consent forms, data analysis and demographic questionnaires were kept in separate pass word protected files uploaded to Google Drive, to ensure strict containment of information and privacy. Any paper copies were scanned to file and then destroyed.

### **The interviewing**

“Phenomenology asks the simple question, what is it like to have a certain experience” (van Manen, 1990, p. 44). As such, I sought the ordinary, mundane and everydayness in the experience of mothering a young child with severe multiple disability as it is in the typical, that the essence of a phenomenon truly shows itself, to be itself. To align with this thinking, I developed a series of questions (Appendix J) to prompt the participants to share their experiences of mothering that would aide in descriptions and phenomenologically rich narratives.

My being silent at times was one way of opening up space for the mothers to voice their experiences, and I was mindful of pausing to give the participants time and respect to allow thoughtful responses. Deeper insights into the experience of mothering a young child with severe multiple disability were gained by staying close to the research question in the interviews with a focus on the everyday. I kept a reflective diary and I would, at times during interviews, write notes, words that stood out to me and points to go back to, and further inquire as necessary.

I aimed to establish relationships with the participants based on rapport, trust, honesty and respect (Seale, 1999; Seale, Gobo, Gubrium, & Silverman, 2007). Open disclosure was reciprocal with regard to the research, and participants were made aware of my obligations to confidentiality.

I was also aware of the need for cultural sensitivity and adhered to the principles of the Treaty of Waitangi.

The Treaty of Waitangi is New Zealand’s founding document an agreement, in Māori and English that was made between the British Crown and about 540 Māori rangatira (chiefs). The document has three articles. In the English version, Māori cede the sovereignty of New Zealand to Britain; Māori give the

Crown an exclusive right to buy lands they wish to sell, and, in return, are guaranteed full rights of ownership of their lands, forests, fisheries and other possessions; and Māori are given the rights and privileges of British subjects. (Ministry for Culture and Heritage)

The principles of the Treaty state the following; consultation with Māori, to protect Māori interests and to act in reasonable and good faith, and to adhere to Māori cultural practices and taonga (regarded as sacred and special)(Ministry for Culture and Heritage). I consulted with Maori cultural advisor to ensure that written materials and interviewing practices were appropriate and fitted within these principles.

The potential vulnerability of the mothers in the context of this study was recognised throughout the research process and the researcher was sensitive to the probable emotional and sensitive subject matter discussed during interviews. Participants were given information about the option to attend counselling services, provided free of charge through Auckland University of Technology, which were available to use at their discretion if required. To my knowledge none of the participants utilised these services.

### **Data Analysis**

Hermeneutic interpretation was used, and the data read and interpreted to identify themes in the transcribed narratives. Guided by the writings of van Manen (1990), a selective or highlighting approach was used to isolate thematic statements and commonalities in texts and themes from the participants. The narratives provided by the participants were read and re-read. I used visual mapping and highlighted key words to draw out the essence of the story, and expose what was being revealed in the experience of mothering a young child with severe multiple disability. The aim was to “hold on to these themes by lifting appropriate phrases or by capturing in singular statements the main thrust of the meaning of the themes” (van Manen, 1990, p. 93) and hence “capture the thematic statements in more phenomenologically sensitive paragraphs” (p. 95). Supervisor scrutiny was used for verification of interpretation, allowing ‘interpretation through hermeneutic conversation’, and ultimately exploration as to the significance of the themes and my interpretation.

Thick description was used to assist readers with transferability; and sufficient information has been made available to readers so they may vicariously experience the phenomena, and conduct their own 'thought experiment' (Seale, 1999). Discussion of the findings was generated in such a manner as to openly explore the inquiry of the phenomenon, and ensure the rigour of the research process.

The researcher followed a recognised method of hermeneutic phenomenology and completed the literature review only once the thematic analysis and development of the data had been completed (van Manen, 1990). This process of deliberately immersing myself in the data of the four participants, without cross referencing to ideas in the literature, was adhered to draw solely from their experiences. It allowed me to unveil an open representation of the mothering experiences and reveal the meaning of mothering a young child with severe multiple disability. Once the grouped narratives were developed and the three themes and 11 sub themes were identified, the researcher worked to understand the meaning in the mothering.

I then turned to hermeneutic phenomenological philosophy and Heideggerian notions to further my interpretations. This method worked to create a coherent research analysis rather than forcing the research to fit with theory. For example, Being Acquiescent, as one of the interpretive notions presented in Chapter Six, came to fruition when searching for a word that would capture the reluctant acceptance that the mothers came to which was identified throughout. Turning to philosophy, the word 'acquiescent' was then found to be an ontological notion conveyed by many authors translating and interpreting Heidegger's works, particularly his 1959 publication 'On the Way to Language'. Blanchette (2003) discussed acquiescence from a Heideggerian notion of being, and being as good. He related acquiescence to a prerequisite in the human activity of being:

to bring out the essence of goodness, we must do so, for it is only through this activity that this essence becomes manifest, just as it is only through the activity of knowing that the essence of truth becomes manifest. (Blanchette, 2003, p. 213)

Truth is desired and in order to obtain truth one must acquiesce (*Zusage*, meaning to promise, consent and agree) in good judgment (Blanchette, 2003).

## Conclusion

***“Reality always partly eludes our grasp; it is not directly seen, but always interpreted in a specific way and from a specific standpoint” (Harman, 2007, p. 32).***

Hermeneutic phenomenology was justified as an appropriate methodology to guide the research design and methods for this study. It is coherent with aiming to understand the meaning of mothering a young child with severe multiple disabilities. The aim of the study was to seek mothers of young children with severe multiple disability and apply this interpretive research design. For this to occur I used purposive recruitment and one on one open interviews, with a semi-structured approach and a guideline of questions specifically designed to openly explore the everydayness, to gain rich detailed stories experienced within the phenomenon of mothering a young child with severe multiple disability. Wright- St Clair (2015) stated “it is the storied, or textual, accounts of in-the-moment experiences that hold the potential to throw new light on the hidden phenomena” (p. 58). After speaking to and being in receipt of many wonderful stories, words evolved into transcriptions that were read and re-read. This is when the thinking deeply started to happen. Thematic analysis, using van Manen’s (1990) selective or highlighting approach with these narratives, provided meaning. I asked myself over and over, what is this story saying about the experience of mothering a young child with severe multiple disability?

The next three chapters will bring forth the findings of this research and reveal the three themes that have emerged from analysis of the participants narratives. Specifically the chapters explore the lived experience of mothering a young child with severe multiple disability in New Zealand society based on the recounted experiences of four women; how they face barriers and consignment, encounter doubt and sorrow, and evolve in order to survive. The following chapters aim to show the mothers’ experiences as they were recounted in this study with an overarching premise that mothers are in a constant state of ‘being’. Recognising that it is inherent for mothers to ‘mother’ and engage in ‘mothering’, it is a constant that is lived and felt. For many the ‘being’ of being a mother is who we understand ourselves to be (Del Fabro Smith, Suto, Chalmers, & Backman, 2011).

The findings chapters have been formatted in a way that the reader may mistakenly interpret the experience of mothering a young child with severe multiple disability as being a linear progression in time and in development. This is not the case. The mothering experience is not fixed in position or characterised by sudden shifts in lived moments and skills. The mothers tell of stepping backwards and forwards, in and out of 'states of being in mothering'. Mothering a young child with severe multiple disability could be likened to the analogy of a roller coaster ride, filled with twists and turns, being hung upside down, teetering precariously and looking out on a scary and thrilling vista, completing a full 360°, and finding yourself back where you were. Mothering as it was experienced by these mothers is not a succinct or precise accumulation of skills and knowledge that allows them to progress from one phase to the next in perfect succession. It is good days and bad days, boring and mundane, joyful and exhilarating. It is pressure, pain and challenge, cuddles and love.

You may ask 'why order the findings in this way of progression if it is not how it is experienced?' And I answer honestly and say, that these themes just evolved. The text showed itself in this way to me, and it just seemed right. "While there is no right way, it is beholden upon the researcher to show in his or her writing" (Wright-St Clair, 2015, p. 67). I present highly illustrative stories followed by interpretation; bringing forward all the voices across the notions. Together the stories show the ontological nature of the phenomenon. I wanted to convey the 'deep transitioning' that was shown to me as a researcher, as mothering a young child with severe multiple disability is a period in which change takes place and movement occurs.

## Chapter Four – Being Visible

*Human life is always immersed in a specific situation, involved with its surroundings in a very particular way... In the environment, all objects gain their meaning only in their relations with one another. Everything belongs to a total system of meaning... things are interpreted according to their significance with respect to other things in the world. (Harman, 2007, p. 26)*

### Introduction

Heidegger proposed that in order to understand human phenomena they must be examined by way of 'doing' or executing in reality. Heidegger coined the term '*Dasein*' which means human existence 'being there' (Harman, 2007). This chapter provides findings from the research describing the participants' experiences of visibility; being seen, in full sight, detected, obvious, distinguishable and in view. Being visible is about being seen by others, being noticed, under the gaze of others in a particular way. It is also about the mothers seeing their children and their disabilities, seeing themselves as mothers of a child with severe multiple disability and how they come to recognise and comprehend themselves in full view of society. These stories recount moments when the mothers attempt to conceal the visible disability of their children, moments where they realise the need to make their differences discernible and how they cope in the everydayness and journey that is the reality of being a mother of a child with severe multiple disability. This first findings chapter offers a range of narratives of the mothering that occurs in full view for judgment, from complete strangers at times; coming face to face with public reactions, complete exclusion, segregation and discrimination. I concur with the old adage that you 'don't get a manual when you have a child'; however with a typical birth and a typical baby or child, a mother at least gets the trajectory of typical developmental norms and what mothering will roughly look like. These stories reveal how having a child with a severe multiple disabilities gives an overtly uncertain journey that becomes visible to others.

The participants of this research share one powerful reality; they are all mothers to a young child with severe multiple disability. The narratives provided by the mothers show them 'being in a special social category' clearly visible to others, stigmatised, labelled, perceived and vulnerable to scrutiny. Each experienced a unique set of

circumstances and events culminating in this socially constructed, owned and speculated occupation; mothering (Llewellyn et al., 2004). What will follow in these pages are the narratives describing real events and moments where these four mothers experienced conscious encounters and lived through similar events or experiences, interpreting their visibility and developing awareness of the differences inherent in mothering a young child with severe multiple disability; and growing their understanding of themselves as mothers.

### **Being Excluded**

When their children are recognised as being different, and it is visible to others that the mothers are also in the experience of being different, the mothers come to know avoidance. Exploring this notion of 'Being excluded', brings together a group of narratives shared by the mothers which feature the rejection of 'difference' within New Zealand Society; discrimination of those with disability and facing judgment from 'others' with limited understanding of mothering a young child with severe multiple disability.

Angelina describes the difficulties she faces when attempting to enrol Maddox in early childhood education:

It was really, really disheartening, it [trying to find a day care] was horrible. I made the mistake of saying 'oh look he's got a couple of issues' and they would say 'oh sorry we have no vacancies'. So then I would ask first if there were any vacancies and I would carry him in, because the wheelchair gave it away.

Angelina's story points to her struggles with having to portray herself and her son in a dishonest way. She notes that telling the truth and revealing his disability in the beginning was a mistake. The reactions she received by the early childhood facilities and their unwillingness to accept her son and consider him a candidate for enrolment, forced Angelina to pull down a veil to mask her son's reality. Angelina's explanation shows how she has to find a way to cover over what was visible in earlier encounters, withholding the information that her son had a disability, by carrying him in because the wheelchair gave the disability away. The wheelchair announces Maddox's disability and reveals Angelina as a mother of a child with disability; the unveiling allows judgment to be passed, which time and time again yields the undesired

response that they are not accepted. There are no vacancies for her son. Angelina states it is *disheartening*, it removes her sense of hope and enthusiasm for the task of finding an education setting that would integrate her son. It was *horrible*, and distressing to be shunned, excluded and discriminated against. Angelina's attempts to successfully commence Maddox's educational journey repeatedly failed.

Chook also spoke candidly about the experience of being excluded when she realised she did not receive the customary enrolment letter from their local school:

So when our second child was due to start school about six months before she turned five, we had a letter from the school saying this is when we are having our 'Meet the Principal - Teacher', blah, blah, blah - come along. Because they know we've enrolled our first child, and they asked about siblings. We never got that letter for Mojo. She was excluded from our local school. And we had been really actively involved with the school, my husband had been on the Board of Trustees, I've been a teacher aide there; I've done a lot of parent-help as well. And she was excluded from that school. So my husband wanted us to say she's coming to school; and I said, "No, no, we'll leave her at pre-school - it's all fine." But then it got to the point where they said, "Well, legally she must be enrolled in a school when she turns six." And I'm like well why? It's actually working as it is.... she's not going to school to learn anything, she's got a degenerative disease. Her life is limited; why are you making this difficult for us. But then, it was this fight with the Ministry of Education. So yes, the local school's been a big problem. She's been excluded; and that really hurt. It hit hard.

In this story, Chook discloses how she did not anticipate that the local school they had been so active in for the last few years would deny their child access. Chook and her husband had already anticipated that they would receive the letter from the school as they had for their other two children; and when it was omitted she was hurt. She was, however, content at the time with Mojo staying where she was at pre-school; it was working for them. Yet as Chook was about to find out, she would have little say in shaping Mojo's educational choices. She states *why are you making this difficult for us?* Not only was Mojo excluded from the local primary school, she was also in the process of being excluded from attending the local early childhood centre, as it is the legal requirement in New Zealand, under the Education Act (Ministry of Education, 1989) for a child to be enrolled in a primary school setting by their sixth birthday. In

contrast to being visible in this narrative, Chook and Mojo were invisible to the local school. The school chose to act in a manner as to veil itself, to hide and act in secret. Being unseen from the local school would prove to produce a number of barriers for Chook and Mojo.

Maree, like Angelina, was aware how a wheelchair would announce Zara's disability to 'others', making them visibly different and announcing to the world. She recounts how it was easy to "pretend to be normal" when Zara was a younger:

She was this super-cute baby-toddler and she looked really normal. And so we tried to hang on to that for a long time, especially when we were in public. People would see us in the street and see a normal toddler in a big buggy. We really didn't want a wheelchair initially because that just screamed disability.

Maree speaks of being overly aware of the perception of others when she was with Zara in public, and she clung to the ideal of creating a picture of normality so they would look just like any other mother and toddler. So she continued to place Zara in a buggy instead of a wheelchair. In a buggy they could blend in and walk down the street in a customary fashion like other mums and babies, unified in their sameness; albeit momentarily. For Maree the wheelchair objectified her daughter's difference – it did not simply show or announce the disability it *screamed* it; it was loud, shrill, and denoted fear, panic and a desperation for the situation. Hence, she held on to her *super cute baby-toddler* in her buggy and the 'normality' of it all for as long as she could. At this point in time it was a way of being able to belong.

However Maree became aware as Zara grew to be bigger in that buggy that she was judged in another way:

Some people would not give way to us or appeared resentful of us; they would make this judgment this kid should be walking... why have you got her in a buggy? And so suddenly we reached a point where I desperately wanted a wheelchair to make that statement to everybody that actually no... my child isn't going to walk and she's not normal, she is disabled! That wheelchair made a huge difference when we left home and walked down the street. She was easily identifiable now. That put a proper label on her that she is different and people's reactions changed. People became more accommodating, understanding. They would make room or open a door for us or something like that. It was hard in a way to come out, to admit to the world that she is

disabled. But it was kind of liberating too because that meant people didn't misunderstand us and they could see, obviously, that she was disabled. I think that was quite an important turning point for us.

Maree's days of blending in to the public were experienced as short lived as Zara grew and she became very conscious of scrutiny when she was out in her community. Her experience was that people were annoyed with her pushing her too large toddler in her buggy; she felt they were *resentful of us*. It seemed to Maree that people were consciously deciding not to step to the side; not to assist Maree in the socially acceptable manner. By Maree's account she was being judged. People were assessing her mothering, forming an opinion about it and disagreeing with it. Maree had gone from belonging; being one of them (a member of the public, by all accounts they looked like a typical mother and young daughter) to being examined and condemned on moral grounds; because mothers should not contain toddlers to buggies when they are of a certain size/age. In the public's eyes, she was not being a good mother by restraining her child and not allowing her child to develop the skills of ambulation. Big toddlers in buggies were begrudged in her community. Maree then identified a sudden needing for the wheelchair, *I desperately wanted a wheelchair to make that statement to everybody*, to show her community the truth. Having spent significant time enjoying the anonymity that came with a partially concealed presentation, Maree now wanted despairingly to lay her cards on the table; my daughter will not walk, she's not normal, she's disabled. Labelled; categorised and classified. They were not normal.

Maree has described beautifully how she came to the conscious moment of needing to become unhidden; no longer concealing the truth of her child's disability and announcing herself as a mother of a child with severe multiple disability. Heidegger would see the wheelchair as the appearance of a symptom of being a mother of a young child with severe multiple disability, in the same way that a cough or a sneeze would appear as a cold. The wheelchair reveals the appearance of the phenomenon, it makes itself known by its appearance, it is self-showing. However, it does nothing to explain the intricate nature of the phenomenon, as it is only announcing it.

“Something which does not show itself announces itself through something that does show itself . . . what does not show itself, in the manner of what appears, can also

never seem” (Heidegger, 2010, p. 28). Maree is spurred on by the disapproval impressed upon her by those ‘others’ who were previously considered her peer group; her community of ‘other mothers’. That judgment and false verdict – that she was a bad parent containing her child to a buggy – and questioning her ability to effectively mother her child forced her to make the decision to present her true reality; she was the mother of a child with severe multiple disability.

In a similar vein, Angelina spoke of holding on to the concept of being ‘normal’ and wanting to belong to the ‘normal motherhood’. She reflected back to when she was encouraged by hospital staff to inform her family that Maddox had severe multiple disability:

We didn’t tell our family for so long, we didn’t tell them that Maddox had anything wrong with him. Because you know, when babies are little anyway, they can’t sit up; they can’t talk; you carry them around with you anyway. It sounds terrible now when I think about it. I think we were in denial; we just thought ‘oh maybe he will grow out of it’... But then he got sick again. Everyone [health professionals] was asking if we had family support. We had to come clean and tell them we hadn’t told our family yet. I remember telling our family. I was worried about them, I wondered if they needed this extra stress. Saying it, was like him being re-diagnosed all over again – every time we told a family member. That feeling, we re-lived that every time. I got to the point where I said “we can’t tell anyone anymore, I don’t know if I am strong enough to do it”.

As Maddox’s disability was not yet apparent to the world, and developmentally he was reaching his milestones like any other baby, Angelina even withheld the truth of his disability from her immediate family. Upon reflection she candidly admits that she must have been in denial at the time and ‘came *clean* to her family’. Clearly announcing her son’s disability was unbearably hard and Angelina questioned her strength and fortitude for this role of mother. You will read on to see that the strength that Angelina reflectively examined and doubted becomes a notable characteristic of her ability to cope and face what comes. She is not the only mother to relay stories with this underlying theme. As the chapters emerge you will see how the nuances of mothering, development of requisites evolve and emerge as their child ages, and the mothers come to grips with their world. The development of coping is not linear and

'coming to terms' is not the finish line. There are good days and bad days and being an entity that is in plain view can be difficult as Maree explains:

It's taken us a long time to come to terms with her disability. I still struggle with being out in public with her, and people's reactions. I hate it when people stare. People don't seem to think I can see their reactions, their stares or comments. People don't understand or don't know how to react. Many other parents, Mums my age with normal kids, will look and then look away, or even worse just stare at Zara. They don't acknowledge me at all by making eye contact. That really bothers me. I don't know whether I'll ever get over that.

Struggling in public was evident in all the interviews undertaken for this research project. Using the word *hate* to describe her feelings when people stare at her daughter, Maree expresses her loathing of outings with Zara where she feels very strongly they are seen; apparent and unmistakably in full view, and she has to face subjection to people's inappropriate and damaging reactions. Maree's coming to understanding is that those who are looking, observing and discerning Zara are unaware that she is in fact able to see them too. As discernible as she and Zara are in public, so too are the reactions of those people. They are obvious to Maree and unconcealed. As the appearance of the phenomenon can be seen by others, in all its strangeness, it opens itself to being visible to the stares and the reactions. Heidegger (2010) stated "the self-showing in itself- means a distinctive way something can be encountered" (p. 29). In accord, the obvious looks away can be just as damaging to the spirit as a glare. Experiencing that people will actively attempt to un-see you despite your obvious, bold and apparent visibility in the world is an ongoing strain on Maree. People do not understand! And Maree feels like she does not belong; she is barely acknowledged and far from becoming accepted.

Angelina similarly described a time when she was upset and protective of her child when confronted in public by the scrutiny of others. She, however, chooses to look at the situation from a different perspective now:

It's funny because when people used to stare at Maddox, we would get quite angry: we were like wow! Especially when he was in his wheelchair, we would get quite defensive. But my husband and I are like...well it's hard, 'cause we stare at other kids in wheelchairs as well! We're staring at the wheelchair 'ooh, what make is that - that's good'. I guess they could be thinking the same 'oh

what are you gawking at'. You know, do you want to take a photo? That's what you think! Now it kind of makes us think. I wonder; why they're staring? Are they staring because maybe they've got a child with special needs or do they know of a child who is, and maybe they're just too shy to come and approach us?

Angelina still encounters the stares and the unmistakable observable reactions people in the outside world have to her son. She, however, consciously asks herself when these instances occur 'why might they be staring?' Perhaps in order for Angelina to deal with the anger she needed to place a positive spin on the situation and see both herself and her son as being tools to assist other people and provide an educative experience, rather than an experience of prejudice. Perhaps in order for Angelina to go about her every day as mother in the world with her son, she preferred to consider those looking as being similar to her, because there is comfort in being like others and this was enough to give her a sense of semblance. Focusing on the supposition that people stare at Maddox because they too have a family member or a child with disability takes away the negative association of the seeing, of being seen; and his obvious visibility.

The nature of 'being visible' is not only experienced by the mothers in this research from the perspective of others creating this condition by their behaviour and actions. It is a phenomenon that occurs in the daily caring for their child where they have moments of clarity and perception of their child's differences and disability; and how this influences and shapes their mothering. Maree shares the tension she experiences when taking Zara to the doctor:

Going down to the GP's practice is another stress trigger; they are always running late. We have to sit in the waiting room with everyone else. Often Zara's breathing is terrible or she is on oxygen and you can feel everyone is thinking the same thing: "that child needs to be in hospital, can her mother not hear that breathing"?

In Maree's attempts to carry out the typical mothering task of taking her sick child to the doctors, she encounters the similar feeling of being watched and judged. Maree talks of feeling in full view for judgment, and she can *feel everyone is thinking the same*

*thing*. Her daughter's loud and strained breathing adds a new element to being noticeable, and reveals the fragility of her disability for all to analyse. In the cold, sterile and clinical waiting room Maree and Zara stand out; they are unmistakably different in so many ways, rendered and vulnerable. Within a short space of time Maree is left feeling completely depleted. Maree senses her ability to mother and adequately meet the health care needs of her child being scrutinised by 'the others' she is forced to share space with; she feels incriminated against and wrongfully exposed.

### **Being Obstructed**

Often it is the physical surroundings, equipment and tools we use in our everydayness that show us, shape us and assist us, or create barriers in our routines and tasks. Being obstructed brings forth a series of narratives that will give rich descriptions and experiences of being hindered in the everydayness whilst caring for a young child with severe multiple disability. The mothers come to realise the limitations now imposed 'whilst doing' the mothering; they come to see the visible uneasiness of places and spaces previously without restriction. They now are noticeably uneasy, ill-equipped, and awkward:

I realised yesterday just how heavy she is - and I have a hoist. But yes I tend not to use it. Yesterday I was just watching how unwell she is. We went to school to pick her siblings up; and there are little kids running around, children she had gone to pre-school with. And just their normality compared to hers. When we got home the other kids had a swim in the pool; for me to put Mojo in the pool – it's a lot of work. I know she loves it, but it's a lot of work getting her in there.

