

**The Experiences of Women who Mother Children with Disabilities:  
Maternity, Relationality, Subjectivity**

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**A thesis submitted in fulfilment of the degree of Doctor of Philosophy**

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University of Sydney**

**2017**

## **AUTHOR'S DECLARATION**

This is to certify that:

- I. this thesis comprises only my original work towards the Doctor of Philosophy Degree
- II. due acknowledgement has been made in the text to all other material used
- III. the thesis does not exceed the word length for this degree
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- V. this thesis meets the *University of Sydney's Human Research Ethics Committee (HREC) requirements for the conduct of research.*

Signature:

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Date: June 30<sup>th</sup>, 2017

**This thesis is dedicated to my Dad, Dr Paul Brock AM.**

**You are my affirming flame.**

## **Acknowledgements**

The women who participated in this research generously offered me their time when they often had little to spare, and shared with me their stories of resistance, struggle, tenacity, resilience, and love. Their poignant reflections, passion, and strength are at the heart of this thesis, and it was an immense privilege to have been given the opportunity to undertake this research. I will be forever grateful to each of the participants, and the essence of their stories will stay with me.

Thank you to my supervisor, Dr Jennifer Wilkinson, and my associate supervisor, Associate Professor Susan Goodwin, for the years of guidance and encouragement that they have provided me. Their suggestions, expertise, and passion as both researchers and educators have had a strong influence on me, and have helped to guide the production of this thesis. I am so appreciative for all of the time, energy, and support that both have given me – thank you.

The organisations – Motherhood Initiative for Research and Community Involvement (MIRCI) based in Canada, and Australian Motherhood Initiative for Research and Community Involvement (AMIRCI) – have provided me with a continual source of stimulation and leadership. Dr Andrea O'Reilly's tireless efforts to advocate for research into and recognition of the work of mothers has inspired and anchored my work. AMIRCI have provided me with a sense of belonging and mentorship within the research community, and special thank you must go to its founder, Dr Marie Porter, and a number of current and previous board members – Dr Jenny Jones, Dr Lisa Raith, and Dr Joan Garvan. Each has given me invaluable guidance and I thank them for their ongoing support. Thank you to Professor Diana Gustafson who I met at my first conference in the first year of my PhD, and who has been there to provide me with enthusiastic encouragement ever since. I would also like to thank Professor Robyn Ewing for all of her encouragement, enthusiasm and support, for the final proof-reading of this thesis, and for being a beacon of light.

I am so thankful to my husband, Matthew White, for his unwavering confidence in me, his unconditional support, and for understanding and respecting my work and journey as a PhD student. I thank him for never once complaining about the time and energy I have put into this thesis, which has often meant the sacrifice of our nights and weekends together. I could not hope for a more understanding, thoughtful, or loving partner to journey through this life with, and I cannot wait to embark on the next adventure with him by my side.

Amelia Brock – my sister – has been a continuous source of strength, particularly throughout the past four years. She inspires and motivates me to challenge myself and to always aim higher. She supplied the ‘PhD Survival Kit’ to help me through the final stretch of writing. I thank her for being not only the most wonderful sister, but also the most extraordinary friend.

My most heartfelt gratitude is for my amazing parents who are the centre of who I am – Associate Professor Jackie Manuel, and Dr Paul Brock AM. Among the countless lessons they have taught me, they have both instilled in me the value of education, a passion for social justice, and a love for writing. Without my Mum, I do not know how I would have garnered the strength to finish the thesis. During the most challenging time in both of our lives, she was the anchor I needed through the last year of my candidature. She provided me with daily motivation, reassurance, and gave me the confidence to trust myself. Every day her fortitude, courage, integrity, and empathy acted as my guide in knowing what direction to take next, and how to overcome some of the most confronting hurdles. I thank her for it all.

Thank you to my phenomenal Dad. Throughout both high school and my undergraduate and honours degree, I would sit with my Dad for hours, working through my writing line by line, making edits and debating ideas: language was so central to his life and work. We had planned to complete this same editing process together on a full draft of my thesis, which I had finished one day before he passed away. In earlier months he had read some chapters within this thesis, and at times commented that he was moved to tears after reading quotes from participants in the study. He was the most brilliant thinker I have ever come across, and embodied virtues that have guided me throughout this research – integrity, ethical sensitivity, resilience, a healthy scepticism, empathy, and passion. Dad, you are infused within my writing. Your resilience, sense of hope, and passion for life, resonate with so much of what the participants in this study embody. Thank you for all that you have done to make this thesis possible, for your steadfast faith in me, and for all that you have left us with. I will continue to do everything I can to make you proud, and for you, I will never give up.

## Abstract

The aim of this thesis is to present, explore, and interpret the experiences of women who mother children with disabilities. The experiences of motherhood and mothering children with disabilities are seldom rendered visible in social research, and have rarely informed developments in social theory, motherhood studies, the sociology of personal life, or theories of the self. This research sought to address these issues and foreground the experiences of an under-represented group, through in-depth qualitative interviews and personal community mapping with 18 women who mother children with disabilities residing in New South Wales (NSW), Australia. The approach to the study brought together the perspectives of two generally discrete fields of sociological inquiry: Motherhood Studies and the sociology of personal life.

The research found that women who are mothers of children with disabilities live within social, cultural, political, and economic contexts which *assume* they have the capacity to 'freely choose' how they live their lives and form their relationships, while also *expecting* them to remain indefinitely self-sacrificing, primary carers for their children with disabilities. Thus, these women's lives are framed by competing and highly problematic sets of assumptions and expectations that cannot be solely understood in terms of individualisation theory, which assumes an individual's agency and freedom of choice in authoring their lives (Beck, 1992/1994). The concept of 'hegemonic maternity', an adaptation of Raewyn Connell's (1995) theory of 'hegemonic masculinity,' emerged from the research as a useful framework in understanding and theorising the normative social, cultural, and structural forces that produce and regulate women's experiences as mothers. It suggests that persistent unrealistic assumptions and expectations around motherhood and mothering translate as obligation and constraint in these women's lives.

Women who are mothers of children with disabilities must navigate and negotiate complex, contradictory, and pervasive assumptions and expectations of how to mother their children, as they conduct their relationships and seek to define their sense of self. The consequences of such endeavours are far-reaching: they expose these women's consistent struggles to both contest and conform to normative concepts of motherhood. The findings also point to the affordances of theories of relationality (Jallinoja & Widmer, 2011; Emirbayer, 1997) in more fully explaining the topography of their lives.

By positioning these women's lives and experiences in the context of concepts and debates around motherhood, personal relationships, as well as the formation of the self and

subjectivities, this research offers a number of original contributions to the knowledge base of the sociology of motherhood, of personal life; and of the self, and contributes to theoretical developments relating to maternal experience in contemporary Australian society. First, this thesis argues for the interdependence of two fields of sociological inquiry in order to forge new understandings within and between both. Second, the study contributes to each field through the development of the conceptual framework of hegemonic maternity. Third, it challenges individualisation theory by demonstrating its inappropriateness for women who are mothers of children with disabilities. Fourth, this research provides substantial evidence that will potentially influence social policy, public attitudes, and future research and scholarship.

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## A Note on Terminology

Throughout this thesis, I have made deliberate choices about terminology and language that cohere with the theoretical and philosophical assumptions at the heart of this study. The most significant terminology is briefly explicated below.

- *Women* who are mothers of children with disabilities: I refer to participants in this way, rather than as ‘mothers of children with disabilities’. This phraseology makes explicit that participants are first and foremost individual women who are also mothers. I needed to make a decision about whether I would use the phrase ‘mothers *of* children with disabilities’ or ‘mothers *with* children with disabilities’. Although the former is grammatically correct and the latter is not, after prompting from a colleague I questioned whether ‘of’ denoted possession, while ‘with’ was a more accurate representation of the relationship. I decided on referring to ‘mothers *of* children with disabilities’. This identifier more closely represents the level of obligation experienced by participants for the care of their children and the significant responsibility each participant felt they had in advocating for their child and ensuring they lived the best possible quality of life.
- Children with disability/disabilities: This descriptor was preferred to ‘disabled children’. I am aware of the debates over identity politics within the disability community and disability studies regarding whether people should be referred to as ‘people with a disability’ or ‘disabled people’ (cf. Butler, 1990; Campbell & Oliver, 1996; Mallett & Runswick-Cole, 2014; Shakespeare, 2006; Watson, 2002), and recognise and respect each side of this debate. My choice of prioritising personhood within the language that I have employed reflects the choice to represent and place the humanity of the child before their disability. Ultimately, it is a personal choice that I have made for the sake of consistency within this thesis, and I do not mean to cause any offense to the reader because of this choice.
- Mother: This term is employed throughout the thesis as both a noun and a verb, whereby one can *be* a mother, and also *perform* ‘mothering’. As a *practice*, ‘mothering’ can be performed by anyone, regardless of their gender.

- **Motherhood:** The use of the term ‘motherhood’ throughout this thesis refers to the institution of motherhood that can be seen to regulate and shape women’s experience, perceptions, and sense of self (Rich, 1976).
- **Maternity:** This term is understood as distinct from, yet potentially encompassing of, shifting definitions of ‘mother’ and ‘motherhood’, as it refers to the institutionalised, material, and lived experience of women who are mothers: “all women who do become mothers experience maternity materially” (Jones, 2013, p. 288). ‘Maternity’ leaves open the potential for recognising the agential capacity and “creative action” (Arendt, in Miller, 2014, p. 12) of women who are mothers. The term also accounts for the relational dynamics between ‘motherhood’ as an institution and the ‘maternal subject’. ‘Maternity’ refers to the ‘maternal’ as a site of both potential agency and constraint.
- **Subjectivities:** Throughout the thesis, the terms ‘subjectivities’, ‘subjectivity’, and ‘self’ are used to refer to what may, in other contexts, be understood as ‘identities’, ‘identity’, or ‘selfhood’. The ‘self’ refers to participants’ reflections on *who* they are as individuals, and the term ‘subjectivities’ refers to a theorisation of the ‘self’. Thinking about the individuals as ‘subjects’ “puts in question conventional notions of an unchanging human essence, commonly associated with the rational, autonomous individual of Enlightenment humanism” (Bacchi & Goodwin, 2016, p. 49). ‘Identity’ can be understood as signifying a fixed entity, with assumptions of essentialism, coherence and unity. In contrast, ‘subjectivities’ refers to an ongoing and more fluid, shifting sense of the ‘self’. The making of ‘subject positions’ stresses the ways the ‘self’ is *constructed* rather than *static*. The study supports the understanding that who an individual is, and who they see themselves as being, is not immutable and cannot be understood in isolation from the context of their social milieu and interpersonal relationships.
- **Family:** Throughout this thesis, ‘family’ is understood not as an *a priori*, transcendent entity or category of human experience. The meaning of family is taken to be contingent, flexible, culturally dependent, and susceptible to change. The ‘family’ and the ‘mother’ are socially constructed terms, roles, and categories, and therefore employing an approach based on the premise that our roles and experiences are largely socially constructed is pivotal to this research.

## PREFACE



Growing up, I was encouraged to cast a critical eye over the way in which society constructs and shapes the roles, identities, and experiences of people based on their gender, and be alert to inequalities and matters of social justice. This was a perspective further solidified during my undergraduate degree after studying sociology, and gender and cultural studies. It became clear to me that motherhood is not only clearly tied to gender, but also that the performance of the 'mother' role is intimately tied to gender inequalities. This is how I came to have an interest in Motherhood Studies.

My initial interest in researching the experiences of women who are mothers of children with disabilities was sparked after I encountered literature on Motherhood Studies within an undergraduate unit of study on symbolic violence that recognised the role of 'mother' as a social construct, with meaning that is value-laden and culturally variable. This research resonated with me, not because I had experienced the 'mother' role myself, but because it aligned with my understanding of the social world. When I discovered this literature on motherhood, I was being trained as a social scientist to use my 'sociological imagination' (Mills, 1959) and to question the social world within which I lived. Thinking about the experience of motherhood as an 'institution' and as social construct not only appealed to my emerging sociological understandings, but it also chimed with and enriched my perspective as a feminist.

My study of mothers of children with *disabilities* involved a more private, personal set of circumstances and experiences. I was raised by my mother and father in a loving, stimulating, and affirming environment, which was also influenced by the presence of severe disability. My father, Dr Paul Brock AM, suffered from Motor Neurone Disease, a neurological, degenerative, and terminal illness. He was diagnosed when I was five years old and when my sister was just one-year-old. Doctors gave him three-to-five years to live. Against the odds, he lived for 20 years battling the disease: he slowly lost his ability to move or perform any independent tasks other than thinking and speaking. My Dad passed away in March, 2016. The story of our family and the tenacity, strength, will, perseverance, and resilience of my parents is one to be shared in another forum.

However, the experience of seeing my father lose his ability to physically care for himself, and watching my mother become his primary carer for many years in our home has provided me insight into the sheer depth and breadth of both the physical and emotional costs of disability. These costs are not only experienced by the person with the disability, but also by their families and carers. In dealing with my father's disability our family were relatively privileged and well equipped. My parents were well educated, in highly regarded professional positions and therefore had a high level of social and cultural capital and resources to draw on. Despite this, our family felt socially isolated and alone at times, experienced significant financial difficulties, and were often unsure about how and where to access support.

The extent to which caring for my father had influenced every aspect of my mother's life as a carer was largely unrecognised by people other than our close family, or a handful of very close friends. This experience led me to ask how women who provide care for their children with disabilities negotiate their role as carers and mothers – often on the margins, often invisible – and the consequences of this for their lives, relationships, and sense of self.



## CHAPTER ONE

### Introduction

*"Mothers of disabled children make their way within a society that devalues their children and in which their motherhood has 'failed' to follow the culturally appropriate trajectory"*  
(Landsman, 2009, p. 10).



This thesis seeks to present the complexity, depth, and richness of the experiences of a group of individuals who dwell on the periphery of public consciousness. Women who are mothers of children with disabilities are infrequently the subjects of inquiry within social conversations, media representations, political discourses, or mainstream academic scholarship. The contours and texture of their lives are seldom rendered visible, theorised, or adequately understood. While increasing attention has rightly been directed at ensuring social inclusion, practical support, community awareness, and equality of opportunity for people with a disability, the quality of life and experiences of the women who are mothers of people with disabilities are at best obscured, and at worst, ignored. It is anticipated that the findings reported in this thesis will go some way towards re-orienting attention to, and extending our understanding of, this generally invisible, yet profoundly significant dimension of living with disability in Australia.

### The Context for this Research

In Australia, it is estimated that more than one quarter of a million children up to the age of 14 years have a disability. Statistics indicate that there are over 96,000 primary carers for these children, 92 percent of whom are their mothers. According to Australian Bureau of Statistics (ABS) data, 99.7 percent of these children live in familial households rather than in out-of-home care (ABS, 2008). Simply put, approximately one in eight families in Australia include a child with a disability. However, these figures do not account for children and young adults with disabilities who are over the age of 14 years, or adults with disabilities whose primary carers are their mothers. More broadly, there are an estimated 2.8 million unpaid carers in Australia, with their contributions calculated at more than 42 billion dollars, annually (Topps, 2014). The care-work performed in Australia, including the primary caregiving provided by mothers of children with disabilities, is not merely a substantial component of the Australian economy: it



constitutes a profoundly significant and integral dimension of individual, familial, institutional, and social life.

Despite these statistics, there is a marked under-representation of qualitative research focusing on women who mother children with disabilities: their experiences, relationships, and subjectivities. This under-representation exists not only within Australia, but also internationally. Zibricky (2014) argues that while new arguments about motherhood have emerged, and mothers of various backgrounds and subject positions claim “space and subjectivity regarding their experiences in motherhood” (p. 39), “very little is known about mothers raising disabled children” (p. 40). Further, Ryan and Runswick-Cole (2008) argue that the study of mothers of children with disabilities “occup[ies] a liminal position because they are often not disabled” (p. 199).

In Australia and internationally – particularly within North America and the United Kingdom – research conducted on the impact of caring for a person with a disability spans disciplines and fields of inquiry such as psychology, nursing, orthopsychiatry, medicine, disability studies, education, social work, gender and cultural studies, economics, as well as sociology (cf. Brandon, 2007; Meyers et al., 1996; Porterfield, 2002; Shearn & Todd, 2000; Wolfe & Hill, 1995). While this corpus of research offers *some* insights into the experiences of women who mother children with disabilities, it is generally limited to four discernible foci: employment trends and socio-economic status; the impact of the caregiving role; the implications for relationships and marriage; and, more recently, the potential positive outcomes associated with parenting a child with a disability (cf. Hastings & Taunt, 2002; Scorgie & Sobsey, 2000).

Similarly, the existing literature on the connections between motherhood, relationships, and an individual’s sense of self tend not to address the nature and their import for women who are mothers of children with disabilities. There is general consensus that motherhood and subjectivities are intricately bound, with the role of ‘mother’ shaping one’s sense of self and influencing an individual’s relational life (cf. Goodwin & Huppertz, 2010; O’Reilly, 2015; Ruddick, 1989; Stone, 2012). The journey into and through motherhood has been shown to have certain consequences for the way a woman thinks about herself, the world, and her place in it (cf. Chodorow, 1981; Juhasz, 2003; Rich, 1976; Stone, 2012). Yet, the lives of women who are mothers of children with disabilities are embedded within relationships that frame both the construction and maintenance of their sense of self and their experience of motherhood. While there is a substantial body of feminist psychoanalytic research about how motherhood affects

the self (Chodorow, 1981; Harvey, 2015; Juhasz, 2003; Stone, 2014), this process is rarely interrogated sociologically, or explored specifically in relation to the maternal experiences of women who mother children with disabilities.

## **The Study**

Against this backdrop, this study aimed to explore the experiences of 18 women who are mothers of children with disabilities within Australia, by gathering, documenting, and interpreting their stories. The task of undertaking a sociological study of the lives of women who mother children with disabilities has drawn upon theories and concepts from the sociology of motherhood (or Motherhood Studies) the sociology of personal life, and perspectives on the self. The study draws from knowledge generated largely within the global North, and while situated within a global context, it was an aim of this research to contribute to, advance, and deepen existing knowledge and understandings of the nature of motherhood in contemporary Australian society, specifically for mothers of children with disabilities. Equally important has been the purpose of shedding light on the lived experiences of a group of women whose stories are too often lived out on the margins of public, political, policy, and scholarly domains.

The central question that has driven this research is:

*With a particular focus on their relationships and sense of self, what are the experiences of women who are mothers of children with disabilities?*

Three subsidiary questions contribute to answering this central question, and serve as thematic strands to structure the presentation of data. These questions are:

1. How do participants experience the “institution of motherhood” (identified by Rich in 1976); how do they resist, conform to, challenge, and/or navigate this constraining institution?
2. In what ways do participants construct and navigate their relationships, and how are their relationships shaped and impacted by their role as mothers of children with disabilities?
3. How do participants understand and express their sense of ‘self’?

## Theoretical Approach

The overarching theoretical framework for this research is informed by feminist phenomenology and social constructionism. These paradigms recognise that because individuals construct their perception of reality, make sense of their experiences, and define their sense of self, that the meaning of experience itself is fluid, negotiable, and created through language and social interaction (Berger & Luckmann, 1967; Schutz, 1973). This conceptualisation assumes that the self is constructed over time in the light of personal experiences, relationships, and the negotiation of cultural norms, material contexts, and prevailing societal expectations (Cosgrove, 2000).

A qualitative research paradigm enabled the collection of data from individual participants in order to “gain in-depth understanding replete with meaning for the subject, focusing ... on discovery rather than confirmation” (Burns, 1997, p. 365). Hence, there were no hypotheses tested in this research nor were there a set of *a priori* assumptions about the participants’ experiences: the inquiry proceeded inductively. In the tradition of feminist phenomenological and social constructionist methodological approaches, the research was deeply exploratory. It was designed to capture participants’ subjective “meanings of their experiences”, accepting that “meanings are varied and multiple” (Cresswell, 2007, p. 20) potentially yielding a complexity and diversity of findings.

All participants in this study were resident in NSW, Australia at the time the research was conducted. All methods employed were qualitative and included semi-structured in-depth interviews, photo elicitation, and personal community maps. In adopting a social constructionist approach to data collection and analysis, I acknowledge that my own subject positions have inevitably influenced decisions about the approach to this research, the interpretations of the data, and the conclusions that I have drawn from the findings. On this point, Gustafson (2015) has spoken of the complexities of negotiating power and reconstructing stories when interviewing mothers. When working on a project with lone mothers, Gustafson’s research assistant – who was also a lone mother – articulated a salient perspective for researchers in the field:

[h]ow dare all these academic types – you know who you are – take my life, my horrible wretched life, and use it to further your agenda. My life of

poverty and destitution, my life of suffering, my life of having to eke out an existence for me and my children, my life of frustration, my life of sadness of not being able to adequately provide for my children, and use it to write papers and show people who should already know how absolutely gut-wrenching-awful poverty is, to realise that they maybe would/should think before they act (Gillingham, in Gustafson, 2015, p. 1).

I wrestled with this proposition and believe that a way forward lies in assessing my own motivations in carrying out this research, interpreting the data, and reflecting on how to represent participants' voices in this thesis. I hope that this study contributes to raising awareness about the lives of women who are mothers of children with disabilities and their families, potentially generating positive change. In this sense, there has been a strong social justice dimension to my motivation for this research. In the thesis, this has translated into an awareness of the need to understand individual experience within broader social, political, and material contexts in order to bring to the fore the embedded nature of inequality, and the significance of structural constraints on participants' lives. At all times, however, I have been cognisant of the importance of positioning participants' voices and experiences as primary and central.

As DeVault (1990) observes, when researchers write about the lives of women, they will constantly be confronted with the danger of misinterpretation, particularly as the very nature of language is highly gendered and interpretive. Talking, listening, and interacting in general are gendered processes and experiences. Therefore, as a researcher I recognised the need to be aware of this in my representations and interpretations of participants' stories, since even the method of writing up transcripts inevitably involves subjective interpretation (for example, representing inflection of voices, tone, and body language). Gustafson et al. (2015) posited that as researchers, we are the *final* writers of the text of participants' lives in our work, and whether we mean it to be or not, writing is political. Recognising this, I take up Gustafson et al.'s (2015) challenge to "write to transgress", understanding that as researchers, we have a responsibility to our research subjects in writing about their lives and experiences.

## **Research Significance**

This research is significant in five distinctive ways. First, it attends to an underrepresentation in scholarly literature and knowledge about the material conditions of the experience of

maternity for women who are mothers of children with disabilities, particularly in terms of their life choices, relationships, and sense of self. The thesis explores and interprets women's experiences by focussing on individuals, while at the same time probing connections between these individuals' mothering roles and maternity as a site for reconsidering human subjectivities. The research reported in this thesis provides a legitimised scholarly platform whereby material and phenomenological dimensions of a participant's 'world' can be foregrounded and represented, often through the verbatim reproduction of significant portions of individual interview transcripts.

Second, this research makes a significant and original contribution to knowledge, theory, and qualitative methodology through combining two previously distinct fields of sociological inquiry: Motherhood Studies and the sociology of personal life. Until now, these two fields of research have remained largely discrete. Through the process of amalgamating these two fields of social inquiry, important new questions have emerged about the changing meaning of the 'family', 'personal life', the experience of 'mothering', and motherhood as "the site of [a woman's] proceedings" (Kristeva, 1980, p. 237).

Third, as a consequence of this melding of Motherhood Studies and the sociology of personal life, the study contributes in original ways to *both* fields of sociological inquiry. To the field of Motherhood Studies, the research contribution includes the development and application of an innovative conceptual framework to understand and theorise the structures within which mothers – specifically mothers of children with disabilities – live. This conceptual framework is explained in Chapter Four: Methodology.

The study contributes to the sociology of personal life through reconsidering the nature of family 'displays', and posing challenges to the assumed consequences of individualisation. The sociology of personal life – which has evolved from 'family studies' – is an established and well-respected field of sociological research. However, despite the ever-expanding canon of maternal scholarship and literature, Motherhood Studies is still struggling to be fully recognised in the mainstream academy despite an expansive and ever-growing body of maternal scholarship (cf. Bueskens, 2014; Gustafson et al., 2015; Heisler & Ellis, 2008; O'Reilly 2008/2015; Porter & Kelso, 2011; Raith et al., 2015; Wigginton & Lee, 2013).

The current and continuing research into the experience of motherhood by authors working in the field of maternal studies; the advocacy of these researchers as well as publishers and

journals such as Demeter Press, *Studies in the Maternal*, the *Journal of the Motherhood Initiative* (JMI); and the work of organisations such as Mapping Maternal Subjectivities, Identities and Ethics (MaMSIE) in the UK, the Motherhood Initiative for Research and Community Involvement (MIRCI) in North America, and the Australian Motherhood Initiative for Research and Community Involvement (AMIRCI), are encouraging a greater focus on the maternal experience as a critically important field for scholarly attention. The study therefore adds to this corpus of maternal literature and further underscores how and why Motherhood Studies should be accorded greater status as a critical field of sociological inquiry.

Fourth, the analysis of data draws on the theoretical positions of Mead (1932), Goffman (1959) and Chodorow (1981) in understanding the self as relational. It also attends to the work of Juhasz (2003) and Stone (2012) on maternal subjectivity in the analysis and interpretation of data pertaining to the participants' sense of self by addressing the often-opposing subject positions of 'mother' and 'autonomous agent'. Each of these theoretical positions relies on social constructionist understandings of the self: understandings that underpin and invest with coherence the analysis and interpretation of data presented in this study.

Last, the findings of this research study potentially inform the growing public policy agenda around caregiving and disability in Australia. The National Disability Insurance Scheme (NDIS) was set to be rolled out fully in July 2016, and at the time of conducting interviews for this research (2013-2014) a number of participants living within 'trial sites' were being inducted into the NDIS. While this thesis does not set out to comment specifically on the NDIS or disability policy, the results do have implications that can be translated into useful evidence-based information for policy developers and researchers within the disability community and beyond. It is important to reiterate that this research does not focus on the experiences of people who have disabilities. However, in an exploration of the experiences of caregivers for those who have disabilities, this thesis provides considerable data of direct relevance to policy, political, and other debates about people with disabilities and their caregivers.

## **Thesis Overview**

This introductory chapter has provided the contextual background for the study; described the aims and purpose of the research; set out the research questions; briefly outlined the theoretical framework for the research; and delineated the significance and intended contribution of the research to the field. Chapter Two: On Parenting Children with Disabilities, critiques the

relevant research conducted on parenting children with disabilities. This chapter encompasses research on 'parenting', rather than specifically 'mothering', and identifies areas of both contestation and consensus.

Chapter Three: On Motherhood, Relationships, and the Self, frames the scholarly context for the research through a critical review of the literature relevant to the major thematic strands of the study: motherhood, relationships, and conceptualisations of the self. Chapter Four: Methodology, addresses in detail the aims and purpose of the research; the theoretical frameworks of feminist phenomenology and social constructionism; the research design and methods employed for gathering data; the ethics, recruitment, and participants; and each step of data analysis. This chapter culminates with the explication of an emergent conceptual framework for the analysis and interpretation of the data.

The presentation of data is structured in sequential chapters based on the three interdependent thematic strands of motherhood, relationships, and conceptualisations of the self. Chapter Five: On 'Motherhood' – Roles and Archetypes, concentrates on the experience of motherhood as it is mediated through a number of roles, some of which are recognisable as archetypes. Chapter Six: On Negotiating 'Normality', examines how participants negotiate socially constructed understandings of 'normality' in their experiences of mothering and how they mother their children amidst their understandings of the 'good disabled child'. Chapter Seven: On Regulation and Resistance, extends the focus on motherhood through reporting on how and why participants self-regulate their mothering; experience regulation and judgement about their mothering from others; and participate in and perpetuate the regulation of other mothers.

Chapter Eight: On *Displaying* 'Family', focuses on what participants understand as their 'family' relationships and sheds light on how participants experience their sense of 'family' through 'displays'. Chapter Nine: On Navigating Personal Relationships, builds on Chapter Eight in order to interpret how participants construct and experience their personal relational networks.

Chapter Ten: The Subjectivities of Women who Mother Children with Disabilities, addresses the third thematic strand of the research – how participants construct and reflect on their sense of self, through the negotiation of various 'subject positions'. This final data chapter synthesises analyses from the previous data chapters by presenting holistic accounts of each participants' experiences.

Chapter Eleven: Findings and Conclusions, provides a summation of the key findings in response to the central research question and the three subsidiary research questions; identifies the implications of each finding; comments on the significance of the research; and sets out recommendations for future research directions.

Throughout this study, I have represented the experiences and perspectives of a group of women who are mothers of children with disabilities who generously, candidly, and bravely shared with me their stories, demonstrating that

[t]hese are not, as stereotypes might lead us to expect, stories of tragedy, nor even of 'triumph' over tragedy, though tears flowed freely and often in their telling ... that women were willing to tell their complex stories – of hope, sorrow, betrayal, challenge, transformation and, unscientific though it sounds, of love – is a gift the full value of which perhaps they alone can understand (Landsman, 2009, p. ix).





## CHAPTER TWO

### On Parenting Children with Disabilities

*"... will he ever have a normal – what we classify as a normal life? Will he ever have a partner, will he ever get married, will he ever go down that track? And I had to talk to myself and say they're my norms, they're my ideals. So if he lives a life of going home to a dog or a bird or something, then that's okay"*  
(Veronica, Participant).



#### Introduction

In order to frame the critique of the literature on motherhood, relationships, and the self, it is necessary to provide an overview of the landscape of research conducted on parents of children with disabilities more generally. The review of the research and scholarship pertaining to 'parents' of children with disabilities (rather than that specifically focusing on 'mothers' of children with disabilities) is relevant when investigating the experience of mothering a child with a disability. Although this study places the individual personhood of the participant at the forefront – rather than her role as a 'mother' – it is important to acknowledge that all participants have in common the experience of parenting a child with a disability.

Within the body of research on parenting children with disabilities (across disciplines such as psychology, nursing and health, orthopsychiatry, medicine, disability studies, education, social work, gender and cultural studies, economics, as well as sociology) I have identified four main themes: the impact of parenting a child with a disability on employment and socio-economic status; the impact of the caregiving role; implications for relationships and marriage; and more recently, research focused on 'strengths' and potential positive outcomes of parenting a child with a disability.

#### Employment and Socio-Economic Status

The relationship between disability and socio-economic status is complex, and it is unclear whether disadvantage may contribute to and precede disability, or whether disadvantage may

be the result of having a child with a disability (ABS, Australian Social Trends, 2008). According to the ABS (2008), in 2003 families with a child with a disability were more likely to be living in areas of greater socio-economic disadvantage. Yet, the ABS (2008) also found that families who include a child with a disability have on average more children than families without a child with a disability. Families with larger numbers of young children generally have lower levels of parental labour-force participation and therefore, lower income levels than families of children without disabilities.

Couple families where neither parent had completed secondary school were almost twice as likely as other couple families to have a child with a profound/severe disability (ABS, 2008). Having a child with a disability also has a marked impact on a parents' opportunity to engage in paid work due to the difficulty parents face in finding employment with flexible arrangements, and the need for specialised care for the child (ABS, 2008). In couple families who had a child with a disability, around 51 percent were both employed, and if a child's disability was severe then this figure dropped to 42 percent, compared to 61 percent of couple families where no child had a disability (ABS 2008). Thirty-eight percent of single parents who had a child with a disability were employed, (29 percent where the child's disability was severe) compared to 52 percent of single parents who did not have a child with a disability (ABS, 2008).

In 2003 the mean gross family income for families with a child with a disability was \$501 per week compared to \$605 per week for families where no child had a disability – reflecting not only reduced income but increased costs associated with raising the child (ABS, 2008). It is important to point out, however, that these figures only reflect families where a child with a disability is aged between 0-14 years, and employment figures do not specify whether parents are engaged in full-time, part-time, or casual work.

Of those raising a child with a disability, 92 percent of primary carers are mothers (ABS, 2008). Fifty-eight percent of those caring for their child with a disability aged 5-9 years, and 52 percent of those caring for children aged 10-14 years, were spending over 40 hours per week providing direct care for their child (ABS, 2008). The intensity of the care that some of these children require, and the hours that carers spend providing for their child, inevitably impacts on their ability to engage in paid work: "the care required for a child with a disability, coupled with a limited availability of specialised and experienced formal child care services, often means mothers who ordinarily would like to work are unable to do so" (ABS, 2008, p. 46). There is an abundance of research documenting that mothers of children with disabilities have greater

difficulties associated with paid employment than mothers of children without disabilities (cf. Brandon, 2007; Meyers et al. 1996; Porterfield, 2002; Shearn & Todd, 2000; Wolfe & Hill, 1995).

Research suggests that a number of factors influence how those who mother children with disabilities navigate employment and whether they are even able to engage in paid work. These factors include the: flexibility of her employers and the position; level of care required by her child; type of disability the child has; health of the mother; support from her personal community; and availability and quality of child-care services (Einam & Cuskelly, 2002). Many mothers report that the sheer fatigue they experience makes outside employment impossible, and the health services their children need to engage with often presume that a parent will be available to attend appointments during work hours (Einam & Cuskelly, 2002, p. 165). As a result of this, many mothers of children with disabilities either cannot work, request junior positions below their qualifications, refuse promotions, are unable to undertake tasks that would lead to promotions, or move from full-time to part-time or casual positions (Einam & Cuskelly, 2002).

Despite obstacles, many women who mother children with disabilities want to engage in paid work, and many successfully do so (Balwin, 1985; Einam & Cuskelly, 2002; Freedman et al., 1995; Todd & Shearn, 1996). A lack of opportunities for these mothers to engage in employment, however, often leads to feelings of isolation, lack of fulfilment, and low self-esteem (Shearn & Todd, 2000, p. 109). Those who do engage in paid employment highly value their positions, and their working life affords them the possibility of forging a sense of self distinct from that associated with their role as a mother.

Employment also offers a literal and metaphorical space where they may find temporary respite from their family concerns and responsibilities, experience a degree of autonomy, engage in adult conversation, and further utilise their skills and abilities (Shearn & Todd, 2000). Yet mothers who engage in paid work can also feel a sense of guilt because of the perception that engaging in paid employment is self-indulgent (Shearn & Todd, 2000, p. 119). Therefore, the benefits they receive from employment can be undermined by either the unfulfilling nature of their work, or the stress and guilt they experience by having to negotiate the demands of their employment with the caregiving demands of their child with a disability (Shearn & Todd, 2000, p. 124).

## **The Impact of the Caregiving Role: Health and Social Implications**

Research has been conducted on the wellbeing of parents of children with disabilities, and how parents cope with and adapt to stress. Wellbeing is linked to the extent of caregiving responsibilities that caregivers are subject to, and this responsibility relates to whether a child with a disability lives at home or in out-of-home support. While there is variability in research regarding the wellbeing of parents of children with disabilities, overall the research indicates that parents of children with disabilities are more likely to experience depression, distress, stress, fatigue, boredom, isolation, and decreased social interaction compared to parents of children without disabilities (cf. Baxter et al., 2000; Cadman et al., 1991; Frey et al., 1989; King et al., 1999; Kornenberger & Thompson, 1992; MacDonald & Callery, 2007; Seltser et al., 2001; Singer, 2006; Smith et al., 2001).

Troubling research conducted by Cummins et al. (2007) found that 56 percent of Australia's carers have clinical levels of depression, (19 percent classed as "extremely severe" and 18 percent as "severe") – considering that at any one time, approximately 6 percent of the Australian population is estimated to be experiencing depression, if these results were extrapolated to the entire Australian population, it would be likely that carers make up a significant percentage of those who suffer depression in Australia (AIFS, 2012). Singer's (2006) research found that depression levels for mothers of children with developmental disabilities are markedly elevated compared to mothers of typically developing children.

Cummins and Hughes (2007) found that: female carers have lower wellbeing than male carers; carers have the lowest collective wellbeing of any other group; carers are more likely to be experiencing chronic pain that is also associated with reduced wellbeing; and "the major reasons carers are not receiving treatment for themselves is that they have no time or cannot afford the treatment" (p. vii). As I noted above, more than 52 percent of those caring for a child with a disability spend over 40 hours per week providing this care, and Cummins and Hughes (2007) found that wellbeing decreases as the number of hours spent on caregiving increases: "primary carer responsibility for any time each day is extremely damaging to wellbeing" (p. vii). Cummins and Hughes (2007, p. vii) also found that the wellbeing of caregivers who live with the person requiring care is "the lowest value we have ever recorded for a large group of people" (p. vii). To reiterate the statistic quoted above: 99.7 percent of children with disabilities in Australia live within original family households. It is therefore reasonable to surmise that these

statistics regarding the low levels of wellbeing of carers are reflective of the rates of wellbeing of mothers of children with disabilities in Australia.

However, it is important to note that the lower levels of wellbeing for parents of children with disabilities is mediated by variables other than the fact their child has a disability, and depression is not an inevitable consequence of parenting a child with a disability (Singer, 2006, p.163). King et al. (1999) found that family-centred caregiving helps to attenuate feelings of distress and depression among parents. Furthermore, lower levels of disability, higher levels of socio-economic advantage, the perception of family and social support, and delivering services in a family-centred way is associated with decreased burdens, less stress, better emotional wellbeing and more satisfaction with services (Hassall et al., 2005; King et al., 1999).

Studies of 'resilience' are also apparent in research focused on parent wellbeing. Walsh (1996, 2002) has argued that families identified as being resilient often demonstrate the qualities of making meaning out of adversity, keeping a positive outlook, and being spiritual or having a belief system. Two necessary factors for resilience are a family's capacity to garner resources, and the level of connectedness within a family (Bayat, 2007, pp. 708-709). There are a number of themes that Gardner and Harmon (2002) identified as contributing to a sense of resilience in a mother of a child with a disability. These include: developing an affirming sense of self; coming to terms with the child's diagnosis; feeling as though they are part of a 'team'; feeling empowered to act; being organised; using support systems; being positive; recognising their own needs; balancing the needs of other family members; and finding constructs for making sense of life and its value.

### **Implications for Relationships and Marital Quality**

Another strand of research focuses on the impact of parenting a child with a disability on relationships and marriage, including marital quality and adjustment, divorce, and the relationship between parents of children with disabilities. Findings vary, but there is a widely held view that having a child with a disability increases divorce rates<sup>1</sup>. A figure that has been regularly quoted by news organisations, advocacy groups and even politicians is a divorce rate of around 80 percent. For example, journalist Denise Ryan (2008) wrote in *The Age* that "up to 80% of marriages fail in households where a child has an ASD." Mary Romaniec (2010) writing

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<sup>1</sup> During the present research study, a number of participants told me that the divorce rates for parents who have children with disabilities is at least 80 percent.

for the 'Talk About Curing Autism' organisation, quoted the 80 percent figure, and MP Don Randall (2009) from the Australian House of Representatives gave a speech in response to the Tax Laws Amendment Bill where he stated that "studies show that up to 80 per cent of marriages where there is an autistic child fail" (Wombles, 2010). It is difficult, however, to confirm this figure of 80 percent from evidence-based research. In fact, the majority of published research has found no significant difference in the divorce rate of couples of children with disabilities compared to couples in the general population (cf. Hauenstein, 1990; Joesch & Smith 1997; Mcubbin, 1989; Namkung et al., 2015; Risal et al., 2004; Sabbeth & Leeventhal, 1984).

The majority of studies specifically investigating divorce rates have focused on couples with children with Autism Spectrum Disorder (ASD), and some of this research did find elevated risk levels for divorce. For example, Hartley et al. (2010) found that parents of children with ASD had higher rates of divorce compared to parents of children without disabilities: 23.5 percent compared to 13.8 percent, respectively. Further, Hodapp and Krasner (2010) found that "families of children with disabilities showed higher percentages of divorce or separation" (p. 71).

Some studies found the risk of divorce was influenced by a number of variables. Joesch and Smith (1997, p. 159) reported that mothers' prospects for divorce are affected both positively and negatively by their "children's health status ... childhood condition, and in the case of low birth weight children, timing within the marriage." Mauldon (1992, p. 356) found that mothers with more education were more likely to divorce, and having older children increased the divorce rate. Urbano and Hodapp (2007) reported that divorce rates among families of children with Down Syndrome were actually lower than those with children with other birth defects and those with children with no identified disability. Freedman et al. (2010) examined data from the 2007 *National US Survey of Children's Health* of 77,911 children aged three to 17 years, and found that 64 percent of children with ASD were in a family with two married biological or adoptive parents, compared with 65 percent of children who did not have ASD.

Other evidence suggests that the more stress parents of children with disabilities have in their daily lives, the more they view their marriages negatively (Bradley et al., 2009; Stoneman & Gavidia-Payne, 2006). In addition, positive correlations have been found between parenting, marital quality, and social support (Bradley et al., 2009). Brobst et al. (2009, p. 38) found that parents of children with ASD experienced lower relationship satisfaction, yet did not differ from

couples without children with disabilities in regards to perceived spousal support, respect for their partners, and commitment. Factors such as family income levels; the extent to which the child's disability is accepted by the community; pre-existing problems in the family; spirituality and participation in religious activities; and the extent to which parents seek support from other family members, all impact on marital quality for parents of children with disabilities (Brobst et al., 2009, p. 39).

Clearly there are some inconsistencies in the findings of research that has investigated marital discord and divorce rates among parents of children with disabilities. Further research needs to take account of the impact of different disabilities and socio-economic factors on marital discord and divorce. However, the majority of evidence points to the divorce rate of parents of children with disabilities being comparable to that of parents of children without disabilities. A more recent study examined the risk of divorce in parents of children with developmental disabilities compared to parents of children without disabilities, tracking the sample longitudinally for over 50 years (Namkung et al., 2015) concluding that "counter to our hypothesis, the risk of divorce of the two groups of parents was not significantly different" (Namkung et al., 2015, p. 519). In fact, their research found that the risk of divorce increased for parents of children without disabilities with their number of children, whereas for parents of children with developmental disabilities, the number of children that they had did not increase the risk of divorce (Namkung et al., 2015).

### **Potential Positive Outcomes of Parenting Children with a Disability**

A relatively recent and emerging area of research has focused on the potential for positive transformative outcomes resulting from parenting a child with a disability. As Hastings and Taunt (2002) argue, "although many researchers have found that families of children with disabilities report more stress than do other families, there is no clear evidence that they also report fewer positive feelings or perceptions" (p. 121).

Some researchers argue that parents of children with Down Syndrome experience less stress, more rewards, and greater wellbeing than parents of children with other intellectual disabilities (Stoneman, 2007; Hodapp et al., 2009). As Hodapp et al. (2009) suggest, this may be because those with Down Syndrome tend to have sociable personalities, fewer maladaptive behaviours, larger support groups, generally greater family incomes, and parents who generally fully understand the nature and cause of the disability. In their study of mothers of children with

intellectual disabilities, Hastings et al. (2002, p. 269) reported that mothers perceived their children as a source of happiness, fulfilment, strength, and family closeness.

Scorgie and Sobsey's (2000) research supported these findings, indicating that most parents reported positive changes of personal growth, improved relations with others, and changes in philosophical or spiritual values because they had a child with a disability. There are suggestions within this literature that positive perceptions and life experiences can not only be seen as an outcome of having a child with a disability, but also as a resource in learning how to better cope (Hastings et al., 2002; Hastings & Taunt, 2002; Scorgie & Sobsey, 2000). Hastings and Taunt (2002, p. 121) further suggest that positive outlooks within families of children with disabilities can potentially ameliorate the impact of a child's disability on family members.

Runswick-Cole's (2013) work on the emotional labour involved in mothering children with disabilities can be interpreted as a challenge to the recent trend in research of underlining positive implications of parenting children with disabilities. She is hesitant, however, to "provoke a move back towards [a] deficit model of mothering disabled children" (Runswick-Cole, 2013, p. 118). In this case, research and scholarship that challenges the implications of transformation are not necessarily attempts to privilege a deficit model of parenting children with disabilities over positive-connotation models.

Hastings et al. (2002) propose that "having a child with more severe disabilities may provide mothers with more opportunities to grow personally and to develop a mature outlook on the world because of increased challenges posed" (p. 272). Further, Scorgie and Sobsey (2000) reported that mothers experience 'transformation' when they have a child with a disability, and this "transformation involved the disintegration or abandonment of one's previous life in favour of a new and clearly better way of living" (pp. 197-198). Such findings suggest that mothers of children with disabilities may transform their lives for the 'better' because of their mothering experiences and the challenges they face. However, a positive life transformation and/or the abandonment of one's previous life does not necessarily mean mothers' lives will be 'better' than they were before. It could be argued that this transformation is dependent on a cluster of unstable influences, including socio-economic factors, and may in fact be a responsive coping mechanism reflecting resilience and adjustment, rather than necessarily positive changes.

In addition, Scorgie and Sobsey (2000) reported three findings that warrant discussion. Firstly, 90 percent of their participants responded with 'agreed or strongly agreed' to whether they had



learned to speak out for their child rather than remain passive (Scorgie & Sobsey, 2000). This response cannot be uncritically endorsed as indicative of a 'positive' outcome. For example, perhaps these respondents were compelled to speak out for their children because of inadequate support services. If they had remained silent and did not speak out, then they may have continued to be excluded from the system and received little support, therefore precipitating suffering for them, their child, and families.

Secondly, Scorgie and Sobsey (2000) noted that several parents reported vocational changes as a result of their parenting experience. Again, this result should not necessarily be immediately correlated with a 'positive' outcome. For example, it may be that parents' career paths change because they are already dedicating so much time, energy, and personal resources to the disability sector in order to secure services for their child, and this renders it both financially and practically pragmatic to seek out paid employment within the disability sector. In this way, the parent may at least receive payment for the advocacy work they already engage in and utilise knowledge they have already built.

Thirdly, Scorgie and Sobsey (2000) found that parents expanded their friendship networks – befriending other parents of children with disabilities, staff from service agencies, and health care professionals. Interestingly, they also recorded that several parents reported friendship losses. Therefore, it cannot be assumed that gaining friendships is a positive outcome of having a child with a disability without a thorough review of parents' friendship networks before they had a child with a disability. Such an inquiry would potentially yield a more valid comparison.

It is important to note that Scorgie and Sobsey (2000) interviewed parents who had been identified as 'good copers' by two parent advocacy groups or two hospital-based service agencies, and participants were selected using criteria of overall satisfactory family adjustments. This method of recruiting, and this type of methodology, which seeks to specifically explore 'positive outcomes' has the potential to skew data results within the research literature reporting on the experiences of parenting children with disabilities. In acknowledging this, it is also appropriate to clarify that there are benefits to investigating and recognising that there can be aspects of parenting a child with a disability that are positive for some or many parents.

There are parents who report the experience as having a life-changing and transformative impact. Further, it is possible that parents with newly diagnosed children may not feel so

overwhelmed if they know there are positive aspects to parenting a child with a disability. Emphasising such aspects may encourage healthcare and social workers to avoid pathologising responses to these families. In acknowledging this, the reporting of research in this area should be sensitive to the need to situate the data within a broader research context and avoid ignoring the need for social and governmental resources to support these families when emphasising such positive transformations.

## **Summary**

This overview of the literature on parenting children with disabilities has synthesised and drawn attention to the strengths and limitations of research in the field, thus offering a broad-brush coverage of a number of key issues, debates, and evidence-based findings relevant to this study. The research confirms that a majority of children with disabilities in Australia reside in the original family home and care is predominately provided by the mother of the child.

The review of this literature has somewhat reflected concerns relevant to the strands of motherhood and relationships within this study, although literature pertaining to these areas will be reviewed in the following chapter. Although the bulk of research in the field of parenting children with disabilities does not directly address issues of 'self' and 'subjectivities', there has been some research conducted on how women who are mothers of children with disabilities reflect on their sense of self (cf. Carpenter & Austin, 2007; Harvey, 2015; Landsman, 1998/2003; Skinner et al., 1999). This literature is also considered in the following chapter, which reviews the research and scholarly literature on the definitions and role of 'mother', primarily in the context of Motherhood Studies; personal life as it is constituted through relationships; and feminist perspectives on the self.



## CHAPTER THREE

### On Motherhood, Relationships, and the Self

*“Maternal scholars do not reduce women’s sense of self to motherhood,  
say that this is what makes her a woman,  
or that motherhood is more important than other variables  
that constitute self; only that motherhood matters and that it is central  
and integral to understanding mother women’s  
oppression in patriarchy and their resistance to it”  
(O’Reilly, 2014).*



#### Introduction

The purpose of this chapter is to critically review the relevant research and scholarship in three interdependent sections based on the major thematic strands informing this study: motherhood; relationships; and conceptualisations of the self. This review is situated within a global context, drawing particularly from knowledge generated within North America and the United Kingdom.

In the discussion of the work conducted in the field of Motherhood Studies, I take up the critical distinction made by Rich (1976) between the experience of mothering and the institution of motherhood. I explore the importance of the institution of motherhood while addressing gaps in our knowledge of how motherhood continues to operate as an institution in the contemporary world. The review of the Motherhood Studies literature covers three main conceptual innovations that have emerged over recent decades: the institution of motherhood; ‘maternal thinking’; and the social construction of motherhood.

The second section of the literature review examines the research and scholarship on relationships within the sociology of personal life. A major debate within the sociology of personal life is the extent to which processes of individualisation have impacted upon and altered the nature of personal relationships, and subsequently, the contours of the ‘family’. After examining the concept of individualisation and the foundations of this debate, I then review concepts of the ‘family’ as a construction, as practice, and as display. These are key concepts that this study draws on, challenges, and extends.

The third thematic strand relevant to this study is 'self' and subjectivities. Given the vast corpus of literature in the field, I have limited the review to perspectives on the self of relevance to mothers and motherhood and reflective of the constructionist methodology employed in this study. To this end, I concentrate on the work of Mead (1932), Goffman (1959), Chodorow (1981), Juhasz (2003), and Stone (2012). I appraise the literature that theorises the connections between conceptualisations of the self, womanhood, and motherhood. This section concludes with a review of the existing literature on the self in relation to women who are mothers of children with disabilities.

While this study focuses on the experiences of women who mother children with disabilities, and not on disability directly, it is worth noting the ways in which disability is defined and represented sociologically. There are a number of 'models' or approaches to disability evident in the corpus of research and scholarship. Three models in particular are prominent and relevant to the study. The first is the medical model of disability, which understands disability as a problem residing within the body or mind of the individual (Landsman, 2005, p. 125). The second is the social model of disability, which perceives the impediments to a high quality of life for people with disabilities as not being the disability itself, but rather the society that discriminates against persons with a disability (Landsman, 2005, p. 132). The third model is the embodied ontological model of disability, posited by Shakespeare (2006). This model of disability "neither reduces disability to an individual medical problem, nor neglects the predicament of bodily limitation and difference" (Shakespeare, 2006, p. 2). Disability *is* recognised as an important factor in the construction of self, but it is not the *only* or the *fundamental* shaping force in identity and self-actualisation (Shakespeare, 2006, p. 3). It is Shakespeare's concept of disability that informs the study. Although, it is important to reiterate that this research draws no conclusions as to the needs of children with disabilities, their desires, or even their lives. It is solely concerned with the experiences of women who mother children with disabilities.

## **Motherhood**

The research literature on motherhood and the experience of mothers is substantial. Since the 1970s in particular, there has been proliferation of research and scholarship on the material, psychological, sociological, cultural and political dimensions of motherhood, mothering, and the role of the mother. Common amongst this research and scholarship is a consensus that

motherhood instantiates a society's cultural, economic, intellectual, and political history (Vandenberg-Daves, 2002). Furthermore, the literature confirms the extent to which race, class, religion, geography, education, socio-economic status, industrial relations, and culture continue to shape and regulate the experience of mothers. Much of this literature is situated within the academic field of Motherhood Studies, to which numerous disciplines contribute, including sociology, women's studies, gender and cultural studies, psychology, and anthropology, among others.

### ***The Emergence of Motherhood Studies***

As alluded to above, Motherhood Studies is a relatively recent field of research and scholarly inquiry in the academy. Its emergence as a field worthy of critical attention occurred in part as a result of the momentous social and cultural transformations of the Industrial Revolution. Scholars have identified the late Victorian period as a key historical moment in the re-conceptualisation of motherhood (cf. Plant, 2010; Wearing, 1984). During this period, there was greater emphasis on motherhood as not merely a role undertaken within the private, family sphere of society, but as one that was explicitly defined as crucial in 'civilising' and appropriately socialising the next generation – particularly boys – as good moral citizens. This paradigm of 'moral motherhood' carried with it the expectation that mothers assumed primary responsibility for transmitting the prevailing and dominant hegemonic religious, ethical, and moral values to their children (Plant, 2010). The narrowly circumscribed roles for women in the public sphere, such as for instance, teacher, charity worker, or 'wife', were regarded as subordinate to and culturally defined extensions of motherhood (Everingham, 1994). Idealised and romanticised notions of the mother as nurturing, empathic, caring, attentive, and morally directive were underpinned by a strong belief that the mother and homemaker role were full-time positions that were not compatible with participation in the paid labour force (Wearing, 1984).

In the post-World War I climate of the 1920s, however, the Victorian notion of the 'moral mother' became increasingly subject to social regulation and surveillance. For instance, the rise and popularisation of scientific perspectives on and knowledge about, for instance, biology and anatomy influenced the social views of motherhood whereby medical and scientific experts and social reformers began to assert their authority over child-bearing and child-rearing practices. As a consequence, the phenomenon of 'mother-blaming' became more explicit and directed towards middle-class as well as poorer mothers (Plant, 2010, p. 3).

Throughout the 1920s and 1930s there were two predominant concepts of motherhood: one espoused by traditionalists and one by modernists (Plant, 2010). Traditionalists revered motherhood as akin to saintly state that women naturally entered into: a mother's love had the capacity to transform and redeem, and motherhood was perceived as one of the strongest pillars of a nation's social, moral and political order. Becoming a mother meant that an individual had gone through a particular biological experience: it did not guarantee that they had experienced a complete metamorphosis of self into a normative culturally and socially defined role. According to modernists, a mother was also a woman who could pursue interests and activities beyond her children and the home (cf. Plant, 2010).

By the 1940s the transformations of gender ideology precipitated 'anti-maternalism' and mother-blame became commonplace (Plant, 2010). The prevailing notion of motherhood in the post-World War II period was attacked by Friedan in *The Feminine Mystique* (1977). Friedan derided this notion that women could only find fulfilment through raising children and homemaking, arguing that women had become victims of a false ideal that they would find fulfilment in constructing their identity wholly around their families and children. She asserted that this false ideal undermined and even effaced a woman's sense of self. However, revisionist scholarship contends that this view of the post-war era is largely oversimplified (Plant, 2010). While these domestic ideals and false promises were clearly promulgated, there was also, according to Plant, an ongoing tension between these ideals and a consistent emphasis on encouraging individual achievement and contributions to public service. As a consequence, women not only felt oppressed by the 'feminine mystique' that influenced their subjectivity, their achievements, and their sense of fulfilment: "they also felt devalued within their traditional, gender-specific roles" (Plant, 2010, p. 16).

There has been a lack of recognition of the specific needs and experiences of mothers by mainstream feminist movements, starting with the first wave in the 1960s and 1970s. Hewlett (in Umansky, 1996, p. 1) wrote in 1986 that "motherhood is the problem that modern feminists cannot face" and O'Reilly (2015) argues that even still, motherhood remains the unfinished business of feminism. Rich (1976) concluded that "motherhood – unmentioned in the histories of conquest and selfdom, wars and treaties, exploration and imperialism – has a history, it has an ideology, it is more fundamental than tribalism or nationalism" (p. 34). Yet, the issues that feminist movements attend to inevitably have implications for motherhood as a category and a lived experience, and political and social shifts that feminism has facilitated have impacts on all

women – whether they are mothers or not. For example, the shifts in the gender makeup of the workforce as the result of feminism, as well as the greater control women have gained over their reproductive capacities, have profound implications for the notion of the nuclear family and conceptualisations of the mother.

Despite all that the late twentieth century feminist movement has achieved in raising awareness of motherhood as an experience and ideology, it still has more work to do. A glaringly obvious example of this is the ‘motherhood penalty’ whereby mothers receive a wage penalty of around five percent for one child and nine percent for two or more children, which emerges over time rather than through an immediate wage decline post-partum (Livermore, 2010). As Crittenden (2001) argues, many women who are not mothers believe that “all the feminist battles have been won” yet “once a woman has a baby, the egalitarian office party is over” (p. 88).

The types of challenges and barriers that women who are mothers face uniquely relate to their subject position as mothers. Therefore, O’Reilly (2015) has called for a specific type of feminism to address these social, political, economic, and equity issues, coining the term ‘matricentric feminism’. As O’Reilly (2015) articulates, the project of matricentric feminism is to emphasise that the category of ‘mother’ is distinct from that of ‘woman’, and that many challenges women who are mothers face are specific to their role as mothers.

Similarly, Jones (2013) urges scholars to move beyond the “merely discursive, to include consideration of the material conditions of maternal experience”, since “rendering the material reality [of maternity] more visible lends political weight to a fight against national standards that disproportionately negatively impact women, especially poorer or working class women” (p. 291). Kawash (2011) argues that currently, Motherhood Studies is “on precarious ground: ignored by mainstream academic feminism, fragmented and discontinuous in the academic margins” (p. 996), and calls for interdisciplinary approaches between academic, popular, and feminist spheres of thinking and creative action.

The term ‘Motherhood Studies’ was coined by O’Reilly in 2008 who identified a vast and growing body of literature focusing on the study of motherhood, spanning multiple disciplines. O’Reilly (2016) has observed that Motherhood Studies is unusual in that foundational maternal scholarship and literature preceded the ‘naming’ of the field of inquiry. Carving out a space for Motherhood Studies in the academy occurred *after* many of the influential pieces of maternal scholarship were published, rather than before. Some of the foundational maternal theorists,

include Adrienne Rich, Patricia Hill Collins, Sara Ruddick, Nancy Chodorow, Sharon Hays, Ann Crittenden, and Andrea O'Reilly.

Despite the canon of maternal literature that has emerged over the past three decades, Motherhood Studies and other maternal research is arguably still struggling to be recognised as an established and legitimate field of study. O'Reilly attributes this paucity of recognition of Motherhood Studies to the ongoing marginalising of a mother-centred feminism:

Over the last forty years, as feminist theory and women's studies have grown and developed as a scholarly field, they have incorporated various and diverse theoretical models to represent the specific perspectives/concerns of particular groups of women... In contrast, I will argue that women's studies has not likewise recognised or embraced a feminism developed from the specific needs/concerns of mothers (Keynote address, *AMIRCI* conference, 2016).

O'Reilly (2015) contends that "while the 'glass ceiling' and the 'sticky floor' are still to be found in the workplace, most scholars would argue that it is the maternal wall that impedes and hinders most women's progress in the workplace today" (Keynote address, *Motherhood and Culture* conference). Contemporary mainstream feminist movements now recognise the marginalisation and gendered oppression specific to class, race, and ethnicity, and have since embraced 'feminisms' in order to address this marginalisation. However, when mothers in the academy and beyond began to call for a feminism of their own, specific to the needs, concerns and experiences of mothers, their calls were often trivialised or ignored: "feminists are able to understand the intersectionality of gendered oppression when it comes to race, class, sexuality, and geographical location but not so for maternity" (O'Reilly, 2015, Keynote address, *Motherhood and Culture* conference).

O'Reilly postulates that perhaps this is because there are few mothers in positions of power in academia to fight for such recognition, or because non-mother scholars fail to understand or appreciate how becoming a mother influences an individual's position and experience in the world. She links these issues to the broader discomfort that feminist movements seem to have with discussing maternal experience. O'Reilly reflects that perhaps this discomfort is because motherhood is seen as a significant factor in women's marginalisation, which the feminist movement is contesting. The tension that O'Reilly highlights when discussing the



marginalisation of the maternal within mainstream feminism represents the broader tensions that exist between Motherhood Studies and maternal scholarship. The challenge in researching and writing about the experiences of mothers resides in the need to explore the impact that becoming a mother has on an individual's life without essentialising womanhood and motherhood. On this point, Jones (2013, p. 288) warns that in theorising and conducting maternal research, any essentialised or naturalised link between the maternal body and the female body should be disentangled.

The work of many maternal scholars takes up this challenge to resist such essentialism through insisting on the particularity of the mothering experience, emphasising how the experience is inscribed with very personal, individualised features. At the same time, scholars seek to also apprehend patterns and similarities across experiences of mothering related to the institution of motherhood. Kawash (2011) proposes that work on motherhood and maternity “simultaneously insists on the particularity and specificity of motherhood while at the same time rejecting any notion of a fixed or essential aspect of maternal experience, desire, or subjectivity” (p. 972). Individual ‘choices’ about whether to become a mother or not are seen to be shaped by factors that are or can be outside of individual control, such as age, race, education and socio-economic status (Jones, 2013). But regardless of age, race, education and socio-economic status, becoming a mother has so often meant a limitation of freedom of individualised choice and autonomy and a reduction in economic security. Some research also points to an overall decrease in health and happiness (Baumeister, 1991; Evenson & Simon, 2005; Jones, 2013; Kandel et al., 1985; Kawash, 2011; Nomaguchi & Milkie, 2003).

### ***Motherhood as Institution***

The distinction between mothering and motherhood draws on the ovarian work of Rich (1976) who distinguished between the “*potential* relationship of any woman to her powers of reproduction and to children; and the *institution*, which aims at ensuring that potential – and all women – shall remain under male control” (p. 13). Rich has argued that the institution of motherhood functions as key apparatus for withholding women from participating equally in public and political life, and that women can become alienated from their bodies by being incarcerated within them. According to Rich (1976),

the power of the mother has two key aspects: the biological potential or capacity to bear and nourish human life, and the magical power invested

in women by men, whether in the form of Goddess-worship or the fear of being controlled and overwhelmed by women (p. 13).

Rich (1976) does not attack mothering *per se*: rather, she attacks the institution of motherhood as it is defined and perpetuated under patriarchy. While Rich's assertions are undoubtedly shaped by the context of the late 1970s, there is still a widespread disempowering as well as devaluing of the mothering role and mother-work; a continuous privatising of mothering; and a persistence of gendered care-work (cf. Jones, 2013). Further, the 'good mother' construct (Goodwin & Huppertz, 2010) is reinforced socially, culturally, and politically, setting impossibly high standards of idealised motherhood. Each of these factors impinge not only on the lives of mothers, but also on the lives of women who are not mothers, and also on the lives of men.

### ***Maternal Thinking***

In addition to Rich's (1976) theory of the institution of motherhood, Ruddick's (1989) concept of 'maternal thinking' is instructive. Ruddick has argued that maternity is not simply labour, but that it is a discipline that requires a particular type of thinking. She drew on Habermas to conceptualise 'thinking' as a collective practice that develops in response to particular demands. For Ruddick, 'maternal thinking' involves the reflection, emotion-work, and judgement required to raise a child. Ruddick (1989) has argued that regardless of cultural context, raising a child requires preservation (of the child's life), nurturance (of the child's growth), and training or socialisation (of the child to become integrated members of society).

A number of critics of Ruddick's work claim that her theory is ethnocentric, based on universalising notions that ignore the 'thinking' that arises out of classed practices and thus fails to take into account histories of enslavement, colonisation, and racism (Lugones, 2003). Lugones (2003) sees "Ruddick as typical of white feminist theorists in that she seems more intent on protecting the integrity of her theory than on addressing and overcoming the problem of racism" (pp. 69-70, in Keller, 2010, p. 836). Ruddick (1995) addresses such critiques, as well as the criticism that her theory fails to address issues related to mothering children with disabilities, proposing that children with disabilities and non-white children are subject to stigma. She redraws on universalism to address such critiques by asserting that "the conception of a human child, or of all children as human, is an antistigmatising act" (1995, p. xvi). She further contends that preservation, nurturance, and training *are* universal features of

mothering, but it is the way in which mothers respond to these demands and how they materially experience them that is culturally contingent and therefore variable.

Scholars such as Keller (2010) and Bailey (1995) argue that Ruddick's interpretation should focus on 'difference' rather than 'sameness'. Keller (2010) attempts to reconcile the critiques of Ruddick's theory through highlighting the importance of social context, where "the social worlds that appear relatively benign to some mothers and children are experienced as hostile by others" (p. 846). Keller goes on to support Ruddick's (1989/1995, p. 95) view that "[t]o abstract is to simplify complexity, in particular to reduce the manifold issues of moral life into dichotomous choices" (2010, p. 846).

Through Ruddick's articulation of the necessary tools required for maternal practice in raising a child, she re-values maternity without reverting to biological or essentialising arguments. Maternity and maternal thinking is, according to Ruddick, a labour – a discipline that is extremely important – that is shaped by the interests in preserving, reproducing and understanding individual and social life. Ruddick argues that anyone can engage in 'maternal thinking' and asks us to advocate for thinking of men as 'mothers' since she believes that men too can engage in maternal thinking. She later problematises this idea by drawing attention to the close association between the language and discourses of 'motherhood' and 'women', and for this reason many men entirely reject the potential for their own 'maternal thinking'. In addition, Ruddick (1989) wrote that "a man who wants to share mothering can be seen as usurping or overriding women's autonomy and power" (in O'Reilly, 2009, p. 28), conceding that she was "afraid of bringing the power of Symbolic Father into the nursery unless mothers were privately self-respecting and publicly respected" (in O'Reilly, 2009, p. 28).

Exploring this notion of the 'male mother', Doucet (2006) in *Do Men Mother?* investigated "the stubborn link between women and domestic responsibility ... to encourage fathers' unpaid caregiving work" but in doing so was "aware of the alarming political and theoretical traps that may await feminist research on fathering" (p. 20). Miller (2016) also considered the possibility of whether parenting can ever truly be equally shared between the sexes by researching maternal and paternal 'gatekeeping' practices, discussing the 'mental labour' that caring for a child requires. As discussed in the previous chapter – On Parenting Children with Disabilities – research into the specificity of raising children with disabilities may involve particular attention to 'mental labour', the 'maternal thinking' and the 'emotional labour' (Hochschild, 1983) required in raising children and how these practices are constructed and reproduced.

### ***Maternal Thinking and Emotional labour***

One of these specificities is the 'cognitive' and 'affective' work expected of those who mother children with disabilities. This type of work can be understood by drawing on Hochschild's (1983) theory of 'emotional labour' and positioning Ruddick's (1989) concept of 'maternal thinking' as *a part of* this theory of emotional labour. The term 'emotional labour' was originally coined and described by Hochschild (1983) as the process whereby an individual's feelings are managed in accordance with normative ideals. Hochschild used the concept to understand the structure of, and social interactions within, service jobs. As an example, Hochschild cited the case of female airline cabin crew who are required to perform not only mental and physical labour to be successful in their jobs, but also emotional labour to manage their emotions and the expression of these emotions.

Emotional labour then, refers to the emotional and relational work involved in an interaction, and is directly pertinent to the lives of those involved in care-work, where the emotions of the carer are as implicated in their experiences as the physical nature of the care-work itself (Steinberg & Figart, 1999). Runswick-Cole's (2013) work is relevant to this study because it connects the concept of emotional labour with the experiences of women who mother children with disabilities. She argues that mothers of children with disabilities engage in emotional labour in multiple contexts, such as "the park, the supermarket, schools, hospitals, clinics, assessment meetings, within the home and across different hierarchical divisions as they interact with professionals, friends and their children" (Runswick-Cole, 2013, p. 108). She studied the ways her participants anticipated and managed the emotions of others as part of a cultural performance of mothering. Runswick-Cole (2013) also marked out some notable distinctions between the emotional labour of service workers that Hochschild (1983) described and the emotional labour of mothers of children with disabilities: "mothers of disabled children also seem to anticipate future emotional labour as they worry about what the future will hold for their children" (p. 117).

Ruddick's concept of maternal thinking encourages understanding 'mother' and 'mothering' as verbs, and describes the ways women who are not biological mothers can 'mother', and the ways in which men can 'mother'. To 'mother' means engaging in an intellectual endeavour: "the work of mothering demands that mothers think; out of this need for thoughtfulness, a distinctive discipline emerges" (Ruddick, 1989, p. 24). Ruddick's work has been influential in

positioning mothering as ‘mother-work’ since this “made possible the development and articulation of the many and diverse voices that created and now compose the new discipline of motherhood studies” (O’Reilly, 2009, p. 297).

While I am drawing parallels between ‘emotional labour’ and ‘maternal thinking’, ‘maternal thinking’ can still be conceptualised as distinct from Hochschild’s concept of emotional labour. Ruddick’s concept specifically refers to the *thinking work carried out by mothers* characterised by the demands of preservation, growth, and training. To illustrate how mothers of children with disabilities may experience and exercise maternal thinking, Kittay (1999) has provided an account of ‘maternal thinking’ in her own experience of raising her daughter who has a disability. Kittay suggests that there are indeed significant practices as part of maternal thinking that differ from Ruddick’s original concept, but that the exercise of maternal thinking can also be similar for mothers raising children who do not have a disability.

According to Kittay (1999), Ruddick’s conceptualisation of the demand of ‘training’ a child to be socially integrated and acceptable as part of maternal thinking means something else for mothers of children with disabilities. This is because the latter have to negotiate concepts of ‘acceptance’ and ‘normality’ in different ways. Mothers of children with disabilities can often go to great lengths to emphasise the ‘normality’ of their child with a disability. Feder and Kittay (2002) reinforce this point with the example of how Kittay is particularly conscious of the cleanliness and type of clothing that her daughter with a disability wears. She strives to ensure that her daughter presents “a face to the world that is as attractive as possible so that the first response to her is as positive as I can make it” (Feder & Kittay, 2002, p. 109).

A further difference between Ruddick’s original concept of maternal thinking and Kittay’s reflection centres on a mother’s capacity to nurture the development and growth of their child:

for a child with disabilities ... development is never a given. It is not only fostering development but *enabling development* that a mother of a disabled child puts her heart and mind to. Enabling the development of a disabled child involved navigating complex straits” (Feder & Kittay, 2002, p. 111).

Elucidating some of the ways in which mothers of children with disabilities engage in maternal thinking reveals how emotional labour can be seen to be embedded in the hegemony of motherhood. The ways mothers of children with disabilities engage in 'maternal thinking' may conform to, differ from, or extend Ruddick's (1989) original concept of maternal thinking, but nonetheless offer further insights to the extent to which emotional labour is a key component of the work of mothering.

### ***The Social Construction of Motherhood***

The category of 'mother' is freighted with value-laden meanings and assumptions, is ascribed a moral dimension, and is bound to the prevailing, dominant ideologies in a society (Hays, 1996, p. 19). It is in Chodorow's influential book – *The Reproduction of Mothering: Psychoanalysis and the Sociology of Gender* (1978) – that this position is most powerfully argued. As Chodorow asserts, when we speak about someone 'mothering' a child, it carries a very different meaning than if we were to talk about someone 'fathering' a child: "being a mother ... is not only bearing a child – it is being a person who socialises and nurtures" (1978, p. 11). Following Chodorow's influential work, there has since been a significant amount of research investigating mothering as an experience and theorising motherhood as a cultural and historical construction (cf. Elliot et al., 2013; Douglas & Michaels, 2004; Goodwin & Huppertz, 2010; Hays, 1996; Maher & Saugeres, 2007; O'Reilly, 2015; Ruddick, 1989).

The notion that motherhood is socially constructed is one that has been extensively explored by theorists such as Chodorow (1979), and it is on the basis of such scholarship that the 'good mother' concept has emerged (Goodwin & Huppertz, 2010). This concept is understood to be one that arises from prevailing ideologies, such as 'the new Momism' (Douglas & Michaels, 2004) and 'intensive mothering' (Hays, 1996). Hays (1996) argues that intensive mothering ideology is a powerful and pervasive concept that constructs the 'good mother' to be self-sacrificing, not subject to her own needs and interests, wholly child-centred, not economically self-sufficient, monogamous, and her mothering is exclusive, emotionally involving, and time-consuming (Adams, 1995, p. 414; Arendell, 2000, p. 1193; Bassin et al., 1994, p. 2; Goodwin & Huppertz, 2010, pp. 5-6). Intensive mothering ideology sets up this image of the 'good mother', through which mothering experiences are mediated, influenced, and judged. The ideology of 'intensive' and 'good' mothering is frequently and powerfully represented in the media and forcefully inscribed and perpetuated in popular culture, thereby creating romanticised and unattainable standards of perfection for mothering.

Motherhood ideology is entwined with an image of the “idealised white, middle-class, heterosexual couple” (Arendell, 2000, p. 1194). This image is implicitly linked to theories of gender stratification but is also adaptive in its constraints: for who is the ‘good’ working mother, the ‘good’ adoptive mother and so forth? (Goodwin & Huppertz, 2010, p. 2). Gurevich’s (2008) discussion of the ‘good mother’ suggests it is a “modern, expert-defined, and culturally white middle class creation” (p. 521). As a product of intensive mothering ideology, the image of the ‘good mother’ is one that has become an established normative construct, “a mechanism through which women do what they ‘should’” (Goodwin & Huppertz, 2010, p. 4) and anything that falls outside the parameters of this construct judged as deviant, deplorable, or even morally corrupt.

Hays (1996) argues that these idealised constructions of ‘good mothering’ ultimately stem from ambivalence about a social and economic system that is based on individual pursuits of self-interest. Hays’ (1996) point goes directly to theories of individualisation, reflexive modernity and Beck’s (1992) ‘Risk Society’, as well as to the rise of neoliberalism over the past decades. Hays (1996) asserts that we have attempted to deal with an underlying uneasiness about self-interest through imposing unrealistic standards and expectations on mothering. This renders motherhood a somewhat contradictory phenomenon within a society that is supposedly fuelled by individual self-interest. For Hays (1996), motherhood is therefore a site in which complex cultural ambivalence is played out.

This ambivalence around, and the evolution of, the ‘good mother’ construct can be historically traced and interpreted, as has been touched on in the review of literature thus far. With the emergence of industrial capitalism and the participation of females in paid employment outside the home, the topography of motherhood began to shift (Brush, 1996, p. 5). Chodorow (1978) has proposed that this shift prompted a separation between the private sphere of domestic reproduction and personal life, and the public sphere of social and economic production and the state. She believes that this separation has produced a “family form reduced to its fundamentals, to women’s mothering and maternal qualities and heterosexual marriage, and continuing to reproduce male dominance” (p. 10). While this explanation seems plausible, by placing such emphasis on the ‘separation’ of spheres, it does not take sufficient account of the complexity of the construction and reproduction of the ‘good mother’ ideal that pervades both the private and public spheres.

Rather than cementing a marked separation between public and private spheres, industrialisation and capitalism may be seen to have had 'blurring' effects on the demarcation of such spheres themselves (Collins et al., 2003, p. 40). Chodorow's assertion – while on the one hand criticising patriarchal structures – is derivative of such structures, being grounded in a liberal humanist model of democracy. Scholars such as Fraser (1990, 1992) challenge such models and argue that the gender stereotyping of the public and private sphere is a falsely dichotomised binary. Instead, Fraser (1990, p. 90; 1992, pp. 598, 610) argues that different spheres are shaped and delineated by political, social, historical, and ideological agendas and variables; and that within and between these spheres there is a gender hierarchy in place that bestows power on men to draw and maintain boundaries between the public and the private as part of the patriarchal control of women.

Despite this gender hierarchy and binary, neither 'gender' or 'motherhood' are adequate signifiers for the experience of mothering. All mothers do not "nurture, protect, or socialise their children in identical ways or circumstances, nor do they necessarily provide such care at all" (Arendell, 2000, p. 1195). Contrary to the view embedded in and perpetuated by the 'good mother' ideology, Kristeva (2005) believes that from a psychoanalytic perspective motherhood is not, in fact, an 'instinct'. Rather, Kristeva (2005) theorises that motherhood is a passion in the sense that complicated emotions turn into love, where the 'good enough mother' (a term originally coined by Winnicott, 1953) succeeds in loving her child as herself, and then as another self. Kristeva's (2005) psychoanalytic perspective suggests that by attending exclusively to the biological and/or social aspects of motherhood, as well as elevating the tenets of sexual freedom and equality, we have become the first civilisation that lacks a discourse on the complexity of motherhood. Bassin et al.'s (1994) work could be offered as a response to that of Kristeva's (2005), as these authors rescue the mother from her status as 'object' by reclaiming 'mother' as 'subject'. They are interested in how women "appropriate, resist, and create a multiplicity of meanings about motherhood" (p. 8). They highlight the contradictions between maternal imagery and maternal practice itself and attempt to "broaden the ground on which motherhood is constructed" (Bassin et al., 1994, p. 8).

Yet as Arendell (2000) notes, the discourses and expectations that have developed as a consequence of the intensive mothering ideology have persisted "despite cultural contradictions and diverse arrangements and practices" (p. 1196). 'Good mothering' ideology has remained the heteronormative standard by which mothering practices and arrangements are perceived, regulated and evaluated. Mothers who do not conform to the script dictated by the 'good



mother' ideology are surrounded by discourses of deviancy (Arendell, 2000, p. 1195). Thus, while becoming and being a mother can confer on a woman a sense of maternal power, it can also be an immense burden of responsibility rendering her subject to judgement by durable and pervasive societal expectations (Arendell, 2000, pp. 1195-1196; Hays, 1996, p. 5). Despite the transformation in gender relations and women's relationship to paid employment, the power of the 'good mother' concept as normative endures (Adams, 1995, p. 427; Arendell, 2000, p. 1195).

There are obvious disjunctions between the construction of the 'good mother' and the actual lived experiences and maternal materiality of women who are mothers. Being a mother carries shifting and fluid meanings, and while individualised experiences may never be homogeneous, it is productive to seek patterns and commonalities in the larger canvass of a plurality of individual lives (Arendell, 2000, p. 1196). Because the experience of mothering does seem so intimate and personal, there needs to be a respect for the diversity of experience, yet at the same time it has to be recognised that there also needs to be a consideration of what mothers share in common (Ryan & Runswick-Cole, 2008, p. 204). As Bordo (1990) encapsulates: "certainly, we often err on the side of exclusion and thus submerge large areas of human history and experience. But attending too vigilantly to difference can just as problematically construct an Other who is an exotic alien, a breed apart" (p. 140).

The fact that many mothers share a broader social context means that there may be certain experiential continuities and a collectivised pooling of common meanings and experiences of motherhood, which in turn invites inquiry into the personal, social, political, cultural and economic impact and implications of the 'good mother' concept as normative in individuals' lives. Thus, in exploring how the social construction of motherhood and the concept of the 'good mother' operates in the lives of women who mother children with disabilities, this study aims to contribute to the scholarship in the field of Motherhood Studies.

### ***Patriarchy and the Regulation of Motherhood***

The question that inevitably arises from an understanding of the social construction of motherhood is: what are the conditions that allow such ideology to become constructed and perpetuated? Chodorow (1978, pp. 8-9) contends that the organisation of a sex/gender structure in our society is created as a systematic way to deal with sex, gender, and babies; and that women's role as mothers is a central and defining feature of this organisation, implicated in the construction and reproduction of male dominance. The idea that all women have an

important maternal role “has a profound effect on women’s lives, on ideology about women, on the reproduction of masculinity and sexual inequality, and on the reproduction of particular forms of labor power” (p. 11). This assumption that the maternal role is ‘natural’ (resonating with the previous discussion of the construction of the ‘good mother’ ideology) presupposes that the structure of parenthood is biologically self-explanatory, and the universal and instinctual nature of motherhood is therefore often viewed as inevitable, natural, and unchanging (pp. 13-14). Chodorow’s response to this phenomenon makes the need for questioning such assumptions even more pressing:

There are undeniable genetic, morphological, and hormonal sex differences, which affect our physical and social experiences and are (minimally) the criteria according to which a person’s participation in the sexual division of labour and membership in a gender-differentiated world are assigned (p. 15).

One of the assumptions of ‘good mothering’ ideology – that motherhood is a central and defining dimension of a woman’s life – still prevails in powerful and socially explicit ways. Take for instance the burgeoning of reproductive technology industries and the pervasive images of ‘woman as mother’ in popular culture and media. Alongside this is an increasing fluidity in gender roles, expectations, and concepts of parenting, together with an anxiety about the nature and forms of motherhood in modern society. As Gurevich (2008) argues, “we are experiencing a period of destabilisation of gender where new concepts and ways of being and relating are coming into play, while the old notions still retain a grip on cultural, political, and legal institutions” (p. 531). Yet, Foucault (2003) suggests that there has been a move away from traditional patriarchal concepts of motherhood towards more paternalist ones involving the state. However, Gurevich’s (2008) account of patriarchal notions of gender within institutional frameworks highlights the continued regulation of the maternal body and on a woman’s ability to reproduce and then undertake mothering.

The way the state reinforces gender norms and sex division is through “their disciplining and normalising discourses of hygiene, nutrition, sexuality, and child-care” (Gurevich, 2008, p. 518). This normalising and naturalising of the ‘good mother’ construct is implicated in the discourses employed to categorise ‘good’ and ‘bad’ types of mothering and behaviours. Goodwin and Huppertz (2010) propose that such discourses have a number of functions. They serve to ensure women take on the child-rearing role, and that their identity as women is tied to their role as

the main caregivers for their children. Additionally, such discourse more generally regulates “families and family life, it controls the reproduction of the next generation of citizens, it is also implicated in shoring up the dominant culture and driving nation-building agendas” (Goodwin & Huppertz, 2010, p. 6).

Regulation of women and their role as mothers is embedded within institutional patriarchy. The ways that patriarchy as an ideology is encoded within society is such that its presence is elusive and seemingly natural (Chodorow, 1978, p. 14). That patriarchy is deeply inflected in cultural and social life affords it a status unlike that of any other social structure (Fineman, 1995, p. 23). Fineman (1995) directly associates the patriarchal system with the system of gender division in the way that Butler (1990) defines it: that is, as a social *construction*. The patriarchal system affects individuals even before their birth, as they will be categorised into a grouping of a sex binary (Butler 1990, p. 25-26). This patriarchal ideology is impressed upon individuals in so many ways that each comes to “adopt it, internalise it, and impose it on others” without ever appearing to question it (Fineman, 1995, p. 23).

If an individual is seen to resist the structures that this ideology requires and authorises, through for example, rejecting the idea of being a mother (if that individual is a woman), or asserting one’s LGBTI identity, then they are seen to exist outside of the ‘norm’ and are therefore considered deviant and/or resistant. The normalised idea that a woman’s gendered self is tied so closely to her ability to produce and raise children is one of the consequences of patriarchy: “hegemonic motherhood remains subordinated to and under the force of hegemonic masculinity” (Arendell, 1999, p. 4, in Goodwin & Huppertz, 2010, p. 5). This study interrogates how patriarchy and regulation is experienced in the lives of women who mother children with disabilities.

## **Relationships**

Research on motherhood foregrounds the constraining effects that the institution of motherhood can have on a woman’s sense of self, her sense of agency, her relationships, and her experience of individual freedom. These constraints are operationalised through institutionalised social arrangements and practices (Hays, 1996). While Motherhood Studies provides recognition of the plethora of research and scholarship on the mothering experience,

and a visible means through which this work may be amplified, the sociology of personal life<sup>2</sup> as a distinctive sub-field of inquiry reflects the development of theoretical insights into and empirical attention to the experiences of the family, kinship, friendship, same-sex relationships, and cross-cultural relationships. The emergence of scholarly interest in the sociology of personal life can be seen as a response to the conceptual developments in understanding how individuals' relationships – particularly familial ones – are socially constructed. Therefore, as Motherhood Studies recognises the social construction of motherhood, the sociology of personal life recognises the social construction of kinship relationships.

Motherhood Studies has not explicitly drawn on nor recognised the scholarship within the sociology of personal life, and conversely, the sociology of personal life has not explicitly drawn on nor recognised the scholarship within Motherhood Studies. As I noted earlier in this thesis, the study seeks to address this lack of continuity through connecting and building on these hitherto discrete areas of sociological inquiry in order to deepen and extend our knowledge of motherhood and in particular, the experiences of women mothering children with disabilities.

One approach to synthesising the existing research on motherhood with that in the field of the sociology of personal life is through a focus on a key theme of both fields that bears directly on this research: that is, the ways in which individual freedoms and the exercising of individual choice influences people's experiences of the 'family' and the relationships that make up their personal lives. Common to both Motherhood Studies and the sociology of personal life is attention to 'motherhood' and the 'family', respectively, as social constructions rather than as biological imperatives. While the preceding section of this review has explored motherhood as an institution and as a construction, the following section explores changes in understandings of the 'family', propelled by processes of individualisation and the ways in which the 'family' has come to be understood as a social construction.

### ***Sociology of Personal Life***

The sociology of personal life has developed as a result of a progression of thinking and theorising about personal relationships and the family (Smart, 2007). The shifts in the definition of the family as a fixed institution delineated by blood and kinship ties, towards understanding family as a construction, has altered the way traditionally named 'family studies' is understood.

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<sup>2</sup> The emergence of the 'sociology of personal life' is a response to the conceptual developments in understanding how relationships operate, and the ways through which individuals' relationships – particularly familial ones – are socially constructed.

Reframing a sociology of the family to the sociology of personal life allows for a variety of definitions of the 'family', and encompasses research into various other conceptualisations and configurations of how people experience interpersonal relationships and connections. Repositioning the 'family' as being about practices rather than being an institution in itself, together with recognising the role of family 'displays' (Finch, 2007), serves to encourage greater inclusivity and fewer restrictions of categories when engaging in research on personal life.

There is disagreement in the literature within the sociology of personal life regarding the impacts that the processes of individualisation have on individuals' personal lives, and the consequences of individualisation for families. This study contributes to the debate regarding the consequences that these processes have on the lives of women who mother children with disabilities, and is attended to primarily within Chapters Eight and Nine. It is important to highlight that within the parameters of this debate – based on the current review of literature – there has been no research within the context of the sociology of personal life into the experiences of women who are mothers of children with disabilities in. This is a significant gap that this study seeks to redress.

### ***Individualisation***

In outlining the theory of individualisation that underpins debates within the sociology of personal life, I am interested in the literature that examines the extent to which individuals are able to exercise control over their lives, and subsequently the construction of their families. This process of individualisation, and the various consequences of the process that have been proposed, inform the interpretation of the findings of this study.

It has been argued that pre-modern societies were based on communal structures where people were embedded within communally formed relationships (Beck, 1992). Beck suggests that communal structures moved to collective structures in early modern societies, where individuals formed relationships based on shared interests, needs and wants. He contends that we are now in a period of late modernity (or reflexive modernity), where individual agency occupies an ascendant position in social systems, networks are flexible, and individuals lead self-monitoring lives. Individuals, according to Beck (1992, 1994), are at the centre of their own self-organising life narratives: they are the authors of their own lives. This view of the primacy of individual choice and flexibility is at the heart of what drives the individualisation thesis. Individualisation theory posits that in light of modernity, industrialisation, globalisation, and

the rise of technology, the nature of our institutions has significantly changed. Because this change has led to a rise in individual freedom of choice, the latitude for exercising individual choice may be at odds with traditional social patterns and expectations.

A consequence of modernisation and individualisation, according to Beck (1992), is the rise of the 'Risk Society'. The risks society faces – caused by human progress – are being negotiated in this period of reflexive modernity. Society has changed and is changing in order to cope with the risks generated by modernity itself. Because of modernisation and individualisation, the structure of the 'family' has been rendered precarious and vulnerable, and therefore this precariousness creates a new and added dimension of risk for individuals (Beck-Gernsheim, 1998). So while individuals may experience a greater array of opportunities to shape their own biographies, they are now doing so, according to Beck (1992), within a 'Risk Society'.

It is important to note that while individualisation theorists argue that individuals experience a greater freedom of choice and agency when constructing their biographies and personal communities, they do acknowledge that the individual is still impacted by structural constraints (cf. Beck & Beck-Gernsheim, 2002; Woodman, 2010): it is just that these structural constraints are framed as somewhat postmodern in nature (Ray, 2005, p. 4). The structures of society are "no longer the mainsprings of family behaviour" and Duncan and Smith (2006) argue that as a result of individualisation, these structural constraints are treated as "historical lags which will gradually disappear" (p. 3).

While individualisation is theorised as a way of explaining changes in social life, it also intersects with trends in sociological thought to "highlight notions of choice and autonomy in writings about contemporary Western societies" (Brannen & Nilsen, 2005, p. 412). Brannen and Nilsen (2005) argue that individualisation intersects with a preoccupation with ideas of choice and agency in contemporary Western society, becoming

an important part of the public discourse as well as social science language used to analyse many fields of people's lives. The freedom to choose is the marker of the free, autonomous individual, and it is an important ingredient in the notion of agency (p. 412).

However, while individualisation features prominently in discourses and understandings of social life, an emphasis on autonomy and choice obscures interdependencies, as well the extent

to which structural constraints place limitations on people's lives (Brannen & Nilsen, 2005). Brannen and Nilsen (2005, pp. 423-424) suggest that while discourses of individualisation can serve an ideological purpose in shaping individuals' *perspectives* about their own lives, it disempowers the very people whose lives are heavily constrained by social conditions.

While Brannen and Nilsen (2005) critiqued the ways in which individualisation has been adopted as a discourse and social theory, Duncan and Smith (2006) identify contrasting debates about the consequences of individualisation on contemporary social life. The first of these consequences is articulated by Weeks et al. (2001) and Giddens (1992) who suggest that individualisation has positive impacts on society, allowing a greater diversity of family forms and lifestyle choices. According to Weeks et al. (2001), individualisation has allowed individuals to be liberated from the confines of social institutions and expectations that dictate what trajectory an individual life should take and how the 'family' should be defined. Ray (2005) also recognises the ways in which individualisation has enabled flexibility, but argues that the generation of a 'risk society' as a result of individualisation, has in reality merely created a different type of obligation. That is, individuals may now have a greater sense of agency and freedom of choice, but they are also more explicitly compelled to take personal responsibility for this freedom. Theorists such as Ray (2005) would suggest that previous obligations based on solidarity and shared interests have now been replaced by obligations born of freedom of choice and individual agency.

The second consequence of individualisation, as proposed by Bauman (2003), is that the changing nature of institutions and social obligations has actually led to the disintegration of the family rather than its restructuring. Individualisation, framed in this way, ultimately results in social fragmentation and isolation. In response to individualisation and the growth of a 'risk society', and reprising Bauman's concerns, Smart and Shipman (2004) contend that

[o]ne can, it seems, begin to predict the growth of societies where kinship networks cease to exist, where few couples will commit to each other beyond a few years, where children who have experienced their parents' divorce become deeply ambivalent about marriage, and where there is almost frenetic emotional mobility and only fleeting, serial relationships (p. 493).

Spencer and Pahl's (2006) critique offers a response to these predictions, arguing that despite individualisation and the changing nature of the family, individuals still maintain strong networks of personal communities and social connections:

Personal communities represent people's significant personal relationships and include bonds which give both structure and meaning to their lives ... personal communities provide a kind of continuity through shared memories, and help to develop a person's sense of identity and belonging (p. 45).

It is worth pointing out here that Pahl and Spencer's (2004) definition of 'personal communities' was utilised as a methodological tool in this research project (see Chapter Four) to provide a lens through which to examine participants' personal lives in the context of theories of reflexive modernity and individualisation.