In this story, Chook tells of remembering yesterday carrying her daughter and feeling her weight. A small unfeigned moment that eventuated into the realisation that it is hard and getting harder to move her, to involve her in life and meaningful engaging activities. As a mother, she was making more sacrifices and working harder for her child. Getting her in the pool is *hard work*, using the hoist would mean not having to lift her weight, but using it to lift her is hard work too. And yet she saw the children Mojo went to pre-school with running around. There it was in plain view, salient for interpretation; her daughter's heaviness, and unwellness versus their physicality and

normality. There is sadness in the interpretation, the helplessness of the situation and the realisation that as a mother all you want for your child is for them to be healthy and happy. There is the sense that she is powerless; incapable of fixing or healing her child, and making her 'normal'. Hence, it is, she stoically resolves to work tirelessly on the latter goal of mothering; and make any and all attempts to make her child happy. Working towards achieving this gold standard of mothering would not be without its challenges or tradeoffs.

Through the stories were suggestions that one of the challenges is having to come to terms with the distortion of spatiality, and modified use of space becomes part of the everydayness when caring for a young child with severe multiple disability. The steps involved when doing the caring and carrying out of daily tasks accumulates in an unprecedented fashion; the ever increasing demands and the workload of mothering a young child with severe multiple disability exudes:

When we are out and about and Zara needs a nappy change, there is never anywhere suitable to change her. She's seven you know, where am I going to change her when she's seven? She is too big for any baby change surface. So it's going all the way back out to the car; unlocking it; putting the hoist down; loading her in the hoist; and then in the end getting her out of her wheelchair, and putting her on the floor and then I change her. It's exhausting for me and meanwhile you've missed your GP appointment or wasted half an hour. You've got to just learn to let that stuff go otherwise it will drive you crazy. It's just really, really hard. (Maree)

Unable to access suitable facilities to care for her daughter's toileting, Maree tells of feeling forced to change her nappy on the floor of their mobility vehicle. A mother with a typical seven year old might simply walk him/her into the toilets and instruct the child to use the toilet. For Maree, nothing is simplistic about having to toilet Zara. The scenario given feels frantic and difficult. Not even a disabled toilet would likely cater to the needs of a child like Zara. The floor of the mobility van is frequently multipurposed as the toileting facility. Being Zara's mother necessitates adaptability as the generic Plan A is not going to be possible. Being obstructed in multiple environments is their daily reality and it demands mothering in a resourceful manner; being conscious to unconventional means at times and seeking a Plan B, C or D.

In a similar way, Chook describes the barriers to transportation and her annoyance at not being able to easily access typical mothering chores such as going shopping with her daughter:

I don't enjoy the transport. It just annoys me. I would walk everywhere if I could, it is so easy. I just find it a real pain. It's just not... jump in the seat, buckle yourself in. We have to use portable ramps because we didn't choose a van with a hoist. Just going to the supermarket, oh and she's too big to go in the trolley and I can't push the trolley around and the wheelchair. So once again, I go when she's at school. Yeah, the whole transport thing... it's hard. And it is time-consuming. And it's hard work.

Chook interprets her irritation and the aggravation of having to use the van that having Mojo forced upon her. Chook, like Maree, describes the barriers inherent when you have a young child with severe multiple disability and the litany of things that do not work for them. She compares the simplicity of how others experience a trip in the car by getting in and doing up their own seat belts, to her necessity to use ramps and do the transporting for her daughter which was time consuming and required an excessive amount of work on her part. Then, at the other end, she has the issue of managing a shopping trip with a child too big to place in the shopping trolley and an inability to manage a wheelchair and have somewhere to place the items you wish to buy. Chook expresses irritation at the loss of her preferences, she would much rather walk everywhere, however it is not possible to push the chair everywhere; just like it is not possible to push the trolley and the wheelchair. The frustrations force Chook to exclude her daughter. Unable to cope with the excess of equipment, excessive time, physical demands and energy required to conduct a mother-daughter shopping trip to the supermarket, Chook feels she has no choice other than to modify the demands of the task and eliminate her daughter from the equation in order to manage task completion. In this scenario, Chook is likely carrying out a necessary mothering skill; scheduling (or timetabling), which could also be seen as planning and management. Coming to terms with the barriers in the environment and with the need to eliminate her child from daily activities in order to achieve self-preservation is extremely difficult, and unpleasant. Certain tasks will need to be carried out in the most straight forward manner (without Mojo) for preservation of energy and time.

In addition to managing the environmental barriers they encounter, these mothers seem to need to come to an awareness of their own happiness when engaging in difficult spaces with their children with severe multiple disability. Amy shares her experience of playing with her son Campbell which is a good representation of realising environmental limitations and appreciating these mothers do not have to do it all:

I enjoy taking him round the garden swinging him. The only thing is that physically he's difficult in the garden I suppose, so it's not as relaxing for me, because I'm putting him on the swing, and then I'm putting him in the trolley. Playgrounds are hard work and I suppose as he's getting older, they're getting harder. I realised lately, as the kids in my family (sister's children) are getting older; a playground's become a place for relaxing for the mums. But it's never going to be a place for relaxing for me, and I've just really started feeling that recently. And I guess I've learned to pull back too, and realise that he doesn't have to do everything. At one stage you might want him to do everything at the playground, and I've realised it's not really that good a look having a Mum crawling around into these tiny little cavities in the playgrounds and I don't have to literally put him into everything.

This narrative gives the reader a visual image of a mother sacrificing a little bit of her dignity for the benefit of her child, and then realising that she perhaps does not need to take her sacrifices to such extremes. Amy came to understand her visibility at the playground. Being at the playground with her family also brought into light the visible differences in the mothering between Amy and her sister; that space was never going to provide her the same benefits as it did for mothers of children without severe multiple disability. These places were not going to afford her a rest or a break to soak up the sun and watch as her child takes risks on play equipment. Mothering Campbell completely altered the function of the environment for Amy. The purpose of a playground is forever distorted and misrepresented to her; it will never be a relaxing place. As Campbell is growing bigger and older he is requiring more effort from her, the playground is creating more barriers for Campbell and Amy, more work, not less as in her sister's case; and it is so blindingly obvious now. Typical children will generally be able to access more and more playground equipment as they grow older; it is the reverse for Campbell. As he becomes heavier and Amy is unable to lift him into structures or crawl around in tight spaces with him, he will have fewer opportunities in

the community. Mothering, like most occupations, involves a great deal of reflection and experimentation, most often with trial and error scenarios. If something is not working or creating the outcome desired such as 'happiness' or 'belonging' a mother will work to change the situation and skew the results, as Amy aptly demonstrated. There may well come a point much sooner than anticipated when Amy and Campbell simply stop frequenting the playground.

Maree expresses a similar scenario; that certain environments can impose physical dominance and elicit feelings of frustration and being ensnared. Some environments emphasise the sense of 'being stuck' in the situation of caring for their young child with severe multiple disability and the difficult nature of mothering in the everydayness. However, it is necessary sometimes that these noticeable environments are frequented, such as a visit to grandmas:

My Mum's house isn't that easy to access. It's an old house and full of narrow doorways and narrow hallways, there's no turning circles, so you constantly feel trapped. You're either running into someone, or banging into something. It puts me off visiting. I guess if you have the right personality, you don't let that get to you, and you can just let that go, but it becomes frustrating at times, because I guess nothing's ever easy. Everywhere you turn, it's always hard.

Maree's narrative aches of the difficulties of everydayness and the task of visiting her mother in her old home. Negotiating a house full of narrow corridors and tight corners, almost maze like in her description, pushing a wheelchair, at times potentially carrying her child, and the bothersome nature of the situation; being blocked; coming up against barriers of people and plaster board. Maree's frustrations also cause her to question her personality, and the notion that she does not have the 'right personality' to handle the awkward space and difficulty of manoeuvring her child around her grandmother's home. There is no escaping in this environment for Maree and Zara; and there is no escaping the need to visit this confronting environment, as the relationship of child to grandchild calls her into it. The house forces Maree to deal with Zara's disability, and the obviousness of an incorrect fit to the environment. They are visible here, always visible, unable to move without alerting people to their whereabouts. Maree describes she is trapped, stuck and is uneasy about the confined spaces and lack of mobility, perhaps because it is all consuming, threatening and

'everywhere you turn it is hard', and 'nothing's ever easy'. Managing all the obstacles in the environment perpetuate the relentlessness of mothering a young child with severe multiple disability.

### **Being Unremitting**

Not only do these mothers express a feeling of being trapped, or cut off by environmental barriers and the physical nature of caring for a young child with severe multiple disability, they also directly addressed their feelings of their attunement to being trapped in a day to day care routine; burdened and overloaded in their role of mothering their young child with severe multiple disability. The mothers are all too aware that friends and family have the course of normal development for their children; where the children will become increasingly independent and more capable to do for themselves. The mothering role will change for those women, no longer changing nappies, putting children into car seats or coaxing them to feed themselves. The mothers who participated in this study come to understand that their mothering path will not be the same.

Angelina candidly group references the researcher into the 'other mum' group when she states:

It's funny talking to other mums. You kind of go on about "oh my life before kids and my life now". And I think 'man, you still have a life now!' We can't just have a sleep-in in the morning and leave our kids to it. We have to be up at seven every day to administer his medication. If he decides he wants to sleep-in, it's like sorry mate; we've got to do this. We're definitely not regretful. If anything, we're grateful for that medication, because its keeping him with us and we are so grateful for it; we just have to keep reminding ourselves that it's for his benefit and it's just life, it's just like changing your clothes and having a shower: we've got to do meds as well and that's just part of our routine.

Interestingly Angelina does not voice her feelings or share the differences in her experience of mothering with the group of 'other mums'. She keeps it to herself and recognises the polarising extremes in the mothering moments that occur in their everydayness, and the necessity to keep to a structured routine to keep their son alive. Angelina often refers to herself in partnership with her husband. She does not describe herself as I; but rather we. Angelina is also quick to justify her commentary

with a silver lining, stating that *'we' are not regretful, we are grateful, it's just life*. Getting up early is just what has to happen to keep Maddox alive; and for that she expresses gratitude, and an acceptance of the differences in her mothering routine compared to the routine of the 'other mothers'.

Chook like Angelina did not want the researcher or readers to judge her for her honesty and openness about the difficulties of mothering her child with severe multiple disability. She too gives a justification mid-sentence about not begrudging the difficulties she experiences with mothering routines:

More often than not nights are disrupted. I have to get up once or twice to settle her, change her nappy, change her position (things she can't do for herself). I get very tired but at the same time don't begrudge it at all as every moment is precious. Lack of quality sleep does take its toll though. It is almost like having a newborn permanently.

Chook can see a resemblance in caring for Mojo that is much like caring for her as an infant. In a slightly different position to the other participants in the study, Chook has been told her daughter will not live past her early teens. Chook is aware that the care is unrelenting, that she is tired; however their time together is being condensed. Mojo is aging in reverse, losing previously attained function and needing more and more care from Chook. Amy also shares insights into altered independence:

There is still a lot of really full-on parenting with him and it's not getting less as he gets older, whereas you know, with the other kids it is. And perhaps it's just become more salient at the moment because even my youngest is getting more independence. I suppose every parent looks forward to having that little bit of extra time when their kids get a bit more independent ...and they start moving away, but we don't, won't get that.

Amy has another younger child who is becoming more independent than Campbell, his older brother, and this spurs her to reflectively consider that her future is going to continue to involve caring for her son Campbell and consistently providing high levels of support to him for the rest of his life. The parenting is relentless. Amy went on to say:

I always think mothering him is the workload of two in one really. And he's an easy child. I think if you had a child who was not an easy child, it would be the workload of four or five: if you've got that child that you've got to run after all the time or one who doesn't sleep, or has some issues, I think that would be very tricky. It's the appointments you've got to take him to... you know the equipment you've got to lug around. ...if he's sick he takes a whole week off... and you have to liaise a lot more: it is definitely more intense parenting.

A strong sense of the extremeness of mothering a young child with severe multiple disability is portrayed in this narrative by Amy. Counting herself fortunate that her son is relatively easy compared to some children with severe multiple disability, Amy goes on to quantify the difficulties apparent in mothering Campbell which intensifies her mothering experience. Having a child with special needs necessitates a forceful approach to mothering. There is without a doubt amplification to mothering when your child has severe multiple disability.

The mothers' words suggest they are more than aware; they are highly attuned to their visibility and the extremeness in their mothering. Normality can, at times, seem to be very brazen to mothers of a young child with severe multiple disability. Maree expresses the lacking reciprocity in caring for her daughter being visible in their relationship. This 'lacking' complicates their relationship, the lacking is a barrier to mothering, it places restrictions on Maree and she struggles to be the kind of mother she wants to be amongst all the caring for Zara. The foreseeable future is ominous:

It is hard to be normal... to have a normal parent-child relationship I guess. Because it's all about caring for her, and no matter how old she gets, it will always be me in that role, caring for her. She's not independent at all, she never will be. She's a really hard child to mother because so much of the relationship is one-sided. There's a lot of nuts and bolts involved in mothering her.

Maree, like Amy, is aware that the everydayness and the direct care side of mothering for her child will never cease, this is the situation she is immersed in. She also struggles with the lack of give-and-take in the mothering relationship with her daughter. The mothering is described as consisting mainly of a high proportion of basic cares, the nuts and bolts and fundamental aspects of mothering; from which

there is no giving back by her daughter. It is Zara's taking, and taking from her day in day out. It is going to be her doing all the giving; it is Maree's everydayness. This narrative also expresses a sense of loss from Maree that she will not be able to experience those mothering moments with her daughter where she is able to gain a sense of fulfilment in co-occupation, nor experience the intimacy that is experienced by typical 'other mothers' with their daughters when they engage in shared experiences; going shopping together, talking about clothes and fashion, music and dancing. Maree reiterated her sense of loss and one sidedness in her relationship with her daughter when she said:

I guess for me as a Mum, I struggle to have a normal relationship with Zara, because you're giving, giving, giving. With a 'normal child' you get those special smiles, and you get those responses. You get something back, and that's what keeps you going. And it's really, really hard seven years without the responses back. To be brutally honest the disability gets in the way so much that it is hard to find the child-mother relationship. And it all just seems like work and nursing care.

Nursing care and the cares required to keep their children alive were discussed by all the participants in the study. Maree has spent seven years with the 'lacking' in her relationship with Zara; no *smiles*, no *responses* that would help her to keep going. Mothering is generally thought of in a way wherein you visualise an exchange of emotion; where you can see emotion from both the mother and the child. When the relationship is void of emotion on one side this would likely have ill effect because as Heidegger (2010) stated, meaning is gained from relations with one another.

## **Conclusion**

***This character of being of Dasein which is veiled in its whence and whither, but in itself all the more openly disclosed this, this 'that it is' the thrownness of this being into its there; it is thrown in such a way that it is the there as being-in-the-world. (Heidegger, 2010, p. 131)***

Living with the visible nature of mothering a young child with severe multiple disability is revealed to be an ongoing confrontation for the participants of this study, where at times the boldness of difference brings out the judgment of strangers. The visibility of

their children's uniqueness and their distorted mothering is also emphasised in time spent between sisters and with friends mothering at the same time and yet in very different ways. The stories in this chapter announce how 'Being visible' brings frequent instances of conscious recognition from the mothers that they are not like 'other mothers', their journeys are going to be shaped in a multitude of different ways. They come to anticipate physical barriers they will be required to negotiate, people staring or worse pretending they do not exist, others will lie to them and exclude them. The mothers will face hardships and thoughtfully continue to mother their children with the understanding that they will always have to provide a high level of care to them with little responsiveness at times. They will, in their words, feel *exhausted, noticed, angry, crazy, trapped and disheartened*.

The mothers of young children with severe multiple disability in this research expressed their immersion in their situation particularly with regard to being with others in a public world. They speak of their children's wheelchairs announcing their disability to the world and the public responses of stares, judgment and discrimination. According to Heidegger "equipment always belongs to a public world" (Harman, 2007, p. 62). In other words, things there for using are woven into our lives, there when we need them and at times in the way when they are not. All things in the world are meshed together and how we interact with them is very dependent on our own being and our own Dasein. The spatiality of the world is made up entirely of equipment which has its own purpose and place (Harman, 2007). The wheelchair has a purpose and it announces to the others and to the mothers in its strangeness the ill-fittedness with everydayness. Strangeness will make us more aware to everydayness (Harman, 2007). It alerts to being in the wrong place when placed near other things. The mothers recount moments of visibility, exclusion, obstruction and the unremitted nature of mothering their young children with severe multiple disability. There are often moments when the mothers question the wholeness of mothering a young child with severe multiple disability, and the thrownness of their situations. "Human Dasein is thrown into a world that it never chose" (Harman, 2007, p. 177). Thrownness is ours, and it provides the possibilities for our Dasein as well as setting limitations. Choices and change are made within the life in which we are thrown (Smith, 2003). In Chapter Five stories continue to emerge which show mothering immersed in situations and

surroundings which challenge the meaning of mothering a young child with severe multiple disability.

## Chapter Five – Being Challenged

*“You don’t realise how strong you are until you need to be” (Callander, 2014, p. 184).*

### Introduction

This chapter gathers together stories heard across the data suggesting these mothers are experiencing being in their everyday as different from that of ‘other’ mothers. In their everydayness they talk of facing a plethora of challenges. Confronting at times, the role of mothering of a young child with severe multiple disability places the mothers in conscious states of inner turmoil, where they encounter indifference and intolerance, and a sense of being absent. They will question themselves and impose self-doubt and negativity in being regretful. They experience being overwhelmed and over powered at times. Finally in this chapter the mothers will address living with the uncertainty of their child’s future; being in precariousness shows the nature of the disability and how it enforces particulars on their relationship. In the ‘Doing’ of mothering they will encounter these challenges and persevere in their everydayness.

### Being Absent

Whilst living the routines of mothering in their everydayness the participants of this research are always living with an awareness of the polarising disparity in how the ‘others’ live their lives. The interpretation from the mothers is, at times, the feeling of being missing or absent from the thoughts of others. Maree shares how being absent in the thoughts of others makes her everydayness more difficult and adds to the burden in caring for her child with severe multiple disability:

I think it’s mainly people’s ignorance which makes my life much harder with Zara. There’s been incidents at school where somebody has parked in the disabled park, and I get there and I can’t park with Zara, and we are already late for school. They have no idea what it’s taken to get Zara to school in the morning, and I’ve been so close to going up to them and saying ‘oh you can have my car and you can have my daughter, and her oxygen tanks, and all her medication, and all her other nebulisers and equipment and you’re welcome to it; if you want to park in my park, you can have the disability too’. So that really bugs me: people’s ignorance..., I guess. They have no idea... I know it’s unfair of me to expect a lot of people to even have an inkling of what it’s like to try and raise a disabled child, and it’s unfair of me to expect that... but you know it’s the little bits... it’s the small things. It’s a common courtesy. It’s really what

gets me annoyed, things like that. You see, I've had a hard morning and I know something's gone wrong and you just want to scream at everybody.

Dropping one's child off to school on time is a mothering routine that many may find stressful. However as Maree describes it, the influence of others can push her to breaking point. Maree cites the ignorance of 'others', their lack of awareness of her necessity to use the disabled car park over theirs, lack of awareness of how difficult it is to be Zara's carer and provide all her needs, lack of knowledge about disability (and the purpose of disabled car parks), lack of the regard for her and her daughter and lack of politeness and respect. Maree's words suggest she experiences her life as hard enough without having to deal with people who show an inability to care at a basic humane level. Yet, in her narrative, Maree does not confront the people, she is silent and imagines what she would really like to say. Within the same breath Maree expresses the desire for people to understand how hard it is to mother the way she has to. Maree's use of the words *they have no idea* may hint that she is in need of validation, that it is a difficult role that she is living, perhaps she is in need of empathy; and then Maree realises her expectations are unfair, how could they possibly understand how hard it is? They could not possibly comprehend it unless they were living it themselves.

Describing similar feelings, Chook uses a novel way of focusing her anger towards ignorant people in her life. In stark contrast to Maree, the people who incite anger in Chook are old friends and family members who choose not to be part of her life anymore since her daughter was diagnosed:

I've got this list called the asshole list. And every now and again, I go over it. There are probably about a dozen people who I've spent a good part of my life with who are gone. I get cross, so I have to do my asshole list, and that makes me feel better. It just makes me cross when people disappear.

Whereas Maree's story above described one particular experience of strangers' seeming disregard for her challenges in going about her day as a mother, Chook's story conveys the challenge when those close to her become absent. Being able to cope with the ignorance of a stranger is difficult enough to rationalise, so when you experience it from your nearest and dearest it is truly excruciating. Chook speaks of a

*dozen people* who make the decision to exclude her and her daughter from their lives without any regard for the damage they cause, or at least that is the way that Chook has interpreted their actions or lack thereof. Chook invested large chunks of her life engaging with people who turned away from her, neglecting to support her, neglecting to attempt to understand the differences in her life and the life of her daughter. Instead of providing love and support to Chook; friends and family become absent; *gone*. Unable to cope with the visible changes to Mojo and the altered roles for Chook as her mother, those individuals vanish from their lives, and become a name on her *arsehole list*. A list created by Chook for the jerks, inconsiderate, rude, mean, contemptible people who choose to be *gone*. Chook also describes how difficult she can find it at times to be empathetic to others' situations and her intolerance towards them:

There was someone about a year after she was diagnosed, one of the mothers at the school... her child's been in our daughter's class... since it was day dot, and they play sport together in the same team. One day she came over to me and gave me a hug, and just started crying; she said, "Oh I just haven't been able to talk to you about it - it just upsets me so much". I felt like, get a grip – with your nice car, your nice house, your three healthy children. I'm like, it upsets you so much! But that was her.

Chook's encounter with the 'other' woman gives an insight into Chook's intolerance to the apparent selfishness of her old acquaintance's attitude and her poor excuse for being absent. In saying *I felt like, get a grip*, Chook suggests a need for the woman to get a hold of her emotions and behave more calmly. There is a sense that Chook would have appreciated a more honest selfless stance towards how sad it is for Chook to be in the situation she is, not for the other woman to cry and discuss her own sadness, her empathy in this situation was also absent. Although Chook comments about the things in the other woman's life, her *nice car; nice house; three healthy children*, she is making superficial judgments of what she thinks her life is like. She too is not living in her shoes, just like the other woman is not living in Chook's. Chook seemingly begrudges the woman feeling sadness over Chook's situation and her life, and she resents the insular approach she takes to the situation and the woman's indulgence in her own emotions rather than reaching out to acknowledge Chook. Her words are tinged with anger, yet showing her tolerance towards the other woman,

Chook dismisses her insensitivity and offers the excuse in her final sentence; that the tactless nature of the occurrence is due only to the other woman's ways; *that was her*. Chook later reflected on her ability to shift between tolerance and intolerance:

I think it makes you harder, but also more ruthless; more intolerant of people. So when mothers are whinging to me about things at school, I just go, "Yeah that's terrible isn't it?" And for them, it is terrible. Little things that would have been drama before aren't now. You know, it's made me harder and intolerant to some people, but also more tolerant to other people. Intolerant to the fluffy ducks who think the worse thing is, oh they had to cancel their hair appointment because school athletics day was changed, or something like that. You know that sort of drama, because that goes on a lot around here.

In the telling of this story, Chook is expressing the difficult nature of hearing others complain about issues which seem of such little importance in the grand scheme of things. Although Chook does not like to think about it, it is never far from her consciousness that her daughter has a degenerative disease. She will die in the next 6 years or less. As Chook had previously described, on a daily basis she has to care for her six year old who is as dependent as a new born baby. *'Little things that would have been drama before aren't now'* suggests that in her everydayness of mothering her daughter there is little or no ability to sweat the small stuff; Chook finds it hard to tolerate people who do. The 'others' most likely have no idea what real drama is; or at least not the kind of drama that Chook is actually living. It is Chook who is living under a veil of crisis, her spirit in turmoil at times, helpless to heal her daughter, helpless to change their situation. She said:

As a mother the hardest thing for me is watching your child suffer, feeling helpless and not being able to fix it for them.

Knowing her daughter's time with her is so limited; however knowing as a mother she has to function effectively, suck it up and do what needs to be done, Chook knows she has to be harder and ruthless, truck on, doing what is necessary for her children and her family as a whole. She too must come to 'being absent' and disregard the helplessness of mothering her child with severe multiple disability. Confronting the absence is a challenge. The mothers have to find within themselves perseverance in doing the mothering; regardless of the sorrow, intolerance and anger.