A further repercussion of individualisation that is coextensive with the two consequences identified by Duncan and Smith (2006) is the evolution of the idea of personal agency and individual responsibility. Ruitenberg (2014) draws on the work of Everingham, Stevenson and Warner-Smith (2007) to propose that "concepts such as individualism and the possibility of self-agency have created the expectation that people are able to make their own decisions, and so are appropriately responsible for their own choices" (p. 19).

This notion of individual responsibility has implications for the ways in which motherhood is understood and lived out within the context of individualisation. For example, Duncan and Irwin (2004) demonstrate the ways in which mothers' decisions are socially patterned and prescribed rather than directed by individualised rationality. Hence, the debates within the field of the sociology of personal life about the nature of individualisation and its implications for an individual's lived experiences have direct bearing on this research inquiry: they offer contested perspectives on the applicability of individualisation theory and these are explored as part of the analysis of data gathered in this study.

### ***Family as Construction***

In concert with developing theories of the consequences of individualisation, work in the field of the sociology of personal life has sought to reframe and reconceptualise personal relationships



and the family. As I have discussed above, researchers such as Bauman (2003) argue that individualisation has resulted in a fracturing of social ties, and therefore has consequences for the make-up of the 'family'. This link between the impact of individualisation and the structure of the family is supported by Ribbens and Edwards (2011) who observe that "much of the contemporary debate about family in European and New World societies centres on the idea that there has been unprecedented change in families since industrialisation and into the twenty-first century" (p. 62).

Mason (2008) suggests that individualisation has prompted a fascination with kinship and tracing genealogy, which is an indicator that in contemporary social life individuals do not feel deeply connected and are thus seeking this sense of security and meaning in tracing kinship lines. Affinities are regarded in some ways as negotiated and also as creative (Mason 2008). Further, Finch and Mason (1999, 2000) suggest that the assumptions people make about the obligations that they have towards family do not necessarily stand up to empirical scrutiny. In their research they found that respondents remained ambiguous regarding kinship obligations, and this reflects the fluid and mutable ways in which kinship relations are defined and kinship obligations are understood (Finch & Mason, 1999; Mason & Tipper, 2008). As a result of these altered perspectives on kinship, Mason and Tipper (2008) argue that we need to move beyond the idea of the traditional Western concept of the 'family' towards broader understandings of concepts of relatedness. Kinship relationships, they contend, are shaped through both shifting public and legal understandings of 'relatedness', as well as through individuals' own creative negotiations in their private and public spheres.

### ***Family as Practice***

Extending this view of the family as an unstable phenomenon, Morgan (1996) conceptualises the family as being constituted by a set of *practices*. He argues that the 'family' is not an institution, but is instead a manifestation of social life, representing a 'quality', rather than a 'thing' (Morgan, 1996). This understanding of the family as set of practices emphasises a sense of individual agency, drawing on the theory of individualisation. Morgan (2011) goes on to stress, however, that although people may appear to 'do' family and carry out family practices, this does not necessarily mean that they do so willingly:

individuals might wish to 'do' family in a particular way, to be 'good' parents and so on but feel constrained, through the scarcity of key

resources, from doing so to the fullest extent. It may be argued that these notions of 'good' themselves constituted another kind of ideological constraint (p. 67).

In Morgan's (2011) revised definition of 'family as practice' he acknowledges the persistent constraints placed on such practice. Countering Morgan's view, however, Widmer et al. (2008) suggest that family relationships continue to be embedded within social structures, are highly complex and nuanced, and their nature and constitution cannot be explained through practices alone.

### ***Family as Display***

Building on the work of Morgan, Finch (2007) has argued that 'displaying' family is just as important as 'doing' family. Like Morgan, Finch regards the family not as a 'thing', but rather as a quality that is to be 'displayed' so it can be established and recognised. So while Morgan's (1996) work redirected an analysis away from considering the 'family' as a structure towards understanding the family as a practice, Finch (2007) extends this analysis to understanding family practice as being constituted, enacted and reinforced through 'display'. There are a number of theorists who have subsequently both critiqued and elaborated this notion of 'family as display'.

Heaphy (2011), for instance, advocates for the concept of 'display' to be refined in order to account for and address issues of power and politics. He warns against the concept being appropriated to elevate or privilege particular forms of display over others, where 'displaying' family may only be recognised and validated depending upon how these displays reflect and affirm normative understandings of the family – which are typically middle-class and white. He suggests that links can be made between display and performativity to acknowledge the nexus between notions of 'display' and indices of power. Similarly, Gabb (2011) has added that not all forms of 'display' receive recognition and affirmation, since sometimes family practices occur that fall outside of the prevailing definitions and parameters of 'display'. This is a particularly useful understanding to be mindful of when considering the various ways in which participants in this study may interact with their children with disabilities. Such interactions and displays may not necessarily align with or mirror those commonly accepted and evident in broader, public contexts. On this point, Gabb (2011) draws attention to an important distinction by arguing that display is not a factor in the internal workings of relationships. Therefore, the

utility of analysing 'display' is contingent on identifying, interpreting, and assessing what exactly is being displayed and why these displays appear in the forms that they do (Gabb, 2011). This distinction is particularly salient for this study of women who are mothers of children with disabilities.

In the preceding section of this review, I have discussed selected literature on relationships in order to generate new and significant associations between the emergence of Motherhood Studies and the development of the field of the sociology of personal life. The literature I have concentrated on here has clear relevance to this study's analysis and interpretation of the participants' experiences of being mothers and having personal lives and relationships. Equally apposite in a study exploring experiences of motherhood and relationships is the literature on the self: the third of the three thematic strands of this research.

### **Theories of the Self**

A study of motherhood and relationships inevitably requires consideration of concepts of self, since experiences of mothering and other relationships are often constitutive and reflective of, and also challenging to self-formation. Sociologists, psychologists, psychoanalysts, philosophers, educators and scholars from a host of other disciplines have wrestled definitions of the human self for centuries. Indeed, the exploration of concepts of the self can be traced to the work of the Ancient Greek philosophers and theorists such as Socrates, Plato, and Aristotle. Given the extent of research and scholarship on the self, the scope of the following review is necessarily focused on the literature directly relevant to the study of women who are mothers of children with disabilities. My interest here is in feminist perspectives on the self. I begin by situating the review within the foundational work of Freud (1923), Mead (1913/1934) and Goffman (1959) and then link this work with the feminist literature on the self by Kristeva (1980), Chodorow (1981), Butler (1990), and Juhasz (2003) and examine the specific connections between notions of self, womanhood, and motherhood. I conclude this section by reviewing the extant literature concerned with 'self' and mothers of children with disabilities.

A dominant stream of modern Western philosophical thought has championed the individual, and this championing has extended to analyses of the self, and the theorising of a concept of the self that is not subject to ambivalence, violence or anxiety (Willett et al., 2016). The two streams of thought that characterise this view are based on the Kantian ethical subject that sees reason as transcending cultural norms to discover 'truth'; and *homo economicus*, which is based on

utilitarianism to rank desires and ultimately maximise individual desire satisfaction (Willett et al., 2016). Countering these concepts of self, a number of philosophers and theorists, particularly feminist philosophers and theorists, have argued that rationality alone does not constitute the self, and neoliberal models championing individualism often encode misogynist subtexts (Willett et al., 2016). Key feminist perspectives on the self move beyond an understanding of self based purely on rationality to theories that strive to disentangle the normative conflation of womanhood, the female body, maternity, and human subjectivity.

### ***Feminist Perspectives on the Self***

Although feminist ambivalence regarding the theories of Freud (1923) has been well-documented in the research literature, aspects of his work can offer instructive insights for understanding the self from a feminist perspective. Freud (1923) argued that the human psyche is not static or one-dimensional, but is made up of a variety of different parts. Freud's and some feminist perspectives on the self may initially appear to be an unusual alliance, since aspects of Freud's work positions women as 'the problem', and can be interpreted as misogynistic (Cohler & Galatzer-Levy, 2008). Considering the enduring currency of Freud's theories of the self, manifested in the 'story' of "the (male) subject fighting for his subjectivity distinct from his maternal origins", Jones observes that the "mother represents both romanticised origin and existential threat" (2013, p.284).

However, feminists have interpreted and appropriated dimensions of Freud's work for a range of feminist purposes. For example, psychoanalytic feminists such as Adler (1927) and Horney (1967) have drawn on Freudian theory to explain the implications of patriarchy and subordination for a woman's subjectivities. In critiquing Freud's positioning of women as inferior to men, a number of feminist theorists deploy Freud's theory to interrogate the key issues of sexual difference and the way women are 'othered' in response to men (Graff, 2012). Freud's theory of the self contends that humans can experience multiple feelings, thoughts and impulses simultaneously, and that the (male) self is entangled, complicated, and often ambivalent. In this way, an understanding Freud's fundamental concepts of self and identity formation is useful in a feminist analysis of the self in that these concepts represent the entangled, complicated, and often ambivalent nature of the (female) self in the context of patriarchy and women's subordination.

An extension and critique of Freud's (1923) work on the self is offered by Mead (1934) who argues that the self is primarily constructed through an individual's interactions with other people. This understanding of the 'self' as developed through interaction with, and in reference to, the 'other', has become a central theme in feminist theory (Fischer, 2009). Mead rejects Freud's assertion that biological factors determine aspects of the self, and suggests that the key to understanding how the self is formed is to attend to the process and dynamics of how individuals understand others. According to Mead, there is a nexus between one's sense of self and one's participation in society, thereby establishing the 'other' as constitutive of the self. The self that is formed through interaction with the other is termed the 'me' by Mead (1932). Mead also conceptualises the 'I', separate to the 'me', but argues that the 'I' functions as an individual's source of spontaneity and freedom. This 'I' that constitutes part of the self, however, can never be recognised by us or reflected on: if we partake in reflection then we are doing so from the 'me' dimension.

Just as Mead (1934) recognises the impact of social interaction on the self and argues that the self develops through social exposure and interaction, Goffman (1959) similarly elevates the significance of social interaction on the formation of the self. He argues that we assimilate, learn to act out, and embody socially prescribed roles based on this social interaction. Both Mead and Goffman assert the primacy of the 'social' when conceptualising the self, although they disagree about *how* the self develops in relation to the social. Goffman sees the self as a constellation of Mead's 'me' roles, whereby an individual learns to adopt a range of social roles and enact behaviours that are seen to be consistent with appropriate social behaviour and norms.

Goffman argues that an individual engages in inferential reasoning to assess and seek out information about each situation, and then adapts their behaviour to suit that situation. Therefore, there is a 'self' that informs and shapes an individual's behaviour, and a 'self' that is on display in the social world. When the individual presents this 'self' that is on display, they will perform in certain ways to "incorporate and exemplify the officially accredited values of the society" (Goffman, 1959, p. 45). For Goffman, the 'self' that lies behind an individual's behaviour is that person's perception of how others regard them. This notion of self as being the result of learned performance is in contrast to Mead's 'I' as a spontaneous part of an individual's identity. West (1996, p. 353) highlights the significance of Goffman's work as a feminist tool for "analysing the politics of and in the personal sphere."

This foundational work on the self has been interpreted by feminists such as Kristeva (1980), who reconfigures Freud's (1923) conceptualisation of the self within a feminist framework. She proposes the existence of the 'semiotic', which is an emotional field that lives within language and represents the pre-mirror stage state of an infant. In the pre-mirror stage, a child distinguishes itself as separate from the 'other' and as they develop language they become an identity separate from their mother – with this separation labelled 'abjection'. However, as the child grows, it does not develop a fixed identity, but rather emerges as a subject forever 'in process' (Kristeva, 1980). This approach to defining the self in terms of the process of separation from the maternal forms the fabric of later influential feminist and other concepts of the self (cf. Stone, 2014).

Kristeva's (1980) theory challenges the idea that the self is formed from reason in isolation from emotion and desire. Through shifting a focus back onto the relationship between self-formation and the maternal, Kristeva sought to 'reclaim femininity' (Willett et al., 2016). This process of reclaiming and revaluing of the feminine finds parallels in Chodorow's (1981) theory of the self. Chodorow (1981) contests the seemingly dichotomising boundaries of the 'self' and 'other' set up by those such as Kristeva (1980). Chodorow (1981) instead claims that the self cannot be separated from the dynamics of interpersonal relationships: the self is and always will be relational (Willett et al., 2016). Her work examines how the structure of family shapes an individual's gender identity, and how this gender identity serves to reproduce and sustain dominant social and cultural gender roles as normative. Chodorow (1981) ultimately argues that male children reproduce patterns of male dominance, and that female children reproduce gendered patterns of desire for motherhood in their own lives.

Butler (1990) disputes Kristeva's (1980) and Chodorow's (1981) respective accounts of the self by arguing that these accounts

camouflage the performative nature of the self and collaborate in the cultural conspiracy that maintains the illusion that one has an emotionally anchored, interior identity that is derived from one's biological nature, which is manifest in one's genitalia (in Willett et al., 2016, *Feminist perspectives on the self*, *Stanford Encyclopaedia of Philosophy*).

Butler's (1990) poststructuralist account of selfhood contests understandings of the self as static and fixed, asserting instead that the self is a 'discursive node' that shifts according to fluctuating discursive currents. Her position rests on a view of the performative and relational nature of the self, and how the categories of sex, gender, and self are protean and thus unstable.

While these feminist accounts of the self offer deeper understandings of the constructions and representations of the self and motherhood, none offers an adequate account of the relationship between the self and maternity. Even in Kristeva's (1980) and Chodorow's (1981) theories of the self, which recognise the complex relational formation of self in connection to maternity, the mother is positioned as "the nourishing soil of her child's subjectivity-to-be" (Stone, 2014, p. 325). According to Baraitser (2009) we need to develop a "specifically maternal subjectivity. To fail to do so leaves the mother's particular concerns and paradoxes hopelessly unarticulated": we need to "uncouple maternity and femininity ... for the sake of the maternal" (p. 10).

Juhasz (2003) attempts this uncoupling of maternity and femininity through elucidating her understanding of maternal subjectivity in the context of the act of writing. In Stone's (2014) view, Juhasz renders the maternal subject as "constituted by a process of weaving between multiple relational positions: those of mother and child, the mother and her own mother, mother and woman, ideal and real mother" (p. 334). For Juhasz (2003), maternal subjectivity involves navigating multiple subject positions that are often simultaneously complementary and contradictory: "separation and connection orchestrate the trajectory of motherhood" (p. 404). Therefore, when attempting to understand the self in relation to the maternal experience, we must recognise the co-existence of plural subjectivities, fragmentation, coherence, and ambivalence that can constitute a maternal subject.

### ***Connections Between the Self, Womanhood, and Motherhood***

Exploring a number of prevailing theoretical perspectives on the self provides a basis for a review of the literature focused on the connections between the self, womanhood, and motherhood. Conceptualisations of the self and motherhood are key themes explored throughout this thesis, and common to both of these themes is the concept of womanhood. Willett et al. (2016) propose that a woman's notion of self has been largely occluded and effaced within a Westernised philosophy that has privileged mostly white, heterosexual men, echoing Simone de Beauvoir's (1949) declaration that "he is the Subject, he is the Absolute – she is the Other" (p. 6).

Understandings of female subjectivity have been and continue to be shaped and constructed through attention to a female's reproductive capacities. In everyday discourses, for example, 'womanhood' is often synonymous with 'motherhood', where the experiences and conceptualisations of each category are presumed to be coterminous and inextricably bound (Arendell, 2000, p. 1192). The expectation that women will become mothers informs normative discourses, where there is an implicit assumption that in order for a woman to be regarded as an 'adult' and 'feminine' she must be a mother (Ireland, 1993, p. 1) or aspire to motherhood. This conflation of female sense of self and the role of mother is derived from the assumption that the 'natural' (that is, biological) role of a woman is to be a mother and if she is not a mother then in many senses she falls short of the constructed benchmark of womanhood (Rich, 1976, p. 11). On this point, Letherby (1994) argues that all women, regardless of whether they are mothers or not, live their lives against a "background of personal and cultural assumptions that all women are or want to be mothers" (p. 525). If a woman is not a mother or does not want to be a mother, terms such as 'barren' or 'childless' are used in derogatory, derisive and condemnatory ways to classify such women as deficient, aberrant and incomplete (Rich, 1976, p. 11).

Rogers and White's (1998, p. 305) research found that when it comes to a woman's sense of self, the status of being a mother (or not) is more powerful than marital status or occupation. This single criterion can influence the way many women think about themselves, the way their lives will take shape, and their very sense of purpose and worth. For this reason, the journey into and through motherhood is one that has certain consequences for the way a woman thinks about, defines, and expresses her sense of self. Based on her own experiences, Gieve (1987) claims that there is fear involved when navigating the terrain between the self and motherhood, since committing to the passion or obligation of being a mother may be to "consign yourself to a conservative role and abandon the possibility of power and independence" (p. 39). She attributes this fear to a lack of control whereby her desire to have a baby triggered a fear that her "identity and purpose as an adult might be lost. If I let go and allowed an infant to dominate my life there might be nothing of me left" (Gieve, 1987, p. 42).

Thus, the relationship a woman has with her child and her perceptions of her role as a mother have significant consequences for her sense of self. Rich (1976) describes the role of mother as one in which a woman sacrifices herself and her desires for the sake of a child: a mother undergoes so many unexpected and unanticipated changes and feelings that she risks losing her



'self'. Chodorow (1978) reinforces the important symbiotic connection between mother and daughter, while Flax (1978) contrastingly sees the relationship as troubled whereby the mother feels devalued in comparison to her daughter's achievements. Benjamin (1988) regards the role of a mother as being one in which a woman is very much her own person, but tries to facilitate both a type of connection as well as a type of separateness from her child. In Benjamin's (1988) view, motherhood is complex and paradox-laden, with a constant tension between the development of a child's sense of self, and the concurrent maintenance and development of a mother's sense of self.

The relationship between sense of self and motherhood has been explored in the sociological literature largely from a feminist psychoanalytic perspective. There is still much to learn, however, when it comes to the connections between self and motherhood. Studies of mothers' negative feelings are under-represented in the literature, which could point to the fact that the prevailing 'good mother' ideology provides little legitimacy for negative feelings of mothers towards their children (Arendell, 2000, p. 1197). In fact, the development and perpetuation of the 'good mother' ideology can be seen to drive and reinforce connections between normative constructs of womanhood and motherhood.

It is expected, for instance, that the 'good mother' have endless patience when parenting, and be fulfilled and happy in the role of mother. If mothers demonstrate feelings of antipathy or ambivalence towards their children, or their children seem troubled or not completely happy, the woman can be labelled as a 'bad' or inadequate mother (Arendell, 2000). While motherhood can be personally fulfilling, joyful, and a catalyst for personal development and growth, it can also (simultaneously) be a distressing experience, giving rise to feelings of anxiety, disorientation, loss and regret. Clearly, further research is necessary to explore these dimensions of the experiences of motherhood, along with the powerful associations between such experiences and 'bad mother' imagery, which is typically generated in binary opposition to the pervasive hegemony of 'good mother' ideology (cf. Arendell, 2000; Ross 1995).

### ***Sense of Self of Mothers of Children with Disabilities***

Research specifically focused on questions of the self and self-perception of mothers of children with disabilities is limited. The findings of the research that does exist in this area have implications for the way we think about and approach research about how mothers of children with disabilities construct, interpret, and represent their human subjectivity. For example,

Carpenter and Austin (2007) have explored the experiences of women who mother children with ADHD. They outline a fascinating and useful way of framing these women's experiences through the metaphor of the 'text' and the 'margin'. They position the ideology of 'good motherhood' as the 'text' that dominates normative discourses on mothering, and denote the 'margin' as the space outside of this text that they argue their participants fell within. This prompts discussions of isolation and segregation experienced by participants but the authors do not directly discuss how this metaphor may operate when it comes to self-perception among their participants. Similarly, Green (2007) addresses the issues of stigma associated with mothering a child with a disability, and Sibricky (2014) offers an auto-ethnographic account of raising a child with a disability. Both offer meaningful findings that encourage thinking about mothering children with disabilities and women's sense of self, but neither comment explicitly on this relationship between the self and mothering experiences.

One notable exception to this is Skinner et al. (1999) who examined how Latino mothers of children with developmental disabilities constructed and expressed their sense of self in relation to disability. They found that the majority of mothers in their study used the technique of constructing a narrative to portray themselves as 'good mothers' in line with dominant cultural understandings of motherhood and the ideology of the 'good mother'.

Harvey (2015) conducted research on maternal subjectivity in mothering children with disabilities from a psychoanalytic perspective, and sought insights into the impact of a child's disability on a woman's sense of self. She concluded that "the early experiences of mothering a child with a disability may be that much more psychologically complex as they raise feelings of inadequacy, promoting an experience of ambivalence towards one's baby, one's self, one's partner, and society" (p. 9).

Harvey focused on the ways in which the emotional responses that mothers have to their children may challenge their sense of self and subsequently how mothers make sense of these experiences: "[t]hus mothers are likely to constantly grapple with the external, tangible aspects of their child's disability, and at the same time with how this resonates with their psychological fantasies and internal object relations" (p. 10).

In the same vein, Landsman (1998, 2003) has discussed the relationship between mothering a child with a disability and a mother's sense of self. Her work examines the role of the mother as she is positioned at the intersection of competing discourses surrounding mothering and

disability. She interrogates the cultural imagery of motherhood in modern society, analysing the depiction mothers of children with disabilities and how these mothers then reject, accept, assimilate, or reconstruct these representations in their own experience. Landsman (1998) concludes that “advocacy for one’s disabled child becomes part of the identity of the mother, but it is born of the recognition of the child’s humanity and of one’s fear that the full value of the child is missed by others” (p. 87). She avoids oversimplifying the qualitative data she gathered on mothering children with disabilities, insisting that her participants’ stories are not of ‘triumph over tragedy’, but are complex reflections on hope, grief, betrayal, challenge, transformation, and love (Landsman, 2009).

## **Summary**

In this review of relevant literature, I have identified common themes within the literature on motherhood, relationships, and conceptualisations of the self. I have highlighted research that is fundamental in shaping and informing this study, as well as areas of research that demand further attention.

Within Motherhood Studies, there is the need to understand how the institution of motherhood operates in contemporary society. Further, the experiences of women who mother children with disabilities has, so far, not been addressed or investigated in the context of Motherhood Studies. Similarly, within the sociology of personal life, there is a need for research focussing not only on the experiences of mothers, but also on the experiences of women who mother children with disabilities. The study responds to this need for understanding how women who mother children with disabilities experience motherhood, a sense of family, and other relationships.

Although there has been some scholarly inquiry into how women who mother children with disabilities experience a sense of self, this area of knowledge requires elaboration.

Conceptualisations of the self need to take into account maternal subjectivity: how women who are mothers occupy the subject position of ‘mother’. The study contributes to the existing emergent research on maternal subjectivities by exploring how women who mother children with disabilities experience a sense of self.

In the following chapter, I discuss the methodology that has underpinned the research.



## CHAPTER FOUR

### Methodology

*The process of data collection, data analysis, and report writing are not distinct steps in the process – they are interrelated and often go on simultaneously in a research project. Qualitative researchers often learn by doing*  
(Cresswell, 2007, p. 150).



#### Introduction

The purpose of this chapter is to provide details of the practical dimensions of this sociological inquiry into the experiences of 18 women residing in NSW, Australia, who self-identified as mothers of children with disabilities. To this end, the chapter is structured in six sections:

1. Stating the research aim, purpose and questions.
2. Establishing and justifying the theoretical and philosophical framework of feminist phenomenology and social constructionism as suitable for addressing the research aim, purpose, and questions.
3. Detailing the design and data collection strategies and processes.
4. Describing and justifying the appropriateness of the selected research methods.
5. Explaining the processes of data analysis.
6. Defining an emergent conceptual framework for the analysis and interpretation of data.

#### Aim, Purpose, and Research Questions

The key aim of this research was to explore and understand how 18 Australian women who are mothers of children with disabilities experience motherhood, negotiate their relationships, and reflect on their sense of self. In undertaking this study, my purpose was to represent and render visible these experiences and thereby address the identifiable deficiencies in knowledge and understanding of the experiences of women who mother children with disabilities.

It is worthwhile to restate the research questions since these have informed the choice of methods and the structure of the data analysis in the chapters that follow. The central research question is: *With a particular focus on their relationships and sense of self, what are the experiences of women who are mothers of children with disabilities?*

Three subsidiary questions guided the collection of data in order to answer the central research question:

1. How do participants experience the “institution of motherhood” that Rich identified in 1976; how do they resist, conform to, challenge, and/or navigate this constraining institution?
2. In what ways do participants construct and navigate their relationships, and how are their relationships shaped and impacted by their role as mothers of children with disabilities?
3. How do participants understand and express their sense of ‘self’?

My initial review of research conducted on the experiences of women who mother children with disabilities, revealed that the majority of this research was based on psychological discourses and methods or time-use surveys to examine the impact of caring on paid work. Typically, the research did not focus on the experiential, phenomenological elements of these women’s experiences (with the notable exceptions of Landsman, 2003; Green, 2002; and Runswick-Cole, 2013). I sought to add to this limited amount of research, through drawing on Motherhood Studies and the sociology of personal life.

## **Theoretical Framework**

This research is firmly located within the qualitative research tradition. From the outset, the research proceeded inductively as I did not set out to test a hypothesis, deduce findings from a closed research question, or impose “predetermined constraints on the findings” (Best & Kahn, 2006, p. 250). To complement the qualitative focus of my research and data collection strategies, the study was theoretically grounded in the two traditions of feminist phenomenology and social constructionism. These traditions have their roots in the disciplines

of philosophy and sociology, respectively (Best & Kahn, 2006, p. 255). Both perspectives eschew positivist approaches that assume an 'objective reality', instead elevating the significance of individuals' perceptions and understandings of their lived experiences, sense of self, and social world (Cosgrove, 2000). Since the study was ultimately interested in participants' lived experiences, sense of self, social lives, and interpersonal relationships, this theoretical framework affords a robust basis for the study.

### ***Feminist research***

From the outset, this research was driven and sustained by feminist motivations. The study set out to understand the experiences of *women*, and how living within gendered positions as mothers can shape and frame participants' lives. I recognise that gender does not have an ontological status but rather, is culturally produced and reproduced. In accordance with social constructionist methodology, gender is understood in this study as a social construction rather than natural or essential. Part of the focus of this research, therefore is on how gender is produced and *accomplished* (Cosgrove, 2000) within the particular context of mothering children with disabilities. To reiterate a caution articulated in Chapter One, this thesis is careful in its attempt to avoid the assumptions of gender binaries or to reify gender. As a result, throughout the study I have resisted essentialising gender while employing a methodology that is robust enough to support and explain the ways in which "gender is *both constituted by and constitutes* contemporary meanings" (Cosgrove, 2000, p. 249) of motherhood. Participants' positions as women who are mothers are ineluctably connected with the accomplishment and performance of their culturally-contingent gender.

This research acknowledges, respects, and draws from the existing feminist literatures and methods and in so doing endeavours to contribute to feminist goals of providing a platform for women's voices to be heard in their diversity and to resist the further universalising of experience (Acker et al., 1983; Ang, 2003; Bohan, 1993; Cain, 1994/1995; Cosgrove, 2002; Wesselius, 1998).

### ***Feminist phenomenology***

This study is phenomenological in the sense that it explores the lived experiences of women who are mothers of children with disabilities, and is specifically interested in the associations

between individual experience and social life. An epistemic assumption characteristic of a feminist phenomenological methodology is that social reality is a product of human interaction and experience. As Cosgrove explains: “the strength of a phenomenological approach is that it emphasizes the richness and complexity of an individual’s lived experience” (2000, p. 247).

Phenomenology is concerned with describing the structures of lived experience by investigating that experience beyond the assumptions made about individuals’ lives (cf. Best & Kahn, 2006). Phenomenology understands the world as open-ended with a variety of complex meanings, where knowledge and experience is fluid, changing, and always unfinished (Fisher & Embree, 2000). However, the thinking of foundational phenomenologists such as Husserl, Heidegger and Merleau-Ponty has been critiqued for being shaped by masculine, racialised, and Eurocentric assumptions, which do not recognise or theorise sexual difference (Alcoff, 2000, p. 39). It is argued that these theorists largely took a masculine worldview as the norm, which in turn informed the foundation for their epistemological practices (Simms & Stawarska, 2013, p. 11). Butler, for example, critiques the work of phenomenologists such as Husserl, Merleau-Ponty and Mead for their lack of attention to gender as constitutive, and draws on de Beauvoir’s work to position gender as an identity that is “instituted through a stylized repetition of acts” (1988, p. 519). Butler reprises de Beauvoir’s distinction between sex and gender and the cultural interpretations around what it means to *become* a woman: “to induce the body to become a cultural sign, to materialize oneself in obedience to an historically delimited possibility, and to do this as a sustained and repeated corporeal project” (1988, p. 522).

Thus, while phenomenologists throughout the eighteenth and nineteenth centuries recognised that reason and knowledge are limited by intellectual and perceptual capacities, and that reason and knowledge are both embedded within and shaped by history, by the late twentieth century reason and knowledge came to be recognised as marked by sexual difference (Alcoff, 2004, p. 248). Similarly, Simms and Stawarska (2013) argue that “[p]henomenology is *feminist* as long as it includes questions related to gendered experience and sexual difference within its field of study” (p. 6).

Drawing on the work of Al-Saji (2010), I have utilised feminist phenomenology to investigate how descriptions of participants’ lived experiences encourage new understandings of how ideology, social structures and institutions can shape participants’ lives. Simms and Stawarska (2013, p. 9) point to the ways in which feminist phenomenological research explores individual descriptions of human experience and seeks to highlight the complexity and depth of

individuals' lived realities and subjective journey "from the interior" (Flick, 2002). This same intention underpins the study, which aimed to understand the qualitative intricacies of individual experience, rather than produce statistical quantitative data. In focusing on the depth of individual experience, feminist phenomenology also understands that the experiences of participants are "embodied, inter-subjective, and contingent" and that individual lives are positioned within "personal and cultural webs of signification" (Simms & Stawarska, 2013, p. 12) that structure experience. A feminist phenomenological approach is therefore appropriate to the aims, purpose, and research strategies of the study, since it "emphasises the importance of the individual's lived world and the interpersonal realm in the constitution of identity; it stresses the importance of the structural unit of ... experience, body and environment, which is referred to as being-in-the world" (Cosgrove, 2000, p. 258).

However, Cosgrove (2000, p. 259) also acknowledges that a phenomenological approach alone, while it accounts for questions of individual agency, is not always robust enough to explain an individual's experiences of resistance and choice. Cosgrove suggests that a social constructionist approach supports and strengthens phenomenology. This study thus amalgamates these methodological paradigms, acknowledging the phenomenological underpinnings of the research, while embracing the equally important tradition of social constructionism in the development and analysis of the data.

### ***Social constructionism***

Highlighting the points of convergence of phenomenology and social constructionism as methodologies Cosgrove explains that: "social constructionism and phenomenology share a commitment to examining the lived experience of individuals, and, in doing so, focus on the *meaning* of the discourse/text/narrative under investigation" (2000, p. 257). Both social constructionism and phenomenology oppose positivist assumptions of the existence of an 'objective reality' that needs to be 'uncovered'. Therefore, the use of social constructionism in this study complements and enriches, rather than competes with, the feminist phenomenological approach. Indeed, a social constructionist approach to research proceeds on the premise that individuals' realities are not necessarily made up of discernible facts, but that individuals construct their perception of reality (Berger & Luckmann, 1967). Social constructionism is sometimes also referred to as social phenomenology and its foundations are in phenomenological understandings of ontology. The central questions driving this approach include: "[h]ow have the people in this setting constructed reality? What are their reported



perceptions, 'truths', explanations, beliefs, and worldview? What are the consequences of their constructions for their behaviours and for those with whom they interact?" (Best & Kahn, 2006, p. 255).

Schutz (1973) was the first to establish the tenets of social constructionism, arguing that human beings interpret the world through commonsense constructs of the reality of daily life, consequently enabling them to orient themselves and navigate their social and cultural environments. Schutz was influenced by the phenomenological philosophy of Husserl (1913, in Beyer, 2015), who argued that we create our reality through our thoughts and beliefs. Extending the work of Schutz, Berger and Luckmann posited that: "the world of everyday life is not only taken for granted as reality by ordinary members of society in the subjectively meaningful conduct of their lives. It is a world that originates in their thoughts and actions and is maintained as real by these" (1967, p. 33).

Since, from a social constructionist perspective, meaning is understood as fluid, negotiable, and created through both language and interaction, the process of conducting research that involves, for example, interviews, contributes to the active production of knowledge and experience. Drawing on the work of Goffman (1959), the enactments of the individual are the equivalent of social performances. Our own dominant cultural and social scripts ground and shape these social performances, and we embody them in culturally conventional ways (Butler, 1990; Manderson et al., 2006).

These connections between an individual's construction of reality and their performance and experience as individuals (cf. Goffman, 1959) underline the ways in which social constructionism is sociologically important. While individuals are creators of their own social realities, these realities are embedded within particular social, cultural, and political contexts: "[a]lthough we view people as active agents in their own lives and as such constructors of their social worlds, we do not see that activity as isolated and subjective. Rather, we locate individual experience in society and history, embedded within a set of social relations which produce both the possibilities and limitations of that experience" (Acker et al., 1983, p. 425).

Social constructionism, then, "allows for a sophisticated and richly textured view of the research situation: it does not see descriptive accounts of women's experiences as a straightforward way to obtain access to women's 'true selves' or inner experiences" (Cosgrove, 2000, p. 257). Rather, "it problematizes women's subjective accounts, understanding meaning to be produced (or

even policed) through discourses rather than revealed” (Cosgrove, 2000, p. 257). Especially relevant to this research is capacity for the social constructionist paradigm to accommodate a multiplicity of views of ‘reality’: “diverse viewpoints regarding social realities” (Teddle & Tashakkori, 2009, p. 89) and even divergent perspectives on the same phenomenon exist. The researcher’s role entails a recognition of and respect for such multiplicity and a need to locate the research within the context of a “community paradigm” (Kuhn, 1970, p. 46), where ‘paradigm’ is understood as “the consensual set of beliefs and practices that guide a field” (Morgan, 2007, p. 49).

Through explicating the theoretical framework for this study, I have provided a rationale for the suitability of blending a feminist phenomenology and social constructionism to the aims, purpose and questions of this research. I turn now to the details of the research process itself by focusing on the design and data collection strategies, the ethical requirements, the process of recruitment, and the sample of participants.

## **Research Design and Methods**

The qualitative methods utilised in the design of this study can be understood in terms of a continuum “anchored by art and science, with vast middle spaces that embody infinite possibilities for blending artistic, expository, and social scientific ways of analysis and representation with the vast middle – ground a space for innovation and representation” (Ellingson, 2011, p. 596). To access accounts of experience, a research design including a range of strategies was developed: a pre-interview questionnaire; a schedule for semi-structured interviews; a technique called ‘photo elicitation’; and personal community mapping. These methods will be discussed in detail in the section below that explains the data collection process.

It was anticipated that these mixed methods would allow access to “the multi-layered context of a life” (Cresswell, 2007, p.76). This allowed an “openness to adapting [the] inquiry as understanding deepens and/or situations change; the researcher avoids getting locked into rigid designs that eliminate responsiveness and pursues paths of discovery as they emerge” (Best & Kahn, 2006, p. 250). The exploratory and phenomenological orientation of the study allowed for individual women’s experiences to be considered as “information rich and illuminative ... offering useful manifestations of the phenomenon of interest” (Best & Kahn, 2006, p. 250). Importantly, the study “aimed at insight about the phenomenon, not empirical

generalisation from a sample to a population” (p. 250). Overall, this approach optimised the potential for accessing and gathering detailed accounts of how each individual experienced and made sense of their worlds as women who are mothers of children with a disability.

## **Ethics, Recruitment, and Participants**

### ***Ethics***

I received approval for the study from the University of Sydney Human Ethics Committee (see Appendix J) before I commenced recruitment processes. Research of this nature requires careful consideration of the complex dimensions of collecting and analysing highly personal data. For this reason, the process of the research necessitated the development of clear protocols for recruiting and interviewing participants, and for the analysis of the collected data (see Appendix C and H). To protect participants’ privacy, all names used in this thesis are pseudonyms, and all identifying information from transcripts were erased.

### ***Recruitment***

Recruitment of participants for this study began in January 2014. I identified organisations within NSW that potentially had contact with women who are mothers of children with disabilities. I aimed to contact organisations in a variety of locations across NSW in order to obtain a diversity of participants. I contacted organisations that were primarily respite services, day programs, therapy centres, and other organisations whose primary objective is to provide support for families and carers for people with disabilities.

Initial contact was made with organisations either by phone or email, where I provided a brief outline of the project (see Appendix A). I then asked if they would be willing to display a flyer with information about my study in the reception area of their office, or if they were able to distribute a digital copy of the flyer through their email networks (see Appendix B). Asking organisations to disseminate information about the study and requiring participants to initiate contact, rather than directly approaching potential participants, ensured that potential participants felt under no direct obligation to take part in the study.

As the result of my emails and phone calls, over 20 organisations across NSW in suburban, city, and regional areas agreed to disseminate information about my study. Participants involved in this study were recruited directly from these organisations, therefore I have chosen not to disclose the names of any of the organisations in a further effort to protect participants' anonymity, and pseudonyms have been used for all participants.

More than 30 women who were mothers of children with disabilities expressed interest in participating in the study. From this pool of potential participants, interviews were carried out with 18 participants. This is because other respondents either did not reply to follow-up emails and phone calls, or later said that they were no longer able to participate. Participants were self-identified mothers of children with disabilities. No participant was denied participation because of the nature of their child's disability. In fact, no woman who is a mother of a child with a disability within NSW who showed interest in participating in this study was denied participation.

When any potential participant contacted me in response to the recruitment poster, I explained the nature of the research in more detail, and emailed them a copy of the *Participant Information Statement* (see Appendix C), and a *Pre-Interview Questionnaire* (see Appendix E) to complete. The *Participant Information Statement* formally outlined the aims of the study, what the study would involve, the voluntary nature of the study, and the contact details of the researcher and supervisor. Prior to conducting interviews, participants completed the *Pre-Interview Questionnaire*, providing background, demographic and other profiling information.

No participant was excluded on the basis of their responses to the pre-interview questionnaire. Once participants had read the *Participant Information Statement* and re-confirmed their willingness to be involved in the study, I arranged a time and place for our interview. I then sent a *Participant Letter* with details regarding the community mapping exercise. When we met for our interviews, I offered participants another (hard) copy of the *Participant Information Statement* to keep, and asked them to read and sign a *Participant Consent Form* (see Appendix F). The form asked them to consent to being audio recorded, reaffirmed the nature and conditions of the study, and reiterated that they were able to terminate the interview at any time, and if they chose to do this, then all the data gathered from them would be erased. I also obtained verbal consent that participants understood and were comfortable with being audio recorded. It was made explicit to participants that withdrawing from the study would not affect

their relationship with the researcher, or with the University of Sydney at that time, or in the future.

### ***Participants***

A pre-interview questionnaire (see Appendix E) was completed by participants before interviews took place. The questionnaire sought to gather demographic information, rather than act as a mechanism for recruitment screening. The questionnaire asked for a participant's age bracket, relationship status, sexual orientation, household income, ethnicity, education, number of children and their ages, and the nature of their child's disability. Questions were worded to avoid positivist assumptions. For example, instead of asking "what ethnicity are you?", the question read, "to which racial or ethnic group(s) do you *most* identify?" Further, an option of "prefer not to say" was available for each question.

Table 1 below presents each participant's profile. Aligning with the social constructionist methodology underpinning the study, positivist approaches are resisted. However, this table offers the reader a useful snapshot of participants that may act as an *aide memoir* during a reading of the data analysis chapters. The categorisations within this table should be understood as partial and contingent.

**Table 1: Profile of Participants**

| Pseudonym | Age range   | Location               | Marital Status | Sexual Orientation | Household Income  | Ethnicity        | Education Level                                          | Child + Disability                                                                                                                                                                           |
|-----------|-------------|------------------------|----------------|--------------------|-------------------|------------------|----------------------------------------------------------|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Jill      | 45-55       | Hunter Region          | Married        | Hetero             | Prefer not to say | Caucasian/ White | Doctoral Degree in progress                              | Cindy, 16 – Landau-Kleffner Syndrome                                                                                                                                                         |
| Kelly     | 35-45       | Hunter Region          | Married        | Hetero             | 80-100k           | Caucasian/ White | Masters Degree                                           | Blake, 8 – ASD, sensory processing disorder, severe language delay, developmental delay                                                                                                      |
| Nancy     | 45-55       | Hunter Region          | Married        | Hetero             | 30-50k            | Caucasian/ White | Bachelor Degree                                          | Oscar, 12 – ASD, developmental delay, ADHD, sensory disorder, PICA (non-verbal, incontinent)                                                                                                 |
| Sheryl    | 35-45       | Hunter Region          | Married        | Hetero             | 130-160k          | Caucasian/ White | Vocational Qualification/ TAFE                           | Jayden, 7 – ASD, Cerebral Palsy                                                                                                                                                              |
| Danielle  | 45-55       | Greater Western Sydney | Married        | Hetero             | 130-160k          | Caucasian/ White | TAFE, Associate Diploma, Bachelor Degree, Masters Degree | Jacob, 37 – Down Syndrome                                                                                                                                                                    |
| Tania     | 35-45       | Hunter Region          | Divorced       | Hetero             | 30-50K            | Caucasian/ White | Bachelor Degree                                          | Leonardo, 11 – Pervasive Developmental Disorder – not otherwise specified + sensory processing disorder<br>Marko, 8 – ASD, severe intellectual disability, Sensory processing disorder, ADHD |
| Sally     | No response | Central West           | Married        | Hetero             | Not answered      | Caucasian/ White | Not answered                                             | Dom, 2 – Diagnosis debated, developmental delay and needing to be tube-fed                                                                                                                   |
| Jessica   | 45-55       | Hunter Region          | Married        | Hetero             | 130-160k          | Caucasian/ White | Year 12 HSC or equivalent                                | Angie, 6 – chromosomal problem resulting in no vision, epilepsy, cannot walk and currently cannot speak                                                                                      |
| Charlotte | 55-65       | Upper North Shore      | Married        | Hetero             | 130-160k          | Caucasian/ White | Year 10 School Certificate or Equivalent                 | Jason, 16 – Prader-Willi Syndrome                                                                                                                                                            |

|           |       |                    |           |        |            |                  |                                        |                                                                                                                                                  |
|-----------|-------|--------------------|-----------|--------|------------|------------------|----------------------------------------|--------------------------------------------------------------------------------------------------------------------------------------------------|
| Veronica  | 45-55 | Mid North Coast    | Divorced  | Hetero | 50-80K     | Caucasian/ White | Advanced Diploma                       | Lloyd, 25 – Autistic Spectrum<br>Linda, 17 – Autistic Spectrum, ADHD, processing issues                                                          |
| Adriana   | 35-45 | Sydney North       | Married   | Hetero | Over 160K  | Caucasian/ White | Associate Diploma/Degree               | Eden, 8 – Autism Spectrum Disorder – mild to moderate with significant speech delay                                                              |
| Katherine | 45-55 | Sydney North       | Married   | Hetero | Over 160K  | Caucasian/ White | Bachelor Degree                        | John, 6 – Agenesis of the corpus callosum, oesophageal reflux disease                                                                            |
| Jacinta   | 55-65 | Sydney Inner West  | Divorced  | Hetero | 30-50k     | Caucasian/ White | Vocational Qualification/ TAFE         | Dean, 31 – Cornelia de Lange Syndrome + intellectual disability                                                                                  |
| Jayda     | 45-55 | Central Coast      | Married   | Hetero | 130-160K   | Caucasian/ White | Masters Degree                         | Elise, 18 – autism + moderate intellectual disability                                                                                            |
| Keira     | 55-65 | South Coast        | Separated | Hetero | 50-80k     | Caucasian/ White | Bachelor Degree                        | Annabelle, 26 – intellectual disability                                                                                                          |
| Hannah    | 35-45 | North Shore Sydney | Married   | Hetero | 80-100K    | Caucasian/ White | Bachelor Degree + 2 associate diplomas | Sandy, 5 – 18P syndrome, dyspraxia including verbal, delayed bone growth, low muscle tone, low IgA levels, chronic constipation, eczema, anxiety |
| Jocelyn   | 25-35 | South Coast        | Married   | Hetero | 100-130k   | Caucasian/ White | Bachelor Degree                        | Anthony, 6 – autism and intellectual disability.<br>Kasey, 8 – Autism                                                                            |
| Dana      | 55-65 | Illawarra Region   | Widow     | Hetero | unanswered | Caucasian/ White | Diploma                                | Scarlett, 35 – Down Syndrome                                                                                                                     |

This table shows that despite my desire to explore a diversity of experiences, the sample included many women with shared class and ethnic backgrounds. For example, all participants in this study identified as Caucasian. Many had socio-economic profiles as above average, placing them in middle and upper income quintiles, and most had formal post-compulsory education qualifications. Many had the social and educational capital to find out about – and the financial resources to purchase – private respite care and medical and allied professional assistance. On this point, I reflect on Lorde’s (1979) frustration in feeling as though existing feminist accounts of mothering need to be reinvented before they speak to the experiences of mothering for those occupying the full diversity of social, cultural, historical, and political positions. As Lugones (2003) states, “[w]hen I do not see plurality stressed in the very structure of a theory, I know that I will have to do lots of acrobatics – like a contortionist or tight-rope walker – to have this theory speak to me without allowing the theory to distort me *in my complexity*” (p. 74).

I recognise that the experiences of the small group of Caucasian women in this study risk compelling those who sit outside their accounts to walk such a tight-rope. Recognising the scope and limitations of the research does not, however, diminish the significance of the experiences of participants or the value of this research contribution to the field, although it does highlight the difficulties of accessing participants from more disadvantaged contexts.

## **Data collection**

### ***Semi-structured Interviews***

Prior to the data collection phase of the study, I designed an interview schedule (see Appendix G) to serve as a guide for the interviews themselves because the “purpose of interviewing is not to put things in someone else’s mind ... but to access the perspective of the person being interviewed” (Patton, 1990, p. 278). The development and content of the interview schedule was informed by the research question, together with a review of the literature in the field. It was structured around the general themes of the ‘good mother’ concept, networks of support, disability and society, employment, and motherhood and identity. Examples of questions asked included: “what were your expectations of mothering before you had children?”; “in what ways has being a mother of a child with a



disability impacted on your expectations of mothering?"; and "what type of impact has mothering a child with a disability had on your relationships?"

The semi-structured interviews were intended as a "conversation with purpose" (Mason, 2002, p. 67) that would actively generate rather than merely collect data, thereby affording an active co-production of meaning. The interview schedule was therefore designed to allow for flexibility and the researcher's in-context responsiveness to unanticipated perspectives and ideas from participants.

The flexible design of semi-structured interviews allowed me to modify and adapt the structure of the interview schedule, as well as the questions I had planned to ask, according to the unfolding direction of the participant's responses within the dynamic of each interview situation. The interview strategy allowed for an examination of how participants construct meaning and organise their lives, and how this meaning subsequently influenced their actions (Minichiello et al., 2008, p. 9).

Individual interviews ranged between 1 hour and 15 minutes and 2 hours and 20 minutes. All interviews were recorded and subsequently transcribed. There was one occasion during an interview when a participant asked for the recording device to be turned off for approximately five minutes during the interview. This was due to the type of information the participant was disclosing regarding a funding allocation for their child. The recording device was turned off, and I verbally reaffirmed the participant's consent to be audio recorded before turning the recording device back on.

Participants chose the location and date of their interview according to what was most convenient for them. This resulted in 11 interviews being conducted in participants' homes; three in cafes; three at the participant's work place; and one interview in the prayer room of a participant's church. These various locations had subtle impacts on the amount of time it took to establish rapport with participants. Participants seemed generally more at ease when interviews were conducted in their homes, yet some participants were also conscious of my potential interpretations of their homes as a stranger entering their private environment. However, these participants very much welcomed me into their homes, and made me feel at ease and comfortable as a 'guest'.

When a participant met me at their workplace, the interview dynamic initially differed to that when conducted within the home, suggesting a sensitivity to their position as an employee. However, after approximately 15 minutes into the interview, each participant seemed more at ease and, from my perspective, spoke candidly. Two of the interviews conducted in workplaces were in private rooms with the door closed. One was conducted in the reception area of the workplace, which was the participant's own business and was empty except for one other employee who, for a portion of the time, was cleaning around the reception space near where we sat, and her presence inevitably impacted on our discussion.

The presence of another person in the context of an interview had an influence on another interview conducted in a participant's home. During this particular interview, the participant's husband was present for almost the entire time and thus inevitably influenced the generation of data during this interview.

When interviews were conducted in cafes, the dynamic was different again from the interviews conducted in the workplace or home. Often there were more practical issues to contend with in cafes, such as making sure we were seated somewhere with a reasonable amount of privacy; that there was not too much noise for the audio recorder to record our voices; that the audio recorder was positioned on the table in a way that would capture the participant's responses; that the participant had enough room to complete their personal community map; and managing to conduct the interview while we both ate food and responded to enquiries from wait staff. Overall, conducting interviews in cafes was more difficult, but these interviews still generated rich and meaningful data.

### ***Photo Elicitation***

Photo elicitation is a methodological tool that utilises photographs during an interview as a prompt to trigger reflection, further analysis, and deeper discussion. As a data collection strategy, photo elicitation can assist in establishing rapport between researcher and interviewee; it can disrupt some of the power dynamics involved in the interview process; it can serve as an important tool to both gather data and empower the interviewee; and can encourage the surfacing of meanings that otherwise may have remained tacit (Clark-Ibanez, 2004, pp. 1512-1513). The method can enable the researcher to access a "different part of human consciousness than do words-alone interviews" (Harper, 2002, p. 23). As

part of the interview process, participants were asked to bring along photographs that they felt represented their journey as a mother and their lives more broadly.

As a method, photo elicitation did not prove to be particularly useful in this research for a number of reasons. First, participants already had to sacrifice over an hour of their very limited time to take part in the interviews. Asking them to then also think about and collate different photographs to bring to the interview was an added task that many did not have the time to complete. Second, there has been a move from printed photos to photographs stored on technological devices such as phones or computers, meaning that many participants simply scrolled through photographs on the camera roll of their smart phones. This limited the type of engagement a photo elicitation exercise encourages. Moreover, in order for participants to show photos from five to ten years ago, they needed to find physical photo albums, which were often stored away in a place that was not easy to reach, thus further adding to the burden of the task. Finally, I found that the time we spent looking through photographs disrupted the flow of the interview, rather than supported it.

For these reasons, unless a participant had explicitly pre-prepared photographs to show me during interviews, I did not ask them to engage in the activity. Therefore, the relatively limited data gleaned from any participants during this activity has been integrated within the analysis of the data from interviews, rather than being addressed in a separate analysis.

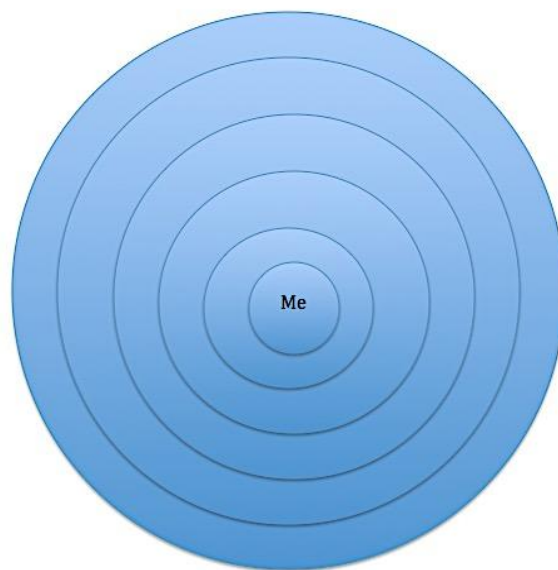
### ***Personal Community Maps***

Personal community mapping is a method developed by Pahl and Spencer (2003) for their research on personal communities and friendships. Personal community maps were also used in this study to stimulate further discussion about participants' relationships, and to deepen an understanding of their personal lives (see Appendix D). A participant's personal community includes anybody of significance to them: for example, friends, family members, neighbours, colleagues, or acquaintances. An individual's personal community represents their important social bonds and personal ties with others, and thus serves to structure their lives and shape their sense of self (Pahl & Spencer, 2003). Moreover, according to Spencer and Pahl (2006), a personal community emerges from an individual's own biography, so gaining insights into the ways personal relationships can operate

provides a powerful avenue for examining an individual's social networks, sense of self, and lived experience.

Following Spencer and Pahl (2006), prior to the interview, participants were asked to write down the names of people who were important to them on individual pieces of post-it notes. During the interview, the participants were given a cardboard 'map' – consisting of circles inside of circles. An example of a template of the map is provided in Figure 1, below.

**Figure 1: Personal Community Map template**



The centre circle represented the participant and each consecutive circle outside of the centre signified the relative closeness or distance the participant felt from the named person. The participant placed post-it notes with the names they had written on various parts of the map, and were then asked to explain each placing and their relationship with the person named.

When participants took part in the activity of creating a personal community map they engaged in a process of balancing and weighing up certain criteria relating to what extent and why certain people are important in their lives. Asking participants to create a personal community map helped them to clearly identify influential people in their life and

created a tool that could be used to ignite new understandings and encourage further reflection, for both the participant and the researcher.

Exploring an individual's personal community enabled insights into two important dimensions of their life that this study is interested in: the participant's support network, and the social and cultural framework that influences their sense of self. Studying an individual's personal community also allowed the researcher to learn about the quality of their different relationships; render visible the distinctive features of certain relationships; identify sources of help and support; and investigate the meaning of particular relationships.

Although participants were sent instructions on how to complete the community map prior to the interview, almost all sought clarification during the interview as to what was expected of them when completing the mapping activity. Some participants struggled with where to place particular people on their maps, and wrestled with who qualified to be included on their map. They sometimes asked questions such as "so it's *my* support people on here?" and "it's in relation to *me*, not my child?"

However, part of what made this activity so interesting and beneficial was this very ambiguity, as it revealed participants' own preconceptions about what they believe researchers expect of them: that is, they frequently assumed that the research focus was solely on the child rather than themselves. Positioning the participant at the centre of the activity meant that I was able to further investigate the ways they constructed and experienced their personal ties. When a participant struggled with where to position someone on their map, following Spencer and Pahl's (2006) example, it allowed me to prompt discussion about what criteria they were applying when judging the nature of their relationship with that person, and what would qualify a person as having a close personal tie or connection with them.

Most participants constructed the map during the interview and therefore were restricted by time. If participants had further time to reflect on their maps, or could come back to their maps days or weeks later, then perhaps their maps would have changed.

Ultimately, I used the personal community maps to stimulate further insight, reflection and meaning-making. There was flexibility in how participants chose to construct their

maps and there were few 'rules' involved. I allowed participants to construct their maps in whatever way they felt best reflected their personal communities. Each participant experienced the mapping activity in a different yet interesting way, and their diverse experiences constructing the maps added a unique dimension to the data gathered in this research, and reinforced the cogency of the social constructionist premise that there exist "diverse viewpoints regarding social realities" (Teddlie & Tashakkori, 2009, p. 89).

## **Data Analysis**

The data analysis strategies were informed by what Patton (2002) has identified as the five key strategies for approaching the analysis of data in qualitative inquiry. These strategies are not intended to be hierarchical. Rather, the strategies offer an overarching guide and include: the assumption that each 'case' is unique, with analysis "respecting, and capturing the details of the individual" (Patton, 2002, pp. 40-41) data set prior to seeking cross data set themes, patterns and discontinuities; a fidelity to inductive analysis through immersion in the data with the goal of exploring and confirming "important patterns, themes, interrelationships", ending "with a creative synthesis" (pp. 40-41); a holistic perspective that understands that the meaning of an inquiry is more than the sum of its parts; a sensitivity to the context of the inquiry, including attention to the social and temporal aspects of the data and findings; and the researcher's reflexivity, demonstrated through the capacity to recognise their own subjectivity and its potential impact during the analysis of data (cf. Patton, 2002).

The process of conducting interviews, transcribing and then analysing these involved substantial resources of time and attention. In setting out below the steps involved in the analysis of data, it is important to emphasise the recursive nature of the process of analysis.

### ***Step 1:***

Information collected from pre-interview questionnaires were recorded and logged into the Table 1 above. This table was employed as a useful reference throughout the analysis process. Once each interview was transcribed verbatim, the initial phase of the analysis consisted of repeated close reading and critical reflection and annotations on the 'story' of each. Annotations included notes about key ideas and points requiring further clarification. From this early phase of reading and reflection, general 'themes' within and

across the transcripts became evident, along with perspectives and content unique to the individual transcript. For each participant, I constructed a brief narrative in order to gain a deeper sense of the key aspects of their responses.

I identified general themes and distinctive elements of the content of the transcripts to apprehend descriptive phenomena, to attend to the broad classification of these and to examine how different themes may interconnect, overlap and relate to each other (Dey, 1993, p. 31). Since oral language was the primary medium through which participants communicated their phenomenological experience of mothering a child with a disability, attention to language formed a critical component of the data analysis: it was essential to explore *how* participants' stories were being constructed and expressed through language, and how identity, experience, relationships and *meaning* were created through particular discourses. As Nunkoosing and Haydon-Laurelut (2011) explain, "a discourse is a particular form of language that constructs versions of the world that have consequences for selves, relationships and morality" (p. 408) and to analyse this discourse is to interpret how language can socially construct and represent the world to serve a particular end. In this study, participants' discourses were analysed in order to examine how they both constructed and understood their experience of motherhood, and how they constructed and defined their sense of self, personal communities, and relationships.

### ***Step 2:***

After this phase of intensive 'immersion' in the data, the program NVivo was utilised to assist in organising the volume of data into a range of themes and categories. NVivo was not used to assist with *analysis* itself: rather, it was used to aid in *organising* and *categorising* data. Categories were developed inductively from the data, with coding ensuing from this categorisation. The 'meaning unit' of coding was at sentence and word level, with a number of initial categories conflated due to overlap. All coded sections of the transcripts were then examined individually and referenced to their original contexts.

### ***Step 3:***

When all interview transcripts were coded, there were initially 96 categories. These categories, after sorting and connecting, were reduced to 27 major themes. Sub-themes were then identified and placed under one of these 27 themes. For example, the sub-themes of 'attitudes to out-of-home care', 'financial impacts', and 'the NDIS' were coded under the major theme of 'Support Services'. After this process, from the now 27 separate

themes, five key themes were selected since these had the highest number of references across and within all interviews, and were referenced in *each* of the 18 interviews. There was some cross-over of data between themes. For example, some data coded within the 'Motherhood as Institution' theme were also coded under the 'Self' theme. In this way, the analysis process was inclusionary rather than exclusionary.

#### ***Step 4:***

During the later stages of the analysis of data, it became increasingly evident that the complex nature of the data required a conceptual framework for interpretation that would function in concert with theoretical foundations of feminist phenomenology and social constructionism. Such a framework emerged directly from the data and offered an interpretive lens for making meaning that did not exist at the outset of this research (and could not have existed, given the exploratory and inductive intent of the inquiry). As Miles, Huberman and Saldana (2014) explain, "conceptual frameworks ... evolve as the study progresses" (p. 20) whereby a conceptual framework is analogous to "the current version of the researcher's map of the territory being investigated" (p. 20). As an inquiry proceeds, the researcher's knowledge of the territory develops and deepens, with the 'map' steadily becoming more sharply delineated.

I reached a point in the data analysis process where I was unable to move forward in categorising and structuring the "territory" (Miles, Huberman & Saldana, 2014, p. 20). Grappling with this, and mindful of "attention to the process of the research that assumes change is ongoing within the research context" (Patton, 2002, pp. 40-41), I turned to Connell's (1995) work on hegemonic masculinity to explore the utility of Connell's use of Gramsci's concept of 'hegemony' (1971). While re-reading Connell's work on hegemonic masculinity, I was struck by the ways in which her understanding of masculinities as subject to 'hegemony' could be translated and applied to motherhood. Revisiting Connell's work in the light of the data I had gathered was a catalyst for conceptualising motherhood as 'hegemonic': this insight offered a fresh and potentially powerful conceptual framework to present the data and analyses of this research, facilitating original understandings of how women who are mothers of children with disabilities make sense of their lives and construct meaning from their lived experiences.

Developing and then applying a conceptual framework of 'hegemonic maternity' in this way allowed me to represent the dense and layered nature of participants' experiences of



motherhood as a social category. It also enabled meaningful interpretations of how participants experienced their relationships and defined their sense of self. The concept of 'hegemonic maternity' is therefore both a finding from the analysis, and is used as a tool for analysis.

### **An Emergent Conceptual Framework: Hegemonic Maternity**

The concept of 'hegemonic maternity' is a re-imagining and Connell's (1995) concept of hegemonic masculinity that also extends previous understandings such as Rich's (1976) identification of the institution of motherhood, and understandings of motherhood as a 'construct' and 'ideology' (cf. Goodwin & Huppertz, 2010; Hays, 1996). In delineating the contours of 'hegemonic maternity', I use 'hegemony' in the same way that Connell (1995) did in her development of 'hegemonic masculinity'. She drew on Gramsci's understanding of 'cultural hegemony' as the ways in which some social groups dominate others. Connell and Messerschmidt (2005) recognised that Gramsci's work on hegemony focused primarily on structural class change. In Connell's (1995) original application of the term 'hegemony', she did not specifically focus on the same types of large-scale historical change. Rather, it was applied in the context of understanding how masculinities are produced, reproduced and perpetuated. The power of hegemony – the hegemonic set of beliefs that constitute it – requires that individuals act in relation to these beliefs through adopting them, being complicit in their reproduction and defending the status-quo, or through resisting, challenging or subverting them (Connell & Messerschmidt, 2005).

This broad definition of hegemony can be applied to motherhood and affords a means of understanding how the experience of and sets of beliefs about motherhood and mothering are likewise constructed, reproduced, regulated and cast as normative. Such a definition resonates with Donaldson's (1993) interpretation that "hegemony involves persuasion of the greater population, particularly through the media, and the organization of social institutions in ways that appear 'natural', 'ordinary': 'normal'" (p. 644).

In order to apprehend the usefulness of the concept of hegemonic maternity, it is necessary to parallel the similarities in development between understanding 'masculinities' and 'maternalities'. In *Masculinities* (1995) Connell argues that masculinities are patterns that people practice and engage with to position themselves within a gender order. Such 'masculinities' are plural, changeable, complex, and

sometimes contradictory. Additionally, just as there are multiple ways to experience motherhood, there are multiple ways of representing motherhood and mothering. These multiple representations are also malleable, complex, and sometimes contradictory.

For example, representations can be understood as the 'good mother ideology' or the 'good mother concept' (Goodwin & Huppertz, 2010; Hays, 1996). Images of the 'good mother' pervade popular culture, social institutions, and public policy (Goodwin & Huppertz, 2010) depicting idealised, sanitised, and heteronormative tropes of motherhood. Good mothering representations powerfully impact upon the lives of both women who are mothers, as well as women who are not mothers. The 'good mother concept', in the context of this research, can be understood as a *consequence* of hegemonic maternity. Hegemonic maternity refers to the overarching *hegemony* that pervades and shapes 'motherhood', while good mothering ideology refers to idealised *representations* of motherhood.

The other way that 'motherhood' has been theorised is through the institution of motherhood that Rich (1976) described. The concept of hegemonic maternity builds on Rich's (1976) conceptualisation of the institution of motherhood. While Rich identified the institution of motherhood as the way patriarchy attempts to exert control over women's reproduction and experiences, a hegemonic view of maternity understands the ways motherhood as an institution, as experience, *and* as representations, is constructed, regulated, negotiated, experienced and practiced.

The concept also takes account of the diversity of motherhood institutions, experiences, and representations. Just as Connell (1993) argues that there is no singular, unitary masculinity but rather a multiplicity of masculinities with each masculinity associated with differentiated positions of power, so too does hegemonic maternity assume a multiplicity of maternalities within the category of mother. Connell provides a foundation for assessing the ways in which categorical thinking has shaped discussions of gender and in doing so, establishes the *relational* constitution of gender, enacted through social practices. Similarly, the relational category of mother involves a relationship between the mother and a child, and the reinforcement and recognition of this relationship by others. Everyday social practices and relationships can be understood to *enact* maternity in the same ways that Connell (2012, p. 1677) conceptualises gender as enactment.

Connell (2012, p. 1676) asserts that gender identities “are not expressions of an inner truth but are subject positions in discourse” (p. 1676). I contend that mothering identities are not expressions of an inner truth, but are in fact “subject positions within discourse.” Connell describes the ways in which gender – and in particular, masculinities – are constructed and sustained through institutional settings that authorise prevailing regulatory, cultural, relational and social systems. In the same way, when women become mothers they engage with and within institutional settings marked by established norms, expectations and practices. Such institutional settings may include medical settings, schools, childcare, and social welfare services. Women are required to navigate the norms, expectations and practices of these institutions in order to acquire a sense of legitimacy and recognition as a mother. Such interactions within institutional settings contribute to the understanding of motherhood as a relational category that operates in the same ways that gender does. But to reiterate the cautionary note that Connell (2012) makes about the relational category of gender: the relational category of motherhood is “not a simple one. It is a relation involving multiple people and categories, linking bodies and institutions” (p. 1677).

Reinterpreting Connell’s concept of hegemonic masculinity and applying it to motherhood therefore offers a new conceptual framework for approaching the analyses and the representation of women’s experiences of motherhood.

## **Summary**

In this chapter I have explained the research design; choice of methods; ethical considerations; recruitment processes and participants; data collection and data analysis procedures; and the overarching theoretical and conceptual orientations in order to coherently address the aim, purpose, and research questions of the study. I have provided a rationale for the conceptual framework of hegemonic maternity as it is applied as an interpretive lens throughout the following chapters.



## CHAPTER FIVE

### On 'Motherhood': Roles and Archetypes

*"You have to find some way of  
seeing the world that puts value  
on your child and also on what you do"*  
(Nancy, Participant).



#### Introduction

This chapter marks the first of six consecutive chapters in this thesis that present an analysis and interpretation of the data generated by this study. In this chapter, I concentrate on the participants' perspectives on motherhood, mediated through their responses to questions during an interview about their lived experiences as mothers of children with disabilities. I discuss the interview data in terms of the 'how' of hegemonic maternity.

#### Motherhood as Production Through Roles

A significant organising category established from the data analyses was participants' experiences of motherhood that can be understood in terms of a range of roles, a number of which are recognisable as archetypes. Prominent amongst these were: the primary carer; the expert; the advocate; and the 'modern day saint'.

I discuss and interpret of each of these roles in turn, foregrounding the responses of participants throughout. Structurally, each one of these roles is treated in discrete sections of this chapter. It is important to stress, however, that these roles are often interdependent and can be considered within the conceptual framework of hegemonic maternity.

#### Mother as Primary Carer

All participants in this study identified themselves as the primary caregiver for their children – except for one participant, Jessica. Jessica's husband was present for the

duration of our interview, and when I asked Jessica who was the primary carer for their daughter, she responded by looking at her husband and saying: “I think it’s a team effort – don’t you darl?” At the time of the interviews, another of the participants, Nancy, had only recently identified herself as her children’s primary caregiver after recently leaving paid work. Prior to this she reported that her husband was classified as the primary caregiver.

The self-positioning of most participants as the primary caregiver for their children is reflective of the findings broader quantitative research. The majority of those who care for children with disabilities are the children’s mother, demonstrated by an ABS (2008) study finding that 92 percent of primary carers for children with disabilities were their mothers. As Lilley (2011) argues, “in contemporary Australian society government agencies, social services, medical services and educational institutions all position mothers as the primary caregivers of children” (p. 208). The gendered nature of care is corroborated by the findings of this study.

The expectation that mothers will provide the primary care for their children has been associated with the good mother concept (Goodwin & Huppertz, 2010). However, the extended period of time that women who are mothers of children with disabilities are expected to provide care for their children (sometimes well beyond the childhood stage) is something specific to ideologies of good mothering for mothers of children with disabilities. This expectation that care will be provided indefinitely had significant consequences for the lives of women in this study. Participants recognised and responded to the expectation that they were the primary caregivers for their children in various ways, which will be discussed below. Ultimately, however, mothers’ experiences of being the primary carer for their children and providing this care in perpetuity, may suggest ways in which care-work continues to be devalued and mostly unrecognised (Leiter, 2004).

As discussed in Chapter Three, the expectation that mothers will be the primary caregivers for their children is reinforced through social and institutional practices and assumptions. Discourses about intensive mothering practices, reifying the mother as the only suitable primary caregiver for their child, remain the normative standard by which mothers’ practices are judged (Arendell, 2000, p. 1195). In order to be considered a ‘good’ mother, a woman is expected to structure her existence in terms of her child’s real, perceived, imagined and anticipated needs (Gurevich, 2008).

This imperative that the mother should be the child's primary carer is intensified for women who are mothers of children with disabilities. While many mothers of children without disabilities may feel their role as a mother continues well beyond the point where their children reach adulthood (whether that is interpreted as legal or social adulthood), the intensity of their caring responsibilities generally diminishes, particularly in relation to the physical care-work that dominates early childhood. Yet, for women who are mothers of children with disabilities, the expectation that they will remain primary caregivers for their children is prolonged, as is the intensity of care: caring for a child with a disability requires "intensive, time consuming contact" (Green, 2007, p. 154).

One participant, Sheryl, affirmed that she is "absolutely" her son's primary caregiver: "I mean [my husband] doesn't even come along to most of the things, he doesn't even know half the stuff." She confided that one concern that keeps her "up at night" is not knowing who will provide care for their son once she and her husband die: "when we're gone I don't know what he's going to do." When I asked another participant, Sally, whether she was her child's primary caregiver she declared: "oh god yeah". She differentiated her role from that of her husband: "he is there, but he leaves it all up to me, saying that I know best."

Sally went on to recount a story about when their son was sick and in hospital for two weeks. Her husband phoned and said: "I'll come down and relieve you and you can have a break" implicitly conveying the assumption that Sally was the primary carer. She also conveyed her gratitude that she could be the primary carer in this situation, because "he would not know how to deal with it. It would be like me trying to drive our semi truck – I just wouldn't even get in the door. It's crazy." This recollection demonstrates the extent to which Sally had accepted and internalised the assumption that she is the parent best equipped to provide such care.

After participants established that they were the primary carers for their children, they often then reflected on the role of their partners (who in most cases was the father of their children). Danielle, for example, articulated her role *in relation* to her partner's role when she said:

Look, my partner ... he's very good, he's great, I couldn't knock him in so far as being supportive, he's always been very supportive, and he takes on a big part of the role, I'm not dismissing that by any means.

Danielle continued by adding that she is the one who makes all decisions, makes and attends appointments, generally orchestrates and meets all of her child's needs, and takes days off work when her child is sick. Her view was that "that's fine, that's just the way it is." Similarly, when Adriana spoke of her partner she asserted that: "he's very hands on with the boys, he's a great dad, absolutely. I wouldn't for a second put any aspersions on his fathering at all."

These types of comments underline the belief and the expectation that mothers should be the primary caregivers for their children, and therefore their partners should not be subject to critique if they are not the primary caregivers: whatever caring they perform is understood as exceptional and worthy of recognition and praise.

### ***Naturalising the Gendering/Maternalising of Care***

Participants rarely critiqued the gendered assumptions about care-work: it was accepted that it was the role of the women/mother, rather than the man/father, to provide primary care. The responses from many participants revealed what can be regarded as an essentialist view of gender when it comes to parenting. That is, the role of the mother is rooted in biology: a woman's role is to bear children and nurture them to adulthood (Coulter, 2010, p. 358). Essentialist understandings naturalise the gendering and the maternalising of care-work. While these understandings are critiqued sociologically (cf. Annandale & Clark, 1996; Fuchs, 2001; Hakim, 2007; Sayer, 2008), many of the participants drew on an internalised set of essentialist assumptions to explain why they are the primary caregivers for their children, and why they feel that it is indeed their *a priori* responsibility to fulfil this role. Participants' perspectives demonstrate "the ways in which a naturalised discourse about heteronormativity, as well as the patriarchal essentialisation of the female as mother, continue to haunt our assumptions" (Jones, 2013, p. 284).

Jayda, for example, was explicit in articulating this essentialism when she said "it's usually the mum [who is the primary caregiver]. I think it's something that's just innate in women that we become that." Sheryl, Charlotte, and Hannah also all drew on essentialist notions

to explain why they not only felt as though it was their responsibility to be the primary caregiver, but why they felt their partners were ill- or under-equipped to take on this role. Sheryl spoke about a father she knew who was the primary caregiver of his autistic child. The father committed suicide. Of this, Sheryl remarked: “men can’t handle it I don’t think.” Charlotte reflected that “most men just bury their heads in the sand and just do their own thing.” Hannah spoke of how her husband went through a period out of work and therefore took on the primary caregiver role for her children: “It was ... we got through (laughter) let’s just say he was glad to be going back to work and I was glad to be coming back home!” Even though she was working and her husband was at home, she was still doing the majority of the domestic labour at home. When I asked her why she believed it is so often mothers who take on the primary caregiver role she replied:

Men just aren’t built that way. They can’t multi task, they don’t have that emotional ... they’re totally different. I mean, I’m totally not sexist in any way, but men are designed with muscles, they’re good with hard labour ... So it’s just the way women are designed is to have that nurturing sort of thing, and also ... it’s like the guy look in the cupboard, you know when they look in there and they can’t see anything? It’s just – they’re not as in tune. I’m not saying that there aren’t men that aren’t like that – this is not a generalisation because there are some women who are just the most shocking-est mothers and I just go, ‘how the hell did you become a mother?’ and they laugh and say ‘yeah that’s why my husband carries that load’.

An analysis of Hannah’s comment evinces a number of important points. First, she employed essentialising understandings of gender as biologically and genetically determined when she described the way men are ‘designed’. She also mentioned the way women are ‘designed’ to be ‘nurturing’, again attempting to link biology with particular gendered traits suitable for mothering. Here, Hannah was firstly making a link between ‘nurturance’ and ‘women’, and then between ‘women’ and ‘mothering’. These links between nurturance, women, and mothering, reinforce and reflect the assumptions that to be a woman is to be a mother; that to be a woman is to biologically possess particular capacities such as ‘nurturance’; and that to be a ‘good mother’ you will be nurturing. This assumption was further illustrated by Hannah’s proposition that some women do not have these traits because not all mothers are naturally ‘good mothers’. Therefore, according to



Hannah, 'good mothers' nurture, and "shocking mothers" do not. Hannah's comments highlight the contradictions inherent in the assumption that mothers are the 'naturalised' nurturing primary caregivers. Hannah defined 'good mothers' as the child's primary caregiver, and "shocking mothers" as those women whose husband/partner is the primary caregiver. Thus, Hannah's discourse underlined the ways in which the connections, complexities, and contradictions between essentialism, femininity, womanhood, motherhood, masculinity, fatherhood, and good mothering ideology can play out.

In the same vein, Veronica drew on essentialising perspectives in her reflection on why it may be that mothers are generally the primary caregivers:

whether we're wired a little bit differently ... whether they [fathers] respond more from the primitive part of their brain, whether that is a factor with it. Whether, because females are more in touch with our emotions so we're willing to look at the picture and address the emotional side of things, whereas a male may not want to so they hold it at arm's length because it's easier to deal with it that way.

For Veronica, women are 'naturally' better parents and therefore it is 'naturally' the case that women are the primary caregivers while men are not.

Participants frequently relied on these rationales, perhaps suggestive of their hesitancy to attribute any sort of responsibility – or what could be interpreted as blame – to their partners and their lack of caregiving. It may be that drawing direct attention to their partner's *perceived* inability to be the primary caregiver, or their lack of action in providing care, could render a participant's status as a 'good mother' vulnerable. It appeared that in order to be a 'good mother', the participants felt they must be not only willing to take on the primary caregiving role, but they must also do so without resentment or ambivalence. Related to partners *not* taking on the primary caring role, many of the participants who were married indicated that they were 'lucky' because, from their anecdotal knowledge, they perceived that many fathers of children with disabilities did not remain in their marriages/relationships. For example, Kelly spoke about how her husband would say he felt like a terrible Dad, and she would assuage this sense of guilt by replying: "well you're here aren't you? Like, a lot of Dads aren't here afterwards. A lot of them go."

Many participants also relied on traditional understandings of the 'breadwinner' model of family life in order to explain why they are primary caregivers rather than their partners.

Adriana observed:

I guess it's that sort of, stereotypical, looking at years gone by ... it's almost like the unspoken arrangement that we have is that I do all the boring but important kid related stuff. And he pays all the bills and mows the lawns sort of thing. And it's a very traditional way of doing it.

Both Adriana and Danielle perceived their husbands' roles as 'traditional': they framed the male role in terms of gendered historical and cultural norms, perhaps to offer a sense of legitimacy to their family organisation and to convey an image of adherence to a culturally-established set of practices. This 'traditional' construction of the parenting role, embedded as it is within patriarchal understandings of gender, positions women as the 'natural' caregivers and men as the 'natural' providers.

However, participants also revealed the fluid ways in which they believed they actively constructed their role as primary caregivers for their children, and the significance of this primary caregiving role for their sense of agency. While Hannah drew on essentialist assumptions to explain why she is their children's primary caregiver, rather than her husband, she constructed her role in a way that can be interpreted as empowering. She said:

like 'oh they should be equal' well I'm sorry but no, it is still the Mum ... so it's always going to be. If you think, like in business, major managers who have to coordinate and stuff it's all men, but in this situation where it's human life who we're managing, it's the women.

In this way, Hannah sought to make meaning from her experiences by reclaiming her position from one bound by gendered constructions, to one that represented, for her, power, authority, and significance. When participants recognised that nurturance and caregiving are not necessarily biological imperatives for women alone, they often spoke in terms of the reflexive quality of their experiences of caregiving and conveyed an

impression of being overwhelmed and constrained by the indices of a broader hegemony of motherhood.

### ***Institutionalisation of Expectations and the Unequal Division of Labour***

Some participants explained their assumptions of nurturance and caregiving in terms of essentialist understandings, while others referred to their recognition of institutional roles and their attendant limitations. The dialogue of participants such as Danielle and Adriana disclosed their enactment of gendered roles, yet they also recognised the restrictions that institutional structures impose through reflecting on the differences in their workplace arrangements compared to their husbands'. Danielle described the flexibility built into her employment, whereas her husband's position would not allow him to take time off work to care for their son or to leave work early to attend appointments. Adriana stated that she is the one who has "got the flexibility in my job." Both women conceded that their 'choices' are generally shaped by social and institutional factors, including inflexible or flexible work practices. However, Adriana acknowledged the inequality of the split in caregiving in this response:

... look I do resent it sometimes, and I get cranky with my husband...and he doesn't understand how busy I get with it. It's like I've got  $\frac{3}{4}$  of a full time job up the road [at work] and  $\frac{3}{4}$  of a full job with all the kid's stuff and with Eden it's an extra loading on top. So I'm working two jobs. But it's just the way it is – I'm sure most of your other mums will say the same.

Adriana simultaneously critiqued and submitted to this gendered split as normative and naturalised through her assertion that "it's just the way it is."

Both Danielle and Adriana can be seen to be performing mother-work that has been feminised. Combined with the institutionally-based differentials between paid and unpaid care-work, these factors reflect the way motherhood is experienced as hegemony. The gendered nature of care-work not only contributes to the marginalisation of women's experiences: it also imposes a barrier to men engaging in such care-work. These factors, along with continued inflexible work practices and the gendered wage gap, combine to make it difficult for men, rather than women, to take up the primary caregiving role, and

for women to have any other choice but to do so. Thus, the paid and unpaid work divide that men and women experience demonstrates the relational and varied nature of how hegemonic maternity can operate to produce and sustain good mother ideology and maintain the gendered nature of care-work.

### ***Hierarchical Ordering of Care-Work***

Based on an analysis of participants' experiences of primary caring in comparison to their perception of their partners' experiences, there exists a hierarchical ordering of mothers and fathers as carers, which is constructed and perpetuated through the gendering and devaluation of care-work. Caring for a child without disabilities, particularly during infancy, is demanding work. Yet caring for a child with disabilities generally intensifies the type of care-work required, the length of time that it needs to be performed, and the skills required to complete such care-work. All participants in the study had to acquire specialised knowledge and understandings of medical terminology and the way government supports operate in order to provide adequate care for their children. This entailed spending a substantial amount of time acquiring knowledge and discourses to enable them to not only interact with healthcare professionals, but to also position themselves as 'valid' and 'legitimate' carers for their children in the eyes of healthcare professionals and social workers. These extra requirements, added as they are to the practical everyday care needs of a child with a disability, and the care of other children if they have more than one child, meant that many participants laboured at care-work seemingly endlessly, leaving them little time for responsibilities or leisure-time outside of care-work and paid-work.

Data from the ABS (2008) support the findings from this research, with over 52 percent of those caring for a child with a disability – who are mostly women – spending over 40 hours per week in providing direct care for the child. This is in addition to managing household responsibilities, caring for other children, orchestrating appointments with medical professionals, and gaining the knowledge and expertise required to fulfil this caregiving role. In support of this data, Leiter et al.'s (2004, p. 379) research found that almost one out of every five mothers of children with disabilities provided at least 20 hours a week of direct health care at home to manage their child's or children's

disabilities<sup>3</sup>. This research, which drew on surveys from almost 2,000 mothers of children with disabilities, found that more than half of respondents reduced their paid employment hours because of caregiving demands, and over half of those mothers who were not in any paid employment reported that they ceased employment because of their child's needs (Leiter et al., 2004, p. 379). Mothers' paid work participation, then, is often significantly influenced and impacted by the intensity of the labour required when caring for a child with a disability.

Despite the way caring is framed within the hegemony of maternity, care-work remains *work*, even when it goes unremunerated. Crittenden's (2001) analysis of care as work highlights the contradictions that abound in societies that emphasise the importance of 'the family' but devalue the care-labour that it takes to manage a family. She argues that female caregiving is taken for granted, and investigates the devaluation of care-work specifically in the context of mothering: "[t]he devaluation of mothers' work permeates virtually every major institution. Not only is caregiving not rewarded, it is penalised" (Crittenden, 2001, p. 191). As Crittenden (2001) argues, two-thirds of all wealth is created by 'human capital' and therefore the parents who raise, provide care, and foster learning for future generations are literally contributing to and shaping the future of human capital, often invisibly.

Despite the research and theorising that has established the nexus between the devaluation of care-work and women's subordination, women are still the ones who perform the bulk of care-work (Home, 2002). Women's participation in the labour force has not shifted the gendered nature of care-work, and in fact, Lee (1998) and DeVault (1999) argue that the intensity of the emotional components of care-work has grown, as the "high economic, social and psychological costs borne by women go unrecognised" (Home, 2002, p. 1). These consequences can be directly related to the hierarchical divide between the experiences of mothers and fathers in unpaid caregiving, and paid-work. This hierarchical divide is both a consequence and also constitutive of hegemonic maternity.

The positioning of care as not only a labour of love, but as laborious *work* that is undervalued, was recognised by a number of participants. For example, Charlotte spoke about the advocacy and work that she had undertaken for the organisation that represents

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<sup>3</sup> Data were collected from the USA.

her child's disability. She sought to secure funding for supported accommodation. She remarked that: "I'm finding now that I'm doing a hell of a lot of work for that but I'm not being paid for it." Further, Jacinta explicitly highlighted not only the lack of financial remuneration for care-work, but also the financial consequences of performing care-work over paid work: "[t]here's no financial reward for any of this." She spoke about her separation from her husband and how her necessary financial dependence on him while she was caring for their son when they were together, meant that all combined assets had been in her husband's name. As a consequence, when they divorced she had no financial history or records that she could refer to (such as having a no-claims history on her car insurance) when attempting to establish her financial independence.

These sorts of impacts demonstrate Crittenden's (2001) point that "a mother's work is not just invisible; it can become a handicap" (p. 3). Crittenden's (2001) analysis resonates with Jacinta's comment: "I can't believe that I've had this intense job for 31 years." Jacinta further reflected that the labour of the care-work required for her son "extends for years and years and years and after a while you realise that hey, I didn't get back to that career I thought I was going to have. Or hey, I never took that holiday. I never did anything, really. Because I was always the carer."

Jacinta's comment is a clear example of not only the ways in which care-work is devalued and largely unrecognised, but also the extent to which this devaluation precipitates the hierarchical ordering of mothers', and in turn fathers', experiences.

### **Mother as Expert**

A prominent dimension of participants' experience of motherhood centred on the expectation and requirement to develop expert medical knowledge about their child's disability and health. Yet, once acquired, participants often described the ways in which this knowledge was frequently invalidated, dismissed, or ignored. The role of the mother as 'expert' stems from and is intimately bound to the role of 'the primary carer', because participants reported the need to both manage the care of their children, and be equipped with the knowledge to manage their child's disability. Therefore, the responsibility for being the primary caregiver of a child with a disability also carries with it the additional responsibility for decision-making regarding their child's care, the development of

expertise in disability, navigating healthcare systems, understanding disability policy, and negotiating allied systems of support.

All participants in this study developed a level of expertise about their child's health that is not necessarily required of mothers of children without disabilities. The positioning of women who mother children with disabilities as 'experts' is supported by research from Green (2007) who found that "mothers of children with disabilities become experts in navigating the health care and social service delivery systems" (p. 158). Further, the role of participants as 'experts' supports Voysey's (1975) use of the phrase 'special competence' to describe the skills of mothers of children with disabilities in performing their role of caring. They occupy this position not simply because they want to ensure the provision of the best care they can for their children in managing and living with disability, but also because many feel they have to compensate for what they perceive are the failures and deficiencies within the healthcare system. Further, many participants expressed their belief that health and allied care professionals expected that they should understand and in fact orchestrate and oversee, the care being provided to their children.

### ***Knowledge from the Time of Diagnosis***

From the time of diagnosis of their child's disability, participants became actively and heavily immersed in the task of acquiring expert knowledge. For example, when Jacinta's son was first diagnosed 37 years ago she visited the NSW University Medical library: "I photocopied everything and it had all these really big long words with no idea what they meant so I had to go get a medical dictionary to work it all out." Kelly kept detailed diaries and records of all her son's milestones which doctors were then able to draw on to provide her son with the diagnosis of autism. Nancy recalled that when she took her son to the paediatrician she was asked what she thought her child's diagnosis was:

he said, 'well what do you think it is', and by then ... because I'd done a social science psychology degree and I'd read one little portion, probably three paragraphs at most, on autism and in the end ... I said 'is it this autism?' and he said 'I think it is' and *that's* how I got my diagnosis.

Before Sheryl's son's diagnosis she "was madly scrolling through the Internet trying to work out why he wasn't smiling and I was typing 'baby not smiling, baby not smiling'." Danielle was a student when she had her son with Down Syndrome. She recalled:

I tried desperately to find out anything I can do ... I remember ringing up a researcher at Concord Hospital and saying to him 'look I'm a student, I'm a parent, I have a son with Down Syndrome and I'm very aware of the correlation with Alzheimer's, is there anything I can do to prevent, slow down, or whatever?'

Tania suspected her child had autism. At one point she said, "I literally got out the yellow pages, and I looked up autism which came up as ASPECT NSW, rang them, and I just said to them 'do you recommend anyone that can assess my child for autism?'" It was only after Jessica noticed and then researched symptoms that her daughter was displaying that she phoned her paediatrician and said "'I think she's got epilepsy.' So then we went and had the tests and she's got the epilepsy but it's a different type ... it's rare."

### ***Interactions with Professionals***

Participants' involvement in the initial stages of their children's diagnoses were triggered by the intensive efforts to understand their child's condition. In fact, many drove the search for, and acquisition of, knowledge about their child's condition. Hannah's interaction with her daughter's orthopaedic surgeon was a clear example of such initiative and assiduousness. She said that her daughter's surgeon was "confused" by some x-rays of her bones, and in Hannah's words, the surgeon said:

'oh I'm going to have to go talk to some associates', and I said 'look, let me get back to you, I'll go chat to the mums and I'll go find out what's going on and get back to you'. As soon as I got on Facebook and said 'guys, here's the x-ray, can you tell me what's going on?' They said 'oh it's just delayed bone growth, she'll catch up by the time the growing finishes which is at about the age of 10', and so I emailed back to his surgery and he actually acknowledged when he sent a letter to my GP ... he said, 'I actually have confirmed that that is correct' and I was like oh my god you've acknowledged it.



Hannah chose to be proactively involved in the search for answers about her child's condition, and positioned herself as the primary investigator over the orthopaedic surgeon. She then drew on her online networks of support, including a private Facebook group of mothers from across the world who have children with the same genetic condition as Hannah's daughter. The posting of her daughter's x-rays on the Facebook site, and the questioning of these other mothers not only demonstrates the initiative Hannah displayed in investigating her child's condition: it also illustrates the significant amount of trust she placed in this online community. The confirmation by the surgeon of the Facebook community's suggestion about her daughter's bone growth, validated Hannah's trust in this online community. It also shaped her perception of the surgeon himself. Hannah expressed shock that the surgeon acknowledged that she was the one who proposed the diagnosis, and that he confirmed that it was correct.

For Hannah, the surgeon had legitimised her position as 'mother as expert' and this legitimisation significantly changed the way she positioned and perceived this surgeon. This was evident when she described a follow-up appointment with him saying: "he was actually asking my opinion and I was like wow I'm in with this guy, obviously." Hannah's role as 'the expert' was buttressed by her knowledge capital gained from her degree in Health Sciences. This capital enabled her to engage in the medical discourses and present herself to specialists as a 'scientific person':

that's how I've managed to get around any of the specialists, I respond to how they are and they respect you, but I think if you went in and showed yourself as to not be an intelligent person, not because you're not intelligent but because you just haven't had to have been a medical expert, they would walk all over you.

It can be suggested then, based on Hannah's experience, that one way mothers can acquire the mantle of the 'expert' is through acquiring medical or scientific education, either formally or informally.

Not all participants, however, came to the role equipped with specialist educational qualifications to build on in order to acquire the expertise, experience, and knowledge needed to care for their children. For example, Jacinta said that

the professionals would teach me how to teach him and I would work on him every minute ... Every time that I was doing something I would explain what I was doing. Absolutely everything ... So it was all trying to teach him.

Of her son, Katherine observed:

I'm his specialist because I understand him, and I always felt like I can work with this kid, I can get him to do stuff ... The truth is, I don't think he'd be doing what he's doing now if it wasn't (pause) for (pause) me. It sounds almost conceited but it's true.

Katherine's son required a feeding tube and she described the stress and trauma involved when her son would pull the tube out and they needed to go to hospital to have it put back in. She commented that "I've watched these stupid nurses do it and I watched the trainee nurse do it and I thought – what's the difference between the trainee nurse and me?" She described how she would eventually insert her son's feeding tube herself to avoid the difficulties associated with regularly attending the emergency department:

I mean the things I did, I'm not qualified to do it but I couldn't put him through the trauma of sitting in emergency and having an emergency registrar practice on him, so it was better that I just do it.