## Being Regretful

In addition to persevering with absence, it was evident that in the challenges of mothering a young child with severe multiple disability the mothers all experience significant regret. Narratives portray feelings of being responsible, and consciousness of not always fulfilling their roles and responsibilities as mothers. Falling short of expectations; often self-imposed and sometimes the result of not being able to meet the demands placed upon them by 'others'. Most commonly the mothers expressed these moments of consciousness and regret as guilt, self-imposed, and committing themselves to the notion and ownership of blame.

Maree expresses guilt and feeling like a failure when she does not carry out all the necessary 'therapy stuff' on a daily basis. She clearly articulates a dislike towards the necessary demands of 'doing' daily programmes to her daughter. Maree struggles with the tedious nature of the activities, the time and energy involved when she has to carry out therapy:

I feel guilty that I fail as a mother if I don't do her stretching programme every day or her therapy-based programmes every day, and... Yeah... that's a burden on me that I have to deal with. You know all the therapy stuff we have to do can be tedious, the physiotherapy programmes: stretching programme... chest physio programme, nebulisers, boring... I know they are really important in helping to keep her well but, I just find that such a drag some days. The time and energy it takes when putting her in equipment, in her standing frame, floor sitter or wheelchair, the hoisting involved is so time-consuming, and it drives me to distraction some days. People have no idea.

Maree had already mentioned she had been told by the physiotherapists that she must incorporate stretches into the everyday mothering of Zara because stretching benefits her daughter's health. In using the words *guilty* and *fail* Maree reveals a deep neglect, she feels immense regret and that she is falling short of what is a good mother. Her guilt may potentially be a mode which spurs Maree into action so she doing the stretches the following day. This, however, does little to alter the *burden* of the stretches, the chest physiotherapy, and all the necessary equipment and positional changes. The everydayness in this part of mothering Zara is repetitious and uninteresting to Maree and it, like the guilt, is wearing.

Amy, like Maree, expresses guilt when it comes to carrying out the therapy demands and management of her child's physical disabilities. She states:

I can think of trying to wake up early in the morning and do all his stretches before he had breakfast, so that I could fit that in, and I didn't have to do it later, because he didn't like the stretches, and I just wanted to get it out of the way. And I would last about five days and then that fell by the way. And I would end up feeling guilty at the end of the week, and looking to see whether his feet had full range and just feeling really bad, because it's really hard to do that when a child doesn't want to do it. It's really hard when you're on your own coping and you're still feeling quite fragile yourself, and then you're being asked every day to grab your child; do something they really don't want to do, that's actually a really tough thing to do emotionally.

Amy is emphatic about the difficulty of the task of carrying out passive stretches with her son, she uses the word '*really*' often to express how unmistakably significant it is. Amy would structure her day so that the dreaded stretches were dealt with first, wanting to get *it out of the way*, and struggling with imposing the unnatural task on both herself and her son. Amy is able to manage the physical nature of the task, what she expresses is the heart ache of having to do to her son something that he does not want or enjoy. She regrets the stretches and inflicting them on her son. The prescription of this therapy goes against Amy's natural mothering instinct to nurture and bring happiness to her child. Manually handling her son and forcing activity on him that they both dread is daunting. When she finds it unbearable she ceases to do it. This, however, causes her to feel immense guilt and worry that she is causing him physical deformity by not carrying out the demanding and emotionally tough 'dreaded stretches'.

Angelina shares her emotional journey and the regret, guilt and grief she faces everyday with Maddox, who was born prematurely after she was involved in a car accident:

I get that emotion and that feeling every time that he's in hospital, ... I always revert that to... he wouldn't be sick if I hadn't had a car accident; he wouldn't have been premature; he wouldn't have all these issues. I was inadequate, I couldn't even hold him to full term; and that is constantly something that I have to deal with every time... every day I deal with it. It's at the forefront when he is in danger, when we have those situations when he is medically

compromised. I think his life completely changed from that one moment. If only time was different. Not only his life changed, the whole family's has changed, just from that one moment.

Angelina is often faced with reverting back to that one life defining moment, and faces *that emotion and that feeling every time*, blaming herself and the fate of timing when her pregnancy was cut short. She refers to herself as *inadequate*. In effect she labels herself as ineffective; a failure to her son and her family stating *I couldn't even hold him to full term*. Her guilt in this narrative is all consuming; she feels responsible for his disability. She is a mother denouncing herself; articulating her shame, struggling with loaded self-condemnation and blame and dealing with it every day. If only that moment had not occurred. In contrast to many of Angelina's other narratives she alone takes ownership. *I was inadequate, I couldn't hold him to full term, I have to deal with it every day*. And within her judgment a fleeting glance at what could have been 'if only time was different'.

These mothers' stories uncover the frequently confronting nature of mothering their children with severe multiple disability and the challenges of dealing with the emotion of regret. At times the challenging sentiment that is shared by the mothers is one of being overwhelmed and overpowered.

### **Being Overpowered**

Being in an occupational role as challenging as mothering a young child with severe multiple disability, the participants shared stories about being completely overpowered and overwhelmed in the everydayness of their lived world. These feelings were not always as a result of the day to day mothering of their child, however can be related to the scores of people who become involved in their lives. Amy discusses the intrusion she felt during a vulnerable time:

You've got this crisis you go through; you've just got this child that's really severely disabled, and you get this onslaught of people coming through and not all of them are useful you know. But you just get this myriad of people into your private space while you're having a crisis. It did feel like quite an invasion, all these people were just coming through my house.

Amy is explicit. She is challenged and overpowered by the system during a very vulnerable time; she states an *onslaught* an *invasion*. She is grieving; she states *going through a crisis* and *having a crisis*. Amy is dealing with this extreme and unexpected reality of having a baby with severe multiple disability. She repeatedly uses the word *crisis* to describe the moment, and that she *got this child that's really severely disabled*. Amy is mourning the birth of her 'perfect child' and having to let go of the expectation of a normal mothering experience. She is thrown into this reality, her reality. Amidst this pain and hurt she feels attacked, her privacy is disregarded. Amy blatantly questions the timing of involvement and the invasion she encountered when she was struggling to come to terms with her child's disability and her roles as a mother. Amy also queries the validity of the involvement, and the usefulness of the overwhelmingly large numbers of people interested in providing interventions with her son.

Amy is not alone in her staggered response to the difficulties of managing the many parties involved when mothering a young child with severe multiple disability. Children with multiple needs can have huge teams of people involved and invested in their care, and it is often the role of the mother to act as the coordinator. Maree shared:

Going to mainstream school is a big deal for someone like Zara. It is incredibly challenging juggling meeting and learning to manage many different personalities; the politics and egos and things that I would never have thought I would have to have to deal with. It takes so much energy from me to sort out the problems that come up, so... yeah, it's a huge job.

Maree's words point to her feeling blindsided by the responsibility and energy consumption of having to manage people at her daughter's school. Having a child with severe multiple disability necessarily imposes a role on Maree as coordinator or manager of a team of people who all demand various things of her with regard to caring for her child. This role is not valued by Maree, she feels overpowered by it, weighed down by politics and egos. When she spoke during this point in the interview I was aware of her exhaustion and frustration; of being overcome at times in her mothering Zara. As Maree discusses the challenges of school, Amy continues to struggle with the demands of visitors in her home:

I did actually work it out once that we do over an appointment a week, and that's with us actually saying 'no' to some of the therapists. We just said, "We don't actually want the visits that often". Some therapists have got something really important to offer, like the on-going need for equipment, but some therapists would come in and they would do stuff that I felt, we already did at home. And it wasn't really worth putting my time aside for.

Amy feels there is a distinct intrusion on her time and is frustrated at the loss of time she has to experience mothering her child due to the input of the many other parties involved. Amy has developed clear understanding of what she feels is important for her child, what she wants offered and what she feels is being taken care of in her day to day mothering with her child. She has created a values system for the approved therapy interventions, and where necessary she is making time for what she deems as having validity and need in their lives. Amy came to a place in her mothering where she was able to recognise being overpowered and say 'no'. This may be a necessity in mothering a young child with severe multiple disability. Amy also expresses a hope for change:

I like to think that in future, people will look back and go, "What the hell were we thinking?" You know! What were we thinking sending all those different parties, and all of them have got some advice that they want you to fit into your day to do and you're thinking, 'well when am I going to be a Mum? When am I just going to hold my child or just read them a story? It is a bit crazy sometimes. I definitely think there is a need for change. I mean community base probably works well when you've got a child with just one need or a couple of things. But when you've got a child with multiple needs, if you actually think of the amount of advice that you've been handed and what you're supposed to fit into your day to do with your child, I mean it's just a bit crazy really.

Amy expresses the value she places on time, it is a commodity and she shares it reluctantly with the 'others'. Time is precious with her child, being a mum and doing mothering activities with some sense of 'normality' with her son is important. The expectations of others forced onto her and her family is too much; it's *crazy*. It is overpowering having restrictions placed on her mothering, dictating how she spends her time with her child and displacing the mothering she wants to do. Amy is expressing a desire for change, she wants her time back, and she wants to be

empowered not overpowered. She is aware that her time for mothering is limited, she is aware that the clock is ticking.

### **Being in Precariousness**

The awareness of time was shared by all the participants at some point during their interviews. Each mother expressed awareness of the temporal nature of time with their child. Having a young child with severe multiple disability in some way alters their lived experiences of time. They do not have the same experience of time as others; they cannot depend on it or trust that there will be an abundance of it. Time is in essence scarred; marked and damaged. Time with their child tends not be isolated to the present moment at hand, it brings with it a heaviness of being precarious, limited and slipping from grasp:

I remember in the early days I would go to the shops and there would be sales on, and I would never want to buy winter PJs or clothes for the next season for her, because I was never sure she would be here. It's hard to look into the future; we constantly live with an underlying feeling of 'how long have we got her for', what happens, if she dies. How are the kids going to cope with that? All they've been through... 'it's like living with a terminally ill child', you don't know when she's going to go. It's hard to live with. And planning for the future with her, what are we doing...do we plan for her? Do we put her in our will? ... is she going to outlive us or is she going to be a burden to her sisters, ...will we be able to look after her when we are old or be faced with putting her into care? It's huge. (Maree)

Maree's story is showing her fear and the difficulty of facing this unknowingness of time with her daughter, with being able to expect her daughter to be alive in the future; plan a future with or without her daughter in it; and how the unknowingness hangs over her and her family. Maree not only worries about living with the fear of her daughter dying, she is also concerned about burdening her children if Zara continues to live, and outlive her. In a similar way Amy also considers the fragility of her son's life and considers what should be of importance and of focus whilst he is alive:

We don't know... I mean we hope he'll live well into adulthood, but we would have less guarantees for that than other babies. What if it did happen, would I want to look back and go oh well, at least you got him walking. Or would I

want to go, he had a really nice childhood. And I think at some point I made the decision that I wanted him to have a really nice childhood. At the end of the day I want him to look back and remember that he had really nice relationships, he had fun. Not that he did hours and hours of therapy every day.

Amy questions the quality of a life her son will experience if it is spent focusing on improving his physicality. Amy places value on her son enjoying his life, she expresses the need for him to live a life that consists more of friendships and family than therapy. Amy's uncertainty with time pushes her to give value to the time that they do have and to use it well whilst time exists.

For Chook time was typical and not temporal until her daughter started to regress and she received her diagnosis. Time then almost went backwards for Mojo, the countdown was real:

And in a way, I mean yes it's fortunate we've had that time of her being normal, like any other child, but the other side is you see her decline. So, yeah it's bitter-sweet. But you can't let yourself spiral downwards, you haven't got the energy to think about it; there's too much muddle going on anyway. I have received advice from families in Australia who have lost their children. You say something to them about how they're feeling or whatever, or you can't imagine what it's like. And they just go don't imagine. Do today. Do today and then do tomorrow. You don't need to think about the future. You know, don't go there until you have to.

Unable to consider the gravity of the future, Chook faces life with her daughter on a day to day basis. Chook states a fear of being too attentive to what will happen ahead, and is warned by people in the know that this is not the path to take. Allowing herself to contemplate and plan for the future places her at risk; *you can't let yourself go there, you may spiral downwards* into a dark place. The being precarious forces Chook to be ever present in time. She must stay present in real time and if she indulges in being retrospective, she needs to quickly return to being present in real time to escape the certainty of time ceasing with Mojo. In contrast to Chook and her avoidance of planning for the inevitable, Angelina shared:

Being a mother of a child with special needs, you've got to look at everything so differently. I sometimes just think of all the emotions that I would not experience if I was not being a mother. How would I feel? And what would it be like? He's changed my life. I remember when he woke up from a crisis in ICU. At the end of his bed, we had a photo of him in his All Black gear with his headgear on that he had to wear all the time. We had brought the photo in because no one in ICU had met Maddox before this time, and we had wanted them to see what he was actually like. He was probably asleep for 3 weeks. When he opened his eyes he looked at the picture at the end of his bed and he said "rugby". And it was just like ahhh! It was so overwhelming I didn't really know how to react, there were so many emotions. We had prepared for the worst, and he was like "rugby?" I think the sad thing about it too is that we've lost two boys: two other times that we have been in ICU that we've been quite close with; and we're still quite close with one of the families, and we are constantly reminded every time we see them. We just feel their pain. It sounds kind of terrible, but we're lucky that we brought our son home. You know, even though we brought him home in a condition that was quite different to what he had gone in with, even though he's deteriorated, we were just thankful that we got to bring him home. Their son is no longer with us. We are constantly reminded of that.

Angelina has witnessed children dying in the intensive care unit; it was something that was a reality, so facing the unthinkable and preparing for the potential loss of her son, Angelina states we had *prepared for the worst*. Was it an effective way of living with their reality, to consider the eventuality of death, and embrace the precariousness of time? Was it an attempt to create a buffer, so that when his machines started to beep, when he started to slip away and cease to move or breathe, it would lessen the impact? Can a knowingness of the eventuality of death ever prepare you fully for the death of a loved one? Most would say no, the pain of loss cannot be diminished by understanding the inevitability that it is going to occur, that death will occur.

## **Conclusion**

***The existential sameness of disclosing and what is disclosed so that in what is disclosed the world is disclosed as world, as being-in, individualized, pure, thrown potentiality for being, makes it clear that with the phenomenon of anxiety a distinctive kind of attunement has become the theme of our interpretation. (Heidegger, 2010, p. 182)***

In the being of mothering a young child with severe multiple disability, as revealed by the participants in this research, there are multiple experiences of being challenged. The mothers are at times challenging themselves and coming to terms with responsibility, guilt and conscience. There are moments of being challenged by others and the absence of understanding or wanting to understand. At times the challenge is overwhelming, and a sense of being overpowered by the demands placed upon them by the system and displacement of their mothering time. Finally, being challenged manifests in the uncertainty of the future hung precariously over them. Being challenged is experiencing the very real doubt and sorrow that is encountered by the mothers in the everydayness they share with their children with severe multiple disability; and the mothers persevere by 'doing mothering'. In the knowing of today's challenges and the awareness that tomorrow they will encounter much as they did today, the mothers come to know within themselves that they can endure. The mothers come to throw off their thrownness; that is, they seek to challenge it and their situation. Heidegger calls this freedom, it is human action to situation (Critchley, 2009, June). The mothers are resolute in their ways of encountering challenges from the others, from the system, from their child and from within themselves. The mothers show persistence and a determination to act, and to be. In Heidegger's way of thinking, the mothers have come to understand that:

Dasein factually can, should, and must master its mood with knowledge and will may signify a priority of willing and cognition in certain possibilities of existing ...attunement discloses Dasein in its thrownness and, initially and for the most part, in the mode of an evasive turning away. (Heidegger, 2010, p. 132)

Heidegger believed that the trueness of human existence could best be obtained by considering 'average everydayness'. "Thrown into its 'there' Dasein is always factually dependent on a definite 'world' – it's 'world'" (Heidegger, 2010, p. 285). In this way, these mothers come to understanding and consciousness in doing mothering, despite its challenges, and the awareness and fear of the past, future and present. This 'triple structure of life' was seen by Heidegger as the truest form of temporality:

Life does not choose the state in which it finds itself. There is no erasing our current situation, no matter how glorious or miserable it may be; our current life is already there before us, as the hand we are forced to play. The most we

can do it try to work with the situation as we find it – and every moment, no matter how dull or horrible, has its possibilities. (Harman, 2007, p. 28)

## Chapter Six – Being Acquiescent

*“He is perfectly imperfect... my old self would have never seen a child like this. I didn't know I had this mother in me. I am so much stronger. We all are”*  
(Callander, 2014, p. 72).

### Introduction

In this chapter are the stories mothers shared which tell of a shift in experiencing the everydayness of mothering; and yet, a deep progression in thought and action emerges, distinctively different to the themes from the two previous chapters. The sentiment the mothers provide display the transition; from the limitations of visibility and exclusion, to being overwhelmed and ambivalent, to a silent consent and conformity of mothering a young child with severe multiple disability. Being acquiescent is the giving in and the assent to mothering in a unique way. It is acceptance. In being acquiescent the mothers embark on discovery of strengths, characteristics and methods of practicing mothering that will enable them to survive and at times thrive in this role. This ‘coming to terms’ leads the mothers to find belonging; with their children, with other mothers and within themselves.

### Being Accommodating

Being accommodating is about adjustment and the mothers adapting to the demands of mothering their children with severe multiple disability. The mothers realising the necessity for accommodation and undergoing the adaptive process is about evolution and survival. The first step in the evolution to survive is developing a certain proficiency in the everydayness of mothering; it is the careful negotiation, the necessary juggling, adapting and changing that the mothers engage in on a daily basis. It is developing strategies and mechanisms that allow the mothers to hold it all together. Being accommodating is the authority and acceptance in using trial and error type mothering. At times it is the realisation of a missed opportunity and identifying that next time things will be carried out differently; and acceptance of that fact. Being accommodating encompasses the mothers lugging equipment, having all the bases covered and the flurry of activity necessary when caring for a young child with severe multiple disability. It is also the careful management of emotions and mothering in a way that enables them to cope with the very realness of a daily grind.

Being accommodating becomes basis for belonging; as the mothers undergo the necessary modifications and variations there is a real sense in needing to connect with people. The mothers tell of needing support; they need to know that they are not alone, that they are making the right changes, or the necessary changes.

Accommodating to meet the necessary demands of mothering their child with severe multiple disability also becomes about finding belonging for their child, which is as important as finding belonging for themselves.

Maree shares a story which gives the reader insights into the busyness in her everydayness:

I just try to put one foot in front of the other. She's often up in the night and I change her nappy in bed. In the morning she needs time to wake up and I give her time to stretch. It's all about caring. Getting her dressed and washed, giving her medications, flushing her tube and turning her feed pump off. I think about what I need to take to school with her; I need to record a new message on her switch for sharing at school. I've got to draw up her meds for the day, and make sure she's got food and water and syringes, and it's all nursing stuff, it's all consumables and what she needs for the day.

Maree shares how she goes about the everydayness of mothering Zara by *putting one foot in front of the other*. She conveys the necessary caring she is doing for Zara, and the passivity of Zara in the caring for, is also very apparent. When the 'doing to her' part of the routine is finished, Maree describes taking responsibility in preparing what is necessary for her daughter for the rest of the day. There is an undercurrent in Maree's story that she is begrudgingly being prepared; with all the *stuff*, and the fact that it is *all consumables*'. ACC provides all of the 'consumables' that Zara needs and this statement hints at the resentment that Maree continues to feel towards her situation; she has come to reluctantly accept it. Maree tells her story in a matter of fact kind of way, suggesting it is just what any mother would do, she simply does what is needed for her daughter, that is what mothers do; they do the caring. However, it is all about doing to Zara, and it is nursing stuff, all consumables; and what Zara needs. Maree's routine is familiar yet imposing. She *just tries*, tries to come to terms with it, and yielding to the necessities in mothering Zara.

Chook is accustomed to identifying brief opportunistic instances when two or more jobs can be carried out at any one time; it is a familiar and necessary accommodation to make when mothering a young child with severe multiple disability. Unfortunately, for Chook, in this story she makes a few errors in her haste:

I thought I would cuddle her on the couch while she had her dinner, and so I moved her out of the wheelchair on to the couch; and all her feed went everywhere because I didn't stop it (the feed) and clamp it off and do all the things you should do. I just went oh yeah, that would be right. So that's that then. I'll tell you, she's taught me to chill out. I don't get worried about the little stuff I used to get worried about. So if the feed goes everywhere it's just like what a silly idiot I am! She's taught me a lot about what's important and what's not.

Chook is so focused on wanting to cuddle Mojo she neglects to carry out the couple of steps of clamping off her feed beforehand, stating *I didn't stop it*. Chook simply thought *I will cuddle her*. Chook does not say why she thinks to pick Mojo up for her cuddle, it maybe because she wants to catch a moment with her daughter, to show her how much she loves her, or to feel her child's warmth and affection.

Chook looks reflectively at the scenario and recognises how much she has changed; how she is accommodating. Chook reveals she is changed through her caring for Mojo and watching her struggle has changed Chook. Moments where she previously would have found anxiety and stress, Chook now faces with a more relaxed sense. For Chook, living in the day to day context of her daughter's decline, with that huge and unthinkable reality of her short lifespan, everything else would seem rather insignificant. She says *she's taught me to chill out and I don't get worried about the little stuff I used to get worried about, she's taught me a lot about what's important and what's not*. She also calls herself out by stating *what a silly idiot I am!* Suggesting she willingly takes account of the little things that go wrong when there is the bigger issue of concern always overshadowing her in her everydayness. Although Chook does not hold the thought in her consciousness at all times, it is never far from thought that she will have to face a reality where the belonging with her daughter ceases to exist. Chook develops in her mothering and shows a coming to assent, to mothering Mojo; stress-free when she can.

Chook shared more insights into how she copes with mothering and how she has come to accept changes to her mothering:

I have changed, probably not as much as I would like to. I still sometimes check myself when I'm tough on my other two. I think wow! I am very tolerant with Mojo; she can't do anything wrong, and she doesn't do anything wrong, and I am still pretty hard on my other two; but a lot more relaxed than I was. So I started really, really uptight, and I've sort of come down quite a few notches. My husband copes with it differently from me. I'm more a day-to-day, whereas he is thinking more about what's going on overall; so he is more cut up most of the time than I am. I don't think about the future - I deal with today. I can't change the future.

Chook had already mentioned that before Mojo's diagnosis she was pretty uptight; she has mellowed out quite a bit. Distinctly different in their approaches, Chook deals with things as they come, living in the present and unable to conceive of the future; in stark contrast to her husband who is a big picture thinker. Chook notes that his coping style is much harder emotionally. Chook is the main carer for her daughter, and the whole family. It is possible that living in the everydayness, and needing to be the person who carries out the caring, disables the ability of forward planning and big picture thinking. If Chook went about her mothering in the same way as her husband does his fathering, she would live with that emotion, that unthinkable pain and turmoil in such extreme amounts all the time. Perhaps that is the poignant inability of a mother, to not be able to see the big picture, to not be emotional in times when the everydayness must continue. The relationship of mothering is too ever present and in the context of the now, dealing with today, and doing what is necessary. The big picture is threatening; it endangers the belonging with her child, it looms and intimidates.

Angelina also noted that she had accommodated to mothering her son Maddox in a similar way to Chook:

It's hard because, I'm just like... head down - just methodical; just do what needs to be done. I'm not the girl in the relationship. I don't do the crying; I don't do the... oh poor me, and that sort of thing: I'm like, so what's happening; what needs to be done..., that sort of person.

This insight into herself has Angelina noting that it is difficult to be systematic, disciplined and precise in her mothering. Perhaps it is that having a child with severe multiple disability necessitates mothering in this way, and being emotional cannot occur; because it is simply not helpful. Angelina reflects she is not the girl in the relationship with her husband. She does not give free reign to her emotions. She does not allow herself to feel sorry for her situation or draw comfort to herself. Perhaps if the emotion seeps in it could be all consuming? Perhaps a hardening has to occur when you are the person present in the everydayness of caring for a child with severe multiple disability?

Angelina also shared insight into the preparedness required for Maddox's care:

The hardest thing is probably having to be so pedantic about his medication. We just can't send him off for a couple of hours with his mates and stuff like that. If he has a seizure, we would need to have some medicine. They would need to know what a seizure is, and all the protocol; that sort of stuff. So that's the hardest thing day-to-day; we always need to make sure we are prepared. So we might be going out, just to the markets this morning, but he'll be due his lunch time meds: we've got to pack them just in case we're not back. And we've got a spare set in the car. But you've always got to be that five to 10 steps ahead. His life depends on it.