Katherine's experience reveals a distrust of and frustration with healthcare professionals in contrast to her confidence in her own ability as an expert in her child's condition. She was unequivocal and resolute in her stance and in her decision to act to protect and ensure that her son was well cared for.

Frustration and a sense of indignity were palpable as Katherine spoke about her son's treatment by a team of doctors during one hospital stay:

... they would speak about him as if he was a book case, in front of me, like he was just a thing, without the personal side and no sensitivity. Or

give me this medical file and I would read it – they didn't realise – I would read it so I knew everything that they suspected. And I would hide from the blood test people too – because when you're in hospital they're not allowed to take blood unless the mother gave permission and if I thought he was too tired I would just leave as soon as I saw them and I'd spy because I knew he needed to sleep more than he needed that test.

Katherine's knowledge about the permission required before taking blood tests, coupled with her own positioning as the expert in her child's condition, afforded her a certain degree of control over her son's treatment. However, she gained this control through manipulating the system, rather than through the medical professionals outwardly recognising her authority as a mother-expert. This is reflective of Blum's (2007) description of mothers of children with disabilities becoming 'vigilantes' in battling medical establishments on behalf of their children.

Katherine's relationships with her son's medical professionals clearly impacted on her perception of his treatment and reaffirmed for her the importance of maintaining her position as a mother-expert. When her son was in hospital, Katherine would call the team of doctors: "the pack of wolves ... to me they were the pack of wolves because they'd come and they'd ask me the same questions over and over again cos we were their interesting case." These compelling examples from Katherine's experience support the findings from Lilley's (2011) research on mothers of children with autism. Lilley found that, similar to participants in this research, mothers often perceive themselves as knowing more than healthcare professionals, and "sometimes covertly resist or overtly challenge professional knowledge and practices" (Lilley, 2011, p. 210). They do so, motivated by their compulsion to ensure their child receives optimal care.

Therefore, while both Hannah and Katherine resisted, challenged, or took pro-active and mother-expert approaches in their interactions with medical professionals, they both had contrasting experiences and perceptions of the professionals. Hannah's background with a degree in Health Sciences enabled her to understand, interpret, and engage with medical discourse, and therefore she experienced generally positive interactions with health care professionals in the treatment of her daughter.

Similarly, Keira described her position as a mother-expert as one that was supported through tertiary qualifications, which firmly established her as an expert: “I’m also trained in disabilities and I also teach it, so I do know what I’m talking about. So I have a lot of skills that I have imparted onto them [her students]”. In this way, Keira recognised the benefits derived from educational qualifications to support a mother-expert position, and the ways in which a mother-expert position has supported her role as a TAFE educator.

How these roles cohered when caring for her daughter is worth exploring. Keira’s daughter lives in a group home for five days a week. Keira recounted a number of stories that underscored a lack of understanding from care-workers about her daughter and her condition. Keira also described her attempts to educate care staff on how to treat her daughter and talk with her in order to elicit an appropriate response. When I asked if the staff seemed receptive to her suggestions Keira replied:

ninety-nine percent of the time. I have had a few staff sacked over the years but I can back every single thing I say up with evidence ... and it actually makes you a scary component to the person’s life. Like I’ve had some staff say, ‘well what the hell does she know, she’s only the mother.’

Keira’s comments illuminate the competing identities of expert-based-on-educational-training-and-‘evidence’, compared with expert-based-on-knowledge-acquired-as-mother. The combination of these two sources of capital rendered Keira “scary” in the eyes of care-workers and other care professionals since she was equipped not only with the knowledge about what was best for her daughter, but also with the educational qualifications to validate her approach. Interestingly, Keira’s comment about the attitude of others – “she’s only the mother” – also points to the pervasive devaluation of the views and perspectives of the mother-expert position.

Conversely, participants such as Katherine, who did not have the formal educational background specific to science or disability, but who had acquired knowledge through years of care-work and interaction with healthcare professionals, struggled to be recognised and respected as mother-experts. The majority of participants spoke about the battle to have their expertise and opinions heard and validated by healthcare professionals. Two participants’ experiences are particularly clear examples of this phenomenon.

The first is that of Veronica, whose son has autism and lived through a period when he was suffering psychotic episodes. She said these episodes were

really, really, really scary because he was totally delirious. We didn't know what he was capable of ... he was totally delusional. He was hallucinating. He would see monsters and he would think that his dad was going to kill him and was trying to kill him ... He would hallucinate and try and dive through the floor like the floor was water – so he was hurting himself.

On one occasion during an episode occurring at 2am, Veronica called an ambulance: “we wanted some help. We desperately needed some help. It was really scary, all of us were up”. When the ambulance arrived:

they just said ‘oh wake Mum, he’s just been experimenting with drugs’ and I just felt like hitting him and telling him to get out of my house ... I must admit, I was absolutely livid ... Really, really angry, very insulted... At first I said ‘you don’t know my son, he looks very normal but he would never ever, no way, drugs’ and he just said ‘mum you’re living in fairy land’ and I said ‘you don’t know my son’ ... and at that point I thought there was no point continuing – just get this guy out of my house as quickly as possible because I needed to manage and deal with this. So that’s what I did... The next morning, I thought I should go and do a formal complaint and raise some sort of awareness. But I didn’t. I think I was too tired and just wanted to get back on track.

Veronica’s experience epitomises the continued lack of understanding – even by medical professionals – of autism and mental illness. It captures some of the frustration and indeed fury that mothers of children with disabilities feel when their knowledge is undermined, dismissed, ignored or not taken seriously. Veronica eventually found a doctor who helped to equip her with strategies to manage and prevent her son’s psychotic episodes. The fact that Veronica eventually found a healthcare professional who was able to help her son, and that she thought about putting in a formal complaint but did not, reflects the competing demands on participants’ time, energies, and emotional, physical, and

intellectual resources. Not only did the ambulance driver undermine Veronica's knowledge as a mother-expert, but his blatant scepticism and patronising, dismissive attitude also put her son at serious risk.

A similar though even more dire example of the marginalisation of the mother-expert came from Charlotte, whose story is worth retelling in some detail. Charlotte's son has Prader-Willi Syndrome. Amongst other symptoms, he has an inability to control his temperature, does not vomit, and has a very high pain threshold. Because of this, Charlotte took her son to their new General Practitioner (GP) to establish a relationship with him:

'This is Jason. This is normal Jason. Now when I come to you and say he's got something wrong with him but you can't tell – let me tell you, there is something wrong with him ... If I come in and I think there's something wrong with him then you need to investigate'. They just look at you like pfft, crazy woman.

Charlotte pro-actively set out to manage her son's health care and directly asserted her role as mother-expert. When Charlotte noticed there was something wrong with her son's leg, she took him to the GP: "I said 'look I don't know what it is, I think he's pulled a hammy, maybe he doesn't want to go to respite'." The doctor responded: "'I don't know what it is'." Charlotte did not accept this response and proceeded to take her son to a number of other doctors and to physiotherapists, without being provided with an explanation. She then received a call on a Friday night from "one of my professionals" – who had treated her son earlier – who said that she thought she should have her son's hip x-rayed. Charlotte raced to the nearest medical centre, saw a doctor, and told them she needed an x-ray of her son's hip: "the doctor just looked at me and goes 'why should I give you an x-ray? A, you're not my patient. B, why should I give him an x-ray on his hip?' 'Because he needs one'", she responded. When he had the x-ray done the doctor said there was a fracture in his hip: "and I go, 'thank you'. And he was rude as to me." Charlotte then made an appointment with a physiotherapist, but became increasingly worried, so she took him to the children's hospital: "they took one look at the x ray and said 'emergency surgery – tomorrow'."

Charlotte's son had popped his femur out of his hipbone, and she was told that when it is out for more than 24 hours, blood supply is generally lost, which meant his leg had turned

necrotic. He underwent emergency surgery that lasted 8 hours: he was pinned and plated in both hips, and was subsequently bound to a wheelchair for 12 months. Whilst he was in hospital, he became non-verbal, violent, and incontinent. "He was just not the same person. So I had a hard time at the hospital saying – this is not my son, there's something wrong we need to find out what's going on." But Charlotte's concerns about her son were blithely dismissed. In response to this she recalls taking the matter into her own hands: "I got on the Internet and spoke to people all over the world ... I've got such a strong network of people, I was going through all the people I knew, knocking on doors." It was only when Charlotte spoke to a geneticist and told him her son had stopped eating – and people with Prader-Willi Syndrome always have a ferocious appetite – that the hospital finally accepted there was something else going on.

Medical professionals reported that her son had experienced psychosis for over a month because of the stress and trauma of his injury and surgery. They began treating him with anti-psychotic drugs: "And then one day we just walked into the room and he was back again." He was 14 years' old.

After the psychotic episode, Charlotte's son was bound to a wheelchair during his rehabilitation, and was therefore unable to easily access the family home. Charlotte contacted the Department of Ageing, Disability, and Home Care (ADHC) in desperation: "We can't do it anymore. We won't. We're not going to bring him home from hospital, you need to do something for him." She remembers that

it was a nightmare. They [ADHC] were like – well he's your son, you've got to take care of him. It was like – well, have you ever tried to do this? ... we said look, physically the house would not work, and mentally we couldn't cope with him. Because he was still pretty unstable psychotic wise. And I said I just can't do it – if you impose that on me, not only will he have problems but I'll have problems as well.

Eventually after two months of negotiation and continued pressure, ADHC admitted Charlotte's son into a medical facility for 12 months while he recovered, and he came home approximately every weekend during that time.

As the mother-expert, Charlotte's tenacity and perseverance with the medical institution was vindicated. Yet her story offers deeply compelling insights into the often 'life-and-death' consequences of the institutional marginalisation of the mother's expertise. That Charlotte had to navigate a system that devalued and dismissed her expertise is both disturbing and also indicative of the seriously deleterious impact of cultural and institutionalised beliefs and practices around motherhood.

Charlotte's experience is also a powerful example of the important role that mother-experts play in not only identifying problems within their children, but also in persistently following-up on their suspicions even when faced with consistent opposition. It demonstrates the critically important role that doctors and healthcare professionals *can* play in taking seriously a parent's concerns for their child. Further, it reinforces the significance of having in place an informed support network – particularly of healthcare professionals – who know a child and the history of their condition. Crucially, it underscores the importance of government funded out-of-home supports and the potentially disastrous results if such supports are not in place. Not least, Charlotte's experience epitomises the determination, fortitude, and resilience that many mothers of children with disabilities demonstrate in order to receive appropriate care for their children.

### ***Orchestration of Care***

A further difficulty that participants faced as part of their necessary yet under-recognised positions as 'mother-experts' was the sheer logistical organisation of the healthcare professionals required to attend to their children, along with the management of information between such professionals. For example, many of the children of participants required the support of paediatricians, speech therapists, occupational therapists, and physiotherapists on a regular basis. Yet in the majority of the participants' experiences, these specialists had little to no interaction with each other. Therefore, it was up to the participant to absorb and, if necessary, relay any information about her child that their paediatrician may provide, for example, that would be relevant to their speech pathologist. Participants encountered situations in which a GP would recommend an MRI, and their child's dentist had recently suggested the need for an x-ray. So she would attempt to organise both of these appointments to occur at around the same time in order to manage the often-complicated logistics of travelling to and attending appointments.



Participants in this study reported a myriad of ways in which they were expected to: *acquire* expert knowledge; *exercise* such knowledge; fight for *recognition* of such knowledge when it was challenged or ignored; and then *manage* the interpretation of such knowledge with and amongst a number of professionals. As Tania reflected, the road to discovering the forms of support needed by her child, and the processes involved in obtaining such supports was “horrendous. I basically did a lot of it myself... It’s me who manages everything. So I’m researching the intervention therapy, I’m deciding what we should do, I’m deciding who should do it, I’m tracking that person down, making appointments.”

Whether participants chose to or not, many were forced to become experts in the disability of, and care required for, their children. This finding supports Lilley’s (2011a) research that reported mothers of children with autism were forced to become experts in their child’s condition regardless of whether they chose to or not. Further, once mothers acquired such knowledge and took on this expert position, they did not passively absorb such information, but instead were actively involved in advocating for and studying information given by service providers, healthcare professionals, and other mothers. As Lilley (2011b, p. 153) found: “mothers are expected to research and decide on therapies, search for ways to fund multiple services, and ferry their child back and forth across the rugged landscape of early intervention.” Based on the data from this study, I would add that this “rugged landscape” is not restricted to early intervention, but characterises the entire disability sector. As Blum (2007) argues:

Mothers confront treatments and services fragmented across bureaucratised educational and medical systems competing over professional turf and expertise. And they confront neoliberal budget tightening, at the same time, weighing heavily against the costly, controversial needs of their children (p. 222).

Blum’s (2007) research also supports the findings of this study, because although mothers are expected to become experts in their child’s disability, their knowledge is routinely undermined and devalued. Importantly, Ryan and Runswick-Cole (2008) suggest a link between the expert knowledge mothers of children with disabilities are required to have –

“deemed to be the norm for successful mothering” (p. 206) – and the largely undervalued role these mothers occupy as ‘activists’.

### **Mother as Advocate**

Therefore, linked to the expectation and requirement that mothers of children with disabilities acquire expert knowledge in their child’s disability is their need to be ‘activists’ and advocate for their children. Many participants reported that they had little choice other than to occupy the role of ‘the advocate’ in order to fight for the provision of services to support them and their children. This expectation that women who are mothers will ‘advocate’ for the ‘best’ for their child, and will go to almost any length to provide high quality care for their children is embedded within hegemonic maternity. As Tania stated:

It’s been a long, long, long road with the boys. I can’t honestly remember what it was like beforehand – so yeah, this is everything. It’s all-consuming. And you have to make decisions that you don’t necessarily want to make but you have to – you’re their advocate ... you’ve got to be their advocate.

Participants came to occupy the advocate position in different ways and for different ends. Some regarded their advocacy role as being tied directly to the wellbeing of their own child, and felt that they had a responsibility to use their own voice to speak for the needs of their child who could often not speak for themselves. Participants were particularly sensitive to the need to advocate in a way that met the needs of their child, whilst also being conscious of the fact that their child is a unique and individual person who may not always necessarily agree with, or wish to be advocated for. On this point, Veronica said of her son: “I had to do lots and lots and lots of advocating for him.” She recounted incidents of bullying on the bus when he was in school, and having to talk with the bus driver about it. Veronica recognised the inherent tensions in her role: “Being *that* parent. But doing it in a way that doesn’t ostracise or embarrass [my son] as well.” In this way, Veronica was conscious about meeting the needs of her child whilst also seeking to respectfully acknowledge that his understandings of these needs may differ.

The tension between balancing these two objectives was clear during a situation involving Veronica’s son’s first job. She knew from her other daughter (who does not have a

disability) that her son was being severely bullied in his workplace. He was confiding in his sister about the bullying he was experiencing, but specifically said that he did not want his mother knowing about it, because he did not want her pursuing the issue in his workplace on his behalf. Veronica recalled:

that's where I had to really respect him because he was worried that I would go and say something ... So that absolutely killed me so we just had to hang in there and have faith, and he got through it.

In this situation, Veronica recognised that her role as an advocate also meant being considerate of the express wishes of her child, even if she felt his wishes were not in his best interests.

Another way participants became advocates for their children was through engaging in lobbying and activism with outcomes directly related to their child's health, wellbeing and care. As Sheryl noted: "I want what my son deserves, and you're not fighting for yourself either – when you're fighting for your kid you want everything you can get for them." Keira was compelled to become a fierce advocate for her daughter when she entered a residential care facility:

I have had a few staff sacked over the years. I am a bitch. But I'm a good advocate for [my daughter] ... And I throw duty of care at them. Anything it takes. I will throw legal action. I will throw media. When it's life threatening on either of those two.

Jill's experience offers another example of how mothers advocate for the rights of their child. She took out a case against a company for discrimination against her daughter with a disability and won, declaring: "I'd do it again. I won't sit on my hands and let people walk on my daughter ... I go to bat for [my daughter] whenever I have to." After the case was settled, Jill remembered walking into a room filled with other children with disabilities for a Christmas party:

I walked in and I'd been so overwhelmed all day and when I walked in and saw these kids I just started to cry, and I felt so embarrassed

because there was no logical explanation behind my tears except for looking at these kids and thinking to myself – I didn't even say to anyone – that I could've made it better for one other person in that room with what I did.

In exercising agency and a determination to legally address discrimination on behalf of her daughter, Jill felt she had made a difference – not only in her personal sphere, but in potentially far-reaching ways.

Charlotte described advocating for the needs of her son through trying to direct public and political interest towards the needs of all children with Prader-Willi Syndrome, given the desperate need for services, funding, and support:

I first started writing letters in May 2012, wrote to the ministers, wrote to everyone – Federal, local ... they all ... the minister never really looks at anything. And all you get are bunches of rhetoric. I've got files this thick of rhetoric ... But seriously, you'll get knocked back, knocked back, and knocked back. And it just becomes disheartening ... I was just obsessed. I am still obsessed. I'll sit here and work on more letters. I write to the newspapers, I write to the television, can please somebody help us. And this is just me. I'm just one little person out there in the whole world of disability, so how hard is it for people who don't have a voice ... that's another thing I'm trying to advocate for – to educate parents to become advocates for their children because there's nobody out there that does it for you, and you're your child's strongest voice.

The beliefs, values, vision and actions of Charlotte and other participants accord with the findings reported in research conducted by Ryan and Runswick-Cole (2008). They describe the “enhanced advocacy role adopted by most of the mothers” (p. 50) through a commitment to social and political activism such as lobbying politicians and drawing on opportunities for raising awareness through the media.

Sally, another participant, also adopted this role of advocate for both her own child and also for other children with disabilities in her local area which lacked the appropriate provision of services. Sally raised such a profile in her local community through

advocating that when she was denied a request from an organisation “they wanted to know my name, that’s how I’m red-tagged, that’s how much noise I’ve made.” Sally’s experience of advocating and fighting for the rights of her child and for services for other children with disabilities, exemplifies Ryan and Runswick-Cole’s (2008) finding that “many of the mothers demonstrated a sophisticated engagement with key social and political issues and had clear goals and objectives to achieve social change and yet did not reflect upon how this work remains unpaid and largely invisible” (p. 51). Sally added that “I just said to the social worker today – she said ‘oh I read in your file that you’re a very proactive mother’ I said YEP! ‘and a great advocate’ and I said YEP!”

While many of the women in this research adopted this role of advocate for their children and others in their community in an overt, public way, others advocated for their children and others in more subtle, behind-the-scenes ways. Kelly, after reflecting on the ways other women who mother children with disabilities advocated within the disability sector, commented on the ways she felt that she too advocated in her role as a teacher:

I advocate in a kind of different way... I’ll get to put my cents in at work about children with additional needs – it doesn’t always go my way and I find it really hard not to get emotional about it because it’s like I’m charging forth for this child and how far they ... It’s really hard for me not to take it too far... I think you need a lot of extra energy to do those things, and a lot of that advocacy. It becomes a mission, and I don’t know that I’ve got that sort of energy. I’m actually going to be studying natural therapies this year as a side-line to teaching, and I suppose that’s in a way, doing something that’s related to our situation. Because I want to feel like I’m of help to other people, and that’s part of being a teacher too.

Participants often had little choice than to occupy the role of the advocate in order to fight for and secure support services. The role of the advocate can be seen to be continuous with the requirement that participants develop expert knowledge in their child’s disability. The expectation that participants occupy such a role in addition to their caring and other responsibilities once again exposes how hegemonic maternity continues to operate and remain pervasive in the lives of women who are mothers of children with disabilities.

## **Mother as 'Modern Day Saint'**

Woven throughout these responses were references to self-sacrifice, personal struggle and the willingness to do anything for their child, invoking imagery of the archetypal saint. An often poignantly-rendered thematic thread was evident as participants spoke of their experiences of self-sacrifice, and the consequences of such sacrifices for their lives as women and as mothers. Many felt they had little choice other than to sacrifice their own time, personal aspirations, goals, interests, paid-work opportunities, leisure time and indeed, at times their selfhood, in order to dedicate themselves to caring for their child with a disability: "in maternity, one often experiences a mode of generosity that is excessive in what is demanded and taken, a profoundly unilateral economy of the gift" (Jones, 2013, p. 290).

A significant number of the participants in this study had children with disabilities who required continuous high care. Many of these same participants also engaged in considerable advocacy work and medically-oriented research in order to provide care for their children. The notion of self-sacrifice as it emerged in participants' responses was frequently cast in metaphors and analogies of 'saintliness'. Further, participants articulated their perception that mothers of children with disabilities can often be regarded by onlookers as particularly gifted, special and 'out of the ordinary' people, revealing the extent to which the archetype of the self-sacrificing 'saintly' mother is inscribed in and naturalised through discourses of motherhood and 'good mother' ideology.

Participants in this study also identified the ways they both accepted and resisted this notion of self-sacrifice. For example, Katherine spoke of her responsibility in managing her son's behaviour, using an example of their attendance at a family birthday party that coming weekend: "I'm going to have to hold it together ... I always do the RIGHT thing. I'm a right-thing person. So I will go, but already I'm thinking, 'okay brace myself, we have to bring this, this and this'." She then talked about wanting to go to a professional development day that same weekend, which she felt was important for her career. However, attending both the birthday party and the professional development program would have potential implications for her health: "I will probably get sick. I can feel I'm coming down with something now". She spoke about needing a 'recovery' day: "I've got

work to do, I've got to wash, I've got to prepare for the working week. I can't lose a day. I do not have time for this. It's terrible."

When Katherine described herself as a 'right-thing person' she was identifying her felt-expectation that she forego the opportunity to focus on her own needs and desires in order to be considered by herself and others as a 'good mother'. However, she also recognised the ways in which meeting such expectations impacted on her personal wellbeing: "I think I'm strong, I think I'm so strong. I'm fragile all the time ... But to do what I've done (starts crying) I cannot believe what I have endured. (Whispers) It's unbelievable." The personal cost of the performative demands of hegemonic maternity are exposed in Katherine's heartfelt and candid expression of the inner conflict generated by the need to display strength through 'good mothering', whilst seeking to self-manage her inner sense of fragility, exhaustion, and vulnerability. She acknowledged her capacity for endurance and self-sacrifice, but did so almost as if she were a spectator of her own life – "It's unbelievable."

It was a common theme throughout the interviews that participants felt they were perceived as 'saints'. The idea that mothers of children with disabilities are 'gifted', 'special' or capable of 'doing it all' was considered to be offensive rather than complimentary to those participants who discussed this notion. For example, Jacinta remonstrated: "and 'god only gives special kids to special people' and I think – ohhh vomit! ... I know they're well-meaning and I try very hard to accept their well-meaningfulness, but I just think – what bullshit." Similarly, Jill remarked: "I get people saying to me 'I don't know how you manage, I have no idea how you balance your life and your children' ... sometimes I get angry because I'm no different to anyone else."

One participant, Sheryl, explained why she was offended by being referred to as a 'saint': it obfuscates and effaces her motivations for carrying out advocacy work. In this way, Sheryl challenged the assumption that mothers are naturally self-sacrificing. She recounted an experience to illustrate this:

I walked into the post office the other day and the bloke behind the counter goes 'oh the modern day saint is here' because I raise money and you know, so I've actually been called that ... I do that for my own mental health, raise money, I do that because it makes me feel good. I do

that for me because it relieves some of my guilt, and I like doing it, I think it's fun. But being called that was very uncomfortable in front of half of [the suburb] that was in the post office.

Occupying the role of the self-sacrificing 'saint' is embedded within the operation of hegemonic maternity. Participants' attempts to live up to this expectation can have extraordinary consequences on the way participants managed their personal lives, relationships, and subjectivities. While they generally acquiesced to the power of such an expectation of self-sacrifice, it was often performed at a great personal cost.

## **Summary**

This chapter has explored the ways in which motherhood is produced for women who are mothers of children with disabilities in this study. All participants positioned themselves as the primary carer for their child or children with disabilities. In doing so, each identified the complex and often insurmountable conditions that shaped and structured their experiences of mothering. In response to these conditions, many participants adopted and enacted a range of roles and archetypes that can be understood in terms of hegemonic maternity. Participants were often compelled to take on the roles of the primary carer, the expert, the advocate, and the 'modern day saint' in order to ensure the quality of their child's care; locate themselves within normative frameworks of the 'good mother'; and negotiate a constellation of assumptions about what 'good' mothering in the material world entails. As a consequence, their choices and behaviour were often driven, mediated and regulated by such frameworks and assumptions over which they felt they had little control. The roles positioned participants in relational ways that inevitably framed and impacted on their personal relationships, actions, perspectives, and life choices.

These findings corroborate Green's (in O'Reilly, 2012) view that:

[c]entral to understanding women's experiences of mothering is recognising that motherhood is not restricted to merely bearing and/or caring for children – which themselves take enormous amounts of energy and commitment – but that motherhood also includes the culmination of social structures and meanings that create conditions



under which women are expected to parent, and thus, prescribe and shape the circumstances of women's lives (p. 24).

In the following chapter, I extend the analysis of participants' experiences of motherhood by examining how and why they are compelled to negotiate discourses of 'normality'.



## CHAPTER SIX

### On Negotiating 'Normality'

*"...my life changed so dramatically, because I wasn't even prepared to have a normal child. Like if I had a normal child, I'd be breezing through life ... I think people with normal kids just have no idea what we go through"*  
(Sheryl, Participant).



#### Introduction

The purpose of this chapter is to examine the ways participants, as mothers of children with disabilities, negotiate the ubiquitous discourses, images, and socially-promulgated standards of 'normality'. As Davis (1995) argues in his seminal work critiquing normalcy, "we live in a world of norms... There is probably no area of contemporary life in which some idea of a norm, mean, or average has not been calculated" (p, 23). Davis' work is situated within critical disability studies and focuses on the construction of what is 'normal' and the role it has played in governing how we understand people with disabilities. This recognition of the ways the language around classifications of 'normal' and 'abnormal', and the construction of the concept of 'normalcy' itself, is useful to recognise when interrogating cultural assumptions around what it 'normally' means to be a mother.

During interviews, each participant described an intense process of grappling with their own understandings of 'normality' and what they considered to be those of others'. The task of negotiating the meanings of 'normal' and 'normality', not merely as abstractions but as powerful influences on behaviour and perceptions, emerged as a key dimension of participants' experience of motherhood. Their frequent referencing of the terms, and their attempts to reconcile indicators of hegemonic 'normality' within their own lives, revealed the multiple, sometimes unstable meanings and expectations attached to this signifier.

Discernible within the interview data were predominant themes in participants' dialogue about 'normality' which included:

- consequences of comparisons between children;
- prior perceptions of 'normality'; and
- mothering the 'good disabled child';
  - the child is not physically violent
  - the child demonstrates potential for 'improvement'
  - the child's appearance is considered to be physically attractive.

In the following discussion, I address each of these themes in turn, providing evidence of participants' experiences of negotiating, contesting and seeking to make sense of concepts of 'normality' in their own lives.

### **Consequences of Comparisons between Children**

Although many participants made comparisons between their child with a disability and other children, they often found it challenging to speak about this topic without contributing to the perpetuation of discourses of the 'other'. For example, Jill who has three children, one of whom is disabled, captured this dilemma when she stated:

if you had one child with a disability you'd know no different, but because I'm a mother of children who are – I hate that word, I hate normal. So I use the word mainstream. I hate normal because I don't think anybody's normal.

Jill deliberately avoided the word 'normal', which for her was associated with difference and perhaps discrimination. Interestingly, she refrained from using the word 'normal' when describing the contrast between her children without disabilities and her child with a disability. Her explanation for why she 'hated' the term was because of everyone else's *abnormality*. In this way, Jill rejected discourses of 'normality' but also sought to situate her child *within* normative discourse by asserting that she did not think that anybody was 'normal'. So for Jill, her child's *abnormality* is located on the same continuum of *abnormality* that applies to everyone else. She appropriated and then redefined the meaning and parameters of 'normality' to encompass her child and family within these parameters. Comparisons between her child and others, therefore, did not serve to

exclude her child from the continuum, but to include her child on the continuum of 'normality' / 'abnormality'.

It was often by comparing other children with their own child that participants came to an awareness of the extent of their child's disability. In other words, overt comparisons heightened their cognisance of difference. Kelly described taking her three-year-old child to a theatre show. She found herself comparing his behaviour with the other three-year-olds watching the performance. She met her husband after the show: "I said, 'there's something really wrong with him' and I just dissolved into tears." The realisation of difference and having a child who seemingly fell outside of the normative framework was confronting and painful for participants who experienced this.

Sheryl too observed the differences between her own family life and what she perceived or imagined to be 'normal' family life – that is, families of children without disabilities, and for her, this was a source of anguish. She spoke of the projected image of what life is supposedly like for 'normal' families but concluded that this image is "quite hurtful, because that's just not us and it's never going to be us." 'Normal', for Sheryl, had a fixed meaning and this meaning excluded her experience of family. Yet Sheryl seemed comfortable with the term 'normal', unlike Jill, and she used it in a way to emphasise the difference and isolation that she sometimes felt. She spoke about watching "normal kids" interact with her husband, and reflected: "Sometimes I think – 'just leave and go and find someone else and have some normal kids and be a good dad to them. So just so one of us can have a normal life out of us'." This poignant comment bespeaks the depth of pain, stigma, and separateness that Sheryl experienced as a consequence of feeling that her family existed outside the normative ideal of family life. She drew on the discourses of 'normalcy' to convey how her own family life did not meet these standards.

Throughout our interview, Sheryl continued to use the phrase 'normal' to both describe *and* create a contrast between her own experiences and the perceived experiences of parents of children without disabilities:

I loved my life before I had kids and I was really depressed about how it was going to change if I had a normal kid let alone this child, so my life changed so dramatically, because I wasn't even prepared to have a

normal child. Like if I had a normal child, I'd be breezing through life ... I think people with normal kids just have no idea what we go through.

Her comments revealed her perceptions and even idealisations of what life is like for families who have 'normal' children. She juxtaposed this imagined life with her own and as a consequence, experienced a sense of alienation, disappointment and stigma. Sheryl's experience of stigma and negative societal judgment was capitulated when she exclaimed: "I don't know why people have to judge everything you do if it's not 'normal' you know? So the judging really pisses me off."

Like Sheryl, Nancy spoke about the life she imagined parents of children without disabilities have in contrast to her own. When her child was diagnosed with autism, their family story suddenly and dramatically "didn't fit into the image, you have to rewrite." She reflected on what she perceived life is like for families with children without disabilities:

... life flip flops ahead ... Yeah Johnny got into a bit of drinking there but he got back into this – it just flip flops ahead, you don't have to be challenged. When it's bang – life isn't your life or your child's life is not the normal, you start saying well what's the meaning, what am I to do about this? What's my direction? How do I look at the world now? ... You have to find some way of seeing the world that puts value on your child and also on what you do.

Nancy's comment is illustrative of the pervasive strength of hegemonic maternity in establishing the normative ideal of motherhood, and the associated images of 'normal family life'. Having a child diagnosed with a disability, that is not part of such a normative construction, precipitated a monumental rewriting of her worldview, in order to make meaning. Nancy's comment positions the experiences of families of children without disabilities in stark contrast to her own, by saying that even though they may go through hardships and struggles, their life 'flip flops ahead'. This apparently 'normal' trajectory of family life was set in direct contrast to the constant difficulties and struggles that her own family has experienced.

Nancy employed the word 'normal' in a way that clearly demarcated the experiences of other families and her own and this sharp contrast was reinforced by her language –

“bang” – that she repeated a number of times throughout our interview. The exclamation of “bang” is laden with symbolic meaning: a violent upheaval of taken-for-granted assumptions, beliefs, and values, that is shocking, destabilising, and impossible to ignore. Nancy highlighted the ways in which the projected image of what constitutes a normal life did not reflect her own experience, which forces her to radically redefine her experience and purpose, and also shift her understandings of a normative framework. This experience resonates with Darling’s (1979) finding that parents of children with disabilities try to lead as ‘normal’ a life as possible, whilst often striving to contest established notions of ‘normality’. Nancy engaged in this process of reconfiguring and rewriting her own perception of what ‘normal’ means for her life.

### **Prior Perceptions and Ideations of ‘Family’**

A number of participants negotiated the term and tropes of ‘normality’ based on ideations of what they imagined their family would be, and what their prior understandings of ‘normal’ were. For example, Tania had envisioned her family as one made up of boys, and they would behave in particular ways because of their Italian heritage:

I had this perception – I wanted boys – and I had this perception that I’d have these rowdy, fun-loving boys, who played soccer and got dirty and would be a handful, but would be extremely loving and naughty, and that we would do stuff as a family. That was my perception. And it was anything but that.

Her first child, Leonardo, has a developmental and sensory processing disorder. Before he was born, Tania and her partner “had this vision of the little Italian boy with the Italian name ... being a fabulous soccer player, doing what he wants to do.” Her second child Marko has autism, sensory processing disorder, and a severe intellectual disability. Tania’s dreams, ideations and expectations of her children and her family were informed by projections of normality. The birth of her children with disabilities profoundly disrupted these prior images. She mourned the loss of her imagined family, and this particular sentiment is something that I will explore further in Chapter Eight.

While some participants experienced the negative impacts of normative expectations from others once they had their children, Tania was particularly affected by normative

expectations before she even had her children. This compounded the grief that she has experienced since receiving diagnoses for both of her children. Tania reflected: “I sometimes think, ‘I wonder what my life would be if I had normal kids?’” But then she spoke about how grateful she was that her children do not suffer even graver illnesses, in contrast with the other very sick or disabled children that she had seen. Tania recognised the difference between her own experience and what is perceived as ‘normal’ but then she worked to alter and transform her understanding of the impact that such a difference can have. Tania’s experience reflects and supports Bassin, Honey and Kaplan’s (1994) view that mothers appropriate, resist, and create a multiplicity of meanings about motherhood against the backdrop of normative societal expectations.

Participants such as Tania came to motherhood carrying a suite of expectations about what their mothering experience would be like, based on the meanings of motherhood that they had encountered. When participants’ lived experiences do not conform to these normative understandings, they then seek to reflexively challenge these understandings and create new meanings to frame their experience as ‘normal’.

Keira, like Tania, attempted to unpack the complex expectations people can have about children before they are born, and how these expectations of ‘normality’ can be adjusted in the light of lived experience. She talked about the ways that people imagine what their children will look like and the dreams they make for them. She then compared such constructions with her own children, one of whom does not have a disability and one of whom is intellectually disabled. She said of her daughter without a disability: “She’s gone to uni, she’s got a nice guy, she hasn’t quite got the marriage and the picket house, but you know, it’s coming!” And of her daughter with a disability: “Over here Anna, guess what? Already she had five fingers and toes, yes she couldn’t talk but guess what? She actually attended school. She’s actually attended TAFE [Technical and Further Education]. She’s done modified TAFE courses, but look, uni – TAFE.”

Initially, Keira identified Anna’s inability to meet normative societal standards but then she redefined these expectations to situate Anna within the boundaries of what she perceived these standards were. She described how Anna had finished high school, had a job, and said: “Mmmm maybe you could say she’s had a boyfriend when she got the red rose at Valentine’s Day. Will she get married? Probably not. Will she have a kid? I hope to god not ... But look at it – they’re [normative standards] just modified.”

This 'modification' of normative standards of 'normal' enabled Keira to acknowledge the differences that normative expectations perpetuate, and the prevalence of such expectations before the birth of a child. However, by comparing her daughter's achievements with that of a so-called 'normal' child, she effectively expanded the normative framework to include her daughter. Therefore, while Keira was not necessarily contesting the framework of normality itself, she redrew its parameters in order to include her daughter.

Veronica also sought to position her child with a disability within a normative framework by describing the relationship her son has with his siblings. Her other children who were not disabled would say about their brother: "'that's just our weirdo brother Lloyd. Don't worry about him' and then it was – oh my god that's so horrible – but it was also normalising that too, because that's what siblings do to each other." When her son with a disability was being bullied in his workplace she concluded: "I suppose that's a part of normality as well." Veronica experienced difficulties in deciding whether and when to reveal and disclose the nature of her child's disability: "do you educate people? But then do they then see this person as different, but then they were already stigmatising them?" While Veronica worked to position her son within normative frameworks, she also experienced tension around whether he actually fitted within such frameworks:

... will he ever have a normal – what we classify as a normal life? Will he ever have a partner, will he ever get married, will he ever go down that track? And I had to talk to myself and say they're my norms, they're my ideals. So if he lives a life of going home to a dog or a bird or something, then that's okay.

This comment exposes not only the challenges Veronica experienced in deciding how to position and think about her son's disability: it also highlights the normative expectations she carried for his future, and her attempt to reconfigure such expectations. In this way, Veronica's approach to making meaning from her set of lived experiences was similar to Keira's: both recognised that their child did not quite fit normative expectations. But unlike Keira, Veronica did not adjust the framing of normative expectations to suit her child. Instead, she proposed an alternative framework altogether. Both Veronica and Keira exemplify Ryan and Runswick-Cole's (2008) belief that "adjustments and refinement to



notions of normality may involve retaining particular aspects of family life while losing others, as well as incorporating new aspects” (p. 205). Participants adjusted both their notions of normality in order to incorporate their children and their experiences within normative frameworks, and at the same time they contested and sought to renegotiate such frameworks.

Another important way that some participants grappled with and took on the role of the negotiator of definitions of ‘normality’ was through their reflections on their child’s future potential relationships. This is a theme which will be elaborated in Chapter Eight in the context of exploring participants’ descriptions of their ‘family’. Participants expressed a deep sense of ‘loss’ of their vision of ‘normality’, grieving that their child would not access or experience the imagined ‘normal’ trajectory of life – with its socially and culturally defined norms, rites of passage, milestones and patterns of public ritualised experience. When Veronica reflected on whether her son would ever have a partner or get married, and Keira contemplated whether her child would ever marry, both were verbalising the ongoing grief and anxiety generated by having a child who does not fit the prevailing normative standards of ‘normal’.

On this theme, Dana also reflected on her child’s future and questioned what life would be like if she were to marry:

for years, a long time, even now occasionally I look at her and wonder  
‘what would it be like if she was normal?’ If she was married would she  
be having kids? ... But I remember when we were first told in the  
hospital in the first few days and I thought, ‘oh she’ll never be married’.

For these participants, marriage is one of the powerful indices of ‘normalcy’ – a part of the dominant script – that individuals who live ‘normal’ lives are assumed to follow. Marriage in a Westernised context and within an idealised, normative framework, can symbolise maturity, independence, and ‘success’. For participants wondering whether their children would ever be married, such anxieties, inflected at times with hope and poignant resignation, forcefully underline the extent to which the normative standards and expectations around ‘normal’ serve to add to the complex, challenging, and often invisible emotional labour of women who mother children with disabilities.

Jayda's strategy for negotiating the concept of 'normal' was to actively position her daughter (who has autism) within as many supposedly 'normal' and 'mainstream' situations and activities as possible. In this way, Jayda associated 'normality' with 'non-disabled' and therefore sought to integrate her daughter into this 'normal' life through her involvement in contexts, activities and social groups that were accepted as 'normal'. For example, her daughter attended a mainstream school and participated in activities with non-disabled children at the school. Jayda believed that the progress her daughter has made is due to "sending her to the regular pre-school and treating her normal." Jayda described how when her children were growing up, she had two lives, reflecting her two children: "so we had two lives – that with Elsa and the typical, and then this pathway of disability." Yet, Jayda was determined to perform and maintain rituals associated with her concept of normality in order to minimise the impact of the pathway of disability on their family's life.

Jayda's autistic daughter is verbal and has been able to integrate to a certain extent into mainstream settings. This verbal ability, coupled with Jayda's commitment to embedding her daughter within as many mainstream settings as possible, reflects what Birenbaum (1970 in Ryan & Runswick-Cole, 2008) termed a "normal appearing round of family life" (p. 205). Jayda's experience similarly supports Ryan and Runswick-Cole's (2008,) findings that "creating a new normal for families will depend upon the extent to which their experiences of having a disabled child differ from the experiences of families with non-disabled children" (p. 205). This perhaps accounts the various ways in which participants negotiate the term 'normal' and either work to 'fit' their child within existing frameworks, or attempt to reshape and reframe the definition of 'normal' to accommodate their particular circumstances. Ryan and Runswick-Cole (2008, p. 205) speculate that the closer a child with a disability is to what is considered 'normal', the greater importance is placed on seeking to operate within existing frameworks of 'normality'.

Jayda constructed the meaning of her experience within existing frameworks of normality. She gave the example of "doing the script" for celebrations such as her daughter's birthday through hosting a party. Jayda's performance of this seemingly 'normal' celebration of hosting a birthday party, despite her daughter not wanting a birthday party, echoes Goffman's (1959) theory of the performance of self. Goffman (1959) theorised that there is a difference between individuals' 'authentic selves' and their visible performance for others. He represents this difference through the metaphor of the 'front and back stage',

where the front stage represents our performance in front of others, and our backstage represents our selves that are less often on display. To borrow aspects of Goffman's (1959) concept, we can interpret Jayda's performance of the rituals of a birthday celebration (even if her child is not present or engaged) as 'front stage' behaviour, intended to demonstrate an adherence to 'normality', and therefore afford Jayda a sense of belonging and acceptance within a broader social context.

Combining aspects of Goffman's (1959) theory with Butler's (1990) notion of performativity enables a deeper assessment of the way in which participants negotiate 'normality'. Butler (1990; 2010) theorises performativity mainly in relation to gender studies, as she sees gender as a performance that is scripted through repeated social action and interaction, and rehearsed and enacted by individuals. In this way, Butler (1990) suggests that individual behaviours are shaped through hegemonic, largely heteronormative, ideologies and institutions. We can therefore similarly think about the ways in which the behaviours of participants in 'performing' 'normality' are shaped through hegemonic understandings of motherhood.

Importantly, in the same way that Butler (1990) understands gender as that which one performs, rather than who someone *is*, I would suggest that we can understand participants' enactments of 'normality' as a performance, rather than an embodiment. Therefore, in each example explored above, participants wrestled with the concept of 'normality', and in depicting their children and their experiences as existing within or outside this framework, they were simultaneously *constructing* and *reflecting* social understandings of 'normal'. In other words, when Jill declared, "I hate normal", and when Keira said her daughter's experiences were just a "modified" normal, they were recognising and reflecting hegemonic understandings of 'normal', but at the same time challenging and re-scripting such understandings to make sense of, and render meaningful, their own lived experiences.

### **Mothering the 'Good Disabled Child'**

Participants' enactment of roles and their confrontation with discourses, images and expectation of 'normal' and 'normality' can be seen to produce and reflect the impact of hegemonic maternity and thereby structure participants' experiences of motherhood. Enmeshed in this production of hegemony, a further mothering role identified during the

process of analysis of the data was that of the mother of the 'good disabled child'. This role can be understood as a manifestation of the concept of the 'good mother' identified by Goodwin and Huppatz (2010). As I have explored in the 'Motherhood' section of Chapter Three, the definitions and associated imagery of the 'good mother' have established a normative construct and mechanism through which women's behaviour is shaped, monitored and judged. Any dimension of experience, action or behaviour that lies outside the tacit parameters this 'good mother' construct is considered deviant (Goodwin & Huppatz, 2010). In the same way, the imagery of the 'good disabled child' is set up as a normative construct and mechanism through which the behaviour of a child with a disability is shaped, monitored and judged. If a child does not appear to live up to this image of the 'good disabled child', then their deviant or failed status is reflected back onto the mother. Thus, the imagery of the 'good mother' and the 'good disabled child' are intimately bound, framed by the overarching hegemony of maternity.

In considering the concept of the 'good disabled child', it is important to add that those children who display behaviours that appear to fit within the terms of this concept are *not* automatically privileged or free from discrimination and judgement. It is appropriate at this stage to reiterate that this research did not focus on the experiences of children with disabilities. Whether a child is deemed a 'good' disabled child or not *does*, however, impact on the level of stigma and stress experienced by their mother. Further, it is a child's behaviour in a particular social situation that is deemed 'good' or not, and therefore while a child may be viewed as a 'good disabled child' in one situation, they may not meet the expectations of the 'good disabled child' in another situation. In the same ways that participants can be judged as being a 'good mother' in one situation and not in another situation, so too can their children be judged according to the context, and these judgements flow through to influence the status of the mother as 'good', or not.

The role of mothering the 'good disabled child' is one that emerged from the accounts of participants in the study. It can therefore be interpreted as a reflection of the ways in which participants felt that their child was categorised as a 'good disabled child' or not, rather than whether such imagery and expectations are also constructed outside of their experience. This understanding aligns with the social constructionist paradigm that underpins the study: the participants' subjective view of their experience and navigation of the social world around them has been at the heart of this study.

Throughout this thesis I refer to a 'child with a disability' rather than 'disabled child' in order to position their personhood before their disability. When conceptualising the role of mothering the 'good disabled child', rather than the 'good child with a disability', I have placed the word 'disabled' first in order to reflect the ways this role focuses on the child's disability as the defining criterion in judgements about whether they are 'good' or not. Therefore, the role of mothering the 'good disabled child' reflects constructed social expectations of how a child with a disability should behave and exist in order to be classified as 'good'.

Based on the findings of this study, there are four prominent features of the concept of the 'good disabled child': the child's disability is recognisable and identifiable; the child is not physically violent; the child demonstrates potential for 'improvement'; and the child's appearance is considered to be physically attractive.

### ***The child's disability is recognisable and identifiable***

A finding that at first glance may seem surprising, was that participants whose child/children had an identifiable and recognisable disability found it easier to cope with public interactions. This can be explained partly because others could visually recognise that the child had a disability and could thus adjust their responses to the child. For example, Dana whose daughter has Down Syndrome, observed: "so at least people with Down Syndrome, you might not know what it is but you know that something's not right ... people might not have known what the problem is, but they knew there was a problem." It can be inferred that one criterion for being seen as a 'good disabled child' is that the disability is first and foremost visible. If the disability is not visible, physically or in other ways, then participants felt as though others had expectations that their child would behave 'normally'. When the child did not behave in expected ways, mothers felt compelled to justify or explain their child's behaviour.

Jill felt particularly challenged by the fact that her child *appears* as non-disabled and as a consequence, she felt obliged to explain her child's condition to others:

I hate that about me. I hate that about myself. I hate that I just can't be comfortable with Cindy being anywhere – the minute she says something a bit silly I find myself explaining to people ... I hate that, I

hate that. I'll say 'I'm not sure if you know but Cindy has a developmental disability, or an intellectual disability so she might say a few silly things so please have some patience.' Or say if she's going somewhere, I always let them know up front. I justify it by saying I feel like I'm protecting her so they don't have high expectations of her or put her in awkward positions where it'll make her uncomfortable.

The duress experienced by Jill because of her need to explain her daughter's disability was generated by the weight of normative expectations and the deep desire to "protect" her child from adverse judgements and situations. Nancy is another participant who felt she must explain her child's disability as it may not be obvious from his physical appearance: "he comes across as smiley and lovely so I'll have to say 'well he can be like this and this', I almost have to paint a worse picture than they're seeing presented."

Adriana similarly found it problematic in social contexts since her son's disability is not physically obvious: "so you go to a playground or something and he looks like a normal kid, so the expectations is that he should behave like a normal kid. So when he does something impulsive, which is quite a normal trademark of a kid on the spectrum, they think he's being naughty." She went on to describe a situation in which her son had an interaction with another young boy in a play centre over a toy. Adriana explained to the other child's mother that her son has autism in an effort to clarify why her son was behaving in the way that he was. She remarked that when others

see a kid that in every other regard could be the kid next door, their expectation of him is like that of any other kid. So you find yourself, you know, ready – you steel yourself for, you're ready. You're at war. And that's me – but I feel like I've got to be on guard.

This sense of being at 'war', with a constant 'fight or flight' mind-set, the motivation to protect her child, and the nature of the responsibility she feels for her child's behaviour, echoes the experiences of other participants.

Often, if a child did not fit the image of the 'good disabled child' – because, for instance, they appeared to be non-disabled but their behaviour indicated that they had a disability – the mother felt judged as a 'bad mother'. Charlotte made this point:

if you see a picture of Jason now or if you met him on the street then you wouldn't necessarily think there was anything wrong with him – it's not until you talk to him for a little bit that you realise that he's got a developmental delay.

She spoke of feeling harshly judged by others because she is seen in public with her 16 year old son – whose behaviour does not accord with normative standards of a mother and teenage son relationship: “no other mothers are walking around with 16 year olds. And you just feel like – oh people must think ... and then he'll start a conversation or whatever and you just think (groans).”

Tania expressed relief that her child's disability is visible to others: “it's okay now because people know something's wrong with him – you can tell by looking at him. But when he was two it was just like ‘oh you bad mother’.” Veronica similarly noted the common perception of a ‘good disabled child’ being one whose disability is visually identifiable: “if you've got a physical disability or an intellectual disability where it's very obvious – that's probably easier.” When Veronica said that it is “probably easier” she is alluding to the ways in which it may be “easier” to manage and deal with the interactions between her child and the public when the public can recognise that her son is disabled.

### ***The child is not physically violent***

Participants' responses drew attention to the issue of physical violence in judgements about a ‘good disabled child’. A number of participants emphasised their child's non-aggressive nature as evidence to support their description of their child as ‘good’ or socially acceptable. For example, Nancy said: “even though he's not an aggressive boy, he's got a lovely nature.” When describing their child's disability, other participants explicitly stated that their child was *not* violent. When describing her daughter, Dana added: “she's not naughty or violent or anything.”

A number of participants, however, highlighted the aggression their children sometimes display as a means of conveying their frustration, pain, confusion or other feelings. Tania described her experience with her son:

He's very destructive ... he is really quite destructive ... His meltdowns have escalated ... I've probably cried twice in the last two years during a meltdown. And quite often I'll draw blood – like he will scratch me ... hasn't bitten me but he will head bang which is quite typical of autism, they'll head bang ... so they lash out and you get scratched and bruised and whatever, so it's usually then. But then, you know, you just keep going.

Whether a child is physically violent or not, forcefully affects how participants manage their child's behaviour while in the home and around their other children. Crucially, it also influences how their child is perceived in public, and therefore on the type of stigma they experience. Tania recounted a story of when her son had a 'meltdown' in a shopping centre and began hitting his head against a shopfront glass window. She said the shopkeeper came out to check whether the window had broken and she said to him: "yes the window's okay, and so is my son's head' ... and so he's on the floor kicking and screaming and I'm just standing there because you can't do anything."

These kinds of experiences, coupled with either the inaction from others surrounding them, or stares or comments that are interpreted as judgemental, add significantly to the level of stigma, isolation, and stress that can characterise the daily lives of women who are mothers of children with disabilities.

### ***The child demonstrates potential for improvement***

Participants often reflected on their child's ability to potentially improve in the future as an index of being regarded as a 'good disabled child'. The hope of improvement was something that influenced the way in which participants spoke about their child. Hope was often contingent on whether or not their child was able to communicate verbally. Jessica expressed this duality of hope and anxiety because her child is not able to talk because of her disability:

... but she's my little girl, she'll talk. She's starting to verbalise a little bit more. She calls me 'ner' because when I was teaching her to say 'mum' I



was like ‘meh, meh’, and so it comes out ‘neehhr’ ... [directed to her child] was that her making a noise? On her hand? I’ve never seen her do that before ... I think her first word was ‘chink’.

Here, Jessica acknowledged the ways her daughter does not live up to normative expectations, which are typically based on developmental milestones, but she also expressed deep optimism and hope in the potential for her daughter to fulfil this potential.

Keira too emphasised the potential and the ability of her child and her steadfast hope for her child’s continual improvement. She spoke about the advances her child had made in her language and writing skills – “she sends me emails” – and recounted her delight and excitement when her daughter sent her a message independently, without the help of a carer: “So I was like ahh this is gorgeous! So I actually got 3 emails like that.”

For Katherine, her son’s ability to communicate verbally and the potential for him to improve in the future were equally important sources of optimism and hope:

I’m completely hopeful for the future because John is a complete star. He’s just amazing ... he can read phenomenally well – at age at least if not beyond. I think he’s beyond ... He doesn’t talk like a regular 6-year-old but he’s steadily improving so I think as he gets older the gap will narrow ... the fact that reading has come so easy to him shows me he’s bright so I feel very hopeful about the future.

Like many mothers, the participants in this study actively sought to construct narratives of hope, possibility, and triumph in the face of the lived realities of their child’s disability and the often profound challenges to every aspect of their lives.

### ***The child’s appearance is considered to be physically attractive***

The final, and arguably most pervasively dominant criterion in judging the ‘good disabled child’ is whether or not they appear to be physically attractive in terms of societal norms and images of physical attractiveness. This was an intriguing and unexpected finding that was clearly evident in the responses of almost every participant in this study.

Jill in particular emphasised the way her child with a disability fits into Western normative ideals of beauty, and explained this through comparisons with her daughter's twin sister, Teagan, who is not disabled: "Teagan's flat-chested, Cindy's been gifted with 12D breasts. Teagan's light brown, Cindy's white blonde. Cindy's got a nice figure ..." Jill pointed to a picture of her daughter with a disability and said: "she's the one sitting down, she's just gorgeous ... Cindy always gets told she's the pretty twin." The physical beauty of Cindy is perhaps an indicator of her 'normality', and is therefore something that Jill took pleasure and pride in highlighting:

... as a little girl there was nowhere where you couldn't take Cindy where she wouldn't be perceived as an angel. And she'd just flutter her eyelashes and got whatever she wanted wherever she went. She was street smart even then. But now she's a teenager she's a cow, a right little cow ... So I often think she's just been sent to destroy me.

Despite the undercurrent of ambivalence in her comments about her daughter, Jill stressed Cindy's physical, beguiling beauty, which figured as an important affirming factor in social interactions. Her physical attractiveness was a catalyst for social inclusion and acceptance and by extension, Jill accrued esteem in being the mother of a beautiful baby.

Other participants also often focused on the appearance of their child in preference to talking about their disability. For example, when Sheryl spoke about the diagnosis of her son with cerebral palsy when he was first born she recalled that: "when I first saw him I thought he had it yes but then when I went and saw him in the nursery he was all pink and pretty – he was a pretty baby ... he was a very alert and a very pretty baby – I thought he was a pretty baby ..." Disability is not typically associated with normative images and standards of physical attractiveness, demonstrated by participants such as Sheryl who struggled to reconcile how their child could be both 'pretty' and 'beautiful', and also disabled. Similarly, Jayda experienced this same confronting misalignment between culturally-constructed notions of beauty and disability: "the biggest one that I found really hard to come to terms with was her look. Because she just looked so beautiful and she didn't look intellectually disabled."

Keira also spoke about how others find it difficult to recognise or believe that her daughter has an intellectual disability because her child is physically attractive: “well because she’s pretty, they don’t know – see the photo up there with the seal? She’s pretty, she looks normal to a degree...” ‘Normal’ is equated with ‘attractive’, and ‘attractive’ is equated with ‘non-disabled’.

Adriana provided another example of the ways participants emphasised the physical beauty of their children:

Physically, he’s perfect. He’s beautiful to look at, I’ll show you some photos so you can see. He’s a really good looking kid – like if you see him you’d just think ‘wow that kid is really fit and toned and brown and healthy and really bright green eyes, gorgeous skin and brown wavy hair. I mean he’s just a really gorgeous looking kid.

The physical appearance of their child was important to participants because of the substantial currency of physical attractiveness in contemporary society in contrast to the stigma and marginalisation that often accompanies perceptions of disability. If their child is physically attractive, then their child (and they themselves) can be seen to meet or exceed the requirements for ‘normality’ according to at least one highly-valued social category.

Jessica too was keen to highlight her child’s appearance, partly as a strategy to distract attention from the impairments she suffers from: “I just think she was gorgeous ... she’s always, always smiled ... [to her daughter who was in the room] that’s a beautiful straight back – she dances now, she’s a good dancer.”

Jacinta struggled with the sense of sadness and loss that she experienced after learning of her son’s disability. She regarded the physical beauty of her son as an attribute that should be acknowledged and appreciated since it was, for Jacinta, somehow a measure of his ‘normality’ which should be valued in ways that his disability could not be: “I still remember how horrible that was – like this wasn’t the kid that I wanted. It didn’t last long, as in minutes, but I’ll never forget how awful it felt because he was a gorgeous little kid.”

For Charlotte, her son's physical appearance prophesied the challenges he would face because of his disability: "these are all the baby photos when he was first born ... he was a sad looking little thing ... he was a floppy little thing ... he was always a funny looking little kid." When looking at photos of her son, Charlotte was reflexive in aligning her experience and her child's diagnosis of disability with his physical appearance when he was a baby and undiagnosed.

The role of mothering 'the good disabled child' arose from participants' reflections on their children, and how particular aspects of their child or disability has impacted on their experience of motherhood. These aspects include whether the child's disability is physically visible or not, whether the child is physically violent, whether the child will 'improve' or not, and the physical appearance of the child. If a child did not live up to normative standards within these various domains, participants felt they would be judged as 'bad mothers' for failing to exist within the framework of hegemonic maternity.

## **Summary**

This chapter, together with the previous chapter, has illuminated the ways hegemonic maternity was produced in participants' diverse experiences of negotiating 'normality'. In an effort to position themselves within the boundaries of what they perceived to be 'normal motherhood' and 'normal mothering practices' participants readily made comparisons between their child and other children and between themselves and other mothers: that is, between the apparently non-normative and the normative. Importantly, they also articulated and challenged the perceptions of 'normality' that they carried before they had children.

At times, the term 'normal' was invoked to describe other children or people without disabilities. At other times it was employed to signify the normative framework of social and cultural beliefs and attitudes that participants' felt alienated from because their child did not measure up to these prevailing definitions of 'normal'. Many spoke of the stigma they carried because their child was perceived by society as 'deficient'.

Many participants in this study, through the retelling of their experiences, demonstrated their desire to critique and challenge discourses of normality, and to simultaneously position their experiences and their children within a normative framework in order to

accrue a sense of legitimacy for themselves, their child and their family. Thus, discourses of normality were appropriated and then contested to describe the experience of stigma, and to fight stigma, respectively.

An important finding here goes to the heart of participants' experiences of maternity, that having a child with a disability almost automatically situated them outside the parameters of 'normal' and 'normative' ideal of motherhood. Through no choice of their own, they were positioned as 'other' against the prevailing discourses of normality. By implication, they had failed as women and as mothers when they measured themselves against this frequently internalised set of standards. They were barred from entry into the hegemonic sphere of the ideal mother, and socially disenfranchised. Since there are few, if any, social discourses and frameworks that would offer them legitimacy and empowerment, many participants set about creating their own as a bulwark against the hegemony that effectively deprived them of their human entitlement to belonging, acceptance, equality, and social inclusion.

Although participants devised complex strategies required for negotiating discourses of normality, such normative discourses often continue to operate with uncontested authority, rendering the participants' mothering as 'failing' when it does not meet the normative ideal. The normative ideal has an impact on the experiences of all mothers. As O'Reilly (2012) states: "motherhood disadvantages and disempowers all mothers in patriarchal societies, the experience and meaning of such is determined by the specific societal position and positioning of each individual mother" (p. 14). The evidence presented here demonstrates the extent to which mothers of children with disabilities experience amplified and complicated disadvantage and disempowerment.

The following chapter presents evidence of the ways participants experienced judgement in their roles as mothers, and frames these experiences in terms of how hegemonic maternity is regulated and resisted.



## CHAPTER SEVEN

### On Regulation and Resistance

*"I realised at one stage that I was just walking around the shops with my head down, I wasn't making eye contact with anyone because I knew what the reactions are around me"*  
(Jocelyn, Participant).

*"... you get people who look at you a bit differently ... I'm in a supermarket with [my son] and he's 6 foot tall and he wants something and I go 'no! Will you shut up!' and people look at you like 'god you're a bad mother' ... so you feel like people make judgements of you"*  
(Charlotte, Participant).



### Introduction

This chapter is the third of three chapters that concentrate on presenting and interpreting data on participants' experiences of motherhood within the conceptual framework of hegemonic maternity. The purpose of this chapter is to extend and elaborate the focus on motherhood and hegemony by reporting on the ways in which: participants self-regulate their mothering; experience regulation and judgement from others as part their mothering; and regulate the behaviour of other mothers. This chapter begins with interpreting participants' interview responses that evinced the regulatory dimensions of hegemonic maternity and then details the ways in which some participants seek to contest and resist this hegemony.

The data presented and discussed in this chapter were initially coded according to a number of sub-themes under the major category of 'experiences of motherhood'. These sub-themes included: categorisation of mothering; challenging good mother theory; disciplining; expectations of motherhood; feeling accomplished or powerful; friends' or family perceptions of a child and/or parenting; the influences of the participant's mother on her own mothering; and guilt.

After further analysis and synthesising of these themes what emerged was that participants experienced forms of regulation in their mothering roles, but that they also sought to resist such regulation. The dynamics and implications of regulation and resistance in mothering can be more deeply understood in terms of the framework of hegemonic maternity.

### **Hegemonic Maternity and Regulation: An Overview**

Participants in this study described how they are subject to others' expectations and judgements about how to mother their children. Frequently, these expectations and judgements manifested in others making direct comments about participants' children or how a participant was responding to her child. Almost all participants described feeling the gaze of the 'other' during their mothering experiences. This gaze can be metaphorically understood as the hegemony of motherhood operating in complex and powerful ways to pervade, invade, and regulate the lives of participants.

While participants disclosed their experiences of regulatory expectations and judgement from others, they also revealed the extent to which they police and censor their own behaviour, and engage in judging the mothering behaviours of other mothers. The multi-layered and nuanced ways in which participants both experienced and reinforced regulation attests to Foucault's (2013) analysis of how power operates in the lives of individuals. Although the relationship between feminists and Foucault is a precarious one, some feminist scholarship has drawn on Foucault's analyses of power to examine how disciplinary powers produce experience and facilitate an exploration of "the micropolitics of personal life ... exposing the mechanics of patriarchal power at the most intimate levels of women's experience" (Armstrong, 2005, p. 6). For Foucault (2013), power is the maker of reality: power impacts and shapes networks, practices, institutions and the temporal world around us. It shapes and impacts our behaviour, our experience as individuals and our constructions of reality.

Foucault emphasised the ways in which everyday human practices both sustain and reproduce power relations. This understanding illuminates how hegemonic maternity develops, sustains, and reproduces its power over participants through both institutions and everyday practices. The utility of Foucault's theory of power to feminist theories of

power in gender relations and women's experiences is succinctly identified by Sawiki (1998):

This emphasis on the everyday practices through which power relations are reproduced has converged with the feminist project of analysing the politics of personal relations and altering gendered power relations at the most intimate levels of experience 'in the institutions of marriage, motherhood and compulsory heterosexuality, in the 'private' relations between the sexes and in the everyday rituals and regimens that govern women's relationships to themselves and their bodies (p. 93).

The maintenance of any form of hegemony is dependent on power and how power operates within particular social contexts. Power "reaches into the very grain of individuals, touches their bodies and inserts itself into their actions and attitudes, their discourses, learning processes and everyday lives" (Foucault, 1980, p. 30). The experiences of participants in this study expound how power, as it operates in and is maintained through hegemonic maternity is "inserted" into "the very grain" of their lives. This is exemplified in the response of one participant, Charlotte:

... you get people who look at you a bit differently ... I'm in a supermarket with Jason and he's six-foot-tall and he wants something and I go 'no! Will you shut up!' and people look at you like 'god you're a bad mother' ... so you feel like people make judgements of you.

Charlotte's perception that others were judging her behaviour towards her son in order to determine whether she was a 'good' or 'bad' mother is a clear example of how regulatory gazes operate.

In order to theorise this operation, Foucault (2013) used Jeremy Bentham's concept of the Panopticon. The Panopticon is an architectural design commonly evident in institutions such as prisons and schools. It allows guards in prisons or those in positions of power to continuously watch over inmates or those without power from their central position in the tower, all the while unseen by those being monitored. This constant observation and



surveillance functions as a control strategy to maintain power over others. The operation of this form of control is apparent in the example given by Charlotte. She felt others exerting regulatory power through their gaze alone – they did not need to communicate with her verbally to convey, and for Charlotte to receive, adverse judgement.

Foucault's (2013) perception of power based on the Panopticon model recognises that one effect of this sense of being constantly monitored is that the surveillance from others eventually becomes internalised. This internalising is evident in Hannah's responses. She compared the expectations that she places on herself as a mother with the lived reality of her parenting. She joked that she had until her daughter reached two years of age before her child's memory further developed: "so I've got up until then! And then I've got to be the proper parent!" In this example, Hannah was actively policing and regulating her own behaviour. Similarly, Jill said that she rarely enjoys any activity outside of her paid work and mothering because "I think that I'm selfish if I do anything for myself, I really do."

Observation is the first control mechanism for self-regulation, which then becomes normalised and accepted. Therefore, the ways in which participants described observation and reflection on their own behaviours and practices attests to one of the ways hegemonic maternity maintains a hegemonic status. Participants not only feel the regulatory gaze and expectations of *others*: they also come to internalise this regulatory gaze. It becomes normalised, tacitly influences behaviours and attitudes, and often remains unproblematised and uncontested. Applying Foucault's (2013) metaphor of the Panopticon to the ways participants experience regulation and therefore hegemonic maternity means that people in society become the 'guards' who monitor the practices of mothers (who are the metaphorical 'prisoners'); mothers as 'prisoners' regulate themselves and their own behaviour; and then these mothers also come to regulate *other* mothers' behaviours.

In short, the ways participants describe expectations and judgements from others, as well as the ways in which they police their own behaviour, epitomises to the extent to which participants live their lives within and against the framework that has been established by hegemonic maternity, which maintains its status as *hegemonic* is through regulatory power. This regulation involves the monitoring of mothers' behaviours by society, other mothers, and individual mothers themselves; and the adjustment of their behaviours to conform to the discursive definitions of what a 'good' mother should be.

In the following sections I will examine the various ways that participants experience regulation as imposed by others; regulation as imposed on the self; and the regulation that participants impose on others.

### **Regulation by Others**

All participants in this study described experiencing judgement and regulatory behaviours of others. Sometimes, these 'others' were family members, friends, colleagues, and medical professionals, but they were also frequently members of the public. As Zibricky (2014) reveals in her autoethnographic account of mothering a child with a disability:

judgement became intense, relentless, and just plain harsh. I was ignored, ridiculed and scorned by medical and educational professionals. I continued to be met with disapproval, criticism, and unwarranted advice from family members and strangers (p. 45).

Whether or not members of the public actually *did* impose judgement on participants is not of direct concern in this context. Rather, in line with the social constructionist methodology guiding this research, what is primarily important is a participant's *perception and experience* of judgement. For example, when a participant described being stared at by members of the public when she was grocery shopping with her autistic child, and felt judged on the basis of her child's behaviour, it was not necessarily significant in this context whether the members of the public were indeed intentionally or critically staring at her or not. What was significant was the participant's *perception* that she was being stared at and judged: her perceptions constituted part of her reality.

Katherine, for instance, described feeling as though she should have been behaving in a certain way in order to be perceived by other people as being a good mother. But she qualified this: "as the mother of a disabled child I know I cannot handle things in a normal way, there are certain things that I have to do – or certain ways of managing a behaviour or situation – that other people might not think is appropriate" and she described feeling "frowned upon." Participants were therefore aware of, or strongly believed, there were expectations placed on them by the public for what is appropriate behaviour as a 'good' mother.

Participants also reported feeling as though expectations were placed on their children, and if their children did not look or behave in a particular way – like the ‘good disabled child’ – then disapproving judgement was reflected back on them as mothers. While this notion was explored within Chapter Six, it is also worth highlighting here Nancy’s reflection on how this takes place:

... finally I have got a lot of feedback as a mum where [my son] touches me and cuddles ... it’s so beautiful because I can’t hear his voice. But now I’m thinking oh gees ... like we hopped into the spa yesterday and I was thinking at 25 he’s not going to be able to do that ... just like my other son has learnt what is socially acceptable as Mum ... We’ve just had a refreshment in our hearts over the past three years of really a lot of that affectionate stuff, and I’m going to have to pull back.

Nancy’s comments sharply underline the normative dynamic that is expected to operate between a mother and child: that is, a strong, close and physical bond formed during childhood is steadily loosened and eventually proscribed as the child reaches puberty and then adulthood. Psychoanalysts such as Chodorow (1981) have critiqued this normative expectation of detachment, arguing that the self cannot be separated from interpersonal relationships, and the mother-child relationship is enduringly important.

Yet the nature of the relationship between the mother and child functions as a criterion of judgement of a mother’s capacity to mother, or as an assessment of where she sits in the binary of ‘good’ and ‘bad’ mother. The way that this mother-child relationship can be judged in public situations is through the mother’s and the child’s appearance and/or behaviour and interactions. For example, Tania reflected on how the public recognition of a visible disability, or lack of recognition if the disability is ‘invisible’, influenced how others judge mothers in public spaces. Tania remarked that now that her son is older and his disability is more visually apparent due to the extremes of his behaviour, “people know something’s wrong with him – you can tell by looking at him. But when he was two it was just like ‘oh you bad mother’.” This is a clear example of the expectation that it is the mother who ultimately controls her child’s behaviour, and that a ‘misbehaving’ child means that it is the failure of the mother to control the child, and she is therefore labelled ‘bad’.

Adriana also reflected on the judgement she felt was imposed on her and her child when others labelled his behaviour as “naughty.” When I asked her from whom she feels this judgement, she responded, “the world”, and added that handling these sorts of situations and judgements “is actually one of my struggles as a Mum ... I personally struggle with it.” Likewise, Jill felt that others were quick to judge her mothering based on the behaviour or appearance of her child:

if someone saw my kids dirty that would mean I was a terrible mother  
... if my kids go out of the house without ironed clothes I would think  
people would go ‘well what sort of mother is she?’ And I say that to  
Teagan [her other daughter] – you’re a reflection of me and I want  
people to know that you’re a nice, tidy, good, clean girl and it’s  
important that you look like that.

Jill’s perception that others judge her mothering based on her children’s appearance is an example of the pervasiveness of regulatory mechanisms that enforce hegemonic maternity, understanding the mother as the primary carer, and her child as an extension of herself.

Jocelyn provided another example of the ways in which mothers of children with disabilities have to manage social expectations of what it means to be a ‘good mother’ while in public situations. She recounted a story of standing at the checkout of a grocery store, thinking that her son had done “so well” on their shopping trip, but that

some old man standing there said to him, ‘oh you’re being a naughty  
boy, what are you doing’ and I was just like, went off ... and I’m  
thinking oh wow ... it’s not up to you that he’s being naughty, he’s  
actually being really good, and the guy probably thought, oh slack  
mum doesn’t have much standards or whatever. And I am someone  
who really feels judgement from people, yeah I think that’s why I was a  
bit like ahhh. I like to do well at things and if I’m not, if I’m seen as a  
slack mum then I really feel ohh, because I want to do everything I can,  
well I do, to try and do the best by my son.

This example of others passing judgement on mothering practices through observing and then commenting on the behaviour of the child is one way in which the hegemony of motherhood is produced and maintained. When someone makes a comment in public, as was the case in Jocelyn's reflection, it is often very difficult for mothers of children with disabilities to know how to respond. They wish to be perceived and respected as a 'good' mother in the eyes of the stranger, but they also feel compelled to inform the stranger of the nature of their child's condition and what their behaviour actually means. But participants were often reluctant to risk explaining these factors in such a situation out of concerns that confrontation may ensue, or they would attract additional negative attention, or that an explanation would not be legitimated. They were therefore often left feeling frustrated, hurt, demoralised, misunderstood, angry, and disempowered. An additional dimension of this scenario is frustration that they should not have to 'explain' or defend themselves, or bear the responsibility for educating others who lack an understanding of disability, its manifestations and its impacts.

Jocelyn shared another compelling example of the way mothers of children with 'invisible' disabilities in particular, feel judged and regulated, and how they manage this judgement. Her six-year-old son has autism and is unable to understand much of what she says to him, but when she and her son are out in public she speaks loudly to him:

... just for the benefit for other people, because he had no idea what I was saying. But I'd say 'oh Anthony, you're being so noisy' so people in the shop could actually hear that I'm responding. Because if your child is carrying on in a trolley and you're doing nothing about it, you look like, I don't know ... people are looking at you like do something about your child and I'm like ahhhh 'Anthony you're being so noisy' I don't know! Like he cannot understand words ... sometimes when it's a behaviour where people expect me to do something about it then I'll just say something because it's never for him, it's for them.

Here Jocelyn articulated how she was literally *performing* the role of 'good mother' specifically for the benefit of the public, where her response had absolutely no impact on her child's behaviour. Jocelyn's behaviour can be understood as an enactment of Goffman's (1959) model of performance of self, where individuals behave in a certain way to

appease, please or gain affirmation and acceptance from their 'front stage' audience. Jocelyn managed her front stage performance in order to shape the public's perception of her child as *appearing* to look 'normal'. The presentation of her mothering as 'normal' therefore created a normalised perception of her child's behaviour. The need for Jocelyn to perform in this way highlights the disjuncture between what is observed and judged as 'normal' and 'deviant' behaviour, and how to manage seemingly deviant behaviour. Jocelyn negotiated her 'front stage' persona purely for the purposes of her audience, based on an internalised belief that she had to adhere to what she assumed was their expectations of a 'good mother'.

This is an example of the regulatory power of hegemonic maternity shifting the behaviour and experiences of participants. Yet, while Jocelyn actively performed the role of 'good mother' she also attempted to avert and withdraw from the public gaze:

I realised at one stage that I was just walking around the shops with my head down, I wasn't making eye contact with anyone because I knew what the reactions are around me and it just became like, ah I don't want to look at people. Not consciously but after a while I realised that was what I was doing, that I didn't even look at people or see who was serving me.

Within the everyday context of shopping in a supermarket, Jocelyn was navigating and experiencing the perception of judgement from others, and was subsequently altering her behaviour as a response to such judgement.

Jacinta is another participant who reported feeling acutely the regulating gaze of others, and as was presented in Chapter Seven when discussing judgement from others, Jacinta responds to the anticipation of such gazes by consciously having a smile on her face when in public with her son. When Jacinta did encounter the gaze of others in public, she actively sought to contest and interrupt this gaze. She said that when people stare at her son "sometimes I just step in between to block the line of vision."

Jacinta's comment highlights the ways in which mothers of children with disabilities feel self-conscious as a consequence of feeling judged by others. It also reveals the extent to

which they both anticipate such judgement and also strategise to avert or avoid it. Paradoxically, in anticipating regulatory gazes and then modifying her behaviour, Jacinta managed the situation by further regulating and 'patrolling' her own behaviour. Rather than directly contesting and subverting normative expectations, she felt compelled to conform to these through adjusting her own behaviour.

### ***Not feeling judged***

Even though each participant in this study described the various ways they felt the expectations of and judgement from others, one participant Danielle, reported that she had not regularly felt judged by others in public. Danielle's son is 37 years of age and has Down Syndrome:

... you hear often that parents who go out and have a child with autism or an ID, but look quite normal, if there's a behavioural issue there's pressure on the parent to control that rotten kid who is screaming. Speaking personally, I haven't experienced any pressure to conform a certain way. I couldn't say ... I haven't really experienced that.

Danielle's experience can be attributed in part to the nature of her son's disability, and to what researchers refer to as the 'Down Syndrome advantage' (Hodapp, et al., 2001). Hodapp (2002 in Stoneman, 2007, p. 1006) suggests that generally speaking, individuals with Down Syndrome have more sociable personalities and fewer maladaptive behaviours than those with intellectual disabilities, and there is a greater understanding – by both parents and society – of the cause and nature of the disability. Research by Fidler et al. (2000), Dunmas et al. (1991), Fisman et al. (1996), and Abbeduto et al. (2004) found that mothers of children with Down Syndrome experienced lower levels of depression and pessimism than mothers of children with autism, and other pervasive developmental disorders. However, Danielle also identified the age of her son as a key factor influencing her recent experience as a mother, in that she is able to leave him at home for short periods of time without supervision.

### **Self-Regulation**

Participants not only felt judged by others, but they also judged themselves. Jill provided an example of this dynamic when she discussed the difficulties and anxiety that arose

when her children cried in public: “oh I drove myself insane. I had anxiety and everything’s ten times more difficult for me because I make it that way.” Significantly, Jill placed the responsibility for the difficulty she experienced on *herself*. A further example of this self-judgement came from Sheryl when she described the challenges she has faced in trying to manage her son’s behaviour in public: “I’m obsessed with him not upsetting everyone else.” By implication, her child “upsetting everyone else” would trigger and generate adverse judgements and disapproving gazes from others. In order to cope with this potential negativity, she located the “problem” within herself: “that’s my problem though ... it’s my fault, I need to pull back.” This is a clear example hegemonic maternity operating as a regulatory influence on behaviour and perspectives through the public gaze and, importantly, an example of how it ‘invades’ “the very grain” (Foucault, 2013) of these mothers’ lives through the practice of self-regulation.

Further evidence of this self-regulation came from Tania, who has two sons with autism: “I think women are their own worst enemy. They put pressure on themselves and when you don’t live up to that expectation ...” Further, she reflected that “... we feel pressure that we’re not doing enough, I think it’s rare that the pressure comes from the outside. I think it’s the pressure that we put ourselves under.” This perspective reveals Tania’s internalisation of standards of hegemonic maternity, and the pressure to adhere to good mothering ideology. To be a ‘good mother’, women are expected to not only devote all of their time and energy to mothering their children: they must be doing so through their own initiative. Tania later explained how she saw a *60 Minutes* program on Applied Behaviour Analysis (ABA) therapy for autism, which she could not afford to give her children. This led her to conclude that: “I’m not giving my son the best, and I feel guilty ... yeah the guilt is horrendous.” Furthermore, she disclosed the difficulties she experienced when her son was younger and his disability was not as obvious to the public: “when he was two, it was just like ‘oh you bad mother’.”

Similarly, Hannah recognised the way judgements and pressures to parent in particular ways do indeed stem from an internalising of externally imposed norms and expectations. She cited the influence of her own upbringing on her mothering, and noted her exposure to “what you should be like through tv, magazines and your family.” That she had internalised these social and cultural images and tropes of the ‘good mother’ and thereby the standard for measuring ‘good’ mothering, was revealed in her self-judgement that: “the internal voice going ‘oh my god that’s really shocking what I just did, or how I just behaved, or how



I handled that situation', so you've got that internal voice as well that tells you hmm that's not quite right ...” This internal voice is telling evidence of hegemonic maternity in shaping the perspectives, attitudes and self-image of the individual. While Hannah recognised the existence of such externally-derived forces, she acquiesced and conformed to rather than resisted such expectations.

In order for Tania and Hannah to fulfil the role of the ‘good mother’ of a child with a disability, they self-regulated and evaluated their behaviour against these internalised standards of hegemonic maternity. Each woman self-assessed her worth according to the binaries of ‘good mother’ / ‘bad mother’. Both subscribed to the assumption that ‘good’ mothering and its demands come naturally to women. Yet at the same time, Tania did articulate her understanding that the external pressure exerted by others is intended to ensure a woman is *perceived* to be a ‘good mother’: “[there is] pressure about motherhood in general, it’s horrendous.” She cited the example of how she was ‘examined and judged’ by what she packed for her children’s lunch at school. Such surveillance of how she nourished her children reflects regulation operating through ‘good mother’ ideology, which assumes that it will be the mother who provides all care for her children, and the skills required to provide such care should come naturally.

The assumption that the maternal role is ‘natural’ presupposes that the structure of parenthood is biologically self-explanatory, universal and instinctive. Motherhood is therefore often viewed as inevitable, natural and unchanging (Chodorow, 1978, pp. 13-14). In response to this assumption, Chodorow (1978) has observed that

there are undeniable genetic, morphological, and hormonal sex differences, which affect our physical and social experiences and are (minimally) the criteria according to which a person’s participation in the sexual division of labour and membership in a gender-differentiated world are assigned (p. 15).

The continued promulgation of these ‘minimal’ criteria as the defining criteria of motherhood renders the need for questioning such assumptions even more pressing.

Adriana offered insights into the assumptions around the classification of different mothering ‘types’. She described finding out about a well-regarded school for children with autism: “And I just went ‘he’s just got to get into [that school]. He’s getting in.’ Tiger

mum.” Participants would at times draw on ‘types’, labels, and classifications in order to evaluate and police their own behaviour. Sheryl, for instance, described the importance of her paid work in providing her with a sense of self, reporting that she took a weekend job because: “I just didn’t want to be at home, and I’m always looking for excuses to get away ... That doesn’t sound very good does it? I sound like a horrible mother.” Here Sheryl engaged in self-policing and self-judgement, referencing the expectation that mothers will be the ones to primarily provide care for their children, that they will provide this care intensively, and that they will *enjoy* doing so.

There is a variety of factors that influenced how participants negotiated expectations and judgements from others, and how they perceived and self-evaluated their own mothering behaviours. One of these factors is class. For example, Katherine lives in a suburb on the North Shore of Sydney – a suburb that has a higher than average socio-economic demographic, and this has shaped the way her expectations of motherhood have manifested, and the ways in which she feels regulated and monitored. Katherine observed that: “living around here, you present well ... that’s the other expectation I find so hard – I just feel like wearing my tracksuit, I don’t have the energy ... The North Shore is very much, it’s quite appearance conscious.” She spoke of how “I’m from this, sort of, perfect mother background, I suppose.” With her previous two children, prior to having her child with a disability, she said: “I was a pretty well dressed mum, a well presented mum.” Through these comments, Katherine acknowledged the standards expected of a ‘good mother’ and her previous compliance with these standards but qualified her response with: “I suppose those standards would have changed without question, like I’m too tired”, but that “it’s probably my own expectations more so than society.”

Katherine was unable to live up to the idealised image of motherhood that she believed existed within the area that she lives, but then she also attributed the existence of such expectations to herself “more so than [to] society”. Therefore, Katherine demonstrated the ways in which hegemonic maternity and concurrent expectations of ‘good mothering’ are internalised, the ways in which hegemonic maternity intersects with class, and the role of physical appearance as a criterion for judgement.

### ***Mother guilt***

It was when participants engaged in self-regulation that they often spoke about the guilt that accompanied their experiences of mothering. This sense of guilt arose when

participants judged their behaviour as falling outside the boundaries of the 'good mother' image. Many ideals and expectations designed to regulate mothers' behaviours through hegemonic maternity are almost impossible for any individual mother to meet, and therefore participants inevitably concluded that they had 'failed' at good mothering in some way. They then experienced guilt because of this 'failure'. Every participant in this study spoke explicitly about their feelings of guilt.

Participants' discussions of their guilt fell into three categories: guilt as a result of failing to meet hegemonic maternity standards; guilt in the form of self-blame for their child's disability; and guilt about their perceived inadequate mothering of their other non-disabled children.

### ***Failing to live up to representations of 'good mothering' within hegemonic maternity framework***

Participants spoke about feeling guilty as direct consequence of self-regulation when they judged themselves to be failing to adhere to all of the idealised representations of 'good mothering'. This cycle of self-censoring judgement facilitates the operation and pervasiveness of hegemonic maternity in individual lives. For example, Jill felt a sense of guilt when she considered doing anything for herself that was not directly related to her children, such as, for instance, pursuing her own interests:

I think that I'm selfish if I do anything for myself, I really do. My husband's out playing lawn bowls at the moment, my son's playing x-box, Cindy's out on an activity with a group that takes children out, and my other daughter is out with her friends – I would come home and do the ironing if you weren't here. And I think about having a coffee with someone and I think oh there's ironing to do and this and that.

This guilt stems from the expectation that mothers must be self-sacrificing and devote themselves completely and wholly to the care of their children and families: good mothering ideology perpetuates this expectation. Sheryl echoed similar feelings of guilt when she talked about an overseas fundraising trip she organised for her child's disability organisation: "And we never would've done it as a holiday, but because we were doing it for our charity that do so much for us, it was sort of okay ... I'd be too guilt-ridden if I did

that as a holiday.” Again, Sheryl’s sentiment reflects the expectation that mothers should behave in ways that prioritise the needs and interests of their children, rather than their own needs or desires. Sheryl felt she could not go on a holiday purely for her own recreation: she felt she needed to justify the trip as a fundraising venture for her son in order to alleviate a sense of guilt.

Participants experienced guilt when they believed they were not living up to idealised standards of motherhood in the type of care they provided their child with a disability. As Tania articulated,

the guilt is horrendous ... you might read an article about what a mum’s done – like a family’s sold their house and moved to England to get the best therapy for their child, and here he is at 5 not talking and melting down and here he is at 8, talking like a normal person. And it’s like – oh great, I can’t do that. And what would happen if I did? Am I giving [my son] a worse outcome than I had of ... I don’t know.

Tania’s comment draws attention to the assumptions of what ‘good mothers’ of children with disabilities are expected to do for their children. Her self-questioning about the implications of not being able to meet such standards is evidence of hegemonic maternity colonising consciousness, shaping thoughts and feelings, and regulating behaviours. Guilt figures as a cogent ‘side-effect’ of this dynamic.

Jacinta reported that guilt was also a by-product of her attempts to manage her paid work responsibilities and her mothering: “Whenever I’m at work I’m feeling guilty about what’s not being done at home and whenever I’m home I’m feeling guilty about what’s not being done at work.” Further manifestations of guilt can be traced to the expected role of participants as ‘The Primary Carer’ and ‘The Expert’, as was discussed in Chapter Five. For example, Kelly said: “I was thinking ‘oh well was he autistic then, should I have seen it then?’ It’s more that sort of badgering you do to yourself as a mum. Should I have gone earlier? And in hindsight I really should have.” Kelly’s comments reveal the impact of the expectations placed on mothers for primary caregiving, as well the expectation to be experts in their care of their child, and remain hyper-alert, vigilant and attuned to any changes or perceived abnormalities in their child’s behaviours. The inner voice that ‘badgers’ Kelly is the voice that becomes amplified when participants feel as though they

are deficient in meeting the expectations of good mothering representations within hegemonic maternity.

### ***Self-blame for their child's disability***

A second, pervasive form of guilt (linked to Kelly's comment above) revolved around experiences related to children's diagnoses. Participants such as Kelly, who has a child with autism, often questioned whether they were sufficiently alert to the signs of their child's disability early enough, and whether an earlier recognition of signs may have resulted in earlier intervention for their children. Kelly lamented that: "It was devastating because I was – a little bit in the back of your head you're thinking well maybe they'll tell me it's something else – and I kind of blamed myself for a long time for it."

Self-blame was also a common experience for participants who had children with physical disabilities from birth. Sheryl blamed her son's cerebral palsy on the stress she was under during her pregnancy, and then blamed his autism on the antibiotic treatment he received immediately following his birth. She said of her pregnancy:

So yeah, see all these things awful happened when I was pregnant, that I just thought that I've stressed this child out so much – have had that mother guilt thing going on ... I really do feel that it was my fault, I mean everyone probably does, but it was just such an awkward pregnancy that there couldn't have not been something wrong.

Even in the face of clear evidence to the contrary, as in the case of a disability being associated with chromosomal abnormalities, participants also blamed themselves to some degree. As Hannah pondered: "you blame yourself thinking, 'why didn't I get myself tested before I had kids to know?'" Jill questioned herself regarding whether her child's disability was caused by a genetic problem or not: "I used to feel guilty. I've been to a geneticist to make sure that this wasn't something I gave Cindy or it wasn't something my husband and I gave, it's not hereditary ... it's not ... and Cindy can't pass it on, so it's one of those things." When a child's disability may have a genetic cause, participants tended to assume some sense of blame and a feeling of responsibility about their child's disability. Although Jill received confirmation that her child's disability did not have a genetic basis, she said: "... even after I heard that, it didn't absolve me. I just felt this was something I did ... and he

said that it's nobody's fault it's one of those things that just happens. It's still ... I dunno, I dunno ..."

Jill's perspective shows that some participants carry a deep-seated and enduring sense of culpability that can take on the power of a symbolic 'albatross'. That Jill articulates this experience through the use of the term 'absolve', underlines the extent to which a mother's self-blame and guilt operates in their lived experiences.

### ***Guilt about the mothering of their other children***

Co-extensive with self-blame and guilt about their child's disability and their mothering practices, was the guilt participants experienced in the context of mothering their children *without* disabilities. Participants expressed concern that the attention and amount of care required by their child with a disability meant that their children without disabilities were 'missing out' or were being mothered inadequately. For example Danielle encapsulated this when she reflected that:

I think that my other children, when they surpassed Jacob, there's always that element of guilt. That having a child with a disability or special needs, they do have that special need, so they will take – I guess you have to make allowances. I think that it does impact on the other children and there's always that guilt around that.

Of her other children, Jill similarly observed that:

I don't want them to be screwed up because of my bad parenting or because I took too much time on Cindy, or I let her get away with things. You don't want your children, sitting on a lounge in 20 years' time from now saying 'well it all started with my mother'.

This type of anxiety was peppered throughout Jill's reflections on her mothering, evidence of hegemonic maternity in the framing of mothers' experiences, regardless of whether their children have disabilities or not. In addition, Jill's comments underlined the ways in which the standards of idealised mothering are almost always impossible to meet. Jill's anxiety in this regard was evident when she said:

So as a mum I always worry that I've done the wrong thing, not the right thing by my kids. And that's such a big fear for me, I don't know if other mothers are like that, whether they care enough about that or if they think about it at all – not that they don't care but whether they think about it? I always think about it.

Jill's expressed fear arose in part from her sense of isolation and difference. She questioned whether other mothers of children with disabilities experience anxiety, guilt, and fear as part of their experience. By implication, some evidence that she was not 'aberrant' or 'deficient' – garnered through a knowledge of others' experiences – may have potentially assuaged Jill's guilt and fears. The fact that she had no shared sense of others' experiences highlights the need for participants' experiences to be more fully understood in public and other domains. The isolating nature of some participants' experiences of mothering is exacerbated by their de-contextualised self-perceptions of being 'not good enough'.

### **Regulating Other Mothers**

While participants frequently experienced regulation from others; often self-regulated their own behaviours; and carried significant levels of guilt and self-blame, they also engaged in regulation of other mothers. The ways through which participants described regulating the behaviour of other mothers demonstrates the normative nature of hegemonic maternity.

One example of this regulation of other mothers came from Hannah: "there are some women who are just the most shocking-est mothers and I just go, 'how the hell did you become a mother?'" and they laugh and say 'yeah that's why my husband carries that load.'" Interestingly, Hannah had reflected earlier on a time when her husband stayed at home with the children while she was in paid work, but assessment of this arrangement reinforced an essentialised gendering view of care, since she asserted the importance of the mother being the child's primary caregiver.

The theme of judging other women who seemingly do not live up to essentialist understandings of mothering and care was reiterated by Sally, who said of her sister-in-

law: “she doesn’t have a maternal bone in her body.” Sally said that she made her sister-in-law “have a second one [child] because she can’t have an only child, because my mother-in-law’s an only child and she’s selfish.” Her sister-in-law, according to Sally: “... has no people skills, she’s very odd. I blame that on [her] Mum. I put it down to [her] mum being an only child and being raised by the father. The Mum worked.” Reflected in Sally’s comments was the perception that women are naturally the primary caregivers of their children, and that it is the mother’s responsibility to be the sole carer for children and not be in paid work. Sally’s comments suggest that any perceived problem with a child (and in this case an adult-child) is seen as a direct consequence of poor mothering.