There is a real sense in Angelina's narrative of her loss of spontaneity and freedom when she says, *you've always got to be five to 10 steps ahead*. In the family's everydayness, Angelina must always be completely prepared; Maddox's life depends on her ability to be absolutely ready to handle situations which place him in medically compromising situations. The being accommodating is born from absolute necessity. There is also a sense of loss expressed in the inability of Maddox to participate in the typical activities of childhood, such as going to his friend's house to play. Mothering in such a precise way is a struggle as it seems go against the free spirited nature of who Angelina is and how she would prefer to be able to mother her child. She has to be ahead of the game, day in day out; prepared; the medications ready to hand, all scenarios covered; and the responsibility is on her; Maddox's dependence on life saving medicine is on her shoulders. It is a heavy burden for her to carry. His life depends on the medication and she is responsible for ensuring that it is available wherever they are. Yet Angelina is not solely responsible. Throughout her narrative

Angelina speaks of 'we' not 'I'. She shares the burden with her husband, distributes the responsibility and divides the necessity of pedantically practiced parenting. Having support enhances Angelina's capacity to be accommodating.

Amy also highlighted the lack of spontaneity in her mothering and outlines a missed opportunity:

I did regret it, because I forgot to take the trolley - that red trolley. And with all the busyness, I didn't end up taking it. So all the kids were running on all these lovely big flat grounds and he was stuck with Nana. All the kids were running on the grass, and I thought afterwards oh, I should have brought that trolley; they could have pulled him in it... And you know, he ended up not being part of it, and he would have really loved to be part of it. And I hadn't prioritised it. There is so much equipment: the equipment is probably one of the least pleasant things about it; it's just you're always lugging equipment. Even when I go out to a café I take my own high chair, 'cause probably their high chair's not going to be right for him. Sometimes they have got one sort of right for him, but you know often they don't, so we just carry a high chair. We carry lots of things.

This narrative brings forth a mother's sense of loss when she mistakenly neglects to prioritise the trolley for her son. Her actions cause his exclusion and she expresses her regret at causing this isolation. The busyness of the day (which was actually her wedding day) impacted on her foresight of lugging the trolley to the venue. Most would understand this forgivable omission, given the stress of the bride on her wedding day and everything else there was to organise. She, however, finds it difficult in this instance to forgive herself; she is so characteristically accommodating on a daily basis when it comes to meeting Campbell's needs.

Maree would typically always identify opportunities for Zara's inclusion and ensure it happens. Maree shared:

When Zara was in hospital for 5 months I felt like I became institutionalised. There was a constant attendance of nurses and staff, following the hospitals many systems and routines and protocols, other people in charge, making decisions; you were always surrounded by people and then... suddenly I found myself at home with, two little kids and a toddler and a very medically fragile baby, and things became unravelled really quickly. I look back now and think how the hell did we cope with that... I must have been on autopilot...because I

don't remember how I did that. People often say that, when they are in traumatic situations, you just do it... you put one foot in front of the other, and then you realise when you come out at the other end, that you've actually survived it and you've done it. The other day I was talking to a good friend and I said to her, telling my story now, is like telling someone else's story, the emotion is very rarely there. And I can reel off the whole story in an appropriate way, but the emotion has been detached somehow and put somewhere else... It's like did you know that was really me; was our life; was our story.

Maree describes in so few words the shift from being supported in an organised and structured environment where she felt other people were making the decisions; to going home without those systems, without all those people and only her and her three dependents. Maree remarks that it fell apart quickly – *unravelling*. The sense you get reading her words is that she almost becomes robotic, *one foot in front of the other, on autopilot*, doing what needs to be done for survival sakes. Maree states it was *traumatic*; a powerful shock with long lasting effect on her, and her family. Yet Maree appears to have managed to somehow bury her past in her subconscious as a way of dealing with her situation. This once again gives a sense that mothering a young child with severe multiple disability requires a hardening; avoidance of emotion as a mechanism for survival; an accommodation to the demands of the role of mothering. Maree purported now being so distanced from that time in her life she is detached of emotion when articulating the events to others; struggling to fathom that it is her life she is describing, her story she is telling.

### **Being Supported**

Being supported comes to be a valued understanding when mothering of a young child with severe multiple disability. There is no way to survive in the everydayness of the role without being supported by loved ones, supported by specialist service providers and supported by other mothers. The support gives the mothers strength at times when it is needed and it aids at times when they are enduring the inherent difficulties of the daily grind. Support enables a sharing of differing perspectives, provision of knowledge and assistance in decision making. Support provides validation in times of need; it allows sharing of the burdens and bestows the essential 'belonging'.

Angelina remarked about the complementary differences between herself and her husband:

I think there is a good balance between my husband and I. He's quite a thinker. He likes to have all the scenarios on the board and then he'll make a decision, whereas I'm kind of person that trusts the professionals. "Okay, you're the best trained for this job: if that's what you suggest, go for it". Whereas he would get another opinion, so... it's quite a good balance between the two of us; and because of that, a lot of the paths Maddox's been on could have been quite different along the way. We might have chosen other avenues or treatments to try that could have been detrimental, or perhaps could have been beneficial, but, we've made that decision. So it's important if you are fortunate enough to be the mother of a child with special needs in a relationship, with a husband or a partner; it's not just you making those tough decisions. You know they are not the kind of decisions that I would like to have to make... like is she going to get her ears pierced at five? They are life changing like "should he get a tracheotomy?" Yeah, they are different kinds of choices that you make as parents. They're about quality of life.

Angelina contemplates the difficult nature of having to make the tough decisions and revels in the fortunate relationship she has with her husband. Sharing the burden of the difficult decisions and being able to carefully consider them as a team is something Angelina values, particularly given the importance and significance of the problem solving. The decisions being made are serious and complex, they require many considerations. Not being solely responsible for making these types of decisions is huge. Angelina is also aware that she and her husband each bring a different skill set and way of problem solving and information seeking that complements each other, so all bases are covered. There is a real sense that there is strength in numbers in this narrative and of relief in sharing the load. Angelina describes coming to terms with making the difficult decisions. In their partnership they come to an agreement together, having to make these decisions encompasses their need to be acquiescent with parenting a young child with severe multiple disability. No one else will make these tough decisions for them. Many times the consideration of possible life changing scenarios and medical decisions are made reluctantly, finding the lesser of two evils. Complying with the 'abnormality' of the decision making and of mothering Maddox shows Angelina acquiescing.

Amy also shared an experience of support:

We did conductive [education] for a long time and I think that was my way of trying to go, “you do the physio and then we can just [get on with] mothering him in the afternoon”. We don’t need to think about it ‘cause it’s all being done. I didn’t love conductive to be honest, I think I just needed it for the support at the time. At home I didn’t feel competent, and I was at that stage where I just wanted to get it all right, and I didn’t feel that I had that support to do that... So we went to conductive and did that for a while and I think it probably saved my sanity a bit having that support. The conductors would take over if you needed... if you weren’t doing it right. I really enjoyed the support it offered us, which I don’t think you get with the community model. At least, at conductive, everyone’s together and you can support each other, you know the conductors are very gentle, but also very committed to what’s going on. It makes you feel like you’ve done it... you’ve done something and you’ve done all you can. It took the guilt away because you thought, at least they’ve done that, and now I can just go home and I don’t need to think about it.

Amy involved herself and her son in conductive education as a way of finding some support, and is thankful for the experience that allowed her to build some self-confidence and a sense that she was doing something positive for her child. Amy shows in this narrative that she has a love hate relationship with the physical nature and ‘doing to’ the child that conductive education practices. However, she enjoyed the support and was in a venue with other mums in the same or similar position to hers. Amy notes the stage she was in with Campbell, seeking the support was about timing, and the type of support she needed at that time. There is a transitioning in her thinking and doing, from ‘trying to get it right’ to acquiescence. There was also a sense of accomplishment alongside the support; some of Amy’s guilt was also removed by attending conductive; doing the physiotherapy in the morning and then being able to do the mothering in the afternoon. Receiving the support at conductive education assisted Amy to accept some of the terms of mothering a young child with severe multiple disability. In this venue she was conforming to the mothering a young child with severe multiple disability and developing acquiescence. Amy went on to say:

I think there does need to be something where there’s support for families at that young age... you know when they’re really young and you’re trying really hard to get it right, and you don’t feel safe with what you’re doing, but it’s also the emotional support of having other parents around as well, and I know

people have gone off to group things, but I think there's a time and a place where actually you do need to gather with other people and just learn together.

Conductive provided Amy with emotional support and like-minded people all finding their way in their mothering together; it gave her a sense of belonging and lessened the isolation and incompetence she was experiencing, at the time, alone at home. The sense of inclusion was really important for Amy and her son; particularly as she noted she was in a state of just trying to *get it right* and being unsure if she was. There was comfort in knowing she was not the only one experiencing those thoughts or struggling in the everydayness of mothering a young child with severe multiple disability. Being supported is necessary to come to terms with the mothering; to the survival of the mothering a young child with severe multiple disability; to being acquiescent.

Chook and Maree both shared how the support they gained by interacting with other mothers through Facebook had enabled them to share and relish in the sameness with other mothers of children with severe multiple disability. Chook remarks:

Thank goodness for the dreaded the Facebook; we've connected with other families whose children have this. And they all have very strong opinions on things; but people can talk about, when they are going to stop feeding their child; and some parents come back and go, "You can't do that...blah, blah, blah,"; and other parents fully support you. So, you are very aware that you are going to get all angles. But you can also learn about equipment needs, and how the parents feel after they've lost their child; medications – it's a huge support network. For people who don't have that, it could be incredibly lonely. There are a couple of children in England, and the parents ask questions, and they are about a year and a half younger than Mojo; and so you would just make suggestions. We've tried; worked; didn't work; and other people come back and agree or disagree with everything. I get a lot of support and strength, I suppose, from a couple of people in Australia who have lost their children. I went over there and met their children a couple of years ago, or a year and a half ago, which was incredible.

Making connections with other mums and families is described by Chook as providing her with both support and strength. Chook openly states the opinions of others can be very *strong*, and the topics of conversation are anything but light hearted. On the

forum there is a variety of thoughts and feelings expressed and shared. It gives a sense that the information covers all bases and at least a thorough investigation and consideration of the vastness of experiences is expressed and valued. She has been fortunate to extend the online relationship to meeting some of her supporters in person and visited families who have lost their children. There is a sense of sharing and the creation of a community in the narrative she shares. Discovering the belonging and closeness with others helps the mothers to be acquiescent. Chook is able to gain from the experiences of the other mothers, and reciprocate by sharing her experiences with them. There is a sense of confidence in her narrative; Chook is finding her way, facing what is happening and what will eventuate. Chook is coming to terms with different people and different opinions; she is making different choices and finding peace with it all.

Maree also uses Facebook as a support mechanism:

I've spoken to a lot of other mums (of children with disabilities) about that... 'that the disability gets in the way so much that it is hard to find the child-mother relationship'... and they feel the same, and they won't talk to anyone else about that except other mums - that's why Facebook groups are so brilliant and you can be brutally honest about the facts.

Maree also relishes being able to get support from other mothers because, in a sense, they are living the same existence. There is the recognition that each mother is an expert in knowing their child and the experience of mothering a young child with severe multiple disability. Maree feels vindicated that she is not the only one who feels the way she does, given validation by the other mothers who understand and appreciate the difficulties of the role. Maree appreciates the brutal honesty that is offered on the online forum; and she appreciates that she too can be *brutally honest* in her telling and sharing of her experiences of mothering a young child with severe multiple disability. Maree is freed from holding in the truth of her experience mothering her young child with severe multiple disability, freed from feeling alone, freed from guilt about feeling the way she does, freed from judgment. Once again the narrative shows the strength that can be gained from supportive relationships and how necessary support is in acceptance, essential to evolve, required to survive and vital for acquiescence.

## **Being a Supporter**

In the journey toward being acquiescent and establishing belonging, the mothers shift from being supported to being the supporters. There is a sense that they notice the change in their mothering. In their reflection they come to yield to their difference, they come to sense validation and an overwhelming sense of competence and perception. This perpetuates the capacity in the mothers to identify value in helping other mothers, identifying difficulties in the health and education system and advocating the need to make positive changes to benefit their children and others like them. Being a supporter shows the mothers acting in support of their children, their families and supporting the role of mothering.

Angelina noted:

After that moment I wanted to be that family, that mother that other parents or families living the same as us could talk to. I would have loved someone that we could've talked to about our stuff. Not a clinical person, not a counsellor. We didn't want to hear "but we've read it in a book somewhere". I wanted another mummy or aunty, someone who would not judge, someone who understands the whole dynamic of being a mum to a special needs child. And we thought maybe we could help other families. We would love to help other families.

Angelina identifies the dissonance with medical professionals, clinicians and counsellors offering advice to mothers of young children with severe multiple disability. She is emphasising the need to hear from those who know, those who are living the actual experience and the value that sharing the experience could bring to others. Angelina identifies she lacked this support, perhaps she had been subjected to judgment or at least she felt she was being judged at times in the past. Angelina is expressing the need to protect other mothers from the judgment and provide the much needed support. Support she now feels capable to give. Provision of the support would also provide Angelina a sense of accomplishment and charity, and would not be an entirely selfless act, as she too would reap rewards.

Chook also identifies discord within the system with regard to her daughter. She describes a scenario where anger spurs her into action and advocate for change:

I got the letter from Special Education saying she's been accepted to go to the school, and there would be a review of her progress in five years' time. I was just horrified. One paragraph didn't need to be there [her daughter was unlikely to be alive in 5 years' time]. I left it for a couple of weeks, because I thought, I'll chill out; don't go charging in, because I am a bull at the gate sometimes. So I left it a while so that I was a little more reasonable. I emailed the Minister's office, and had a phone call within an hour; and changes are being made. And that's good – a change will happen out of that. I got on their case again a week ago, because I hadn't heard anything back; they told me they would keep me in the loop with the changes they were making - haven't heard anything back. I know it's a generic letter; but what made it worse was we had met the staff member who had signed the letter - we had had a meeting with her, so we had physically met her. I've met her several times.

Chook understandably advocates for herself, her daughter and potentially for other mothers by championing a need for change with current communication practices within the Ministry of Education. Chook was justifiably pleased that her actions in response to the letter will result in *change* to the system. As a result of receiving the unfortunately ignorant letter something good should happen from her painful experience. She was hurt by the system, as unintentional as it was, it was still unforgiving and Chook took her time to respond appropriately and advocate for her child and herself. Chook describes her persistence with the cause, making sure she *stays on their case*, making sure the *change will happen*. The narrative gives us insights into Chook's need for fairness within the systems she has to negotiate with her daughter. Unable to obviously change what has happened to her, she understands the need to stop it happening to other families in the same or similar position to her. Being acquiescent is the hesitant coming to terms of mothering a young child with severe multiple disability; coming to terms does not however mean accepting the status quo. It does not rob the mothers of the capacity to act, or effect change where it is much needed. Chook is advocating for the Ministry of Education to change its procedures, to demonstrate and practice with integrity and consideration for her situation, to be empathetic and just.

Chook identifies another scenario where she felt similarly compelled to request a slight change in common medical practice. She describes an interesting oversight in the

sharing of information, which she brings to the attention of her daughter's paediatrician:

I find the health system to be fantastic - can't ask for anything else, but just the social environment we live in, it's quite isolating. I was searching one day and I found this amazing website. And I said to the paediatrician, "Why didn't you tell me about this?" I said, "It is an amazing website." She said, "It's on the bottom of all of my letters". I said, "But you're going through lists of medical information on the letters". I was stuck. I've never even looked at it. I said, "Can I suggest you just bring it to people's attention; if anything to point them towards it..." This website had a whole section on grief. It was incredible and she quite rightly pointed it out; it was on there with all the letters.

Chook's words hint at her being astounded by her lack of perception; she had never noticed the website information which appeared on all her paediatric reports. Was Chook not reading the screeds of information on the letters? Was she too overwhelmed by the confronting medical information? Was she so familiar with the list of medical issues that she skim read her letters? Was it just one letter after the next? ... the questions go on. The failure to notice the amazing website address struck a chord with Chook, and upon discovering her oversight she urged the doctor to please, make this information more explicit, point it out to families and highlight it in some way; it was vital that other families be able to access this information, it was vital that they did not overlook it.

Amy also discusses campaigning of supporting systems to improve over time:

There is always something on the agenda. There is always something you're pushing for. I like to have only one thing on the go, which I often have, that one thing that I'm really pushing for. I would like a modified van, but at the moment we've just started a new treatment, so I'm kind of like I'll put that on the back-burner until I'm just ready to pick it up. I think you get clever as a parent. I learnt to say no. And sometimes it's not nice, because some of those people think you're a difficult parent because you say no. And I suppose that's one thing that frustrates me, we get all this funding and it's amazing funding, amazing, huge resources, but we don't get to choose how it's used. I think as a parent, I really know what my child does and doesn't need. I think they need to let parents be more key players in deciding actually what they need and how they want to use that funding. You know, the money is there, why can't they

just be flexible with it, because this is what our family actually needs at this point.

Amy makes a point of not over loading her *agenda*, and only *pushing for one thing*, one cause at a time when it comes to her son, Campbell. One is likely enough, given an already hectic schedule in the daily care for her son. Being acquiescent is the 'having to moderate' when mothering, having to side line other important projects and plans. Amy identifies in her narrative the importance of recognising herself as an expert in knowing her child, and knowing what her child needs. There are frustrations in negotiating the system, which Amy describes as inflexible and lacking a family focus within its intervention.

Being a supporter not only establishes value and importance in helping other mothers, or helping their children. Amy went on to say:

I don't do all the therapy; I suppose I felt a little bit judged for that. But you've got to choose parenting, and I think that's something I've been quite good at doing, just choosing to be a Mum more than anything else. When something's really relevant then I'll push that, and I do the stretches, and I do the standing frame. I do the things that I think, if I don't do them there's a health outcome. I don't ignore those things.

Therefore Amy says 'no'. She chooses to advocate for her need to mother her child and choose mothering. Mothering Campbell is what Amy values most. She supports herself in that role, and supporting mothering over other things she is advised to do requires her to face some judgment, endure frustrations within the system and advocate for what is best for her son and their family. Amy's acquiescence comes from acceptance that others will judge her, accepting that others will judge and being at peace with it. Amy is satisfied that her actions are guided by her own principles.

Amy reflects on the bold, confronting and competing paradigm within the occupation of mothering:

Being a mother does mean a lot of work, let me just say... I think it makes you a lot less selfish, and I don't know. I suppose it's just what you do to continue a bit of yourself in the world really isn't it? I mean I wouldn't ever want to miss out on being a mother. I do actually really enjoy it, but I must say I do get tired

and I do sometimes think, oh just to have a day to sit and read a book. I think most mothers probably think that. I suppose there's two parts: there's the joy and there's the burden, the two parts to mothering. You can't have one without the other.

Amy's description gives insight into the *burden* of mothering; being selfless, giving and giving, with only a little receiving at times. Although Amy loves being a mother, she wishes at times for some time to herself, *just to have a day to sit and read a book, and she states I think most mothers probably think that*. However, the joy experienced as a mother is all powerful. The warmth you feel when you see your child smile, when you see them succeed and accomplish; it fills your entire body. The joy when mothering can keep you going when you are exhausted, when all you want to do is sit down and breathe; the joy that is received from your child fuels your body so you can continue. Being able to accept the joy and the burden of mothering is an important part of being acquiescent. It is important that the mothers are able to identify their value, the hard work and the selflessness of the role. Survival is dependent on the mothers supporting themselves, so they can carry the load; the burden, and revel in the joy that they help to create.

Being a supporter illuminates the worth of their roles as mothers. Maree contributes a narrative with semblance to Amy's; describes the necessity of supporting herself and identification of self-preservation:

Being a mum means everything, 'because that's my job'. I've got amazing girls, and it's my job to make sure that they grow up feeling loved and that they're confident, and happy and that they're well-rounded people. It's a huge responsibility that I take seriously. I want to give them lots of experiences and equip them with enough tools to not just cope with life, but be happy in life. It's important for me to not lose who I am though, and that I retain my identity and that I have other interests. I'm trying to get better at finding time for other interests other than being a mother. I'm a mother: I'm not a martyr, and I think there's a fine line sometimes between those roles.

The occupation of mothering is what Maree does. It is her primary vocation, she values it. She respects it and attaches great importance to it. However, as much as being a mother defines her, Maree is also aware that it is not all she is. Being a mother

to a young child with severe multiple disability likely makes engagement in other occupations difficult for these mothers. However, as Maree states, it is necessary to push for that time to identify with herself and to establish herself in her other life roles. Maree's beliefs about mothering effectively necessitate demarcation and that strong conviction that she refuses to suffer greatly as a result of mothering Zara.

The stories convey how the single most important role a mother has is caring for and supporting her children. Chook shared the following perspective on the way she mothers and supports her children:

[Mothering is] unconditional love; nurturing and ensuring they see their potential. Just being there for them; helping them grow; making sure they get the best start in life, but also they know boundaries as well. Being a Mother means having fun doing the things I loved doing as a kid and appreciating what's around them; people and family. It can be a challenge, but developing that understanding that they appreciate their family and are part of the bigger family is really important.

Chook mothers her children in a way that is allowing them to develop their potential and appreciate, as she does, the importance of *family*. Supporting her children towards experiences where they can develop good qualities and traits that will serve them well in their lives is of great value to Chook. Chook wants her children to see her enjoyment, she wants to support them doing activities that she enjoyed as a child. Chook not only wants to support her children, she wants to support the institution of family and the necessity of belonging to something bigger.

Being a supporter is an extremely vital element to being a mother of a young child with severe multiple disability. It provides value to acquiescing to the experience of mothering, which provides a foundation for developing faith in their ability to mother and advocate for their children, for other families and themselves. Through being a supporter the mothers are able to recognise their experiences as having significance and merit that is worth sharing. They are able to identify systems in need of change, and work to make sure the changes eventuate. Being a supporter shows the mothers tirelessly pushing agendas to improve their children's lives. Finally, in being a supporter, the mothers recognise the value in mothering and all that it encompasses, and come to a place of being where they can also see within themselves some

necessary survival instincts and self preservation. Being a supporter allows the mothers to exploit their strengths and recognise their weaknesses, to appreciate their uniqueness and strive to help others to acknowledge and appreciate it too – because if they do, then they will truly gain that sense of belonging.

### **Being Cognisant**

In this last cluster of stories, being acquiescent is the development of knowledge and the ways of attending to the lived moments and attunement to being the mother of a young child with severe multiple disability. This theme illustrates the mother's erudition in mothering their children with severe multiple disability within the disability sector. The mothers share their insights of skillful negotiation within the system, and how to get the best from it for their children. For the mothers, knowledge is power. Being cognisant also encompasses the mothers observing, recognising and accepting their children's unique abilities to be in the world, and relishing in the joy that it brings. In being cognisant the mothers exude that sense of 'having arrived'; confident that a number of valuable skills are available for them to use in the everydayness of mothering a young child with severe multiple disability. There is a conviction of 'having survived'; and a sense that they have developed this myriad of 'coping' and identification of their strengths and weaknesses. The mothers feel a sense of accomplishment that they belong to this occupational role, no longer flailing; in contrast they are secure, conversant, aware and evolving.

Maree reviews her impression of funding changes for Zara:

When Zara was 4 years old we received ACC cover for her brain injury under a treatment injury. That was an incredibly stressful time, made difficult by the differences in the way a corporation like ACC treats their clients. The format is stark contrast to the MOH framework where the whole family unit is taken into consideration, not just the injured. The service (ACC) is fragmented and is more like an insurance company. The format is so wrong for little kids that are seriously injured. ACC was set up for adults that were functioning normally, working, contributing or whatever, and have an accident. But our whole family have rehabilitated into this life. Ministry (of Health), even though it lacks resources and funding, the people that work in that system genuinely care about us as a family, and they look at us as a family unit - not just at Zara.

Although Maree questions the appropriateness of ACC institutional policies and procedures, she is knowledgeable about the structures within which she must negotiate her child's care. In this sense the working knowledge that Maree has of both MOH and ACC gives her a distinct advantage mothering Zara. She has awareness and is able to point out the differences. This narrative shows us Maree's focus towards family centred care, and the consciousness that her daughter's brain injury as an infant forced her entire family to rehabilitate into their life; the life of having a young family member with severe multiple disability. Maree views Zara as a valued and integrated member of their family, and as such would prefer the funding health system to view them in this way and set up structures to reflect this ethos. Focusing solely on Zara neglects the needs and wants of four other vital members of this family unit; most notably the needs of her mother; her primary caregiver. Maree is vital to Zara's well-being, and to Maree it is nonsensical to overlook her mothering; in its everydayness and all that it embodies.

Chook identified a few strengths she has been able to utilise to traverse the health and education landscapes:

I'm educated; I know how to access supports and I have people who can read things and edit them for me before I send them in, and they make sure they sound right; and I'm not scared of authority.

Chook's statement gives an empowered sense of self. She has confidence, knowledge and is fearless when necessary to tackle the practicalities of negotiating the systems governing Mojo's care and education. She elaborates on this theme of knowledge, when she discusses the need for pro-activity and persistence:

There's lots of organisations and support that are available when you have a child with special needs. But it is up to you to go along to things, and to take that first step. And if you're not the sort of person who wants to go along to those sorts of things ... I think it can be quite lonely. There are morning teas, and there are group things you can go along to, but if you're not really into that, then it's quite isolating. I was just thinking in general, you've got a child with needs like Mojo's, the support is a bit lacking, unless you go looking for it - unless you go get it. I know there are some really good organisations, and I've been to a couple of things. But it's left for you to do.

Chook is tenacious; she wants to obtain as much knowledge as she can. This perseverance may be attributable to her previously described occupation as an astute business woman, and the established practice of thorough research. It could also be Chook's need to learn and gain knowledge from the other mothers of children with severe multiple disability and feeling that sense of belonging in shared experience, driving her to attend the morning teas and group activities, as they walk a similar path in life to hers. Regardless of the rationale, Chook identifies strongly with having to be that type of person for your child, and for yourself as a mother. Being the mother of a young child with severe multiple disability necessitates seeking knowledge and learning how to negotiate the system effectively; and for most, this demands establishing individual action, putting yourself out there and persevering. Being cognisant and belonging in the system compels the mothers to Kia Kaha (be strong, get stuck in and keep going).

Amy shares how establishing an awareness and knowing in mothering can alter one's focus when mothering a young child with severe multiple disability:

I think there's a lot of parents that fundraise for all sorts of things, and you know their whole life is driven by fundraising for the cure - well, not the cure, but some sort of therapy that's going to push things forward. I don't know... I suppose I can understand that, but I don't feel like that's what I want for my life. I think when a child's first diagnosed you've got that thing where you just want to do anything you possibly can that is going to fix them. During this stage you have a good relationship with your therapists. Then I think all parents realise at some stage there's no magic wand. I think then they go through a bit of a hate stage that stage of... this is all a waste of time, and then get quite judgmental and critical. I think parents keep fluctuating with that relationship, because ...I suppose, it depends whether you are in a stage of really hoping, or if you're in a stage of acceptance. Sometimes acceptance can make you less focused on therapy.

Amy brings to the fore the 'coming to acquiescence' stage of mothering a young child with severe multiple disability and the notion of hope versus acceptance. Amy shows us her dogged discernment, strength of character and will, that she will not spend her life searching. Amy's knowledge and experience of mothering Campbell, has guided her towards creating understanding of her child and appreciating the relationship of mothering Campbell as her driving force, not a driving force towards changing him.

Accepting that her child can not/will not be fixed, frees Amy to focus on mothering, and finding the joy in that.

Another facet to being cognisant is awareness. For the mothers of young children with severe multiple disability, being alert to the positive experiences in mothering their children is necessary to belonging to the 'motherhood of mothers'. It is essential that the allowance of time is given to feel right about themselves as mothers; to find the joy in mothering.

The mothers all describe the joy that comes from mothering their young children with severe multiple disability. Sometimes the real joyous moments occur in the strangest of places. Chook shared the following narrative:

We were in the city at Wellington Museum and they had this music... sort of old-time music that was playing on headphones, and I had never thought to put headphones on her before. So we got her out of the wheelchair, sat her on the ground, and put these headphones on. She was just rapt - animated- she was clapping her hands, and making noises. It was so neat to see, because a lot of the time, she'll sit there pretty unresponsive; and that was like oh wow. We sat there for ages with her, because she loved it.

Chook's joy in this moment stems from the enjoyment her daughter is experiencing. For Chook it is an unfamiliar scenario, seeing her child so active. Mothering a young child with severe multiple disability for the most part is a day to day struggle, as has been described in the previous two chapters. In order to 'keep calm and carry on' in the mothering role it is necessary to be aware and acknowledge the joy, and relish in the small moments where smiles are received, giggles are heard and pleasure is gained. At times the mothers will also have to practice mothering in such ways that they use the knowledge of their child and knowledge of situation to focus on and produce joy; because it is what is needed, it is necessary for mother and child. Placing the headphones on Mojo and sharing the experience of music with her daughter, gives both mother and daughter a completely inclusive encounter. Mojo is given the opportunity to experience freedom to bare her happiness in that moment; and they both enjoy the moment, Chook is cognisant and reeling in the belonging it brings them both.

Chook also speaks of another inclusive moment with Mojo:

She went to an old friend's birthday party; it was a disco; I took her along, and because she doesn't walk on her own - I was holding her and she just had a blast. And every now and then, she would get a bit tired; and so she just sort of collapsed on to my feet, and then I would pick her up again, and she was dancing and clapping. And I thought yeah, it's worth the effort - it's fantastic. She does comprehend what's going on; she's having a great time.

Once again, in this narrative, Chook reveals the joy she identifies when Mojo is engaging and experiencing pleasure in a moment of belonging at the disco. Chook is aware in this environment she has to facilitate the belonging by holding her daughter up so she can dance; however, despite the physical strain and demands of the task, Chook identifies the value it brings to them both. Mojo is exhausted and crumbles, yet she does not cease to want to continue, and Chook does not cease to want to provide the enjoyment to her daughter either. In these shared moments described by Chook, the one sided nature of the relationship with her daughter ceases to exist. Mojo is able to share the 'doing', she is able to assist to orchestrate an experience of joy and provide for Chook. In these moments, in being cognisant, Chook identifies with her daughter's happiness, and gains pleasure from it. Being cognisant to these moments; where her child can give back to her, drives Chook to continue to seek and provide them.

Maree also identifies with being rewarded by Zara's joy:

I think cuddles are probably the best thing. I never tire of the opportunities to sit and cuddle. She loves that too. Seeing her smile and laugh is the best thing, 'cause that's what she can do really well, so if we can find an activity that she really loves, then that's really rewarding.

*Maree never tires of the opportunities to sit and cuddle. As expressed in other ways by all the mothers in the study, cuddles are probably the best thing. At times it may be the single thing that keeps them going; knowing that there will be those moments of pure joy; cuddles, giggles and smiles, it makes all the hard work worthwhile and rewarding. Because apart from those cuddles, giggles and smiles there is not really any other reward they will get mothering a young child with severe multiple disability.*

Maree gets fulfilment in belonging with her daughter; cognisant in those moments; sharing Zara's enjoyment in activities, sharing cuddles and smiles. Amy, like Maree, also enjoys spending time cuddling:

I like to spend lots of time cuddling him. He's still really cuddly, which is actually quite nice, so we spend a lot of time cuddling him and he likes having time doing that. I think he's a neat little kid. When I've had a really busy day, they're the kind of moments that you treasure. When you just sit down and think; we're just going to have a cuddle. We have a lot of good mothering moments, because he's a really lovely natured child. He's very affectionate, and he's actually quite a pleasure to be around, so we have lots of lovely moments together. He takes a lot of pleasure from life, it's something I have always noticed with him, he gets a lot of joy out of life and so he is actually quite joyful to be around. It's the really nice thing about him.

Mothers of children with severe multiple disability want nothing more than for their children than to be happy and healthy. As their child's health conditions are beyond their control, in many respects, the only factor that they can truly influence is their child's happiness. Being cognisant to both their child's and their own need for joy and happiness is vital in being acquiescent. The mothers seek to identify activities and co-occupations that can engage their children and provide them experiences of inclusion, belonging and pleasure. This is high on their list of priorities for the mothers of young children with severe multiple disability as it is one the few mediums where their child's enjoyment can be reciprocated.

## **Conclusion**

***Perhaps this experience might awaken: All reflective thinking is poetic, and all poetry in turn is a kind of thinking. The two belong together by virtue of that saying which has already bespoken itself to what is unspoken because it is a thought as a thanks. (Heidegger, 1959, p. 136)***

The narratives provided by the mothers show being acquiescent as a journey of their acceptance of their altered occupational existence. Heidegger (1982) used the term 'Zusage' in his book *On the Way to Language*. Zusage has been translated (Babich, 1995; Zarader, 2006) to mean, consent, consolidation and acquiescence. According to Heidegger (1971, p. x) "one must understand the nature of language by which thinking

is able to say what it thinks”; this was conceptualised by Babich (1995, p. 68) as “thoughts task being that of deeper questioning”. Interpreting this notion in the context of these stories, it implies that mothering is always on the way toward ‘being a mother’ and a way of always questioning how to be a mother of a child with severe multiple disability. These mothers’ stories tell of moving towards understanding and feeling a sense of belonging in mothering, belonging in the special and unique compound of disability, and belonging and asserting themselves in the world of others as expressed in their stories. Heidegger (2010) related this to *Dasein* as understanding; “we sometimes use the expression ‘being able to handle it’, ‘being up to it’, ‘being able to do something’. In understanding as an existential, the thing we are able to do is not a what, but being [sein] as existing” (p. 139). The understanding becomes part of us as beings, it is shaped by and determined by the activities in which people engage (Burch, 2010). In other words, being acquiescent takes the mothers from the essential accommodation, where the mothers take account of the demands of mothering a young child with severe multiple disability; it is the everydayness they encounter things, the emotional demands, the juggling, the dependency. It is a deep transitioning.

The mothers come to understand other indispensable needs when mothering a young child with severe multiple disability, such as finding support. In being supported the mothers seek and secure relationships to assist them to survive. The support assists the mothers to develop strength, to ease guilt and to share the burdens associated with mothering a young child with severe multiple disability, and to move towards inclusion with their child. In being acquiescent the mothers also become supporters; supporters who choose when and where to champion causes for their children, who recognise the need for system changes and advocate for that change. They exude competence, value the advocacy and move closer to inclusion and belonging for their children; and in a sense they are coming to terms with their role as a mother of young child with severe multiple disability.

The final aspect of the shift to acquiescence is the move to being cognisant; where consciousness becomes manifest, knowledge is power, and the mothers become conversant in a variety of environments. The mothers’ stories speak of appreciating

their uniqueness and the uniqueness of their children, push for inclusion and come to belonging. In Heideggerian terms the mothers have come to *Resoluteness*; they have acquiesced and come to grips with mothering a young child with severe multiple disability. Resoluteness describes a genuine way of being oneself (Harman, 2007). Heidegger (2010) stated:

resoluteness means letting oneself be summoned out of one's lostness in the they... In resoluteness, Dasein is concerned with its ownmost potentiality-of-being that, as thrown, can project itself only upon definite, factual possibilities. Resolution does not escape from 'reality' but first discovers what is factually possible in such a way that it grasps it as it is possible as one's ownmost potentiality of being. (p.299)

In the context of these mothers' lives, it means they have come to acceptance; where the joy and the burden of mothering has become their conventional truth, accepted, tolerated, a state of being to which they readily acquiesce.

## Chapter Seven-‘Being a mother’

*The more I read and the more I talked to other parents of children with disabilities and normal children, the more I found that feelings and emotions about children are very much the same in all families. The accident of illness or disability serves only to intensify feelings and emotions, not to change them. (Weatherly, 2012, May 11)*

### Introduction

For over a decade I have spent the majority of my waking hours working and caring for children with severe multiple disabilities and their families. I was fortunate to work in an environment under a creative and empathetic manager who taught me not only about being a better therapist, she taught me about being a better human being. I remember the day I very proudly and excitedly announced to her that I was pregnant with my first child. She hugged me and very knowingly said in her calm and wise tone “*being a mother will change everything, and it will make you a better therapist*”. And as always she was right. Having my son (and then shortly after my daughter) has changed me, in so many ways it would be hard to articulate them. And it made me a better therapist, as it made me inquire in such a deep way, as to the nature and meaning of mothering a young child with severe multiple disability.

Interpreting across the study’s findings, what has been revealed to me in the experiences that were shared of mothering a young child with severe multiple disability is a deep transitioning. To successfully engage in the occupation of mothering, the mothers in this study retold stories of accumulating knowledge and learning to adapt and evolve. Thriving in the role of mothering a young child with severe multiple disability seems to require a variety of abilities and strengths, and a certain few essential requisites to ensuring that alongside the burden of mothering, a mother can experience the joy. Mothering is not only a job with a vastly varied and socially regulated scope of practice, it is also shapes one’s identity, and essentially who one comes to be. Coming to terms with the diversity of skills required to mother is difficult to say the least. It is an occupation that is under constant scrutiny; for which there are many critics. The mothers in this research project are also coming to terms with mothering a young child with severe disability. Throughout the interviews, stories

unfolded of their experiences, and as the researcher I was able to gain a sense of understanding as to how their lives are lived as mothers of young children with severe multiple disability, and how they experience coming to understand their child, their child's disability and the sense of visibility, being challenged and coming to acquiesce. As heard in their stories, being the mother of a child with severe multiple disability is exhausting. The caring and the doing in the mothering is onerous.

My interest in this phenomenon stems from a number of positions, from my interactions with mothers of children with severe disability, and my understanding that at times my relationship with these children and these families enforced unrealistic objectives, despite good intentions; to my own story of becoming a mother and my complete unpreparedness for all that it would come to entail. Despite my professional background, and over a decade of paediatric practice in occupational therapy, I was, and have been, completely consumed by carrying out this research, and the depth afforded by four insightful and fascinating women, mothers, wives and members of society. In being close and coming near to this phenomenon, and the experiences of those living it in its everydayness, I have been profoundly transformed. As a consequence of this deep inquiry new insights into this phenomenon have come to light, and with these insights, new questions exposed.

This chapter will re-capture and interpret across the three themes outlined in the findings of this research, combine these themes with existing literature and research and reveal the all encompassing premise of mothering a young child with severe multiple disability overarching the three themes. Considering the meaning of mothering a young child with severe multiple disability, pertinent hermeneutic phenomenological notions guided by Heidegger (1959, 1971, 2000, 2010) and Van Manen (1990) will be illustrated, alongside positioning the research and relating it to the work of Wilcock (1993, 1999, 2006, 2007) and the four dimensions of occupation (doing, being, becoming and belonging). Wilcock is an occupational therapist, who has contributed and assisted in the development of occupational science as an international discipline. Wilcock (2007) stated:

It is occupational scientists' domain of concern to carry out research inclusive of the minute but from the perspective of the whole picture... health and well-

being of millions can be improved if the job, and its interpretation, is carried out effectively. (p. 5)

What will transpire will be gainful insight into the meaning in mothering a young child with severe multiple disability. The implications of this study and future directions will also be identified.

### **'Being a Mother'**

The experience of mothering a young child with severe disability, from the perspective of these four women, has revealed three key themes: *being visible*, *being challenged* and *being acquiescent*. The narratives that were shared have guided the researcher to an understanding of mothering being a 'constant state' of mixed emotions and altered states of 'dealing with the everydayness'. In essence, the all encompassing premise that was understood by the lived experience of mothering a young child with severe multiple disability' is '*being a mother*'.

*Being a mother* is the overarching premise that within motherhood, and the role and occupation of mothering, a deeply transformative process occurs in which a woman's mindset/self concept/identity, completely changes and evolves. This process of profound change occurs from conception of the child through to a mother's death (Esdaile & Olson, 2004; Francis-Connolly, 1998; Stern et al., 1998). A mother is always 'being a mother' in any and all moments, it is a 'being' the essential nature of oneself, authentically and truth, and the fabric of her nature. There is one determining fact.

or of extreme importance and influence over the status of 'being a mother'; the severity of the disability of her child. The severity of the disability will negatively influence 'reciprocity' in the mother/young child relationship, and it will intensify the burden of care (caregiving). Conversely, the severity of the disability may intensify the mothers experience of joy in 'being a mother'.

Within this state of 'being', a journey of 'mothering' exists. Along this gamut runs the three themes; *being visible*, *being challenged* and *being acquiescent*. In any given moment, within mothering, a mother will exist in one or more of these states of 'being in mothering'. The most complicated state of the journey is acquiescence as achieving this mind set requires a number of requisites.

**Being visible** details the mothers' experiences of 'being a mother' in a publicly observable way. Three sub themes were identified within this notion of mothering. *Being excluded*; illustrates the awareness from the mothers of being a mother facing a public world. Due to the very obvious disability of their child the mothers are notably different, and not normal. They face rejection, see the stares and come face to face with discrimination. The mothers are forced into their own category of mothering, a slightly paralleled path, dominated by their child's disability. Being visible also details *being obstructed*; and the mothers coming to terms with the limitations of the physical environment and spatial relations in mothering a young child with severe multiple disability. What also becomes visible to the mothers is the understanding of their role *being unremitting*; mothering is a lifelong engagement, and the mothers of a child with severe disability find themselves stuck in the everydayness of caring for their child. The need for caregiving will not ease; it becomes the central theme, consuming and relentless in their relationships with their children. The disability dictates this need, it will never go away. Being visible for these mothers is becoming conscious; awareness of the altered journey, identification and seeing themselves and their children in the context of their social and cultural world.

**Being challenged** frames the understanding of mothering a young child with severe multiple disability as being a difficult journey that necessitates the mothers coming to terms with a burdened existence. Being challenged has four sub themes, the first of which is *being absent*; the experiences of being absent in the thoughts of others, and having people distance themselves from the family, which encompasses being isolated. *Being regretful*; brings together narratives shared by the mothers outlining guilt, regret, the sense of responsibility inherent in mothering and at times being inadequate or unfit in their mothering. *Being overpowered*; outlines the mothers exhaustion and feelings of being overwhelmed by enforced ideals of what is necessary to fit into their child's day. Being overpowered expresses the mothers feeling pushed for time, and pushed into relationships and situations, that they do not desire. *Being in precariousness*; is the challenge the mothers must face of an uncertain future for their child and the potential of a shortened life due to their severe disability. The mothers are aware of the need to be present in all moments with their children, and taking it a

day at a time. Being challenged shows the mothers perseverance in doing mothering, despite the constraints of the disability and in spite of the burdens.

**Being acquiescent** comes to explain how the mothers 'come to terms' with mothering a young child with severe multiple disability. It is the reluctant acceptance or assent to mothering in which four requisite sub themes were detailed and appear to be essential in order to acquiesce. *Being accommodating*; comes from stories of negotiating the day, and becoming proficient in the everydayness of mothering a young child with severe multiple disability. *Being supported*; details the importance of the support of partners, loved ones, other mothers and professionals. *Being a supporter*; shows the mothers advocating for their child and for themselves, which creates a sense of validation for their mothering role and positive self identity. *Being cognisant*; explains how the mothers create a knowledge base in order to successfully navigate with their child with disability within the system. The mothers form a unique understanding of their child and an appreciation for the joy that they bring to their lives, and the joy that mothering uniquely affords them. Being acquiescent is the place where the mothers know of the embodied belonging in mothering a young child with severe multiple disability.

## **Being**

"All phenomenological human science research efforts are really explorations into the structure of the human lifeworld, the lived world as experienced in the everyday situations and relations" (van Manen, 1990, p. 101). As has been discussed, Heidegger was concerned with the ontology 'being'. Being is the very humanness of beings, the nature of our existence. There is dualism within 'being' and the differentiation of 'being as such' and 'being as a whole' (Harman, 2007). "Being as a whole refers to the existence shared by all things, whereas beings as such refers to the specific nature of each being that make it what it is . . . both moments are present in everything that exists, at all times" (Harman, 2007, p. 83). Wilcock (1999) likened 'being' to the essential character that one is; 'being' is being true to their own self, and the very nature of who one is, distinctively. In order to be in 'being' one must come to a place of 'being', the time to discover their 'being', ask questions and reflect (Wilcock, 1999). It is for this reason that 'being' is a shifting and transformative state. It encompasses

what a person does, his or her occupational roles; the 'doing'. Most importantly it is about consideration of what we hold close to us, our importance:

The notion of being is important to us in this way, the cultural drives to do better and better alters ways of being in particular roles and overwhelms with a huge range of beings in each of which we are expected to become. (Wilcock, 1999, p. 5)

Being is a large multiply influenced system of personal construction, in which we, as humans, come to understanding ourselves and our place in the world. Being is never static, as our personal capacities grow and change, our directions shift, our potential is altered and our challenges faced. It is particularly difficult for mothers 'being a mother' as time for reflection and time for self evaluation is a rare occurrence. Prior to becoming a mother, I was an occupational therapist, a wife, a daughter, a sister, a friend. I was young and competent, I would go so far to say that I was level headed and self assured. When I was presented with a challenge in any of these roles I always felt confident in my ability to handle myself, face up to what was necessary to overcome the challenge, or completely immerse myself within it. I recall one day speaking to my own mother in the lounge with my little boy (4 months old at the time), and saying that I did not realise that being a mother would cause me to feel completely incompetent, and that I would constantly be questioning my ability to act appropriately to meet his needs; 'being a mother' had me flailing. In this early stage of mothering I was still trying to come to terms with mothering, I had not come to 'being', my role identity had not been formed. I was completely in love with my baby boy and completely ill prepared for all that 'being a mother' intended.

Mothers share in the experience of mothering, and 'being' a mother, involved in caring (caregiving), nurturing, play and teaching within a larger societal context. Yet, each mother mothers in a unique way with her own characteristics, her own identity. Mothering is dependent on the needs of the child, at any given developmental stage. For the mothers of a young child with severe multiple disability mothering is dependent on the needs of the child, dictated to by the severity of the disability, and the mother 'being a mother' within herself, within the everydayness and her own Dasein. The research findings gathered by the four mothers in this study have guided

me towards the notion that one cannot come to 'being' or 'being a mother' without moving through the 'mothering journey'. 'Being' necessitates, becoming, doing and belonging; being visible, being challenged and being acquiescent.

The thing that we are able to do is not a what, but being [sein] as existing. The mode of being of Dasein as a potentiality of being lies existentially in understanding... Dasein is always what it can be and how it is its possibility. Dasein concerns the ways of taking care of the 'world' which we characterized, of concerns for others and, always already present in all of this, the potentiality of being itself... the being-possible, which Dasein always is existentially, is also distinguished from empty, logical possibility and from the contingency of something objectively present, where this or that can 'happen' to it. (Heidegger, 2010, p. 139)

## **Becoming**

Becoming relates to the dimension of change; in essence it is a transformative process in which one identifies the necessity of growth and transformation (Hitch, Pepin, & Stagnitti, 2014; Wilcock, 1999). The capacities are there, available to assist and inspire, becoming is captured as a "situatedness within a continuing life process" (Lala & Kinsella, 2011, p. 248). For Wilcock (1999), becoming was an extremely important dimension of occupation, as occupational therapists often become part of the process of becoming when working with clients. She stated:

occupational therapists are in the business of helping people transform their lives by facilitating talents and abilities not yet in full use through enabling them to do and to be ... to achieve well being, individual people or communities need to be enabled towards what they are best fitted and want to become. (Wilcock, 1999, p. 5)

In being visible, the mothers in this research study faced the realness of mothering a young child with severe multiple disability within a societal context of obstruction and exclusion. Being visible due to their child's disability necessitated the mothers to becoming aware of their own 'normal', to be situated in 'what is', and the unremitting nature of the situatedness. Mothering imposes the pursuit of becoming; becoming aware, becoming an identity and becoming members of a community and society, helping their children to develop in their own way. Becoming is; "to become

(somehow different), to grow, for something to come into being” (Wilcock, 2006, p. 148).