Sally’s comments also revealed expectations about mothering practices, particularly in terms of sleeping and feeding: “I can tell you, none of my children have ever slept in my bed the whole night in their life. Those mothers over there, they would’ve they all would’ve”, and:

People go ‘I’m a martyr because I haven’t slept for a week because my baby’s been teething’ ah, get a grip, there’s no excuse. And all these – oh the baby doesn’t like this – well it’s not that she doesn’t like it, you need to keep trying more than one time. But they’ve got no persistence these days, they don’t try.

Sally’s expectations extended to the way children should be disciplined, saying of her sister’s children: “[they’ve] never had any discipline, never been smacked or told no... they’ve never been smacked, they’ve never had rules.”

Interestingly, Sally’s value-judgements about other mothers’ behaviours included explicit reference to perceived social class. She stated that few mothers of children with disabilities advocate for their children in the way “that they should”, and that “these other [mothers] that are below the middle class, they don’t even know where to start.”

Remembering that Sally has a son with a disability herself, she said of other mothers of children with disabilities in her local area: “they’re not even near middle class, that’s why they have these children with problems.” She then recounted how her baby’s nurse said to her “I wish there were more common-sense mothers like you!” In attributing poor and even deviant mothering to social class, Sally’s comments offer persuasive evidence of how



assumptions about social class and hegemonic maternity are intertwined, functioning as an internalised yardstick for judging other mothers.

### **Hegemonic Maternity: Resistance and Challenge**

As I have explored in the discussion thus far, mothers in the study reported experiences of being subject to regulation from others; self-regulation; and the regulation of other mothers in accordance with representations of 'good mothering' and idealised standards of hegemonic maternity. While participants shared experiences of the ways in which they conformed to, internalised and enacted hegemonic maternity – revealing the various ways in which Rich's (1976) motherhood as an institution persists – they also provided evidence of resisting and challenging its dynamics.

Participants' examples of resistance and challenge, support and extend the limited but emerging literature on 'empowered mothering': a feminist mothering that challenges patriarchal versions of motherhood and hegemonic maternity. In O'Reilly's (2004) edited volume of this emergent work – *Mother Outlaws: Theories and Practices of Empowered Mothering* – empowered mothering is defined as mothering that occurs from a position of autonomy, agency, authenticity, and authority. Empowered mothering conceptualises mothering (as opposed to motherhood and the 'institution' of motherhood, or 'hegemonic maternity') as a site of potential empowerment as a female defined and centred experience.

Acts of contesting hegemonic maternity can provide the foundation for empowered mothering or creative action. Participants in this study resisted and challenged hegemonic maternity in three key ways, through: redefining and reclaiming the signifier of 'good mother'; framing motherhood as individualised; and challenging the expectation of being a primary carer in perpetuity. I will consider each of these in turn.

#### ***Reclaiming the signifier of 'good mother'***

Although participants spoke about the ways in which their experiences have shaped their self-perception as 'not good enough' mothers, they also drew attention to the ways their mothering *is* 'good enough'. Sally, for instance, recognised the hallmarks of good

mothering ideology, but asserted her status as 'good enough' against the idealised version of the 'mother':

I want to bake more, I like baking. I want to sew, I want to be a domestic goddess but shit like that doesn't happen in my way. I want all my washing all ironed and in the cupboards, but that's not going to happen. If it's away, that's happy days. If it's clean, that's good. If the sheets get changed once every fortnight, that'd be lovely.

She identified the societal expectations that define 'good' and 'bad' mothering, but made clear choices to push back against these expectations: "I have a cleaning lady, and I'm really sorry that that's really bad." Interestingly, her comment that it is 'really bad' to have a 'cleaning lady' communicated not only an awareness that others expect that *she* should be cleaning her own house in order to be considered a good mother; but also that having a 'cleaning lady' is demonstrative of 'bad' mothering. She went on to proclaim: "I would like to be superwoman, but I think I'm superwoman enough." In identifying the expectations that she felt she did not meet, she also actively contested these through her declaration that even though she does *not* meet these expectations, she is 'superwoman' *enough*. She not only challenged the idealised version of the 'good mother'; she deliberately recalibrated the meaning of the signifier 'good mother/superwoman' to make it her own, and affirm her 'good enough' mothering.

Jill offered a further example of the ways in which some participants reconfigured and reclaimed the term 'good mother': "But my kids will tell you no. I'm a mum, they tell me I'm a good mum – they do." Kelly recognised that while she previously felt guilt for not living up to the ideals of the 'good mother' by getting angry with her children, she added that

recently I don't do that as much, I try and allow myself to be a bit more human. But I used to spend a lot of my time feeling bad about the way I'd managed something ... And I try not to do that too much. It's hard not to. But I try not to do that.

For some participants, this *process* of redefining the 'good mother' and the 'good enough mother' was celebrated as a personal achievement and even as a form of triumph over certain limiting normative expectations (of others and of themselves). Jayda verbalised

her process of resisting hegemonic maternity: “I’ve got to be the mum. You’ve sort of just got to keep telling yourself that. And that I’ve done well”. In the same vein, Charlotte reflected:

I think I’m coming to the realisation now – and it takes a lot of pounding into my brain from people – that what I’m doing is pretty amazing, and I’ve got a lot more strength than I thought I did ... Maybe I don’t give myself enough credit, but I’m starting to get there.

The act of resistance to certain currents of hegemonic maternity, especially the presumption of the mother as ‘modern day saint’, enabled Charlotte and other participants to begin to reimagine and rescript their narrative of motherhood. In so doing, they moved some way towards assuaging and transforming the patterns of guilt, self-blame and self-deprecation that each experienced to a greater or lesser degree as part of their mothering role. By reconceptualising their role as ‘good enough mother’, participants embraced and affirmed their worthiness, resilience, and accomplishments.

### ***Framing mothering as individualised***

The process of redefining and reclaiming notions of the ‘good mother’ was also evident in participants’ efforts to frame their experiences of mothering as individualised, thereby differentiating their concept of the ‘good mother’ from that which characterises hegemonic maternity. Positioning their mothering as individualised can be interpreted as a means of asserting agency and autonomy, and for their mothering to be considered adaptable and therefore open to change. As one participant noted: “there’s no guidelines on what’s right and what’s wrong. It’s whatever you think ...”

Hannah articulated how some participants challenge hegemonic maternity by individualising their experience of mothering:

I think I’m a person who realises there’s no point having expectations because that’s based on a dream. You can have realistic ideas of where you’re going to go, but if you’re not flexible then you’re going to run into trouble. And I think for every parent, and I know for myself, when I haven’t been flexible that just makes the situation worse because you’ve

got to be flexible. So yeah, no expectations. Don't do it ... I still laugh at my obstetrician who said, so what's our birth plan? And I go 'no birth plan' and he goes 'oh thank GOD for that!' and he said a good birth plan is no birth plan.

Here Hannah recognised the pervasive normative expectations of mothers but argued that these expectations are often impossible to meet. Interestingly, she substantiated her view by repeating a comment she received from her doctor. Although Hannah can be seen to be contesting the framework of hegemonic maternity, she then subtly reinforced this very framework through needing to legitimate her individualised position using the authority of her doctor's affirmation.

### ***Challenging the expectation of being a primary carer in perpetuity***

A number of participants believed that if they did not actively seek out alternative caring arrangements for their children, then they would remain their child's primary caregivers for the remainder of their own lives. A number of participants expressed concern about who would care for their children once they died. Charlotte had the resources to purchase a separate house for her son to live in, and set the house up with facilities appropriate for his condition. She said of the care workers in the house: "I'm building a relationship with them so that I know that my ideals and that will be met ... But yeah it does make a big difference, it makes it feel like a huge burden has been taken away."

Similarly, Jacinta set up alternative care arrangements for her child through joining with a group of other mothers of children with intellectual disabilities and petitioning the government to build a group home facility for their children. She said that if the group home did not receive funding from the government to be built then "we would've still been in a panic thinking, I can't die, because if I do then what is going to happen?" In this way, participants such as Jacinta and Charlotte pro-actively planned and established alternatives to address their deep concerns about what will happen to their child when they are deceased or can no longer be the primary carer. Their forward-planning and pragmatic decisions were a direct consequence of the refusal to accept that there are no alternatives other than being their child's primary carer for the remainder of their lives.

## Summary

This chapter, together with the previous two chapters, have focused on addressing the first subsidiary question of this study:

- How do participants experience the “institution of motherhood” that Rich identified in 1976; how do they resist, conform to, challenge, and/or navigate this constraining institution?

This chapter has presented evidence of participants’ experiences of motherhood as regulation and resistance. The analysis reveals how, and the extent to which, hegemonic status is maintained in the lives of women who mother children with disabilities, despite their creative agency in questioning and problematising the expectations it places on them. Participants resisted and challenged normative expectations around the ‘good mother’ and ‘good’ mothering practices through: reclaiming the signifier of ‘good mother’; framing mothering as individualised; and resisting the role of indefinite primary carer. The intensity of participants’ emotional labour was especially striking, attesting to Landsman’s (1998) observation that “caring for a child with disabilities is emotionally painful, physically exhausting, time-consuming hard work. Each mother, if she could, would eliminate her child’s disability in a flash. Yet few would choose to give up what they have learned from the experience” (p. 92).

However, an important caveat for consideration is that many women who mother children with disabilities do not have the financial resources, social networks, or political traction to lobby for and secure alternatives for the future care of their child. For those participants who had less financial, social, and political capital, the exigencies of their circumstances offered few alternatives to the prospect of being the primary carer of their child for the term of their own life. Thus, while these participants carried a profound anxiety around the future care and wellbeing of their child, the dearth of suitable alternatives and caring options continued to bind these mothers to the hegemonic expectation that they will indeed be the primary carer in perpetuity.

In the next chapter I turn to the data about participants’ relationships with others as they are developed and maintained specifically through their constructions, understandings, and representations of ‘family’.



## CHAPTER EIGHT

### *On Displaying 'Family'*

*"... some days we'll go out and he'll be okay – it's only ever okay,  
we'd never be great – but most times it turns out to be a  
nightmare and you want to come home and neck yourself ... like  
everyone doesn't have to go around having to explain everything  
about their children to everyone, they just go out and live"*  
(Sheryl, Participant).

*"I was doing the script even if she wasn't part of it ..."*  
(Jayda, Participant).



### **Introduction**

This chapter is the first of two chapters that elaborate participants' experiences by exploring their relationships, concentrating on evidence pertaining to the second subsidiary question of this study: In what ways do participants construct and navigate their relationships, and how are their relationships shaped and impacted by their role as mothers of children with disabilities?

By drawing on data generated through interviews, this chapter focuses on what participants understand as their 'family' relationships – recognising that 'family' is a fluid and contingent term with increasingly permeable boundaries. As was the case in presenting and interpreting data in the preceding chapters, this chapter approaches the coded and themed data mindful of the conceptual framework of hegemonic maternity and social constructionist perspectives as lenses to crystallise and advance understandings of participants' lived experiences.

As discussed in Chapter Three, an individual's relationships, including those that constitute 'family' and personal communities, are understood to be socially constructed phenomena that form as a consequence of an individual's greater agency and freedom of choice (Beck, 1992; Weeks, et al., 2001). Important theoretical developments in the field of the sociology of personal life have contributed to new understandings of: the family as a

social construction; the ways through which family is practiced (Morgan 1996); and the ways that families are established through 'displays' (Finch 2007).

Equally relevant to this discussion of relationships is the emergent research within the sociology of personal life that conceptualises relationships, including those under the umbrella of family life, as relational (Jallinoja & Widmer, 2011). Emirbayer (1997) argues that research within the sociology of personal life often only emphasised the ways interaction *between* individuals is relational, reflecting a substantive understanding that individuals are 'things' who interact and relate with others. Such substantive understandings "*begin* with a notion of pre-existing entities 'among' which relations happen" (Emirbayer, 1997, p. 285). These types of understandings promote sociological dualisms such as the 'individual' versus 'society'. Yet, what Emirbayer terms the 'transactional' approach of relationality, or 'relational sociology', understands that individuals are actually influenced, altered, or created through interactions with others. This understanding recognises the ways individuals are influenced or changed *through* their personal relationships.

Emphasising the 'relational' aspect of human experience grew partly from sociological critiques of individualising discourses. As Jallinoja and Widmer (2011) explain it: "when challenging individualism as an omnipresent sociological toolkit family sociologists found, or more correctly, rediscovered relationality, or the embeddedness of the individual in family and kin relationships" (p. 5). They argue that individualism is "waning as a frame of reference and relationality is set to conquer the empty space that the dislodged individualism is leaving behind" (Jallinoja & Widmer, 2011, p. 5). The shift in conceptualisations of family has prompted attention not only to the importance of relationality in the production of relationships, but also to the performance of *practices* involved in constructing 'family relationships' and the public *display* and enactment of such 'family relationships'.

The following discussion, then, is aided by an understanding of individualisation theory and the extent to which it may operate in concert with relationality and hegemonic maternity in exerting influence on the nature of participants' relationships. The discussion is structured around three major themes from the data that shed light on participants' experiences of family relationships as mothers of children with disabilities:

family displays and stigma; family displays and grief; and re-imagining family displays through contesting normative paradigms.

## **Participants' Experiences of 'Family'**

### ***Participants experience stigma when 'displaying' their family***

According to Finch (2007), 'family-like' qualities need to be established and validated within and/or against wider systems of meaning about what it is to be part of a family, and in turn, these 'family-like' qualities are 'displayed'. Finch (2007, p. 77) cites the use of photographs as an example of how people 'display' their family. Displaying through photographs (including through visual images on social networking sites) is a means for people to visually display their familial relationship to others, establishing as well as conveying what this relationship signifies. However, participants' reflections on their family, particularly on mothering their children in public spaces, challenge the concept of display, at least in the way that Finch has defined it.

Participants' experiences mirrored those documented by Leipnik (2015), a sociologist and mother of a child with a disability. Leipnik described an encounter when one of her students visited her office and asked her where the pictures of her family were. The student knew Dr Leipnik had a daughter, since she would often talk about her in class. Yet when the student inquired about the absence of photographs of her daughter, Dr Leipnik realised that she did not display any: "I subconsciously avoid publicly displaying my own parenthood in my office" even though family displays are evident in colleagues' offices. She goes on to reflect that:

Pictures ... may confirm or challenge presumptions about normality, family, and disability. Where disability is evident they arguably fail to generate connections to similar personal experiences or create a unifying symbolic space in the normalised office (2015, p. 1289).

For Leipnik, because her family appeared to sit outside normative understandings of family, the act of 'displaying' her family in her institutionalised workspace would seemingly disrupt a 'normalised' office space. This anecdote reveals the extent to which



'displays' are built on normative understandings and beliefs, and can therefore be interpreted as political in their presence or absence.

For participants, it was often during a discussion of their experiences in public places that this concept of display entered the conversation. Participants' spoke of their acute awareness of the felt-expectations placed on them when they ventured into public spaces with their child or children. For example, Keira felt as though "the community expects the mum to minimise the interaction or creation of noises or bad stuff out in public", and recounted a story about when her daughter

wanted this Barbie in Coles one day and I did not have enough money to even buy it if I wanted to. And so there's a magic spot if you grab someone it basically nearly paralyses them. And I've got a hold of her, walking her out and she's yelling the place down. And people are coming at me and I'm like it's okay, I'll get her out.

In this example, Keira choreographed the actions and reactions in a public space in accordance with hegemonic expectations of good mothering and what constitutes good behaviour from a child. She felt that her child's behaviour, and her means of dealing with it, would be judged by others. She enacted the role of the 'good mother' and sought to shield her daughter from being judged as somehow 'deviant'. In order to conform to what she perceived to be the expected protocols and obligations for a mother and a child in a public space, she saw that retreating from the public gaze was her only choice. This incident stands as a powerful example of stigma and its flow-through impact on the perspectives, decisions and behaviour of mothers of children with disabilities. It also underlines the extent to which the perspectives and actions, and freedom of choice of mothers of children with disabilities are regulated and highly constrained.

When participants recalled episodes of negotiating public displays with their children with disabilities, they highlighted the ways that their displays fell outside normative understandings of 'good mothering' associated with hegemonic maternity. Scholars such as Harman and Cappellini (2015), Kehily and Thomson (2011), and Almack (2011), have attended to the myriad of ways that the concept of 'display' often masks normative aspects of family life and mothering. Significantly, when participants struggled with this concept of display, they experienced stigma as a troubling corollary.

The ways participants described managing experiences of stigma within their everyday lives is reminiscent of Goffman's (1963) work on stigma. Goffman (1963) defined stigma as a set of negative perceptions that others assign to an individual or a group on the basis of their apparent difference from society's normative understandings. People who experience stigma are often perceived as an aberration of the 'norm' and are therefore classified as the 'other' and treated in discriminatory ways as a result. Almost all participants recounted an experience of stigma and ensuing discrimination, and all experienced what Goffman (1963) would describe as 'courtesy stigma' because of their mothering relationship with their child with a disability. These incidents of experiencing stigma were peppered throughout participants' discussions of relationships, paid working environments, and interactions with healthcare professionals, and indeed are identifiable implicitly or overtly throughout all of the data chapters in this thesis. They spotlight the limitations on participants' scope for freedom of choice and the powerful influence of internalised normative expectations on their behaviours.

When it comes to participants' experiences in public spaces, it is instructive to draw parallels between the findings from this study and those of Turner et al. (2007) who carried out a study of parents of children with Proteus syndrome. These researchers found that their participants experienced four types of stigma: intrusive inquiries; devaluing remarks; staring and pointing; and social withdrawal. The majority of participants describe stigmatising experiences that accord with each of these four categories (Turner et al., 2007).

Katherine provided an example of an 'intrusive inquiry': "I've had people in the lift go 'what's wrong with him, what's the matter with him?' As if he's stupid. And I just go 'I don't know' because nobody knows and it's not your business and I'm trying to work it out myself." When Charlotte's son was diagnosed, she recalls the 'devaluing remark' of a doctor: "'all he'll ever be is fat and retarded'." Jacinta also recalls remarks made about her son that fit into Turner et al.'s (2007) category of devaluing remarks: "we were going up a traveller and this kid was coming down the other traveller and very loudly said to his Mum 'look at that funny boy!' and people still say exactly that phrase – look at that funny boy – even though he's a man."

There were a number of participants whose experiences corresponded with the stigma category of 'staring and pointing' (Turner et al., 2007). Generally, for participants whose child had a physical disability or a visual marker of disability, the experience of staring and pointing was common. Whether or not their child's disability was physically discernible, participants were affected by 'staring and pointing' in various ways. Participants whose children had ASD or an intellectual disability often spoke of their frustration that their child's disability was not obvious or visibly recognisable. When their 'physically normal-looking' child's behaviour does not align with what is perceived to be their 'normal' appearance, there is a disjuncture that produces a space for stigmatization. For example, Keira said of her daughter: "Because she looks normal, until she opens her mouth people don't know there's an issue", and it is in this space of the expectation of 'normalcy' and the realisation that the child's behaviour does not fit into this framework that the potential for stigma arises.

Conversely, when a child with a disability looks physically different from normative standards, this physical difference can lead to stigmatising and discrimination. Katherine's statement encapsulates this point: "I don't like being looked at and everyone looks at you when you've got a disabled child. Everyone looks." Similarly, Jacinta's son's appearance would attract the staring and pointing that Turner et al. (2007) identify as one marker of stigma. Jacinta describes feeling 'exposed' when in public with her son, and recounts a story about one situation on a boat when another little boy could not stop staring at her son:

[my] Mum and I looked at each other and knew we'd have to take turns blocking the line of vision, and so we spent the whole cruise with Mum and I manoeuvring ourselves between Dean and this kid ... and I just felt so exposed, and there was nothing I could do ... I think 'why do I have to put up with this every time I go out with my son?'. And when I go out without him it feels strange that people aren't staring! It's really weird. It's very odd ... I feel as though I've lived the last 31 years teaching people to be tolerant, teaching people not to stare, teaching people to think about what others are struggling with.

The burden of stigma pervades the lives of mothers to such an extent that the absence of people staring becomes disorienting. These stories also figure as evidence of how

'displays' can become highly stressful and disruptive. In the example from Jacinta above, what may perhaps be framed as an example of family 'display' of a mother, grandmother and child enjoying a boat cruise, actually becomes an example of 'exposure' of the ways people with disabilities are stigmatised as not belonging to or accepted by a 'normalised' social group. Katherine described how she responds to situations where her child's behaviour falls outside of understandings of good mothering or good behaviour: "I just sort of put this shell around me and just deal with it. And people will just watch. No-one will offer to help ... no-one will offer to help."

The experience of exclusion through perceived difference, otherness and stigma left Jacinta feeling 'exposed' and Katherine needing to insulate herself and her child by constructing a 'shell' around herself. Their experiences find echoes in Carnevale's (2007) work on public spaces in which he draws on Goffman (1993): "the stigmatised will feel that their privacy is invaded as others stare at them or approach them at will – where they are not afforded the social respect that is commonly accorded to others" (p. 10). Furthermore, the significant work of Green (2003, p. 1363) on stigma and mothers of children with disabilities found that, based on modified labelling theory, there are three common responses by mothers to this sort of stigma: secrecy; education; and withdrawal. Jacinta's comment that she feels like she has lived the last 31 years 'teaching people', is an example of the 'education' response that Green (2003) identified.

While Jacinta has experienced anger and frustration at people staring at her son, she also spoke about how the child on the boat was "just a kid", partly reflecting Green's (2003) finding that: "mothers develop coping styles that encourage them to see the stigmatising reactions of others as acts of benign ignorance rather than malicious intent" (p. 1367). So for Jacinta, part of her repertoire of strategies for negotiating displays with her son in public included the task of educating and managing the emotions of others, a finding that chimes with the research findings of both Green (2003) and Cahill and Eggleston (1995). Yet as Turner et al. (2007) have emphasised, a mother's response to experiences of stigma changes according to context, which is supported by Jacinta's comment that: "... some days I feel like slapping strangers and other days I'm happy to talk to them. But I can't pick what – it just depends on so many things."

Sheryl's approach to managing public situations was further illustrative of the ways that stigma can be manifested as highly regulatory. But her comments also revealed the ways

in which some participants rail against and overtly contest what they feel is a need to justify or explain their child's behaviour:

some days we'll go out and he'll be okay – it's only ever okay, we'd never be great – but most times it turns out to be a nightmare and you want to come home and neck yourself ... like everyone doesn't have to go around having to explain everything about their children to everyone, they just go out and live. I don't know why people have to judge everything you do if it's not 'normal' you know? So the judging really pisses me off.

Similarly, Jill tapped into this deep vein of discontent, anger and indignation that can ensue from the discriminatory and marginalising responses to family displays:

I hate that I just can't be comfortable with Cindy being anywhere – the minute she says something a bit silly I find myself explaining to people. I hate that, I hate that. I'll say 'I'm not sure if you know but Cindy has a developmental disability, or an intellectual disability so she might say a few silly things so please have some patience.'

Jill's comments revealed her reliance on well-developed pre-emptive strategies to avert or avoid the likelihood of stigma. She armed herself with these strategies, not only as her attempt to prevent this stigma, but also as a means of protecting her daughter and demystifying her daughter's disability.

Participants often felt compelled to explain their child's behaviour by explicitly referring to the ways that they do not fit into normative understandings of human interaction, physical appearance and/or appropriate behaviour. These examples of participants' experiences serve to reinforce the ways in which family 'displays', and what is considered 'good mothering' and 'good behaviour', are freighted with normative expectations that are shaped by a particular context and for particular audiences (Kehily & Thomson, 2011). However, as the comments by Sheryl and Jill attest, a number of participants profoundly resented the perceived need to explain themselves or their child's disability in public spaces.

Returning to Green's (2003) third category of response to stigma, which mirrors the fourth category identified by Turner et al. (2007), 'withdrawal' from a given situation or context is often the only 'choice' for mothers who seek to avoid stigma. When considering this strategy of withdrawal, Finch's (2007) notion of 'display' offers insights. When experiences of stigma can be seen to correlate with 'failed' displays, this can trigger the strategy of withdrawal from certain situations, contexts and even relationships. Participants' previous experiences of stigma, coupled with a belief that they are not able to produce and perform successful family displays with their child, precipitate their withdrawal from situations where their displays may be publicly monitored and judged. For example, Jocelyn remarked:

I realised at one stage that I was just walking around the shops with my head down, I wasn't making eye contact with anyone because I knew what the reactions around me, and it just became like 'ah I don't want to look at people' ... I didn't even look at people or see who was serving me.

Jocelyn's visceral sense of isolation, otherness, and difference resulted in her felt-need to withdraw from interactions in the public space and cocoon herself through her closed body language, avoidance of eye contact, and her lack of verbal communication. The distress and anxiety inherent in such an experience brings to the fore the profound impact of stigma and the limited range of choices available to Jocelyn in managing her relational experiences in the public domain.

On this dimension of mothers' experiences, Green (2003) reported that the sorts of daily tasks associated with caring for a child with a disability, coupled with the expectation that people with disabilities will encounter negative attitudes, have an incrementally deleterious impact on mothers' levels of distress and resilience (p. 1368). Katherine concluded that the public judgement and stigma she encounters, along with the logistical and physical difficulties of looking after her son in public spaces is "why you stay locked away ... everything is hard."

Not only do these consistent and confronting experiences of stigma add to mothers' distress: we can speculate that when mothers of children with disabilities withdraw or disengage from public contexts it affects their individual levels of distress and their wellbeing. The ripple effects on their children, others in their networks, and society more

broadly are potentially significant. That the options for day-to-day survival are so circumscribed that mothers of children with disabilities feel that their only choice for their own and their child's self-preservation is social withdrawal, bespeaks the human cost of stigma, discrimination, and normative expectations for many individuals and groups within our social realm. What is more, the evidence presented here provides a strong counter-narrative to prevailing assumptions of individualisation theory about freedom of choice and the primacy of individual agency in shaping the nature of individuals' lives.

***When negotiating 'displays', participants grieve the loss of their 'Imagined Child'***

Together with their accounts of stigma, participants' spoke at length about their abiding grief. As a dominant theme in discussions about their experiences as women who mother children with disabilities, grief was embedded within their perspectives on stigma and family displays. The inter-relationship between failed 'displays', stigma, and grief formed the weft and warp of the participants' stories. Grief figured as an intense dimension of participants' experiences, particularly in relation to realising or learning of their child's disability and in relation to the complex aftermath of coming to terms with the often immense gulf between their imagined child and family, and the realities of their child's disability.

Keira recounted an exercise that involved asking people to imagine what their future child might be like – or to think back to before they became parents and remember the dreams and hopes they had constructed around their future child:

... when you first find out 'I'm pregnant', you have these images, you have these thoughts. Like we've got the 5 fingers, the 5 toes, the cute little face, whatever it is. Going to go to school and get a nice education. Maybe go to uni, maybe have a job. Maybe get a husband or a wife, white picket fence? Yeah, yeah ... this nice perfect baby might be missing an arm. Or this perfect baby at the age of 3 now can't walk, can't talk. Doesn't meet expectations.

Keira then spoke of the ways that parents of children with disabilities must modify and even transform their expectations to create a new 'normal' for that child, to enable the parent to celebrate and feel pride. In this exercise, Keira invoked normative ideals to

describe the imagined child: the imagined child does not have a disability. When participants learned of their child's disability many spoke of a period of silent grieving for the loss of their imagined child. The grief is not limited to the period immediately following the realisation of their child's disability: the subsequent experiences of stigma and their challenges in producing normative family 'displays', resulted in an enduring sense of mourning and sorrow.

The perpetuation of 'stigma', coupled with practices of display (Finch, 2007), are direct consequences of prevailing social views of what is 'normal' and the tacit assumption of hegemonic maternity that a 'good' mother will have a 'normal' child. Participants built their ideations and hopes for their child around these powerful normative standards.

It is necessary to note, however, that one participant, Tania, said that because her first child had a disability, when her second child was diagnosed with an even more severe disability, she felt she was somewhat more equipped to cope with the diagnosis and all that this entailed. Of her second child with a more severe diagnosis she said: "I'm not mourning the loss of anything I guess because I didn't really have that in the past." It is also important to highlight the perspective of Sheryl, who did not experience grief at the loss of the imagined child because she had never particularly wanted children. She did not subscribe to the hegemonic assumption that a woman would naturally wish to become a mother, and therefore she did not hold an expectation of normative family displays when she became a mother:

I always thought I was going to have a special needs kid. That's probably another reason why I thought I didn't even want to have one because I always thought it was going to be disabled or something ... I always thought I was going to have a disabled kid, if I had one. Which is one of the reasons why I didn't want them – I didn't want kids anyways but I thought if I did have one it'd be disabled, and it was! (laughter).

Nancy reflected on the ways that her lived reality differs from her previous conceptualisations of 'normal' family life, and she lamented the pervasiveness of grief in her life:



There's change and adjustment to change and there's grieving all the time ... you see families having a BBQ and you think well we can't, we're going back home in the car after spending our 20 minutes in the shopping centre, we won't be able to go down there and have a BBQ. That's grieving ... We realise sometimes, it smacks us in our face when we go out in public or someone, or if we did go to someone's home it becomes evident – it's like a big smack ... it's those forgone losses that you could've done. That is constant.

Nancy described this experience of grieving as analogous with an experience of physical violence – “a big smack”. It is as though the imagined child and family endure as ghostly companions, with Nancy's grief sharpened by ‘ordinary’ experiences, which throw into stark relief her own lost dreams and aspirations.

Danielle explained that there is an ebb and flow to the intensity of grief, but it nevertheless persists as a haunting ‘presence’ in the life of a mother of a child (and then as adult) with a disability:

But I find you go in waves and you get over it and you sort of pick yourself back up and you move forward, and it can present at different stages. When a child turns 13 when they hit puberty, when they hit 21 into adulthood, it can be when your kid starts school and it's like my child isn't going off to a school or my child has special needs. And it sometimes can be out of the blue. It could be the fact that you've got another child that's leaving home or getting a license. Different milestones for that child or other children that bring you back to that child.

This filament of sadness was a common one, woven throughout interviews. Participants reflected on the ways they would look at schools and imagine what it would have been like if their child could attend mainstream school rather than a special school. Or what their child might look like physically if they did not have a disability. Or they expressed their deep sorrow that their child who is blind can never enjoy the visual beauty of nature, or languidly pass the time watching the changing cloud formations, in the way that they themselves were able to. With poignancy and a tone of quiet resignation, Katherine

attempted to verbalise the multi-layered sense of loss and grief she experienced: grief for the loss of the child she had imagined, and grief for the limitations her child now faces:

You grieve the child you thought you had. Whether you thought ... I mean I'd decided what school he was going to. I know that child. So that child dies, so you grieve that child ... It's hard ... it's like what could have been ... as soon as you even hear of someone getting pregnant there are all the images ... unexpected ... And then you grieve for the one you have.

Katherine, and many of the other participants were conscious of the ways in which they perceived that their mothering and/or their families occupy the margins – or are indeed outside the perimeters – of normative frameworks. They therefore struggled to 'display' their families and mothering in ways that are recognised and accepted by others as legitimate. These experiences occur within a social context informed by the assumptions of individualisation: namely, that individuals enjoy a certain amount of freedom of choice and agency in directing the course and contours of their lives.

An interesting example of the convergence of grief, assumptions of individualisation, and hegemonic maternity in a mother's life was shared by Sheryl. It will be recalled that Sheryl differed from the rest of the participants in this study as she said she had never imagined herself as a mother and never particularly wanted children. She did not construct fantasies of her future child in the way that some other mothers may have. During our interview, Sheryl did not speak about the grief of losing an imagined child who was not disabled, but reflected on grief in her life in a different way:

... but when I had my school reunion and [my husband] was playing cricket with all the normal kids and Jayden was sitting in a corner, that was really heart breaking for me, I ended up going home because I was just thinking how awful it is – [my husband] would be so great ... that was a real light bulb moment for me, seeing him with the normal kids and thinking how great he'd be. Sometimes I think – just leave and go and find someone else and have some normal kids and be a good dad to them. So just so one of us can have a normal life out of us.

Sheryl's perspective is telling on a number of levels. Her sadness has ensued not from recognition of the limits on her son's experience because of his disability, but from a sense that her husband's experience as a father does appear to satisfy normative standards. Watching her husband play cricket with other children who did not have disabilities prompted these feelings, and therefore the juxtaposition of his lived reality with his son with a disability, and visions of what could have been, are thrown into sharp relief. Viewing her husband play sport with these other children can be interpreted as an example of potential and desired 'family display', as Finch's (2007) concept would recognise this type of display as demonstrative as well as constitutive of family practices.

Sheryl's comment that she sometimes thinks that her husband should leave and have 'normal' kids, so at least one of them can live a 'normal' life, is revealing of the internalised influence of both individualisation and hegemonic maternity. The capacity for an individual to leave their current situation and/or relationship if it is difficult or unsatisfactory is something that processes of individualisation are meant to allow. According to theories of individualisation and authors such as Beck-Gernsheim (2001), individuals are 'authors of their own biographies' and therefore, would possess the freedom of choice to walk away from a situation such as the one in which Sheryl's husband finds himself. At the same time, Sheryl's comment is also indicative of the internalised influence of hegemonic maternity: it is her husband who she considers should have the freedom to leave. A father leaving his child with a disability in order to have a 'normal' life seems a far more legitimate prospect for Sheryl than to contemplate doing this herself.

The assumption embedded within hegemonic maternity is that the mother will be a child's primary caregiver for all time. A mother leaving her child with a disability to have a 'normal' life is perhaps not as conceivable for Sheryl, as it challenges the hegemonic expectations of others in positioning the mother as the primary carer who is self-sacrificing and puts the needs of her child above all others. Thus, in Sheryl's comments, we can apprehend the ways in which the amalgam of assumptions of individualisation and hegemonic maternity affect the participant's experiences, perspectives, familial relationships, and life choices.

In addition, the ways in which public displays are recognised as legitimate, or not, are built on heteronormative ideals of the 'family', a 'good father', and a 'good mother'. The examples explored thus far in this chapter attest to the ways in which public displays can

be profoundly troubling, complex, and disruptive for those whose 'family' does not correspond to these institutionalised ideals. Finch (2007) has argued that family relationships do not even exist unless they can be displayed successfully. However, based on the evidence presented thus far in this discussion, I would contest this assertion: participants' family relationships do indeed exist, despite not being displayed successfully according to normative ideals. These ideals generally include being white, middle-class, non-disabled, heterosexual, and living within a nuclear family.

The difficulties participants faced in attempting successful displays, combined with the feelings of grief and experiences of stigma they endured, resulted in a number of participants withdrawing from social and public situations, or limiting their sociability and interaction in public spheres. Such behaviours further underline how relationality shapes an individual's behaviours and relationships in both the private and public realms, and in this case, through public displays. In addition, the participants' stories of stigma, exclusion, and the attendant feelings of being ostracised and 'not belonging', serve to reinforce the authority of dominant conceptualisations of family and relationships.

Gabb's (2011) critique of the concept of display asserts that displays do not need to be necessarily recognised, understood, or accepted by others in order to be considered significant and legitimate: "displays may fall outside the registers of cultural intelligibility and therefore what is *on display* may bear little semblance to family scripts" (pp. 53-54). One of the key findings of this study, is the degree to which participants struggle against and also within these perceived "registers of cultural intelligibility" and the far-reaching consequences of this struggle for their mothering and family relationships.

This dimension of the study represents a response to Gabb's (2011) invitation to attend to what *is* being displayed; *why* displays appear in the way that they do; and to recognise the significance of what is *not* being displayed. For participants, 'what is *not* being displayed' is a particularly cogent indicator of the extent to which their experiences fall outside normative understandings, and in addition, of the ways they endeavour to challenge such frameworks through re-imagining and reconfiguring dominant definitions of 'normal' to construct a new 'normal' that encompasses and legitimates their version of family. Whether or not they are effective in broadening the definitions and conceptualisations of alternative versions of family *for others* in the public sphere is the focus of the following discussion.

### ***Participants challenge and re-imagine 'displays'***

Participants experience stigma and grief when they fail to 'display' their mothering and families successfully. Yet participants also devise strategies to adjust their behaviour, or others' perceptions of their behaviour, in order to carry out 'successful' displays, as measured by normative standards. As Ryan and Runswick-Cole (2008) observed: "adjustments and refinements to notions of normality may involve retaining particular aspects of family life while losing others, as well as incorporating new aspects" (p, 205). So while participants may experience stigma and grief when their displays fail to be recognised as valid, they also work to subvert this concept of display, and incorporate new aspects of family life into 'normative' understandings through re-imagining what 'normal' means, and thereby finding affirmation in their 'displays'. One example of a participant purposefully reconfiguring this concept of display is Jacinta. She recounted the experience of a friend who also had a child with a disability. She recalled the experience in order to highlight the often troubling nature of public displays, and to share her decision to adopt her friend's strategy in dealing with these troubling displays:

... she said she always tried to have a happy expression on her face so that people don't think that having a kid with a disability is all horrible ... so I thought that's interesting, so her theory is she can at least make it look like everything's fine and people shouldn't be looking for something that's not fine. So I think I consciously now have a smile on my face when I have Dean with me so people don't think otherwise.

Jacinta decided to perform a particular type of 'display' to fit within normative expectations of the family, in order to avoid stigma. By deliberately smiling when with her son in public she was making a visual claim to reflect normative ideals. By smiling in order to present 'normality', and thereby avoid stigma and discrimination, Jacinta was both acknowledging the 'rules' of successful displays and then also consciously performing this display by adjusting her behaviour. This decision to 'play the game' of successful displays involved a degree of compromise and an apparent acquiescing to the authority of normative and hegemonic assumptions. For Jacinta, the decision to act in this way became a personally empowering experience since she believed she was exerting some degree of personal agency in the face of an otherwise potentially stigmatising situation. Ultimately,

however, Jacinta worked to position herself and her family within the normative frameworks of successful displays.

There is a cluster of other approaches that participants deliberately adopted in charting their way through the complexities of display. Each of the following four strategies were enacted by participants in an attempt to contest the normative frameworks used to judge successful displays, and at the same time, to attempt to situate themselves within such frameworks.

### Language

Most participants were conscious of the language they employed when talking about their children and others. Their language choices both reflected and at times challenged normative discourses. For example, most participants used the words 'special needs' to describe their child with a disability, rather than 'disabled'. However, when they were referring to other children, they used the word 'normal' as a descriptor, to highlight difference. When Sheryl spoke about her expectations of motherhood she said that she was "depressed" about how her life would change if she had a "normal" child, "I wasn't even prepared to have a normal child. Like if I had a normal child, I'd be breezing through life." Likewise, Tania remarked that "I sometimes think, I wonder what my life would be if I had normal kids?". Both Sheryl and Tania perpetuate normative discourses around 'normal child' and 'special needs' child.

Yet, there are also many ways through which participants explicitly challenge such discourses. For example, Jill preferred the word 'mainstream' over the word 'normal' when describing children who are not disabled: "I hate normal because I don't think anybody's normal". Interestingly, while she refrained from using the word 'normal' when describing other children in contrast to her own, in her explanation of why she does this, she highlighted everyone else's *abnormality*. Jill is both rejecting normative discourses through choosing to use the word 'mainstream', but in her explanation of why she does this, she is also situating her child *within* normative discourses. Her child's *abnormality* is the same as everyone else's *abnormality*.

### Comparisons

Participants made comparisons between their children with disabilities and other children with and without disabilities in order to illustrate differences and similarities. They

highlighted differences in order to draw attention to the stigma or discrimination they have experienced, and pointed out similarities in order to position their children within normative frameworks.

As an example, Jill has twin daughters, and one of her twins has a disability while the other does not. Jill went to great lengths to describe the ways in which they are complete opposites from one another in every respect. She described the apprehension she feels in allowing her daughter with a disability to engage in the same sorts of activities as her daughter without a disability, and feels a strong sense of protectiveness over her daughter with a disability because of her extra level of vulnerability. Yet at the same time, Jill emphasised the ways in which she tries to treat her children equally and compares the twins in order to highlight the ways in which her daughter with a disability does fit within a normative framework. For instance, when her daughter without a disability started a part time job, Jill went through an organisation to find her daughter with a disability a job too, but was told she should wait until her daughter reached 18 before seeking out work for her. Jill's response was: "well you can review her then but she's 16 now and her sister's got a job so I'm looking for work for her now."

Sheryl spoke about the ways that she would recognise her son was different from other babies: "It was the smiling, he didn't smile – all the other little babies would smile." Yet she also drew attention to her son's achievements in progressing with his spelling and the way his spelling ability supersedes that of other children his age. She lingered over comparisons with other children to underline the ways her son is different from other children of his age, and the ways in which this difference impacts on both of their lives. She spoke about her niece who is the same age as her son: "... it seems like there's 20 years' difference. He's like a baby, and she just turned 8 and wears make up and listens to One Direction."

Jayda was another participant who made comparisons between her child with a disability and her child without a disability: "we had two lives – the one with Elsa and typical, and then this pathway of disability." But when she spoke about the progress of her daughter with a disability, she stressed the importance of "treating her normal." Similarly, while Dana talked about the difficulties in transitioning her daughter into a group home, she said, "but I look at even my daughter in law last night ... her son is going to school next year ... and she was like 'oh my little boy going to school' so it's even normal kids too."

Sally spoke about the difficulties she encountered feeding her son when he was a baby – because of his condition – but immediately qualified her comments: “But he was happy, he wasn’t crying, I didn’t see anything really different to the others. I used to feed them, wrap them up, change them – they never screamed the hospital down ... none of my babies have been like that.” Participants such as Jessica compared their child’s disability with others’ in order to soften the starkness in the contrast between their children and children without disabilities: “like we have to feed her but some kids have it through the tummy ... She’s happy. Some kids aren’t happy.”

In each case, the participants can be seen to be grappling with conflicting sets of expectations: on the one hand, identifying the reality of difference and the implications of this, and on the other hand, striving for indices of ‘normalcy’. Steering their way through this complex web of assumptions, expectations, and internalised beliefs about what constitutes family and how this can be ‘performed’ to align with dominant models is akin to a high-wire act that participants are repeatedly compelled to undertake. At the heart of this arduous, never-completed journey described by participants was their love for their child, transposed in their efforts to construct their family-life narratives with meaning, hope, purpose, and legitimacy. Another avenue for accomplishing a sense of meaning, hope, purpose, and legitimacy was through the participants’ approaches to celebrations and rituals.

### *Celebrations and rituals*

Normative understandings of ‘family’, relationships, and motherhood are evinced through social and culturally-driven traditions that mark the watershed moments in the ‘normal’, archetypal human life cycle. A host of celebrations and rituals have accrued around, for instance: birth, baptism, childhood, schooling, adolescence, birthdays, anniversaries, adulthood, employment, marriage, retirement, death, funerals, and many others, depending on cultural and historical contexts. The celebrations and rituals associated with such occasions constitute an additional source of complexity and complication for mothers of children with disabilities. While a number of participants engaged in celebrations and/or rituals that either challenged normative understandings or conformed to them in order to achieve a sense of ‘belonging’ within the dominant narrative of their cultural context, others created their own celebrations and/or rituals in order to invest their particular family experiences with meaning and significance.



One example of a created celebratory moment that sits outside of normative understandings of celebrations involved Jacinta, her son and a tissue box. Jacinta described how she was trying to teach her son how to pull tissues out of a box, and when he eventually mastered this task, he pulled all of the tissues out of the box so they were scattered over the floor. Jacinta said: “Anybody else would’ve been chastising their baby for doing that, but I was SO excited!”

A further example of these occasions for celebration that occur outside of normative understandings, came from Katherine. At the time of our interview, Katherine had just started toilet training her six-year-old son, who has always been in nappies. She expressed her elation when her son finally used the toilet:

The toilet training is so big, you would not believe it. But I can’t talk to anyone about it. I mean I’m telling you, but I can hardly tell you about it, but you can’t ring up someone and be like ‘guess what, I am SO excited, you would not believe how significant this is for me!’

For participants, these occasions – such as pulling out tissues from a box or toilet training a six-year-old – represented milestones to be celebrated with as much joy and pleasure as milestones in a ‘normal’ life cycle. In the context of their family lives, these moments were significant, yet the participants’ self-regulated their celebratory mood because they perceived these moments as insignificant to others. Their celebratory mood was generally dampened: they felt unable to share their excitement with others since such milestones sit outside of normative frameworks. Thus, their child’s milestone figured as an additional marker of difference, leading to ‘withdrawal’ in the form of reticence in relation to others, and a compounding of the sense of isolation and ‘not belonging’ that ensued from this.

A number of participants engaged in celebrations in an attempt to situate both their mothering and also their children within prevailing normative frameworks. A telling example of this came from Jayda, who deliberately positioned her daughter, her mothering, and her family unit within existing frameworks of normality, through hosting a birthday party each year for her daughter who has autism. Jayda said her daughter had never actually wanted a birthday party:

See every year when it was her birthday we couldn't have a birthday party for her – well she wouldn't allow us to have one. So that didn't matter, so what we'd do was I'd set up everything, a picnic and we'd go down at the parks and we'd still have the party at the parks.

Jayda said she would invite the friends of her daughter who did not have a disability, and they would have a party in the park to celebrate, even if her daughter with a disability was disinterested and isolated herself from the group by playing on the swings: "I was doing the script even if she wasn't part of it, we still did it ... when it came to the birthday cake, well we'd sing happy birthday and it didn't matter whether she was there or not."

Jayda very clearly recognised that her behaviour and decisions about the party were conforming to the "script" of normality. She persisted in performing this script – even though her daughter overtly resisted it – in order to position herself and her family within normative social and cultural paradigms: that is, families celebrate their members' birthdays and a 'good mother' displays her mothering by hosting a birthday party. An additional motivation for hosting the party was Jayda's desire to maintain relationships and friendships with those who she considered to be 'normal'.