The findings of this research revealed the mothers’ consciousness of becoming; it exposes the rawness in their experiences of becoming spatially aware; becoming stuck or limited by the physical, social and cultural environments in which they mother, in the eye of social judgment and in isolation. This is consistent with Meham’s (2005) findings that alongside the intensity evident on mothers of children with a disability, they also face stigma, the limitations of a spatial world and mourning the loss of their perfect imagined child and life. The realising of the disability, in being visible, and across the research and literature points to Heidegger’s notion of thrownness. “Dasein is thrown into a world that it never chose” (Harman, 2007, p. 177). The mothers were thrown into being the mothers of children with severe multiple disability; thrown by genetics, thrown by a car accident, thrown by delayed medical treatment, medical misadventure and premature births. The mothers come to ‘being a mother’ of a child with disability by being thrown. However, as has been described in the findings chapter, the mothers’ experiences of being thrown, open the way to becoming:

Dasein is constantly ‘more’ than it actually is... it is existentially that which it is *not yet* in its potentiality of being. And only because the being of the there gets its constitution through understanding and its character of project, only because it **is** what it becomes or does not become, can it say understandingly to itself: ‘becoming what you are!’. (Heidegger, 2010, p. 141)

In other words, the mothers are living in their world ‘not yet’ experiencing the experiences that will come to shape them as mothers. They are the mothers of a young child with severe multiple disability, this is there ‘is’, what they will come to experience in its everydayness will come to shape them as the mothers of a young child with severe multiple disability, and become what they ‘are’.

## **Doing**

Being challenged detailed the narratives from these mothers about mothering in its everydayness; the challenge of doing the caregiving and the nurturing within the confines of the disability, whilst confronting the burdens in the ‘doing’. Wilcock does not give a definitive description of doing in her writing; doing is left with a wide

interpretation. In this way it assists with limitless constructional understanding and holism (Hitch et al., 2014). However, doing can be understood as engagement, that it uniquely meaningful to a person, with a purpose, doing often denotes action, and can be observed by others (Hitch et al., 2014; Horne et al., 2005; Wilcock, 1999).

Information obtained from the literature review and the narratives of the participants in this study echo the same construction of doing in mothering. The doing of mothering in its everydayness for all mothers, encompasses four primary tasks; caring (caregiving), nurturing, play and teaching. For the mothers of a child with severe disability, these primary tasks, by their very nature, are 'uncharacteristic'. Food and nourishment is not cooked, but supplied in cans, to be pumped into a gastrostomy tube. Caring comes in the form of passive stretches, changing nappies, administering medications and positioning. Nurturing, at times is about being calm, watching for seizures, providing cuddles and more cuddles. Playgrounds become places for mothers to negotiate; dancing may require physical manipulation or holding a child upright. Teaching is about symbols and assistive technology, sensory programmes and mastering proximal stability in their trunk. The severity of the disability dictates how a mother does the doing. The severity of the disability also demands that certain primary tasks will go unchanged and be required for the length of the child's lifetime. The relentless sameness was described by Maree using words like *boring*, *tedious* and *a drag*. The uncharacteristic doing, becomes the everydayness, it becomes their 'normal'. The severity of the disability intrudes, it takes away time, it forces restrictions on what can meaningfully be gained within the mother's relationship with her child. The severity of the disability will also show to others its strangeness, its uncharacteristic ways. This sadly results in people being unable to accept it, contributing to the isolation and loneliness experienced by mothers of children with severe multiple disability.

Mothers, do the doing, day in day out, and also take on other responsibilities within the home, which impact on mothering time, such as housework, cooking, managing the family/home. Juggling these responsibilities was reported as being exhausting, overwhelming, demanding and a strain. The doing of mothering in its everydayness also requires mothers to deal with the burden of mothering. The burden has been noted as guilt, shame, stigma, financial hardship, strained relationships, sleep

deprivation and isolation. For the mothers of children with severe disability there was a great deal of guilt expressed for not meeting the demands placed upon them by professionals involved in their child's care/therapy. It is important that professionals are able to identify with the demands they are placing on mothers of children with severe disability. Strained relationships in this research relates to professionals imposing on the mothers in times of grief, and imposing on their time with their child.

As the doing becomes habitual and 'normal' to them in their 'being a mother' the everydayness just is. The burdens are faced as they make themselves present; the mothers do the doing one day at a time.

As thrown, Dasein is delivered over to itself and its potentiality-of-being, but as being-in-the-world. As thrown, it is dependent upon a world, and exists factually with others. Initially and for the part, the self is lost in the they. It understands itself in terms of the possibilities of existence that 'circulate' in the present day 'average' public interpretedness of Dasein. Mostly these possibilities are made unrecognizable by ambiguity, but they are still familiar. (Heidegger, 2010, p. 365)

Within 'being challenged', and the doing of mothering, the mothers come to meet the challenges with the challenges of the past shaping them to the new ones. The mothers come to throw off their thrownness, and perhaps subconsciously trust that they can 'do mothering'.

Dasein has always already got itself into definite possibilities. As a potentiality for being which it *is*, it has let some go by; it constantly adopts the possibilities of its being, grasps them, and sometimes fails to grasp them. But this means that Dasein is a being-possible which is entrusted to itself, it is thrown possibility throughout. (Heidegger, 2010, p. 139)

## **Belonging**

Wilcock (2007) came to describe 'belonging' in reference to its influence within health and well-being (Hitch et al., 2014). Interestingly the first references made to belonging were made by Reberio, Day, Semeniuk, O'Brien and Wilson (2001) where belonging was used to describe the needs of people to feel emotionally safe, to seek like minded people to share experience with, and find a "group identity" (p. 496) where social needs can be fulfilled. Belonging brings forth the importance of relationships,

connections we have and make with others, and the value that we can acquire through our interactions with others (Hammell, 2004). The ideal derivative of being in relationships with others is reciprocity, and this notion of mutual exchange is congruent with belonging. Wilcock (2007) came to her definition of belonging after conducting ongoing research into doing, being and becoming, it emerged as “the contextual element, of the connectedness of people to each other as they do and of the major place of relationships within health” (p. 5).

Mothering a young child with severe multiple disability necessitates a shift in expectation, a change in consciousness and of seeking closeness and support with others; an evolutionary process required for ascendancy, and securing the relationship with their child. In the final findings chapter of being acquiescent, the participants’ narratives gave the reader insights into the deepest transitioning, accommodation and yielding to the severity in the disability. The mothers shared stories in which they were able to find within themselves, that they can be a mother, and find joy in mothering their child with severe multiple disability. They saw that despite the lack of reciprocity, that they could find support and strength in relationships with others. They unearthed kinship and closeness in their mothering roles and came to understand the benefits that could be gained when they find places and people with whom they belong. Belonging is in essence about inclusion, an acceptance of who and what they are, their own ‘normal’. Being acquiescent is the accumulative and gradual ‘coming to terms with’ mothering a young child with severe multiple disability. It is a reluctant acceptance and coming to see that it is what it ‘is’. It means having to reconcile the burden and the severity of the disability, and the guilt of knowing that it is not a journey one would ever choose to travel if one had a choice. Being acquiescent for these mothers included establishing routines and undergoing internal changes necessary for developing competence and the shift towards understanding themselves as the mother of their young child in their life world. There is a distinct move through the challenges, persevering to commence the work of laying foundations and establishing their basis for belonging. Being acquiescent encompasses the coming to terms with mothering in an adaptive way; being able to bear with the everydayness and accommodating to the differences it brings. The mothers are orchestrating their own distinct design. They assent to mothering by being accommodating, which

involves juggling in the everydayness and learning the art of adaptation. They also assent by being cognisant, which means being aware, present and conversant in mothering their child with severe multiple disability, and in being supported which is essential in order to sustain mothering. Finally, their assent is apparent in being a supporter, advocating for themselves and their child, in finding a voice and sharing experiences with the aim of assisting others, and in finding affirmation and a place of belonging in broader society. The literature and research outlined in Chapter Two points to support being extremely important for mothers of children with severe multiple disability; similar notions were found in other studies on the importance of mothers establishing a positive role identity or as S. E. Green (2002) stated changing their “master narrative” (p. 22) and coming to accept the child with disability and accommodate. Finding the joy in the mothering was a theme within the literature with mothers sharing how the experience of disability has altered their lives and their child has taught them through their ‘superpowers’ how to live a better existence. Parallels could be concluded with being acquiescent and ‘altering ones family daily life’ from Barbosa et al. (2008) and also ‘normalisation’ as proposed by Seligman and Darling (1997/2007). However, Seligman and Darling’s conceptual framework speculates changes of families with a child with disability, not mothers specifically. It also denotes shifts dependent on periods of development, post partum, infancy, childhood, adolescence and adulthood. I also find the term ‘normalisation’ somewhat disabilist. From the findings of this research the mothers were completely aware that there will be no such thing as normal, and what is normal anyway? We know only the lives we live, they are our own ‘normal’ and everyone has a different ‘normal’.

The research finding of being acquiescent points to Heidegger’s notion of resoluteness. “Resolute Dasein come to grips with its own being in the world, and does not chatter about it with the they. Resoluteness is an authentic way of being oneself” (Harman, 2007, p. 73).

Resoluteness brings the self right into its being together with things at hand, actually taking care of them, and pushes it toward concerned being-with with others... the resoluteness towards itself first brings Dasein to the possibility of letting others who are with it “be” in their ownmost potentiality-of-being, and also discloses that potentiality in concern which leaps ahead and frees. Resolute Dasein can become the “conscience” of others... the essence of this

being is its existence. Resoluteness “exists” only as a resolution that projects itself understandingly... letting oneself be summoned out of one’s lostness in the they. (Heidegger, 2010, p. 285)

In the context of this study, in the caring for their child with severe multiple disability the mothers come to understand themselves and their possibility of being who they are, and to ‘be’ their own potential. When the mothers realise this in certain mothering moments they leap ahead, and free themselves in the moment. It is during these times that joy is often experienced.

For the mothers of young children with severe disability, coming to acquiesce and resoluteness is from the deep transitioning that has occurred in becoming a mother, doing mothering, and always ‘being a mother’; enmeshed with the experience of the salient ‘coming to terms’ with the severeness of the disability and living their own ‘normal’.

resoluteness is not a voluntaristic ideal, but is better understood as an ideal of humility, wonderment, and self-knowledge. Moreover, as I hope to show, though in an admittedly provisional manner, resoluteness makes possible the transformation of Being-with Others in an ethical direction... Heidegger's existential ideal of resoluteness lies in the power of acquiescence to affect an almost alchemical transformation of Dasein's existence. Instead of calculating its way out of inauthentic selfishness, Dasein must instead heed the silent call of conscience, and humbly submit to the mystery of its own Being. (Crowe, 2001, p. 226)

In other words as the mothers come to acknowledge their strengths, they also come to being comfortable and competent in their world with others.

A truly satisfying occupational life is one that is grounded in the value such a life embodies rather than merely the desires we harbor to lead such a life, or our steadfastness in maintaining balance in all that we do of an occupational nature, or our capacity to overcome the difficulties our various occupational pursuits pose. (Morgan, 2010, p. 222)

Coming to acquiescence in their roles as mothers of a young child with severe multiple disability enables these mothers to submit to their being, and their Dasein.

## **Strengths and Limitations**

Despite the small size of the study, the researcher was able to accumulate powerful and deeply intense narratives from the mothers. The richness in the data was only possible from the depth of sharing that was achieved with each participant. As a novice researcher I prepared thoroughly for the interviews, and perhaps my background in conducting interviews for occupational therapy contexts allowed me to relax into engagement with the mothers. The sharing did come freely, so one can assume that the mothers were able to feel comfortable in my presence and allow me to hear their everydayness and perspectives. Two of the four interviews were conducted via SKYPE and this allowed the participants to engage with me on a slightly less intense level of communicative interaction. The medium of real time video and audio could potentially have enabled an artificial confidence and detracted slightly from the actual and real intimacy in the conversational content of the interviews.

Interpretative research has a number of limitations as a method of finding meaning in the lived experience of mothering a young child with severe multiple disability. As the narratives of the experience were gained during open interviews with participants, the way in which I read, and interpreted their words, may completely differ to how another may interpret the meaning in the experiences. My experiences and the lenses through which I see the world are mine only, and the way I encounter phenomenon is influenced by my previous encounters in and of my world. There has however, been robust discussion of these research findings with two research supervisors; my interpretations on the narratives have been thoroughly examined and questioned, the transcripts and audio of interviews have been deeply revised for true reflective accuracy. It is my expectation that mothers of children with severe disability will receive and read these research findings and find within them sameness in their own experience.

The greatest limiting factor of this research is the small size of the study. It was very unfortunate that despite widening the search for participants, and using multiple agencies to recruit potential participants, only five mothers came forward that met the criteria for the study and, of the five, one potential participant decided not to be involved. Given these small numbers gaining a wide range of cultures was difficult.

Three of the participants were New Zealand European, although one participant identified as Māori, which was beneficial to give the research depth.

Interestingly, I did receive a large number of emails from parents of children with severe multiple disability whose children were too old to fit the inclusion criteria. From the literature search it was evident that research into children aged three to seven years was lacking, particularly the pre-school age range. This could give strength to the research findings in the sense that mothering in this age range is very burdensome. Mothers could be in one or more of the destinations on the mothering journey, and if they have not come to acquiescence, or they were not in acquiescence at the time of seeing my research flyer, then they likely would not be prepared to discuss the difficulties (challenges and visibility) of mothering a young child with severe multiple disability. The children mentioned in this study were in the middle to upper end of the requested age range, two participants were five years old, one was six and one was seven years old. For mothers of children under five years of age, they may be so consumed by the doing of mothering in its everydayness that participating in a research project may seem like adding another burden that will only add stress to their already full and strained lives. The developmental milestone of being enrolled and attending school may be a catalyst to a mother becoming acquiescent, or is it simply that this frees a mother to have available time for engaging in alternative interests, such as participating in research. The other potential truth maybe that mothers of children under five years of age with severe multiple disability could still be so immersed in coming to terms with the disability and mourning the perfect child that they had imagined.

### **Trustworthiness of the Study**

According to Koch (2006) credibility is explicit when the researcher gives thorough descriptions and interpretations throughout the research process. Credibility of research refers not only to the description of the phenomenon, but to the faithfulness of the researcher to the actual research question (Koch & Harrington, 1998) and fair representation of participants views (F. Ryan, Coughlan, & Cronin, 2007). In this research project credibility is evidenced by; the interview question outline, demographic information pertaining to participants and their children, use of reflective field journals, providing participants with interview narratives for their feedback and

verification, along with discussion with research supervisors as data was interpreted and themes emerged, and use of the thick description supplied in interviews by participants in the writing of the findings chapters. Prolonged engagement with participants in interviews, and purposive sampling was conducted to present diversity within the participant group. Use of frequent debriefing sessions with research supervisors and scrutiny throughout the research process allowed my interpretations to be challenged and this afforded further insights to the research themes (Shenton, 2004).

Transferability is described as the fittingness of the research (Koch, 2006) and refers to the applicability of the study findings being usable in other contexts and meaningful to those other than the research participants (F. Ryan et al., 2007). Transferability within qualitative research is a somewhat contentious subject. Shenton (2004) proposed that perhaps it detracts from the importance of context in qualitative design and reflection of multiple realities. In contrast, Green and Thorogood (2004) described the importance of conceptual knowledge provided by qualitative research in that it can be beneficial for health practitioners to 'think with'. Wright-St Clair (2015) emphasised that "even though interpretive phenomenology is not applied research it should lead to potentially useful practice implications" (p. 64). The research findings have provided new insights into mothering a young child with severe multiple disability that will assist health or education professional to gain greater insight into this vital and yet little known phenomenon. It is important that professionals working with these children and families would draw on this knowledge when engaging and forming relationships with mothers of children with severe multiple disability. In particular the mindfulness on requests for time, requests which will add to a mothers work load, and detract from the transformative process that a mother needs to undertake in 'being a mother'.

The appropriateness and congruency of research is vital in determining its trustworthiness (Wright-St Clair, 2015). At each stage of the research process it must be evident what is happening, how choices are made, and reasoning provided for conclusions (F. Ryan et al., 2007). A strength in this hermeneutic phenomenological inquiry into the 'lived experience of mothering a young child with severe multiple disability' is the congruency with the methodology and methods that were carried out.

It is clear that the ontological, epistemological and axiological positions, through to implementation, analysis of data (hermeneutic interpretation, identification of themes, member checking and supervisor scrutiny), presentation of findings (use of thick description, hermeneutic interpretation) and discussion of findings (evaluating the inquiry of the phenomenon) have been thoughtfully completed.

Confirmability of qualitative research is a criterion that is reliant on the previous criteria being met, and sets the record straight that “as far as possible the work’s findings are the result of the experiences and ideas of the informants, rather than the characteristics and preferences of the researcher” (Shenton, 2004, p. 72). This research was conducted with the majority of the literature review pertaining to mothering, being carried out at the end the research process. The findings, Chapters Four, Five and Six, were completed before the literature chapter had commenced.

The overarching trustworthiness principle integral from the onset of the research to the final report according to F. Ryan et al., (2007) is goodness. The phenomenon of interest as experienced by the participants and the participants themselves should be respected. Symthe and Giddings (2007) described the importance of “integrity...attention to detail... the manner of your interpretation... and good-fit” when conducting good qualitative research (p. 55). From my perspective the goodness of this research is evidenced by the quality of the data gathered. The true extent, to which it can be deemed good, however, will be when the participants read the summary of findings, and reflect. It will also come to be considered ‘good’ when it is thought provoking to other health care and educational professionals, and potentially influences their understanding and future interactions with mothers of a young child with severe multiple disability.

## **The Implications in this Study’s Findings**

### **For mothers**

This research has explored the lived experience of mothering a young child with severe multiple disability, and it is a complex and deeply transformative process. The implications of revealing this complexity may assist mothers of children with severe disability to feel less isolated in their own experience, in a sense the research findings may enable these mothers to feel validated, and that shifting and being in different

modes of mothering at various moments in time, or all modes at the same time is also experienced by mothers with a similar journey to theirs. I would also hope that that mothers of children with severe multiple disability may feel empowered by the research, that coming to acquiescence is a monumental achievement, and recognising the joy in their mothering can provide them strength and resolute endurance.

This research has also identified the parallel journey that all mothers encounter aspects of identified on the mothering journey; however the journey for mothers of typically developing children is one where they do not have the experience of forced limitations resultant from severe disability, the increased burden, loss of the imagined child, altered doing (extreme caring/caregiving), lack of reciprocity and intensification in mothering. The mothers of typically developing children are also not privy to the intensified joy, that the mother of a young child with severe multiple disability will experience (if they come to being in acquiescence). Perhaps the knowledge that all mothers are different yet we all come to mothering via the same influences will be of comfort? The message that we can all create from this transformative experience our own 'normal' will assist all mothers to appreciate variance in our mothering, and work towards dispelling this myth of the 'perfect mother'. The picture of the 'ideal mother' that is held over mothers' heads for unrealistic attainment, only serves to divide us, add to our burden, exaggerate our guilt. Without it mothers may be able to come to acquiesce with more ease, with confidence in 'being a mother'.

### **Health and disability professionals**

For health and disability professionals this research provides information on a rarely considered yet vital life role. These findings have identified that professionals can both add and detract in the experience of mothering a young child with severe multiple disability. Practitioners may be guided by the findings to assist mothers of young children with severe multiple disability to transition and come to being acquiescent. Occupational therapists, in particular, might positively assist mothers to come to terms with the everydayness and 'being a mother'; assisting mothers to come to positive role identity by way of fostering competence in the becoming, doing and belonging.

Understanding the mothering journey and deep transitioning of motherhood may also assist health and disability professionals to recognise the uniqueness of mothers, and

to create relationships which will support mothers. Providing information that will aid mothers seeking assistance to be supported, find relationships with other mothers of children with severe multiple disability, provide mechanisms to assist with the lack of reciprocity, and find the joy in the mothering.

Health and education professionals should not assume that mothers of children with severe multiple disability are stuck in chronic sorrow or a cycle of grief or that there is a fixed end point or age when mothers come to favourable affirmation in mothering. Each day will present with what it is, and 'being a mother' in the everydayness can be situated at any point or several points on the mothering journey.

### **Further Research**

The findings of this research suggest that further investigation into the mothering journey and its influences would be pertinent. In particular, the influence on mothers with children with severe multiple disability and how lack of reciprocity in 'being a mother' influences this role and the relationships with their children. It is evident in the literature, and in this study, that the experience of mothering children aged three to five years is missing and may hold previously unknown or considered knowledge in this phenomenon. A large longitudinal study of mothers of children with severe multiple disability may also give new insights along the mothering journey.

Aotearoa New Zealand has one of the most ethnically diverse populations in the world due to immigration. It is an excellent population on which to gain knowledge into the influence of ethnicity and culture on mothering practices.

An action research project designed to provide occupational therapy support to mothers of young children with severe multiple disability, with the aim being to accumulate the four requisites to enable 'being acquiescent' could be an interesting area for future focus.

### **Conclusion**

***We have learned humility and to ask for help. We have an incredible sense of community that is very strong. Our priorities have changed, we whittled them down to what is really important, it's about love. It's part of the journey and it makes it great. What you can cope with gets enlarged and you get stronger. It's amazing what becomes normal and OK. (Callander, 2014, p. 92)***

The meaning in the lived experience of mothering a young child with severe multiple disability is the all-encompassing premise; 'being a mother'. 'Being a mother' is a deeply transformative process that is highly influenced by the duality of the joy and burden of mothering, from conception to death. Mothering a young child with severe multiple disability is a life long journey in which mothers come to terms with the everydayness of mothering in their own unique way along the journey of mothering. The mothering journey arranges modes of being in which a mother will be situated at any given time whilst 'being a mother'. The journey represents; '*being visible*' the consciousness of becoming, '*being challenged*' the perseverance in doing, and '*being acquiescent*' the basis for belonging in mothering a young child with severe multiple disability. Coming to terms with 'being a mother' suggests the mother of a young child with severe multiple disability may come to 'being acquiescent', and experience modes of being in the everyday as being accommodating, being supported, being a supporter and being cognisant. These four sub-themes illuminate how mothers come to reluctant acceptance of the burden, of the disability and the constraints it enforces. When a mother of a young child with severe multiple disability comes to acquiescence it may open the way to more fully experiencing the joy in 'being a mother'; a joy that announces her own uniquely normal life journey.

## References

- Ahmann, E. (1994). Family care: Shifting orientation. *Pediatric Nursing, 20*(2), 113-117.
- Allen, D. G. (1995). Hermeneutics: Philosophical traditions and nursing practice research. *Nursing Science Quarterly, 8*(4), 174-182.
- Alvarez McHatton, P., & Correa, V. (2005). Stigma and discrimination: Perspectives from Mexican and Puerto Rican mothers of children with special needs. *Topics in Early Childhood Special Education, 25*(3), 131-142.
- Anderson, L. S. (2009). Mothers of children with special health care needs: Documenting the experience of their children's care in the school setting. *The Journal of School Nursing, 25*(5), 342-351. doi:10.1177/10598405093314146
- Andricksen, R. (2009). Under the weather. *Little Treasures: Pregnancy and Birth*.
- Araujo, C. (2012). A mother's blessing. *PN Magazine, 66*(5), 66-67.
- Arendell, T. (2000). Conceiving and investigating motherhood: The decade's scholarship. *Journal of Marriage and the Family, 62*(4), 1192-1207.
- Babich, B. E. (Ed.). (1995). *From phenomenology to thought, errancy, and desire: Essays in honor of William J. Richardson, S. J.* Dordrecht, The Netherlands: Kluwer Academic Publishers.
- Bagnato, S. J. (2005). The authentic alternative for assessment in early intervention: An emerging evidence-based practice. *Journal of Early Intervention, 28*(17), 17-22. doi:10.1177/105381510502800102
- Bagnato, S. J., Blair, K., Slater, J., McNally, R., Mathews, J., & Minzenberg, B. (2004). Developmental healthcare partnerships in inclusive early childhood intervention settings. *Infants and Young Children, 17*(4), 301-317.
- Barbosa, M. A., Chaud, M. N., & Gomes, M. M. (2008). Experiences of mothers of disabled children: A phenomenological study. *Acta Paulista de Enfermagem, 21*(1), 46-52.
- Barclay, L., Everitt, L., Rogan, F., Schmied, V., & Wyllie, A. (1997). Becoming a mother: An analysis of women's experience of early motherhood. *Journal of Advanced Nursing, 25*(4), 719-728.
- Barg, C. J., Armstrong, B. D., Hetz, S. P., & Latimer, A. E. (2010). Physical disability, stigma, and physical activity in children. *International Journal of Disability, Development and Education, 57*(4), 371-382. doi:10.1080/1034912x.2010.524417

- Barlow, C. A., & Cairns, K. V. (1997). Mothering as a psychological experience: A grounded theory exploration. *Canadian Journal of Counselling, 31*(3), 232-247.
- Barrett, J., & Fleming, A. S. (2011). Annual research review: All mothers are not created equal: Neural and psychobiological perspectives on mothering and the importance of individual differences. *Journal of Child Psychology and Psychiatry, and Allied Disciplines, 52*(4), 368-397. doi:10.1111/j.1469-7610.2010.02306.x
- Black Mosen, R. (1999). Mothers' experiences of living worried when parenting children with spina bifida. *Journal of Pediatric Nursing, 14*(3), 127-163.
- Blanchette, O. (2003). *Philosophy of Being: A reconstructive Essay in Metaphysics*. Washington, DC: The Catholic University of America Press.
- Bowen, J. R., Gibson, F. L., & Hand, P. J. (2002). Educational outcome at 8 years for children who were born extremely prematurely: A controlled study. *Journal of Paediatrics and Child Health, 38*(5), 438-444. doi: 10.1046/j.1440-1754.2002.00039.x
- Broberg, M. (2011). Expectations of and reactions to disability and normality experienced by parents of children with intellectual disability in Sweden. *Child: Care, Health & Development, 37*(3), 410-417. doi:10.1111/j.1365-2214.2010.01198.x
- Bruce, E., & Schultz, C. (2002). Non-finite loss and challenges to communication between parents and professionals. *British Journal of Special Education, 29*(1), 9-13.
- Brydon, S. G. (2009). Men at the heart of mothering: Finding mother in Finding Nemo. *Journal of Gender Studies, 18*(2), 131-146. doi:10.1080/09589230902812448
- Burch, M. (2010). Death and deliberation: Overcoming the decisionism critique of Heidegger's practical philosophy. *Inquiry: An Interdisciplinary Journal of Philosophy, 53*(3), 211-234. doi:10.1080/00201741003784531
- "Burden" (n.d.). In *The Collins English Dictionary*. Retrieved from <http://www.collinsdictionary.com/dictionary/english/burden>
- Burns, N., & Grove, S. K. (1997). *The practice of nursing research: Conduct, critique and utilization* (3<sup>rd</sup> ed.). Philadelphia, PA: W.B. Saunders Company.
- Caelli, K. (2001). Engaging with phenomenology: Is it more of a challenge than it needs to be? *Qualitative Health Research, 11*(2), 273-281.
- Callander, R. (2014). *Super power baby project*. Timaru, New Zealand: Evie's Book Club Limited.

- Carpenter, B., Cockbill, B., Egerton, J., & English, J. (2010). Children with complex learning difficulties and disabilities: Developing meaningful pathways to personalised learning. *The SLD Experience*, 58(1), 3-10.
- Case-Smith, J., & Nastro, M. (1993). The effect of occupational therapy intervention on mothers of children with cerebral palsy. *American Journal of Occupational Therapy*, 47(9), 811-817.
- Casinader, J. (2015, April 11). Tough love. *Canvas Magazine*, 14-17.
- Craig, G. M., & Scambler, G. (2006). Negotiating mothering against the odds: Gastrostomy tube feeding, stigma, governmentality and disabled children. *Social Science & Medicine*, 62(5), 1115-1125. doi:10.1016/j.socscimed.2005.07.007
- Cosgrove, S. (2002). *Leo the lop*. New York, NY: Price Stern Sloan. (Original work published 1978)
- Critchlely, S. (2009, June). *Being and time part 4: Thrown into this world*. Retrieved from <http://www.theguardian.com/commentisfree/belief/2009/jun/29/religion-philosophy>
- Crotty, M. (1998). *The foundations of social research: Meaning and perspective in the research process*. NSW, Australia: Allen and Unwin.
- Crowe, B. D. (2006). *Heidegger's religious origins: Destruction and authenticity*. Indiana University Press.
- Darvill, R., Skirton, H., & Farrand, P. (2010). Psychological factors that impact on women's experiences of first-time motherhood: A qualitative study of the transition. *Midwifery*, 26(3), 357-366. doi:10.1016/j.midw.2008.07.006
- Davis, K., & Gavidia-Payne, S. (2009). The impact of child, family, and professional support characteristics on the quality of life in families of young children with disabilities. *Journal of Intellectual and Developmental Disability*, 34(2), 123-162. doi:10.1080/13668250902874608
- Del Fabro Smith, L., Suto, M., Chalmers, A., & Backman, C. L. (2011). Belief in doing and knowledge in being mothers with arthritis. *OTJR: Occupation, Participation and Health*, 31(1), 40-48. doi:10.3928/15394492-20100222-01
- Dreyer, P. S., Steffensen, B. F., & Pedersen, B. D. (2010). Living with severe physical impairment, Duchenne's muscular dystrophy and home mechanical ventilation. *International Journal of Qualitative Studies in Health and Well-being*, 5(3), 1-9. doi:10.3402/qhw.v5i3.5388

- du Toit, C., Coetzee, Z., & Beeton, H. (2013). Mothers' experiences of caring for a child with severe brain injury in a disadvantaged community in Cape Flats. *South African Journal of Occupational Therapy*, 43(2), 17-22.
- Dunn, W. (2011). *Best practice occupational therapy: For children and families in community settings* (2<sup>nd</sup> ed.). Thorofare, NJ: SLACK Incorporated.
- Ekas, N. V., Lickenbrock, D. M., & Whitman, T. L. (2010). Optimism, social support, and well-being in mothers of children with autism spectrum disorder [Research Support, N.I.H., Extramural]. *Journal of Autism and Developmental Disorders*, 40(10), 1274-1284. doi:10.1007/s10803-010-0986y
- Eker, L., & Handan Tüzün, E. (2004). An evaluation of quality of life of mothers of children with cerebral palsy. *Disability and Rehabilitation*, 26(23), 1354-1359.
- Elvin-Nowak, Y. (1999). The meaning of guilt: A phenomenological description of employed mothers' experiences of guilt. *Scandinavian Journal of Psychology*, 40(1), 73-83.
- Emerson, L. (2007). The inside story. *Little Treasures: Pregnancy and Birth*.
- Esdale, S. A., Farrell, E. A., & Olson, J. A. (2004). Anticipating occupations of mothering and the development of agency. In S. A. Esdale & J. A. Olson (Eds.), *Mothering occupations: Challenge, agency, and participation* (pp. 3-23). Philadelphia, PA: F.A. Davis Company.
- Esdale, S. A., & Olson, J. A. (Eds.). (2004). *Mothering occupations: Challenge, agency, and participation*. Philadelphia, PA: F.A. Davis Company.
- Farber, R. S. (2004). Experience of mothers with disabilities: Learning from their voice. In S. A. Esdale & J. A. Olson (Eds.), *Mothering occupations: Challenge, agency, and participation* (pp. 193-212). Philadelphia, PA: F.A. Davis Company.
- Feldman, R. (2007). Parent-infant synchrony and the construction of shared timing; physiological precursors, developmental outcomes, and risk conditions. *Journal of Child Psychology and Psychiatry, and Allied Disciplines*, 48(3-4), 329-354. doi:10.1111/j.1469-7610.2006.01701.x
- Forcey, L. R. (1994). Feminist perspectives on mothering and peace. In E. N. Glenn, G. Chang, & L. R. Forcey (Eds.), *Mothering: Ideology, experience, and agency* (pp. 355-375). New York, Routledge.
- Francis-Connolly, E. (1998). It never ends: Mothering as a lifetime occupation. *Scandinavian Journal of Occupational Therapy*, 5, 149-155.
- Francis-Connolly, E. (2000). Towards an understanding of mothering: A comparison of two motherhood stages. *American Journal of Occupational Therapy*, 54(3), 281-289.

- Francis-Connolly, E. (2004). Mothering across the lifespan. In S. A. Esdaile & J. A. Olson (Eds.), *Mothering occupations: Challenge, agency, and participation* (pp. 153-169). Philadelphia, PA: F.A. Davis Company.
- Gartstein, M. A., Crawford, J., & Robertson, C. D. (2008). Early markers of language and attention: Mutual contributions and the impact of parent-infant interactions. *Child Psychiatry and Human Development, 39*(1), 9-26. doi:10.1007/s10578-007-0067-4
- Glasscock, R. (2000). A phenomenological study of the experience of being a mother of a child with cerebral palsy. *Pediatric Nursing, 26*(4), 407-410.
- Graungaard, A. H., Andersen, J. S., & Skov, L. (2011). When resources get sparse: A longitudinal, qualitative study of emotions, coping and resource-creation when parenting a young child with severe disabilities. *Health, 15*(2), 115-136. doi:10.1177/1363459309360794
- Green, J., & Thorogood, N. (2004). *Qualitative methods for health research*. London, England: SAGE Publications.
- Green, S. E. (2002). Mothering Amanda: Musings on the experience of raising a child with cerebral palsy. *Journal of Loss & Trauma, 7*(1), 21-34. doi:10.1080/108114402753344463
- Green, S. E. (2003). "What do you mean 'what's wrong with her?': Stigma and the lives of families with children with disabilities. *Social Science & Medicine, 57*(8), 1361-1374. doi:10.1016/S0277-9536(02)00511-7
- Green, S. E. (2007). "We're tired, not sad": Benefits and burdens of mothering a child with a disability. *Social Science & Medicine, 64*(1), 150-163. doi:http://dx.doi.org/10.1016/j.socscimed.2006.08.025
- Griffin, S. D., & Price, V. J. (2000). Living with lifting: Mothers' perceptions of lifting and back strain in childcare. *Occupational Therapy International, 7*(1), 1-20.
- Grue, L., & Tafjord Laerum, K. (2002). Doing motherhood: Some experiences of mothers with physical disabilities. *Disability & Society, 17*(6), 671-683.
- Guendouzi, J. (2006). The guilt thing: Balancing domestic and professional roles. *Journal of Marriage and Family, 68*(4), 901-909.
- Guralnick, M. J. (2000). An agenda for change in early childhood inclusion. *Journal of Early Intervention, 23*(4), 213-222.
- Hammell, K. W. (2004). Dimensions of meaning in the occupations of daily life. *Canadian Journal of Occupational Therapy, 71*(5), 293-305.
- Harman, G. (2007). *Heidegger explained: From phenomenon to thing*. Peru, IL: Open Court Publishing Company.

- Harwood, K., McLean, N., & Durkin, K. (2007). First-time mothers' expectations of parenthood: What happens when optimistic expectations are not matched by later experiences? *Developmental Psychology, 43*(1), 1-12. doi:10.1037/0012-1649.43.1.1
- Hayes, S. A., & Watson, S. L. (2013). The impact of parenting stress: A meta-analysis of studies comparing the experience of parenting stress in parents of children with and without autism spectrum disorder. *Journal of Autism and Developmental Disorders, 43*(3), 629-642. doi:10.1007/s10803-012-1604y
- Heaman, D. J. (1995). Perceived stressors and coping strategies of parents who have children with developmental disabilities: A comparison of mothers with fathers. *Journal of Pediatric Nursing, 10*(5), 311-320.
- Heidegger, M. (1959). *On the way to language*. New York, NY: Harper and Row Publishers.
- Heidegger, M. (1971). *Poetry, language and thought* (A. Hofstadter, Trans.). New York, NY: HarperCollins Publishers.
- Heidegger, M. (2000). *Being and time* (John Macquarrie & Edward Robinson, Trans.). London, England: Blackwell Publishing
- Heidegger, M. (2010). *Being and time*. Albany, NY: State University of New York Press.
- Heiman, T. (2002). Parents of children with disabilities: Resilience, coping, and future expectations. *Journal of Developmental and physical disabilities, 14*(2), 159-171.
- Hitch, D., Pepin, G., & Stagnitti, K. (2014). In the footsteps of Wilcock, part one: The evolution of doing, being, becoming, and belonging. *Occupational Therapy in Health Care, 28*(3), 231-246. doi:10.3109/07380577.2014.898114
- Horne, J., Corr, S., & Earle, S. (2005). Becoming a mother: Occupational change in first time motherhood. *Journal of Occupational Science, 12*(3), 176-183.
- Hostler, S. L. (1991). Family-centered care. *Pediatric Clinics of North America, 38*(6), 1545-1559.
- Hayward, J. (2014). *Principles of the Treaty of Waitangi - nga matapono o te tiriti*. Retrieved from <http://www.teara.govt.nz/en/principles-of-the-treaty-of-waitangi-nga-matapono-o-te-tiriti>
- Jackson, D., & Mannix, J. (2004). Giving voice to the burden of blame: A feminist study of mothers' experiences of mother blaming. *International Journal of Nursing Practice, 10*(4), 150-158.

- James, C., & Chard, G. (2010). A qualitative study of parental experiences of participation and partnership in an early intervention service. *Infants and Young Children, 23*(4), 275-285.
- Janghorban, R., Roudsari, R. L., & Taghipour, A. (2014). Skype interviewing: The new generation of online synchronous interview in qualitative research. *International Journal of Qualitative Studies on Health and Well-being, 9*(24152), 1-3. doi:10.3402/qhw.v9.24152
- Kasari, C., Gulsrud, A. C., Wong, C., Kwon, S., & Locke, J. (2010). Randomized controlled caregiver mediated joint engagement intervention for toddlers with autism. *Journal of Autism and Developmental Disorders, 40*(9), 1045-1056. doi:10.1007/s10803-010-0955-5
- Kearney, P. M., & Griffin, T. (2001). Between joy and sorrow: Being a parent of a child with developmental disability. *Journal of Advanced Nursing, 34*(5), 582-592.
- Kellegrew, D.H. (2000). Constructing daily routines: A qualitative examination of mothers with young children with disabilities. *American Journal of Occupational Therapy, 54*(3), 525-259.
- Kielhofner, G. (1995a). Environmental influences on occupational behaviour. In G. Kielhofner (Ed.), *A model of human occupation: Theory and application*. (2<sup>nd</sup> ed., pp. 91-110). Baltimore, MD: Williams & Wilkins.
- Kielhofner, G. (1995b). Habituation subsystem. In G. Kielhofner (Ed.), *A model of human occupation: Theory and application* (2<sup>nd</sup> ed., pp. 63-83). Baltimore, MD: Williams & Wilkins.
- Kilic, D., Gencdogan, B., Bag, B., & Arican, D. (2013). Psychosocial problems and marital adjustments of families caring for a child with intellectual disability. *Sexuality and Disability, 31*(3), 287-296. doi:10.1007/s11195-013-9308-6
- Kim, H. W., Greenberg, J. S., Seltzer, M. M., & Krauss, M. W. (2003). The role of coping in maintaining the psychological well-being of mothers of adults with intellectual disability and mental illness. *Journal of Intellectual Disability Research, 47*(4), 313-327.
- Koch, T. (2006). Establishing rigour in qualitative research: the decision trail. *Journal of Advanced Nursing, 53*(1), 91-100.
- Koch, T., & Harrington, A. (1998). Reconceptualising rigour: the case for reflexivity. *Journal of Advanced Nursing, 28*(4), 882-890.
- Landsman, G. (2005). Mothers and models of disability. *Journal of Medical Humanities, 26*(2/3), 121-139. doi:10.1007/s10912-005-2914-2
- Lala, A. P., & Kinsella, E. A. (2011). A phenomenological inquiry into the embodied nature of occupation at end of life. *Canadian Journal of Occupational Therapy, 78*(4), 246-254.

- Large, W. (2008). *Heidegger's being and time*. Edinburgh, Scotland: Edinburgh University Press.
- Larson, E. A. (2000). Mothering: Letting go of the past ideal and valuing the real. *American Journal of Occupational Therapy*, 54(3), 249-251.
- Law, M., Darrah, J., Pollock, N., King, G., Rosenbaum, P., Russell, D., ... Watt, J. (1998). Family-centred functional therapy for children with cerebral palsy: An emerging practice model. *Physical & Occupational Therapy in Pediatrics*, 18(1), 83-102.
- Leach, P. (1985). *Baby and child: From birth to age five*. Middlesex, England: Penguin Books Ltd.
- Lee, L. C., Harrington, R. A., Louie, B. B., & Newschaffer, C. J. (2008). Children with autism: Quality of life and parental concerns. *Journal of Autism and Developmental Disorders*, 38(6), 1147-1160. doi:10.1007/s10803-007-0491-0
- Leiter, V. (2004). Dilemmas in sharing care: Maternal provision of professionally driven therapy for children with disabilities. *Social Science & Medicine*, 58(4), 837-849. doi:10.1016/S0277-9536(03)00258-2
- Leung, C. Y. S., & Li-Tsang, C. W. P. (2003). Quality of life of parents who have children with disabilities. *Hong Kong Journal of Occupational Therapy*, 13(1), 19-24.
- Lim, F., Downs, J., Li, J., Bao, X., & Leonard, H. (2013). Caring for a child with severe intellectual disability in China: The example of Rett syndrome. *Disability & Rehabilitation*, 35(4), 343-351. doi:10.3109/09638288.2012.715720
- Lindblad, B., Holritz-Rasmussen, B., & Sandman, P. (2007). A life enriching togetherness - meanings of informal support when being a parent of a child with disability. *Scandinavian Journal of Caring Sciences*, 21(2), 238-246.
- Llewellyn, G., Thompson, K., & Whybrow, S. (2004). Activism as a mothering occupation. In S. A. Esdaile & J. A. Olson (Eds.), *Mothering occupations: Challenge, agency, and participation* (pp. 282-305). Philadelphia, PA: F.A. Davis Company.
- Mackey, S., & Goddard, L. D. (2006). The experience of health and wellness in mothers of young children with intellectual disabilities. *Journal of Intellectual Disabilities*, 10(4), 305-315.
- Malacrida, C. (2009). Performing motherhood in a disablist world: Dilemmas of motherhood, femininity and disability. *International Journal of Qualitative Studies in Education*, 22(1), 99-117. doi:10.1080/0951839080251927
- McKay, E. A. (2004). Mothers with mental illness: An occupation interrupted. In S. A. Esdaile & J. A. Olson (Eds.), *Mothering occupations: Challenge, agency, and participation*. Philadelphia, PA: F.A. Davis Company.

- McKay, R. D. (2008). *Observing mothers lifting their children in their own home to identify factors which might give rise to musculoskeletal disorders*. Retrieved from Auckland University of Technology Scholarly Commons Dissertations and Theses.
- McKeever, P., & Miller, K. (2004). Mothering children who have disabilities: A Bourdieusian interpretation of maternal practices. *Social Science & Medicine*, 59(6), 1177-1191. doi:10.1016/j.socscimed.2003.12.023
- Meeham, R. D. (2005). Mothering a 3 to 6 year old child with hemiparesis. *Journal of Neuroscience Nursing*, 37(5), 265-271.
- Miller, A. C., Gordon, R. M., Daniele, R.J., & Diller, L. (1992). Stress, appraisal, and coping in mothers of disabled and nondisabled children. *Journal of Pediatric Psychology*, 17(5), 587-605.
- Ministry for Culture and Heritage. (2014, August 5). *New Zealand History*. Retrieved March 23, 2015, from <http://www.nzhistory.net.nz/politics/treaty-of-waitangi>
- Ministry of Education. (2013). *Specialist service standards*. Wellington, New Zealand: Author.
- Minnes, P., Perry, A., & Weiss, J. A. (2014). Predictors of distress and well-being in parents of young children with developmental delays and disabilities: The importance of parent perceptions. *Journal of Intellectual Disability Research*, 59(6), 551-560. doi:10.1111/jir.12160
- Morgan, W. J. (2010). What, exactly, is occupational satisfaction? *Journal of Occupational Science*, 17(4), 216-223.
- Moore, L. A. (2005). *The lived experience of being a mother of a child with severe cerebral palsy*. (Unpublished Master's thesis). Medical College of Ohio, Ohio, OH.
- Morse, J. (Ed.). (1991). *Qualitative nursing research: A contemporary dialogue*. Newbury Park, CA: SAGE Publications Inc.
- "*Mother*". (1981) (5<sup>th</sup> ed.). Oxford, England: Oxford University Press.
- Murdock, K. (2012). *What it means to be a mother*. Retrieved April 4, 2015, from <http://www.everydayfamily.com>
- Nelson, A. (2003). Transition to motherhood. *Journal of Obstetric, Gynecologic and Neonatal Nursing*, 32(4), 465-477. doi:10.1177/0884217503255199
- Noojin, A., & Wallander, J. L. (1997). Perceived problem-solving ability, stress, and coping in mothers of children with physical disabilities: Potential cognitive

influences on adjustment. *International Journal of Behavioral Medicine*, 4(4), 415-432.

Oberman, Y., & Josselson, R. (1996). Matrix of tensions: A model of mothering. *Psychology of Women Quarterly*, 20(3), 341-359.

Olson, J. A. (2004). Mothering co-occupations in caring for infants and young children. In S. A. Esdaile & J. A. Olson (Eds.), *Mothering occupations: Challenge, agency and participation*. Philadelphia, PA: F.A. Davis Company.

Palisano, R., Rosenbaum, P., Bartlett, D., & Livingston, M. (2007). GMFCS – E & R Gross motor function classification system: Expanded and revised. Retrieved from McMaster University CanChild website [https://www.canchild.ca/en/measures/gmfcs\\_expanded\\_revised.asp](https://www.canchild.ca/en/measures/gmfcs_expanded_revised.asp)

Paster, A., Brandwein, D., & Walsh, J. (2009). A comparison of coping strategies used by parents of children with disabilities and parents of children without disabilities. *Research in Developmental Disabilities*, 30(6), 1337-1342. doi:10.1016/j.ridd.2009.05.010

Patrick-Ott, A., & Ladd, L. D. (2010). The blending of Boss's concept of ambiguous loss and Olshansky's concept of chronic sorrow: A case study of a family with a child who has significant disabilities. *Journal of Creativity in Mental Health*, 5, 74-86.

Phoenix, A., Woollett, A., & Lloyd, E. (Eds.). (1991). *Motherhood: meanings, practices, and ideologies*. Thousand Oaks, CA: Sage

Pierce, D. (2000). Maternal management of the home as a developmental play space for infants and toddlers. *American Journal of Occupational Therapy*, 54(3), 290-299.

Pierce, D., & Marshall, A. (2004). Maternal management of home space and time to facilitate infant/toddler play and development. In S. A. Esdaile & J. A. Olson (Eds.), *Mothering occupations: Challenge, agency, and participation* (pp. 73-94). Philadelphia, PA: F.A. Davis Company.

Piggot, J., Paterson, J., & Hocking, C. (2002). Participation in home therapy programs for children with cerebral palsy: A compelling challenge. *Qualitative Health Research*, 12(8), 1112-1129. doi:10.1177/104973202129120476

Pillay, D., Girdler, S., Collins, M., & Leonard, H. (2012). "It's not what you were expecting, but it's still a beautiful journey": The experience of mothers of children with Down Syndrome. *Disability and Rehabilitation*, 34(18), 1501-1510. doi:10.3109/09638288.2011.650313

Pischke, M. E. (1993). Parenting with a disability. *Sexuality & Disability*, 11(3), 207-209.

Polatajko, H. J., Backman, C., Baptiste, S., Davis, J., Eftekhari, P., Harvey, A., ... Connor-Schisler, A. (2007). Human occupation in context. In E. A. Townsend & H. J.

Polatajko (Eds.), *Enabling occupation II: Advancing an occupational therapy vision for health, well-being, and justice through occupation* (pp. 37-62). Ontario, Canada: CAOT Publications ACE.

- Price, P., & Miner Stephenson, S. (2009). Learning to promote occupational development through co-occupation. *Journal of Occupational Science, 16*(3), 180-186. doi:10.1080./14427591.2009.9686660
- Prilleltensky, O. (2003). A ramp to motherhood: The experiences of mothers with physical disabilities. *Sexuality and Disability, 21*(1), 21-47.
- Prilleltensky, O. (2004). My child is not my carer: Mothers with physical disabilities and the well-being of children. *Disability & Society, 19*(3), 209-223.
- q on cbc*. (2009, November 4). *Ian Brown on Q TV* [Video file]. Retrieved from <https://www.youtube.com/watch?v=RgvymstNJJl>
- Raab, D. (1999). *Getting pregnant and staying pregnant: Overcoming infertility and managing your high risk pregnancy*. Alameda, CA: Hunter House Inc Publishers.
- Raghavendra, P., Murchland, S., Bently, M., Wake-Dyster, W., & Lyons, T. (2007). Parents' and service providers' perceptions of family-centred practice in a community-based, paediatric disability service in Australia. *Child: Care, Health & Development, 33*(5), 586-592. doi:10.1111/j1365-2214.2007.00763.x
- Read, J. (2000). *Disability, the family and society: Listening to mothers*. Philadelphia, PA: Open University Press.
- Reed, K., Hocking, C., & Smythe, L. (2010). The interconnected meanings of occupation: The call, being-with, possibilities. *Journal of Occupational Science, 17*(3), 140-149.
- Rebeiro, K. L., Day, D., Semeniuk, B., O'Brien, M., & Wilson, B. (2001). Northern initiative for social action: An occupation based mental health program. *American Journal of Occupational Therapy, 55*(5), 493-500.
- Rosenberg, D. (2003). *The new mothers companion: Care for yourself while you care for your newborn*. Naperville, IL: Sourcebook Inc.
- Ryan, F., Coughlan, M., & Cronin, P. (2007). Step-by-step guide to critiquing research. Part 2: qualitative research. *British Journal of Nursing, 16*(12), 738-744.
- Ryan, S., & Runswick-Cole, K. (2008). Repositioning mothers: Mothers, disabled children and disability studies. *Disability & Society, 23*(3), 199-210. doi:10.1080/09687590801953937
- Samson, A., Tomiak, E., Dimillo, J., Lavigne, R., Miles, S., Choquette, M., ... Jacob, P. (2009). The lived experience of hope among parents of a child with Duchenne

muscular dystrophy: Perceiving the human being beyond the illness. *Chronic Illness*, 5(2), 103-114. doi:10.1177/1742395309104343

- Sanders, M. J., & Morse, J. (2005). The ergonomics of caring for children: An exploratory study. *American Journal of Occupational Therapy*, 59(3), 285-295.
- Scornaienchi, J. M. (2003). Chronic sorrow: One mother's experience with two children with lissencephaly. *Journal of Pediatric Health Care*, 17(6), 290-294. doi:10.1016/S0891-5245(03)00123-8
- Seagram, S., & Daniluk, J. C. (2002). "It goes with the territory": The meaning and experience of maternal guilt for mothers of preadolescent children'. *Women & Therapy*, 25(1), 61-88.
- Seale, C. (1999). *The quality of qualitative research: Introducing qualitative methods*. London, England: SAGE Publications Ltd.
- Seale, C., Gobo, G., Gubrium, J. F., & Silverman, D. (2007). *Qualitative research practice: Concise paperback edition*. London, England: SAGE Publications Ltd.
- Seligman, M., & Darling, R. (2007). *Ordinary families, special children: A systems approach to childhood disability*. (3<sup>rd</sup> ed.). New York, NY: The Guilford Press.
- Shenton, A. K. (2004). Strategies for ensuring trustworthiness in qualitative research projects. *Education for Information*, 22, 63-75.
- Sloper, P., & Turner, S. (1992). Service needs of families of children with severe physical disability. *Child: Care, Health & Development*, 18(5), 259-282.
- Smith, E. W. L. (2003). *The person of the therapist*. Jefferson, NC: McFarland & Company Inc Publishers.
- Smythe, L., & Giddings, L. S. (2007). From experience to definition: Addressing the question 'what is qualitative research?'. *Nursing Praxis in New Zealand*, 23(1), 37-57.
- Stanley, M., & Nayar, S. (2014). Methodological rigour: Ensuring quality in occupational therapy qualitative research. *New Zealand Journal of Occupational Therapy*, 61(1), 6-12.
- Statistics New Zealand (2014, June 17). Living with Disability in New Zealand. Retrieved from Statistics New Zealand website: [http://www.stats.govt.nz/browse\\_for\\_stats/health/disabilities.aspx](http://www.stats.govt.nz/browse_for_stats/health/disabilities.aspx)
- Stern, D. N., Bruschiweiler-Stern, N., & Freeland, A. (1998). *The birth of a mother: How the motherhood experience changes you forever*. New York, NY: Basic Books.

- Stoneman, Z. (2007). Examining the Down syndrome advantage: Mothers and fathers of young children with disabilities. *Journal of Intellectual Disability Research*, 51(12), 1006-1017. doi:10.1111/j.1365-2788.2007.01012.x
- Sutherland, J. A. (2010). Mothering, guilt and shame. *Sociology Compass*, 4(5), 310-321. doi:10.1111/j.1751-9020.2010.00283.x
- Thomas, C. (1997). The baby and the bath water: Disabled women and motherhood in social context. *Sociology of Health & Illness*, 19(5), 622-643.
- van Manen, M. (1990). *Researching the lived experience: Human science for an action sensitive pedagogy*. Ontario, Canada: Althouse Press.
- Voysey Paun, M. (2006). *A constant burden: The reconstitution of family life*. Hampshire, England: Ashgate Publishing Limited.
- Wallander, J. L., & Noojin, A. (1995). Mothers' report of stressful experiences related to having a child with a physical disability. *Children's Health Care*, 24(4), 245-256.
- watchmojo.com. (2009, December 15). *Ian Brown discusses rare genetic disorder -CFC* [Video file]. Retrieved from <https://www.youtube.com/watch?v=EEhEHE-n8-0>
- Weatherly, J. (2012, May 11). 5 quotes about parenthood and disability. [Blog message]. Retrieved from <http://thedcard.net/meet-carly/>
- Wilcock, A. (1993). A theory of the human need for occupation. *Journal of Occupational Science*, 1(1), 17-24.
- Wilcock, A. (1999). Reflections on doing, being and becoming. *Australian Occupational Therapy Journal*, 46(1), 1-11.
- Wilcock, A. (2006). *An occupational perspective of health* (2nd ed.). Thorofare, NJ: SLACK Incorporated.
- Wilcock, A. (2007). Occupation and health: Are they one and the same? *Journal of Occupational Science*, 14(1), 3-8.
- Woodfield, M. (2009). Fear factor. *OH Baby, Summer*(4), 36-40.
- Woodgate, R. L., Edwards, M., & Ripat, J. (2012). How families of children with complex care needs participate in everyday life. *Social Science & Medicine*, 75(10), 1912-1920. <http://dx.doi.org/10.1016/j.socscimed.2012.07.037>
- Wrathall, M. (2005). *How to read Heidegger*. London, England: Granta Books.
- Wright-St Clair, V. (2015). Doing (interpretive) phenomenology. In S. Nayar & M. Stanley (Eds.), *Qualitative research methodologies for occupational science and therapy* (pp. 53-70). Oxford, England: Routledge.

Zarader, M. (2006). *The unthought debt: Heidegger and the Hebraic heritage* (B. Bergo, Trans.). Stanford, CA: Stanford University Press.

Zemke, R., & Clark, F. (1996). Co-occupations of mothers and children. In R. Zemke & F. Clark (Eds.), *Occupational science: The evolving discipline*. Philadelphia, PA: F.A. Davis Company.

## Appendix A – Ethics Approval - Original



17 September 2013

Clare Hocking  
Faculty of Health and Environmental Sciences

Dear Clare

Re Ethics Application: **13/197 The lived experience of mothering a young child with severe multiple disability (SMD).**

Thank you for providing evidence as requested, which satisfies the points raised by the AUT University Ethics Committee (AUTE C).

Your ethics application has been approved for three years until 16 September 2016.

As part of the ethics approval process, you are required to submit the following to AUTE C:

- A brief annual progress report using form EA2, which is available online through <http://www.aut.ac.nz/researchethics>. When necessary this form may also be used to request an extension of the approval at least one month prior to its expiry on 16 September 2016;
- A brief report on the status of the project using form EA3, which is available online through <http://www.aut.ac.nz/researchethics>. This report is to be submitted either when the approval expires on 16 September 2016 or on completion of the project.

It is a condition of approval that AUTE C is notified of any adverse events or if the research does not commence. AUTE C approval needs to be sought for any alteration to the research, including any alteration of or addition to any documents that are provided to participants. You are responsible for ensuring that research undertaken under this approval occurs within the parameters outlined in the approved application.

AUTE C grants ethical approval only. If you require management approval from an institution or organisation for your research, then you will need to obtain this. If your research is undertaken within a jurisdiction outside New Zealand, you will need to make the arrangements necessary to meet the legal and ethical requirements that apply there.

To enable us to provide you with efficient service, please use the application number and study title in all correspondence with us. If you have any enquiries about this application, or anything else, please do contact us at [ethics@aut.ac.nz](mailto:ethics@aut.ac.nz).

All the very best with your research,

A handwritten signature in black ink, appearing to read 'Kate O'Connor', written in a cursive style.

Kate O'Connor  
Executive Secretary  
**Auckland University of Technology Ethics Committee**

Cc: Mahoney Topia [mahoney.topia@gmail.com](mailto:mahoney.topia@gmail.com)

## Appendix B – Ethics Approval – Amendment One



A U T E C  
S E C R E T A R I A T

29 January 2014

Clare Hocking  
Faculty of Health and Environmental Sciences

Dear Clare

Re: Ethics Application: **13/197 The lived experience of mothering a young child with severe multiple disability (SMD).**

Thank you for your request for approval of amendments to your ethics application.

I have approved minor amendments to your ethics application allowing an extension to the participant pool and for the interviews to be conducted by telephone and skype.

I remind you that as part of the ethics approval process, you are required to submit the following to AUTEK:

- A brief annual progress report using form EA2, which is available online through <http://www.aut.ac.nz/researchethics>. When necessary this form may also be used to request an extension of the approval at least one month prior to its expiry on 16 September 2016;
- A brief report on the status of the project using form EA3, which is available online through <http://www.aut.ac.nz/researchethics>. This report is to be submitted either when the approval expires on 16 September 2016 or on completion of the project.

It is a condition of approval that AUTEK is notified of any adverse events or if the research does not commence. AUTEK approval needs to be sought for any alteration to the research, including any alteration of or addition to any documents that are provided to participants. You are responsible for ensuring that research undertaken under this approval occurs within the parameters outlined in the approved application.

AUTEK grants ethical approval only. If you require management approval from an institution or organisation for your research, then you will need to obtain this. If your research is undertaken within a jurisdiction outside New Zealand, you will need to make the arrangements necessary to meet the legal and ethical requirements that apply there.

To enable us to provide you with efficient service, please use the application number and study title in all correspondence with us. If you have any enquiries about this application, or anything else, please do contact us at [ethics@aut.ac.nz](mailto:ethics@aut.ac.nz).

All the very best with your research,

A handwritten signature in black ink, appearing to read 'Kate O'Connor'.

Kate O'Connor  
Executive Secretary  
**Auckland University of Technology Ethics Committee**

CC: Mahoney Topia [mahoney.topia@gmail.com](mailto:mahoney.topia@gmail.com)

## Appendix C – Ethics Approval – Amendment Two



A U T E C  
S E C R E T A R I A T

29 May 2014

Clare Hocking  
Faculty of Health and Environmental Sciences

Dear Clare

Re: Ethics Application: **13/197 The lived experience of mothering a young child with severe multiple disability (SMD).**

Thank you for your request for approval of an amendment to your ethics application.

I have approved the minor amendment to your ethics application allowing an additional recruitment location.

I remind you that as part of the ethics approval process, you are required to submit the following to the Auckland University of Technology Ethics Committee (AUTEC):

- A brief annual progress report using form EA2, which is available online through <http://www.aut.ac.nz/researchethics>. When necessary this form may also be used to request an extension of the approval at least one month prior to its expiry on 16 September 2016;
- A brief report on the status of the project using form EA3, which is available online through <http://www.aut.ac.nz/researchethics>. This report is to be submitted either when the approval expires on 16 September 2016 or on completion of the project.

It is a condition of approval that AUTEC is notified of any adverse events or if the research does not commence. AUTEC approval needs to be sought for any alteration to the research, including any alteration of or addition to any documents that are provided to participants. You are responsible for ensuring that research undertaken under this approval occurs within the parameters outlined in the approved application.

AUTEC grants ethical approval only. If you require management approval from an institution or organisation for your research, then you will need to obtain this.

To enable us to provide you with efficient service, please use the application number and study title in all correspondence with us. If you have any enquiries about this application, or anything else, please do contact us at [ethics@aut.ac.nz](mailto:ethics@aut.ac.nz).

All the very best with your research,

A handwritten signature in black ink, appearing to read 'Kate O'Connor'.

Kate O'Connor  
Executive Secretary  
**Auckland University of Technology Ethics Committee**

CC: Mahoney Topia [mahoney.topia@gmail.com](mailto:mahoney.topia@gmail.com)

## Appendix D – Consent Form



# Consent Form

*Project title: The Lived Experience of Mothering a Young Child with Severe Multiple Disability*

*Project Supervisor: Professor Clare Hocking*

*Researcher: Mahoney Topia*

- I have read and understood the information provided about this research project in the Information Sheet dated 4/7/2013.
- I have had an opportunity to ask questions and to have them answered.
- I understand that notes will be taken during the interviews and that they will also be audio-taped and transcribed.
- I understand that I may withdraw myself or any information that I have provided for this project at any time prior to completion of data collection, without being disadvantaged in any way.
- If I withdraw, I understand that all relevant information including tapes and transcripts, or parts thereof, will be destroyed.
- I agree to take part in this research.
- I wish to receive a copy of the report from the research (please tick one): Yes  No

Participant's signature: .....

Participant's name: .....

Participant's Contact Details :

.....

.....

Date:

*Note: The Participant should retain a copy of this form.*

## Appendix E – Research Flyer

### Mothering Children with Multiple Disabilities



My name is Mahoney Topia and I am an Occupational Therapist completing research for my Masters in Health Science (Occupational Practice) at Auckland University of Technology.

I am very interested in gaining greater insight into mothers' experience of looking after young children with severe multiple disability (i.e. inability to mobilise independently coupled with either an intellectual, sensory or behavioural disability). My own experience comes from working with children and families for the last nine years and having children of my own.

If you are the mother of a young child with SMD aged between 3-7 years old, I would greatly appreciate your contribution to my research.



If you are interested please contact me and I can give you more information and answer any questions you may have.

[mahoney.topia@gmail.com](mailto:mahoney.topia@gmail.com)

0508 Mahoney

# Participant Information Sheet



Date Information Sheet Produced: 4<sup>th</sup> July, 2013

**Project Title: The Lived Experience of Mothering a Young Child with Severe Multiple Disability**

## **An Invitation**

My name is Mahoney Topia, for the ten years I worked as an occupational therapist at Carlson School for Cerebral Palsy. I currently work at Professional and Paediatric Rehabilitation Services (PRS), or I can be found at home studying or spending time with my own kids. For the next year I will be working on my Masters in Health Science at AUT. My research aims to find out about 'the lived experience of mothering a child with severe multiple disability (SMD)'. SMD is defined as a significant physical disability-inability to mobilise independently coupled with either an intellectual, sensory or behavioural disability. My goal is to assist therapists and teachers to understand this important care dynamic, so they can use those new insights to change what they do and improve outcomes for children with SMD. Participation in this study is completely voluntary, and you are able to withdraw from this research at any point prior to the completion of data collection.

## **What is the purpose of this research?**

This research will identify meaning in the everyday experiences of mothering a young child with SMD. This important occupational role will assist therapists and teachers to work with young children with SMD and their families in ways that are compatible with their needs.

## **How was I identified and why am I being invited to participate in this research?**

You picked up one of my flyers and you are a mother (i.e. a female who provides mothering) for a young child (3 to 7 years of age) with severe multiple disability.

Please note you will be unable to participate in this research under the following circumstances:

You are unable to speak or understand the English language in verbal or written form.

You cannot give verbal information in an interview situation.

Your child receives therapy input from Professional and Paediatric Rehabilitation Services (PRS).

## **What will happen in this research?**

I will interview up to 12 mothers, separately, at a time and a place that is convenient, for an hour to an hour and a half. You will be provided with a worked story of your interview and asked to check that I have understood your experiences accurately, and then I will analyse all the

interviews (I will read and re-read them to identify themes) and send you a summary of the findings if you would like one.

To help readers of this research identify to how diverse mothers are within this study, I will ask you for the following information at the beginning of the interview once you have given your consent: your age, occupation, ethnicity, living situation, education, your child's age, disability and diagnosis, your child's educational history and the ages of any additional children (if you have any).

The research results may include quotes to assist readers to relate to the study's findings and to ensure sufficient information is made available to readers so they can better experience the phenomena. Any identifying information will be removed or changed.

It is anticipated that results of the research will be submitted for publication in health and education journals. Findings will also be discussed at national and perhaps international conferences (although exact ones are unknown at this stage).

### **What are the discomforts and risks?**

I am conscious of the potential for emotional subject matter to emerge in this research, and as you are sharing your experiences with me, I will be sensitive and respectful with your stories. You can request that I stop recording at any point or choose for comments to be removed from transcripts. Counselling services will be available for you to use through AUT. These are provided free of charge and are offered for you to use at your discretion.

I will maintain cultural sensitivity and adherence to the principles of the Treaty of Waitangi during this research. Incorporation of specific cultural practices are welcomed in the process and you will be invited to identify any you may have. I am also open to having a cultural advisor or support person present during the interview if this is deemed appropriate for you.

Full disclosure will be reciprocal with regard to the research, and you will be made aware of my obligation to report any incidents of a criminal nature or if it is evident that someone is at risk for harm.

### **What are the benefits?**

Your participation in this research will not afford you any immediate benefits; however you might find it helpful to tell your story. Your assistance will support me to complete my Master's thesis, change my practice, and share new insights with other therapists and teachers.

### **How will my privacy be protected?**

All the data that is collected will be securely stored and information that could potentially identify you or any other participants will be excluded from the research, subsequent reports or presentations drawing from this study. My supervisors and I will be the only people with access to the information gathered.

### **What are the costs of participating in this research?**

You will spend a maximum 3 to 5 hours of your time for the interviews and reading the initial analysis of your experiences.

### **What opportunity do I have to consider this invitation?**

After you have read this information, you can ask me any questions you have and I will ask you for contact information (see "what will happen in this research?"). You will then have a couple of weeks to decide whether to participate.

**How do I agree to participate in this research?**

I will contact you after a couple of weeks to ask if you have decided to participate and to arrange the interview. I will also ask you to sign a written consent form when we meet and gather some demographic information once you have consented.

**Will I receive feedback on the results of this research?**

Yes you will be provided a summary of the results of this research. Unless, you decide you do not want this.

**What do I do if I have concerns about this research?**

Any concerns regarding the nature of this project should be notified in the first instance to the Project Supervisor, Professor Clare Hocking, [clare.hocking@aut.ac.nz](mailto:clare.hocking@aut.ac.nz), Ph: 921 9162

Concerns regarding the conduct of the research should be notified to the Executive Secretary, AUTEK, Dr Rosemary Godbold, [rosemary.godbold@aut.ac.nz](mailto:rosemary.godbold@aut.ac.nz), 921 9999 ext 6902.

**Whom do I contact for further information about this research?**

Researcher Contact Details:

Mahoney Topia, [mahoney.topia@gmail.com](mailto:mahoney.topia@gmail.com), Cell Ph: 0508 Mahoney (0580 624 6639)

Primary Supervisor: Professor Clare Hocking, [clare.hocking@aut.ac.nz](mailto:clare.hocking@aut.ac.nz), Ph: 921 9162

Secondary Supervisor: Valerie Wright-St Clair, [Vwright@aut.ac.nz](mailto:Vwright@aut.ac.nz), Ph: 921 9999 ext 7736

## Appendix G – Demographic Information Form

# Demographic Information Form



*Project title: The Lived Experience of Mothering a Young Child with Severe Multiple Disability*

*Project Supervisor: Professor Clare Hocking*

*Researcher: Mahoney Topia*

---

The following information will assist with acquiring participants with diverse and representative backgrounds. I thank you for your co-operation and openness.

### **Mother's Details**

Name:

Age:

Occupation:

Ethnicity:

Highest Educational Qualification:

Who lives in your house?

Do you live urban or rural?

Do you have any other children:      YES                      NO

If yes, what are their ages?

### **Child with SMD's Details**

Name:

Age:

Diagnosis:

Educational Background (current and previously attended early childhood or primary schools):

Project Supervisor's Contact Details:

Professor Clare Hocking      [clare.hocking@aut.ac.nz](mailto:clare.hocking@aut.ac.nz), 921 9162

## Appendix H – Transcriptionist Confidentiality Agreement

# Confidentiality Agreement



*Project title: The Lived Experience of Mothering a Young Child with Severe Multiple Disability*

*Project Supervisor: Professor Clare Hocking*

*Researcher: Mahoney Topia*

---

- I understand that all the material I will be asked to transcribe is confidential.
- I understand that the contents of the tapes or recordings can only be discussed with the researchers.
- I will not keep any copies of the transcripts nor allow third parties access to them.

### Transcriber's

signature: .....

### Transcriber's

name: .....

### Transcriber's Contact Details:

.....  
.....  
.....  
.....

Date:

Project Supervisor's Contact Details:

Professor Clare Hocking

[clare.hocking@aut.ac.nz](mailto:clare.hocking@aut.ac.nz), 921 9162

*Note: The Transcriber should retain a copy of this form.*

## Appendix I – Occupational Therapy New Zealand Ethics Approval

**Dear Mahoney**

Two members have reviewed your application and are satisfied that ethical considerations pertaining to OTNZ members have been addressed. Please now compose an email message to members about the study and include any links or contact details and either post directly to the SIGS you are a member of or email it to Morgan Fitzgerald to circulate on your behalf, specifying which SIGS you would like it sent to. We suggest you include the key points from the information you provided to the ethics committee however what you include is up to you-the invitation will not be edited or commented on. A sentence will be added to your invite indicating approval has been given from OTNZ.

All the best with your project.

**Fi**

**DR FIONA (FI) GRAHAM** • SENIOR LECTURER  
REHABILITATION TEACHING & RESEARCH UNIT (RTRU), DEPARTMENT OF MEDICINE  
UNIVERSITY OF OTAGO, WELLINGTON • PO BOX 7343, WELLINGTON, 6242, NEW ZEALAND  
T: 03 338 3217 or 03 364 0744 | W: [www.uow.otago.ac.nz/rehab](http://www.uow.otago.ac.nz/rehab)  
E: [fi.graham@otago.ac.nz](mailto:fi.graham@otago.ac.nz) Skype: Fiona.graham1

University of Otago

Te Whare Wānanga o Otāgo

## Appendix J – Research Questions

# Research Questions



*Project title: The Lived Experience of Mothering a Young Child with Severe Multiple Disability*

*Project Supervisor: Professor Clare Hocking*

*Researcher: Mahoney Topia*

---

The following questions will be used to guide to a conversational face to face interview.

Opening:

(insert participants name here) I would really like to hear from you today, what it is like to be a mother to (insert child with SMDs name) ..... How you feel about being a mother and some of your experiences of mothering. I would like to hear stories about actual events, things you remember doing. The important things or the little moments that occur during the day.

- Can you think back to yesterday, all the things you did with .... Can you tell me about one of the things you did?
- Can you think of a time where you had a really good mothering moment with ..... could you describe that time to me?
- What was it like to have that moment with ....., how do you feel about it? What do you think it was in that moment that made you feel that way?
- Can you think of some aspects of the day to day mothering of ..... that you find difficult?
- Can you perhaps think of a specific incident when that occurred? Could you share that experience with me?
- Looking back now, do you remember how you felt in that moment back then? How do you feel about that day now?
- Can you describe to me what being a mother means to you?
- How do you feel about being a mother?
- Do you remember a specific time when you felt like you were unable to meet your own expectations? Can you describe it to me? Why do you think you felt that way at that time?
- Is there anything else that comes to mind that you would like to share with me?

Project Supervisor's Contact Details:

Professor Clare Hocking    [clare.hocking@aut.ac.nz](mailto:clare.hocking@aut.ac.nz), Ph: 921 9162