### Adjusted expectations

A fourth way that participants wrestled with the notion of display was through adjusting their expectations and understandings of 'normality'. I have discussed the ways participants negotiate concepts of 'normality' around motherhood in Chapter Six: On Negotiating 'Normality'. Participants sought to reframe their experience of mothering in ways that both pushed back against and adhered to normative understandings of family and mothering. A compelling example of this came from Nancy. She spoke about how she imagined the lives of parents who have children without disabilities in contrast to her own experiences. When her child was diagnosed with autism, their family story suddenly

doesn't fit into the image, you have to rewrite ... when it's bang – life isn't your life or your child's life is not the normal, you start saying, well what's the meaning, what am I to do about this? What's my direction?

How do I look at the world now? ... You have to find some way of seeing the world that puts value on your child and also on what you do.

This striving to make meaning from their lived experiences required of participants a continual process of constructing, adjusting, reconstructing, re-imagining and re-defining expectations, conceptualisations of family, the concept of display, and their sense of belonging and legitimacy as a mother.

## **Summary**

In this chapter I have focused on presenting the findings pertaining to how participants negotiated and sought to make meaning of normative structures and conceptualisations of family and familial relationships, especially in social contexts. The interview data yielded an abundance of evidence of participants' experiences of 'display' and the consequences of seeking and apparently failing to meet dominant normative expectations of a legitimate 'family'.

All participants reported experiencing social stigma and its attendant impacts as a result of their child's disability. Participants articulated the abiding sense of grief that accompanies their mothering: grief for the loss of their imagined child and family; and grief that arises when incidents, events, memories, and aspirations serve to throw into sharp relief the difference or otherness of their family and themselves.

In sharing their experiences of family and family relationships, participants revealed the extent to which they continuously struggled to both conform to and resist internalised normative frameworks of hegemonic maternity and individualisation in order to feel 'normal', to avoid stigma and discrimination, and to feel that they 'belong'. Their efforts to reconcile the tension between wanting to conform, and resenting the need to conform (when they will never be able to meet the institutionalised cultural standards of the 'ideal family and mother'), were manifested in their approach to family displays and their public performance of family displays.

A distinctive aspect of the findings presented here is the utility of the concept of relationality (cf. Jallinoja & Widmer, 2011) in shedding light on participants' constructions of family and family relationships against a backdrop of socially-sanctioned benchmarks

and ideals. Consistently, participants demonstrated the deeply relational nature of their experiences, whether this was through their referencing of 'normal' as the standard against which they constructed their view of their family, or through their assiduous attempts to 'practice' (Finch, 2007) their mothering according to hegemonic standards.

The findings thus support Emirbayer's (1997) notion of 'transactional relationality' in understanding the nature of individuals' relationships and how these are formed and influenced through interactions and transactions with others: individuals "derive their meaning, significance and identity from the transaction" (Roseneil & Ketokivi, 2015, p. 6).

The participants' stories have offered compelling evidence of the inadequacy of individualisation theory to explain and understand the experiences of women who are mothers of children with disabilities. Assumptions about an individual's scope for freedom of choice, personal agency and self-determination (cf. Beck, 1992) were demonstrably contested by the lived and reflected-over experiences of women in this study. The findings here expose the need for individualisation theory to be significantly revised in order to recognise and account for the diversity of individuals whose lives cannot be interpreted or understood through this blinkered theoretical paradigm.

Further, the evidence presented here constitutes a call for change. The stigma, discrimination, exclusion, and isolation experienced by mothers in this study can only begin to be transformed through greater awareness, understanding, and shifts in attitudes and behaviours of individuals in community, social, political, educational, and other institutional contexts.

The next chapter presents and interprets the data generated through the personal community mapping activity undertaken by each participant prior to and/or during their interview.



## CHAPTER NINE

### On Navigating Personal Relationships

*It's completely different ... The day we got the MRI I knew that – because I remember sitting and looking at him [her husband] going – ‘people get divorced, I know what this is going to do’. And I remember feeling really determined that this is going to bring us together not apart. But it doesn't. It's too hard. We're just exhausted all the time*  
(Katherine, Participant).

*No one had ever actually asked me – am I okay, and what's it like to not have choices?*  
(Keira, Participant).



### Introduction

This chapter builds on the previous chapter's focus on the relational dimensions of the lives of women who mother children with disabilities. It draws on data generated by participants' personal community maps in order to further address the second subsidiary question of this study.

The process of constructing diagrammatic representations of their relationships involved participants literally choosing to position the people in their lives on a visual diagram, according to that individual's significance to the participant. The activity proved to be a richly-textured and informative vehicle for prompting reflections.

In the previous chapter I drew attention to the value of the concept of relationality when describing and interpreting how individuals see the world and travel through it. This chapter examines participants' relationships, based on this understanding that individuals are embedded within networks of relationships, and such relationships shape who an individual is and how they understand their sense of self. Paralleling Emirbayer's (1997) work on relationality, Elias (1978) emphasises the interdependencies that exist within human relationships. In order to examine such interdependencies, and fully understand

how participants reflect on their sense of self, it is important to discover not only *who* participants' have relationships with, but also *how* these relationships operate and what role they place in a participants' life.

The personal community mapping activity, created by Spencer and Pahl (2006), provided an avenue for addressing these enquiries, and acted as a tool for capturing participants' perspectives on their personal and family life. As a method, it offered a means of foregrounding the multi-dimensional nature of the experiences of individuals who are, according to Jallinoja and Widmer (2011) "always in context and ... untenable if conceptualised as solitary and self generating" (p. 17). Personal community mapping supports an understanding of individuals as being embedded in relational networks, and of the importance of these networks and relationships in influencing an individuals' life and sense of self (cf. Emirbayer, 1997).

Prior to the interviews, participants were provided with a copy of the template and a guide for completing this (see Appendix D). The aim was to utilise the map to visually represent participants' relationships, and also as a stimulus for probing the nature of these relationships and the reasons for their positioning on the personal community map.

The results from this activity evinced six major categories of influence within the participants' relational networks:

1. Husbands/partners
2. Friends
3. "Special Needs Mums"
4. Others who value their child
5. Absences
6. Parents

The following discussion will address the data on each of these in turn and conclude with a synthesis of the key findings.

### **Husbands/Partners**

Participants positioned their husbands or partners on their personal community maps in ways that both aligned with and challenged socially prescribed categories and normative roles. Although participants were informed beforehand that they had unrestricted latitude

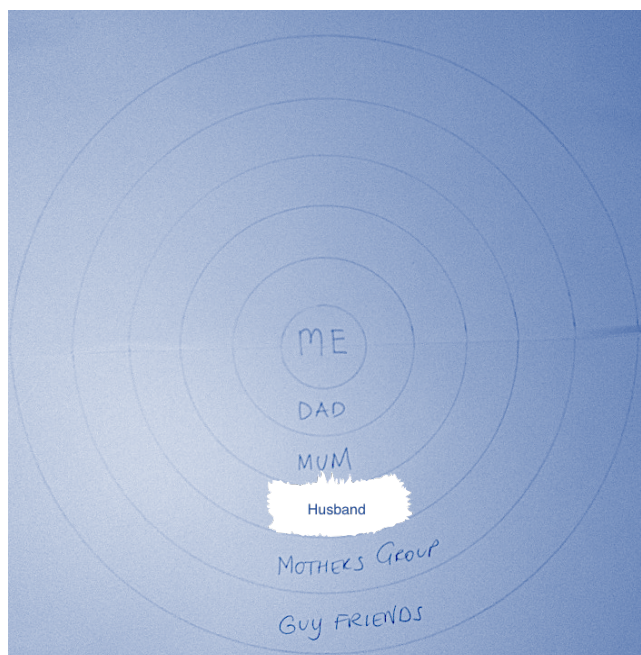
in defining their relationships in whatever way they chose during the community mapping activity, many participants believed they were *expected* to place their husbands/partners or ex-husbands/ex-partners on their maps. This equivocation occurred despite my assurances that they should position others on their map according to their own personal views and feelings: that is, the closer their relationship and feelings of closeness with the person, the closer to the innermost circle the person is positioned.

At the time of the interviews, thirteen participants were married to men, and eleven placed their husbands in the first-tier circle, closest to them in the centre. Although the majority of married participants placed their husbands in the first-tier circle of their maps, the dialogue about the quality and satisfactions of these relationships varied widely. A spectrum of views about husbands/partners was apparent, encompassing views of him being completely supportive and attempting to share primary caring responsibilities, to “being this far away from a divorce” (Charlotte indicating a short length with her finger and thumb).

By positioning their husband in the first-tier circle of their map, despite expressing ambivalent feelings about the relationship, some participants were demonstrating their sense of obligation to conform to the normative narrative of the nuclear family. According to this narrative, partners and children are expected to reside at the centre of the family, figuratively and symbolically positioned closest to participants, regardless of how emotionally nourishing or supportive the relationship may be. The personal community map was designed by Spencer and Pahl (2006) to be constructed on the basis of feelings of emotional closeness *rather than* predetermined social categories. The process of mapping was intended to discourage a default adherence to normative expectations if these did not accord with the participants’ lived experiences and perspectives. This intention did at times prove difficult to realise when it came to some participants’ husbands/partners: “I suppose I’d better put the husband in there too” Charlotte quipped as she placed her husband’s sticker in the first-tier circle.

Other participants did embrace the intention of the maps to accurately represent their perspective on their relationships. For example, Sheryl placed her husband on the third-tier circle of her map after she had placed her father and mother in the first and second-tier circles, respectively, as shown in Figure X below (identifying details about her husband have been removed).

**Figure 2: Sheryl's Personal Community Map**



Others, such as Jill, concluded that because her husband embodied the qualities of a friend, this was an important factor in the decision to place him in the first-tier circle of her map, labelling him as a 'good husband' because: "[he's] a really good friend to me as well, as far as a husband goes. He's fabulous." Implicit here are two sets of criteria – one for a good friend and one for a husband. Jill's husband was positioned in the first-tier of her map on the basis of his 'good friend' status in her life, rather than, in the first instance, as a husband.

Katherine positioned her husband in the first tier of her map. Yet it was a source of frustration that her husband did not actively embrace or show initiative in any caregiving tasks. She spoke about a friend who also has a child with a disability, observing "her husband would just not get up in the night – never, ever ... I just don't think that's fair." She expressed her determination in wanting to ensure that this situation was not mirrored in her own marriage. As a result, she would delegate tasks to her husband to manage his involvement in providing care for their son. This strategy can be seen as an attempt to challenge the gendered and devalued nature of care-work within hegemonic maternity:



so [my husband] used to have medicine and things and I used to say to [my husband] can you just give him his medicine before you go to work – just give him one thing. And then we did that and I thought oh this is good ... but then John's medication changed and he didn't need it at that time. So I found it really hard. So even now I say to [my husband] 'could you just make up' – because he has thickened fluids – 'could you just make it up'. But I cannot get it as a matter of routine, to take on anything.

Katherine's story here is illustrative of many participants' awareness of the pervasive norms of hegemonic maternity that cast women as the orchestrators and managers of the household, and as in this instance, their desire to disrupt this hegemony. Katherine was already responsible for the primary care-work of her child, and in addition to this, she adopted the responsibility of delegating care-work to her husband and overseeing its implementation. Her challenge to the expectations of hegemonic maternity materialised in ways that impacted on the relational dynamics of the marriage: "He will help, but I have to ask, so then he feels cross with me for asking. And I always try and ask because it's not fair." Despite Katherine's desires and attempts to subvert and thereby transform the normative gendered framework of care-work and domestic tasks, the gendered division in her household continued to prevail. She said her husband continued to arrive home from work each day and sit in a front room of the house until dinner was ready. Making sure that her older children who were upstairs at the time of the interview could not hear her, she whispered: "drives me insane."

This frustration expressed by Katherine is emblematic of the consequences of challenging the status quo dictated by hegemonic maternity: her efforts were thwarted, her husband's behaviour persisted unchanged; the relationship became inflected with tension and resentment; and Katherine had little choice but to submit to the power of constraining normative expectations.

When Katherine reflected on her current relationship with her husband, comparing it to what it was like before they received their child's disability diagnosis she pensively conceded that:

It's completely different ... The day we got the MRI I knew that – because I remember sitting and looking at him [her husband] going – people get divorced, I know what this is going to do. And I remember feeling really determined that this is going to bring us together not apart. But it doesn't. It's too hard. We're just exhausted all the time.

A number of other participants echoed Katherine's perception that many couples of children with disabilities separate as a direct consequence of the strain placed on their marriage because of disability. Kelly remarked that: "I do hear of a lot of families with autism where the marriage just doesn't survive it because of the stress." Sheryl said: "We're stuck at home all the time, we don't go anywhere really, we've got a special needs child who really doesn't let us have a proper marriage." Yet, as mentioned earlier in Chapter Two: On Parenting Children with Disabilities, there is no definitive data on increased rates of separation or divorce among parents of children with disabilities compared with parents of children without disabilities. The *perception* that many marriages would break down, however, influenced the way participants tended to rationalise and excuse their partner's lack of support. A number of participants described feeling appreciative that their husbands were still in their lives. They appeared grateful for his ongoing physical presence and could not therefore expect him to provide equal share of care for their children: the latter is the internalised responsibility of the 'good mother', not the father.

Although most participants who were married spoke about the strain on or change in their relationship since having a child or children with a disability, some focused on the temporal nature of such changes, and expressed hopes that their once-fulfilling relationship would be restored again in the future. Both Sheryl and Hannah, after placing their husbands on their personal community maps, attributed the longevity of their marriages to their shared core values as individuals. Sheryl put it this way:

... we've been together for 13 years with no blemishes really in that regard, and it's a one off, I wouldn't get married twice, I don't see the point. Even if Angus and I did break up, which I can't imagine would happen, I would never get married again. And Angus feels the same way, we've got similar ideas about that sort of stuff. Even though we're not Christians or anything.

Sheryl's husband's upbringing was "hard" and she emphasised the ways in which neither of them are people who "give up". Similarly, Hannah believed that her own and her husband's values have provided the foundation for, and fortified, their marriage. They shared the hope that their relationship would grow and deepen, with the development and progress of their daughter with a disability seen as central ingredient in sustaining this optimism:

... with a child with a disability you've got that added extra lack of time, lack of head space, stress ... I'm sure if Tim and I were the sort of people who thought 'oh it doesn't matter, if it's bad you just move on', then we probably would've separated years ago! But because we know that this is just a moment in time, we also know that things will get better, we know that things have ups and downs and it can be crappy for a long time, but you know it's not always going to be like that ... And occasionally you do have that time to better things, and work on things together or you might even have a night out or a couple of hours' spare with each other. Those sort of things make you think oh yeah we do sort of have a connection there, somewhere, it just gets buried in the day-to-day running around doing things, it's like 'oh hi'! I think a lot of it is your beliefs about a relationship beforehand, that it's just an acknowledged thing between us that yeah it's shit sometimes. But, that's okay ... So yeah it's not going to make it any easier, so I think it's just being very practical, not that wild idea of what life is going to be like.

Hannah's summation of her marital relationship encoded a cluster of attitudes and perspectives verbalised by other participants: a pragmatism shaped by the exigencies of daily life with a child with a disability; a determination to extract meaning, hope and optimism for a better future, in the face of considerable personal hardships; a resolve to grasp moments to sustain the 'connection' with her partner; and a tacit belief in the resilience of her relationship because of the robustness of their shared values. The emphasis on sustaining the marriage can also be interpreted as the participant's desire to maintain this particular index of normative social and cultural paradigms, and hegemonic maternity.

The positioning of husbands/partners on participants' community maps, and the way participants reflected on the quality and texture of their marriages or partnerships, points to the enduring significance of intimate familial connections, as well as the flexible ways through which they construct meaning from these. Some of the challenges that participants faced in defining and describing their relationships with their partners epitomised the ongoing tensions they confront, individually and collectively, in living their lives within a context of normative gender definitions, characteristic of hegemonic maternity, and assumptions of individualisation. Participants identified the range of stresses that having a child with a disability placed on their partnerships, yet many also constructed visions of hope that the demands of caring for their children may attenuate over time, potentially enabling a greater focus on their marital relationship, and thereby maintaining a sense of 'belonging' within normative frameworks of marriage and family life.

## **Friends**

The mapping activity revealed that friendship can be significant to a participant, not necessarily because the friend was in regular contact or close physical proximity, but because the participant believed that if they needed someone to turn to, then this friend would be empathic and listen to them without judgement. Fifteen of the 18 participants positioned a female friend within either the first or second-tier circles of their maps, citing the qualities of being a good listener, non-judgemental, emotionally available, empathic, and trustworthy. The decision to include a particular friend on the map was based on the participants' perception that this friend met these criteria. Thus, rather than placing prior importance on factors such as regular contact (or lack thereof) to determine a friend's position on the map, most participants invoked the yardstick of *perceived* support as the critical factor. This support may include practical, logistical support, but most often referred to emotional support. What mattered to a majority of participants was their *perception* of the quality, depth and emotional safety of the relationship.

Jill, however, was one participant whose best friend, Tess, exemplified not only the emotional dimensions of support, but also the more practical dimensions. Jill asserted that her relationship with Tess was as important to her as her relationship with her husband: "when it comes to support outside the house, she's been my rock. Absolutely. And I often think would I have made it without her? How much do I owe Tess? I don't know." Jill

describes Tess' involvement in a court case Tania initiated, and said that she nominated Tess as her support person in court: "I went through that with Tess, not [my husband], I did that with my best friend." Jill highlights the connection she has with Tess through recounting her experience in court:

I knew her well enough to know that she was happy with what I'd said or steam was coming out her ears ... you could just hear it in her breathing or whatever. So then I would back-track or change the subject or whatever and I could feel her breathing change – she was sitting right next to me – I could feel the heat coming out of her ears ...

Jill's friendship with Tess as she described it during the interview, and also through her positioning of Tess in the centre of her community map, stood out as an exemplar of the most practical and intimate of all the participants' friendships.

When participants spoke about the female friend or the friends they listed in the first and second-tier circles of their maps, they tended not to recall instances of practical support or advice. Instead, they declared that this friend *would be there* for them if they ever needed them. While the friends they included on their maps offered a form of refuge and sanctuary from the demands of their role as mothers, and a receptive, empathic other, these friends rarely engaged in any type of care related to the participants' child/children. As Tania described it, "they prop me up when I need it." Of her friend, Charlotte said: "she's always there to listen to me when I've got problems ... and she's another person I can always rely on to help me when the going gets tough ... they're not friends of my husband and I – they're my friends that I can talk to."

While participants emphasised the importance of the perception that their friends are there for them, some admitted that they do not actually call on these friends in times of need: instead, they derived comfort from the knowledge that the friend would always be available, should they need them. As Tania said of her two best female friends: "I just have to get on the phone and they'll be there", but then qualified this by observing that:

I don't actually go to them – I know that they'd be there for me if I needed them, but I don't go to them. I don't go to anyone, actually. But if I need time out and I need to have dinner and a glass of wine and sit

down with them, they're the ones I go to. So we catch up for lunch and they're my 'normal' side.

For Tania, these friendships and the perception of their presence offered her a context beyond that of her role as a mother of a child with a disability. Like Tania, many participants' placed great value on the knowledge that they could, if need be, depend on their close friendships. Despite the significance of these friendships in the minds of participants, however, most concluded that nobody apart from other parents of children with disabilities could really know or understand the realities of their lives.

While 15 of the 18 participants positioned a female friend within the first two tier circles on their map, most described a change in the value they placed on their friendships after having a child with a disability. For example, Katherine described feeling "really, really, really upset with my friends" because they did not visit her and her son in hospital after he was admitted when he was first born. Katherine said she never felt as disappointed as she did with her friends' absence and lack of moral support during that period. Kelly also noted a change in her friendships after having a child with a disability:

I think some of my friendships could be a lot stronger if I had the energy and I wasn't so stressed out so I could put more effort into them. And I think some of my friendships have gone by the way-side as a result of that. I think people might've perceived that I didn't care for them, or they might perceive that I didn't value their friendship as much as I do, but it was just a result of it.

There were a small number of friendships that did not change after participants had their child with a disability. Such friends were often people participants had known for decades, and whose friendship was not affected by the frequency through which they were able to see or speak to each other. Adriana's 35-year friendship with Beth was an example of this: "[she] just knows me at that level", and "it's just an unbreakable bond. It doesn't matter where she is – she's lived in the UK, and LA and stuff and it doesn't matter where she lives, she's always there for me."

As mentioned earlier, the feeling of not being judged by a friend was a key indicator in a participant's decision about whether or not to include someone on their personal maps.

Kelly who has an eight-year-old with autism reflected on her sister's response to her child's behaviour prior to his diagnosis. Kelly felt as though her sister placed the blame for her child's behaviour on her parenting, demonstrated when her sister said she "just needed to be tougher on him". This feeling of being judged led Kelly to say "hence why she's [her sister] not anywhere on here [the community map]".

Kelly later recounted an incident with her son when she was trying to move him from his stroller into the car seat. He was screaming and throwing himself onto the ground: "I was just an absolute mess, I was bawling. I just thought 'I can't deal with this child' and that's how I felt, I just wanted to get in [the car], leave him there and drive." She arrived home and rang her friend Kendall. When Kelly had confided in her friend about this incident, "she didn't judge me for it ... she just listened to me, which I think is amazing." Kelly reached out to her friend and was met with a response that provided her with comfort, a sense of value and support, rather than a response of judgement, which participants often felt they were subjected to. Kelly placed Kendall in the second tier of her map, representing the significance of this non-judgemental friend.

### **"Special Needs Mums"**

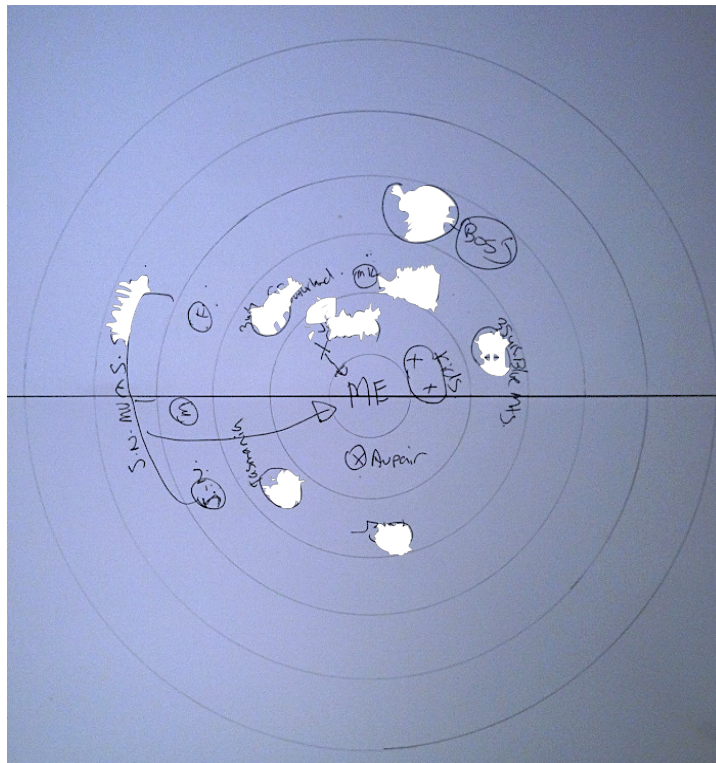
The support and affirmation derived from relationships with other mothers of children with disabilities figured prominently for many participants. Many placed such friends on their maps, or identified groups or mothers' groups specifically for those who also had children with disabilities. The Internet and social media platforms such as Facebook played an important role in establishing and sustaining connections with others who had shared experiences, providing participants with a crucial, albeit often virtual context to share experiences, seek and offer support, and garner a sense of mutual understanding.

Shared experience with other women who have children with disabilities was regarded as a powerful conduit for friendships. Participants spoke of the reciprocal nature of these friendships which enabled them to share their anxieties, needs, and tips for dealing with their children's disabilities and the complex disability system. For example, Katherine observed: "Her child goes to the same school as mine ... but we can go and not see each other and not see each other ... but we're the most amazing - I think we really help each other a lot." Adriana said of her friend: "she's actually my special needs friend ... she's very

sensitive and she cares about me, she's always checking on me ... so I really adore her. And I give back to her too and we help each other in lots of ways."

Adriana placed the label for ‘Special Needs Mums’ (represented by ‘S.N. Mums’ in the fourth-tier of her personal community map). Below is a reproduction of her map, with identifying names removed.

### Figure 3: Adriana's Personal Community Map



The arrow represented how these friendships shifted over time, ebbed and flowed, becoming closer or more distant. Adriana met the ‘Special Needs Mums’ through her child’s special needs school, and came to socialise with them through attending various therapies together: “we kind of share the trench warfare.” She articulated a sense of solidarity because these women shared a first-hand understanding of the behaviours of their children, which meant that they could each relax at social gatherings together: “because we’re all special needs mums they can bring their kids in all their autistic splendour and everyone’s cool about it. It’s no worries, and we relax ...” Letting down her guard, not having to be vigilant about ‘displays’, stigma, or negative judgements afforded Adriana a refreshingly affirming social context:



these women are my – they're the gold in the rough. They're my silver lining. They're the women that I just think – wow they're terrific. And I've never met a special needs mum who hasn't been amazing, but these particular women are just incredible.

Participants also drew support from and developed friendships with other mothers of children with disabilities in more formally structured ways. For example, Jacinta was part of an organisation advocating for appropriate housing to be provided for people who are intellectually disabled. She began the organisation with a group of 20 other families who had children with intellectual disabilities. The families originally knew each other through a carer's group, and then through respite and schooling services that they all used. Jacinta had spent over 10 years advocating with the government alongside these other families, and placed them in the second-tier of her map after her immediate family. However, in the first-tier of her community map, she listed three women who were involved in the disability community to whom she felt particularly close: "they're the ones who, when something goes wrong say with [the organisation] or disability in general, I ring them up and have a whinge and I know they know exactly what it's like, and they can do the same with me."

In the third-tier of her map Jacinta placed the general category of other families who have children with the specific type of intellectual disability that her son has, and emphasised that these families exist across the globe. She is able to keep in contact with these families through using Facebook, and said that the support group of other families who have children with the same intellectual disability has been:

incredibly supportive. We help each other with medical issues that come up, behavioural issues – there's always somebody. And now that we've got Facebook it's just wonderful. And then you get a dozen answers and you think oh ok I'm not alone. So they're really important but it's not only in Australia – it's over the world now. They're really the people I deal with.

Jacinta's experience highlights the importance of social media in providing a vehicle for participants to connect with others who share similar experiences. This source of

connectedness militates against isolation, and allowed participants to instantly interact. Hannah also recognised the importance of her membership of a Facebook group for mothers who have children with the same disability as her daughter. She placed the online group on the outer tier of her map, but placed the individual names of other mothers from the online group in the two outer tiers. She described the relationship with one of these mothers:

I've only met her once but I talk online with her. She's kind of crazy like me and has an unhealthy addiction to caffeine ... I know I can always get online and go bla bla this sort of thing, and it's this strange thing with Facebook, you have these new relationships where you just put a photo up and they say a nice thing about your kid and you'll say 'bla bla did this' and she's like 'oh really' and so those nice sort of conversations happen. And it's kind of nice because we sort of escape our own lives by delving into each other's lives and going 'oh that looks really nice' so she's that emotional sort of, yeah, response.

Hannah also identified another two women who live overseas but are part of the Facebook group and have children with the same disability as her daughter: "they're my all hours of the day contact. If I need – not so much support for [my child's disability], but just that 'life's crap' or 'this is happening' or 'this is really nice' – like she's got a retriever so we talk about our dogs and stuff like this ..." Therefore, Hannah's experience reinforces the benefits of social media for participants in offering the potential to develop friendships and engage in conversations that do not necessarily involve or revolve around children or disability.

Similarly, Sheryl spoke positively about the role of social media in her life as an additional source of support. She would meet with her mothers' group (who all have children with disabilities) once a fortnight in a structured sense, and then on other occasions: "We understand each other more than anyone else understands. No one else gets it. In fact, we get really upset if anybody brings along someone who doesn't have a special needs child." In their private Facebook group they can talk on a daily basis about their problems: "well if someone's having a bad day ... like I wrote on there about 6 months ago 'I fucking hate autism' and then you just get this whole stream of everyone agreeing with you and relates."

These examples demonstrate the ways participants are able to challenge some of the constraints of hegemonic maternity through building and drawing on friendships with other mothers of children with disabilities, often in private online spaces. Such support networks can be understood as both a consequence of, and a challenge to, assumptions of individualisation: a consequence in that through building these friendships participants exerted a degree of agency and autonomy in seeking out support from those who have similar experiences; and a challenge in that personal ties and communities are clearly still pivotal and do not necessarily lack commitment or solidarity. Individuals have not become atomised beings within a society where kinship networks cease to exist. These findings support those from Spencer and Pahl (2006), and Wilkinson (2010), who argue that while individualisation may allow for greater choice in relationships for some, it does not consequently weaken the quality, commitment, or solidarity within such relationships.

### **Others Who Value Their Child**

For a number of participants, it was the relationship that an individual had with the participant's child that was a critical factor in whether a person would feature on their map, and where they would be positioned. In evaluating how others treated their children and therefore how close they felt to this person, participants exercised a level of freedom of choice in determining their personal ties. At the same time, it is also important to note that while individual choice can be seen to be operating here, participants assessed the value of these personal ties not necessarily on the quality of the *participant's* relationship with the person, but on the value that the person places on the participant's *child*. While participants may be *choosing* to emphasise the closeness of some of their relationships, the criterion they employ links back to demands of hegemonic maternity. They see their primary responsibility and obligation as the care-work involved in raising and attending to the needs of their child. Therefore, while participants may have been demonstrating agency and a level of flexibility in determining what value they placed on a relationship, these decisions were still framed around their children.

There are numerous examples of the ways participants emphasised the importance of relationships based on that individual's relationship to the participant's child. Kelly placed a speech therapist in the second-tier of her circle, along with her mother and two close friends. She said of the speech therapist "she's got the professional hat but she, you know

that she actually cares about your child and that's an enormous thing." Similarly, Nancy whose child is autistic, positioned a friend, Kerry, in the second-tier of her circle along with a church friend and her mother. Nancy said of Kerry: "... she loves [my son with a disability], so I feel acceptance there. In fact, she overboard loves [my son with a disability], so that's really good ... she values my son, so that means a lot to me." Sally explained that part of the reason why the friends she had positioned on her map were so important to her was because "they are always there – whenever you need, they always ring me when I'm in Sydney wanting to know how he's [her son] going."

Jocelyn, whose two children are on the autistic spectrum, talked about the importance of people making an extra effort to acknowledge or try to connect with her six-year-old child who is non-verbal. She spoke about the importance of some of her family trying to learn sign language so they could communicate with her son: "so they're the people who, I guess feel more valuable to me."

The relational dimensions of these friendships and other personal ties are strongly directed by the needs and interests of their child. The evidence from participants' personal community maps thus reinforces the pervasive influence of hegemonic maternity on their choices and the nature of their relational networks.

## **Absences**

As discussed in earlier chapters of this thesis, one of the commonly reported consequences of having a child with a disability is an altered social reality whereby participants often felt a lack of support from, and connection to, others; social isolation; stigma; difference; and marginalisation. According to Tania, "having a child with a disability completely annihilates your social life." For Tania, the responsibilities that come with mothering a child with a disability constrained her capacity to develop and maintain friendships and other relationships. This "annihilation of social life" suggests that individuals do not always have the freedom of choice in determining their personal communities and personal life, as individualisation theory would claim. Many participants desperately wanted and needed the support, or at least the offer of support, from people in their personal lives. Yet, so often they were left feeling disappointed and isolated. This finding challenges the claims of those such as Giddens (1991) who has argued that individualisation leads to greater opportunity and freedom in structuring an

individual's support networks. Instead, aspects of evidence from the participants in this study tend to lend weight to the views of theorists such as Bauman (2003) who argue that individualisation leads to isolation.

When constructing their personal community maps, many participants reflected on the ways in which the number and nature of their personal relationships changed after having their child with a disability. These participants lamented a lack of support from both their family and friends. Jill reflected that "we lost friends because I was so tied up with my daughter ... nobody from my family came and helped me ever, ever." Similarly, in response to the question "what support did you have in those early years [after diagnosis]?" Sheryl responded with "nothing".

The process of constructing and reflecting on the personal community maps prompted much of this discussion around the lack of support felt in participants' personal lives. Katherine articulated the clearest example of the ways in which personal community maps can render visible a participant's experience of personal support, and the subsequent finding that participants lack appropriate social support and connection. When we began with a blank personal community map, Katherine said: "I find it really hard thinking about this ... so what do I do?" After explaining the activity to her again, she held the pen in her hand and pointed to different areas on the map, talking about where she would place respite workers, her son's speech therapist, and her parents. Katherine hadn't actually written anything down yet so I prompted her by saying: "who would be in the inner circle?" and she continued to struggle with how to configure her map and what to write. She eventually said: "the truth is, I don't really think there's anyone." The process of completing the community map encouraged participants to reflect on who the important people in their lives were and why, and where they receive support. For some, like Katherine, it was a confronting process since it brought into sharp focus their feelings and experiences of isolation and aloneness.

### **Relationships with Parents**

While participants communicated about feelings of isolation, a lack of support, and a narrowing of personal ties and relationships, they also emphasised the importance of those relationships that had endured. For at least 10 participants, their relationships with their own parents, particularly their mothers, were extremely significant to them. This

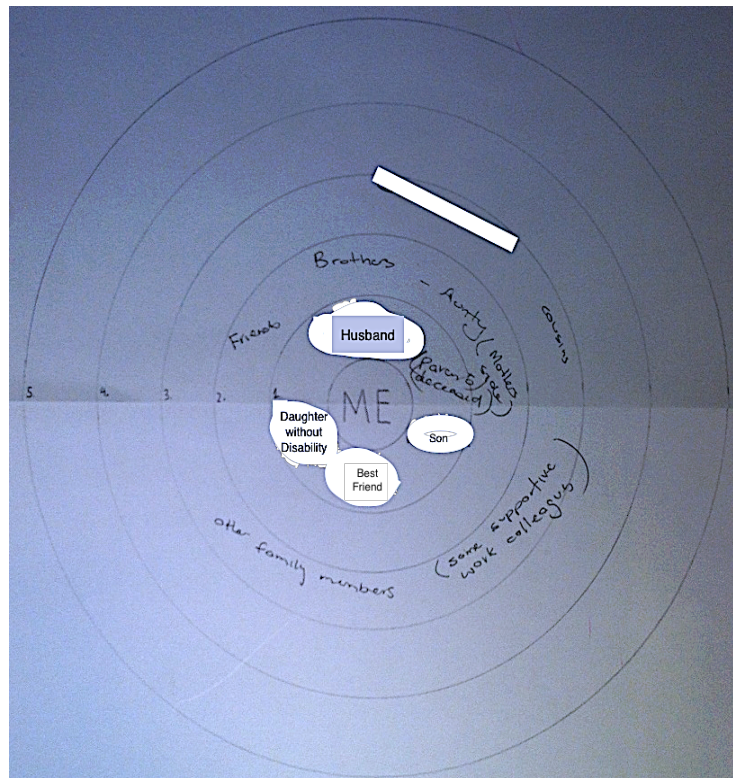
significance was explained in terms of either the practical and physical day-to-day support parents offer in helping with caring for the child with a disability, and/or because of the emotional support participants received from their parents. For example, Tania's mother was the only person she could rely on for practical support and everyday help with her children: "if anything happened to Mum, I would be stuffed, very much so." Sheryl described her relationship with her parents as "brilliant" but she did not receive the day-to-day physical support from them because they lived so far away. Yet she said: "I talk to them every day. I was on the phone crying to Mum yesterday actually", and she positioned her parents on the two closest circles on her map – prioritising them over her husband.

Veronica, whose two children are on the autism spectrum, described her relationship with her parents as: "... really, really close ... extremely supportive. If it wasn't for them I don't know where I'd be ... the support has been my Mum, it hasn't been professional." Jocelyn's Mum too provided practical support: "my Mum's always been very supportive, she'll babysit if I ever need anything, if I want to do a course she'll take them, yeah she's great." Hannah said that both of her parents "are very close to me and give me a lot of support". She recalled her Mum's response when she was having difficulties breastfeeding:

I still remember my Mum coming down late at night, going to the chemist which was open late at night, getting a breast pump and sitting there with me trying to work out how the hell to use this bloody breast pump because she was saying 'ours was so much simpler back when we had them and everything.' So starting from day dot, even if I wasn't asking her questions she was just there. She didn't want to be that pushy mum or anything, she was just there.

Forms of parental support can be significant even when a participant's parent/s are no longer alive. Jill's mother died from ovarian cancer, then 10 weeks later her father died from prostate cancer. Just seven weeks later she gave birth to twins – one of whom is her child with a disability. Jill described the incredible connection she had with both of her parents, and thought: "I'd never survive without my parents – never, never, never." This deep relationship endured for Jill, even after their deaths: she placed them in the centre of her personal community map along with her husband, best friend, and her children without a disability. Jill's map is reproduced below with identifying names removed.

**Figure 4: Jill's Personal Community Map**



Jill reflected that after her parents died “I knew that they expected me to be a strong person, and I guess I drew on that. I felt like I was on my own ... I had two children and a son – three kids – I had to keep going. And I did.” Jill often referred to her parents throughout the interview, and considered her relationship with them as a foundational and durable source of strength, enabling her to continue mothering and caring for her family with resilience and hope:

I think that for me to survive 16 years without Mum and Dad and still be standing, still talking and still be happy ... I miss my Mum and Dad like nothing on earth, every day I miss my parents ... but I just thank them for giving me such good grounding, whatever they did with me they did the right thing. But if you’d told me when they were alive that I would be this capable and this strong and be able to manage other people’s lives I would’ve just gone ‘you have got to be kidding’...

## Summary

This chapter, together with the previous chapter, has presented evidence of the importance of relationality in understanding participants' experiences of their personal networks. When interpreting participants' reflections on their relationships, it was apparent that their experiences were framed by the pervasive assumptions of individualisation. Therefore, not only did participants seek to navigate the obligations of hegemonic maternity within their relationships, but they also conducted these relationships within social contexts that assumed individuals enjoy agency and choice in establishing and maintaining their relationships.

The findings here both challenge and somewhat support Bauman's (2003) contention that individualisation will lead to a fragmenting of social ties: participants did indeed experience a fragmenting of social ties and consequent isolation in various forms, but each also expressed how their relationships were continually significant. This latter finding supports Spencer and Pahl's (2006) argument that despite individualisation, individuals continue to enjoy close personal ties and communities.

The findings here also challenge Giddens' (1991) assertion that individualisation leads to greater freedom in structuring personal networks. Participants live within a social context that assumes they enjoy choice and agency in their lives and relationships, yet there is compelling evidence that for participants in this study, the concept of freedom of choice was heavily circumscribed. This is not to deny that participants still attempt to exert a sense of agency and choice in their lives and relationships, and this is demonstrated through the nature of some of their friendships. However, the finding that expectations of individualisation continue to frame their lives, while also failing to adequately capture their experiences, resonate with Landsman's (1998) view that "[w]hile the concept of choice fits comfortably within a consumer culture, it may have an uneasy place among those who have come to love, nurture, and attribute personhood to the very children whose value a consumer culture diminishes" (p. 95).





## CHAPTER TEN

### The Subjectivities of Women who Mother Children with Disabilities

*"... the ultimate explanation for the difficulties of becoming a mother, I believe, is very deep-seated: in Western civilisation there has been a widespread tendency to understand the maternal body and the self in opposition to one another"*  
(Stone, 2012, p. 294).

*"critics of autonomous self-centered subjectivity who are interested in presenting a notion of subjectivity that is more permeable and whose borders are less substantively and statically defined, have, for the most part, proceeded with a strange absence of reference to ... maternity"*  
(Jones, 2013, p. 294).



#### Introduction

The purpose of this chapter is to address the third and final subsidiary question of this study: How do participants understand and express their sense of 'self'?

In presenting and interpreting the data pertaining to this question, it is appropriate to summarise the key assumptions, theories, and definition of the self, which were discussed in Chapters Two and Three and have informed the analysis of data to date.

The terms 'self' and 'subjectivities' were preferred over 'identity'. While the term 'identity' is taken to signify a fixed entity, with connotations of continuity, essentialism and unity, the terms 'self' and 'subjectivities' refer to an ongoing process of self-formation that is fluid, contingent, multi-faceted, non-linear and relational. Subjectivities and the making of subject positions stresses the ways the self is *constructed* rather than *static*: such a view recognises the social construction of 'motherhood'; the relational nature of participants' relationships; and the importance of social interactions and intersubjectivity to the construction of self. As May describes it, the individual is constructed "*in relationships* with

others, and *in relation* to others and to social norms” (May, 2011, p. 5, in Roseneil & Ketokivi, 2015, p. 3).

In the previous two chapters, I provided evidence of the extent to which participants’ interactions with others shaped their perspectives on and experiences of relationships, exposing the challenges mothers can face in defining their sense of self against the norms and expectations of individualisation. While individualisation assumes choice, hegemonic maternity assumes obligation. Individuals in contemporary social life are pressured to become rational, individualised actors who exercise agency and freedom of choice based on the deep-rooted expectation that in order for individuals to become autonomous agents, they must break away from their ‘mother’ (Stone, 2012, p. 294). Stone found that often, “mothers feel that they have fallen into a formless realm that excludes meaning and agency: the agency to organise one’s own life and to organise one’s own experience into meaningful patterns” (p. 294). This is particularly acute for mothers of children with disabilities whose mothering obligations persist well beyond the expected chronology of intense parenting.

In presenting data and analysing participants’ reflections on their sense of self, gleaned through the interviews, this chapter extends a focus on the tensions between hegemonic maternity and individualisation, and the implications for mothers of children with disabilities. The data presented here draws on aspects of the theories of the self offered by Mead (1932), Goffman (1959), and Chodorow (1981), and on Juhasz’s (2003) and Stone’s (2012) work on maternal subjectivities.

The structure of this chapter differs from the structure of the previous data chapters which were organised thematically. The thematic structure enabled the first two subsidiary research questions to be appropriately addressed in order to attend to commonalities, patterns, and differences in the data. Since this chapter is concerned with individual participants’ stories of self, the data is organised in terms of each individual’s responses, reflecting the desire to represent each in a holistic manner. Participants’ stories are loosely ordered according to those who identified most strongly with *multiple* subjectivities, to those who predominantly identified as ‘mother-subjects’ and expressed considerable ambivalence or uncertainty when reflecting on their sense of self.

***Adriana – “And then there’s my ‘me’ self – my private self”***

Adriana reflected deeply on how she sees herself as an individual, and how her sense of ‘self’ relates to her position as a mother. She stressed the important role that her paid-work position played in her life, and in her sense of who she is: “I’m a worker, I like it. Some people are natural mothers and they stay home all day and they love it and that’s fine, but I’m not her.” Here Adriana references essentialised understandings of mothering as something women ‘naturally’ embody, and her understanding of a ‘natural mother’ is someone who ‘stays at home all day’ and ‘loves it’. Adriana recognised, understood, and accepted this concept of mother, but defined herself in contradistinction to this:

I mean my kids are of my body so of course my motherhood is an integral part of my persona. But I don’t identify myself as a mother. It’s one of my aspects – but it’s not my all. Some ... I know there are lots of women out there who identify themselves as mothers first and then other things after that. But I’d rather see myself in more of a multifaceted way. Depending on who I’m with depends on what side of me comes out. I think my core demeanour is ... I’m the sales manager, I’m a people person, so I really like people, so depending on who I’m talking to they’ll probably all describe me in similar terms whether they know me as a mother, a colleague, a friend, an associate, or whatever. So I’d like to think there are a couple of aspects of my personality that are consistent with all of my faces, if you like. So I wouldn’t identify myself as a mother. I don’t pigeonhole myself in any one way. There are people in my professional life that see me as fairly business like and direct, but that’s just a necessary attribute of that job, but it comes from a humane – hopefully – starting point.

The ‘multifaceted way’ in which Adriana characterised herself is a clear demonstration of the ‘multiplicity’ of subjectivities that participants can occupy: mother; paid-worker/professional; and friend. This multiplicity of subjectivities – drawing from a relational understanding of the ‘self’ – supports Juhasz’s (2003) argument that the “multiplicity that defines and organises maternal subjectivity is composed of a series of relational positions ... a mother-who-is-a-woman in relation to the social world, where she functions as a lover, worker, political being” (p. 400).

Adriana drew on her subject position as paid worker to orient, position, reinforce, and 'author' her subjectivity. While she did not reject her position of mother, she attempted to uncouple her subjectivity from her maternity, saying she would "rather see [herself] in more of a multifaceted way", than identify herself solely as mother.

After thinking a little while longer, Adriana added:

The more I think about it, there's probably three key personae if you like. There's my 'mother' - good, my family self. There's my business self. And then there's my 'me' self - my private self. I like to go to the gym, because that's what I do for myself, that's what I do for my body and health - mental and physical self. And also trying to hold back the years! I'm 45 this year so I'm kind of trying to stay young and fit, and I'm like a 45-year-old paranoid woman. A lot of women my age get freaked out about their age like 'oh crap I'm not 20 anymore - I'm not young and funky and cool and hip and with it! I just see myself at your age - I think oh wah I'm getting old'. So to some degree that's my panic about trying to stay young, so I do that at the gym. But I also quite like - I really like being by myself. Because I've got these other very social, busy aspects to my life, I really need that alone time.

Adriana's observation that there are 3 key personae constituting her sense of self - her 'mother' self, her 'business' self and her 'me' self - is a clear example of Goffman's (1967) theory. In a similar way to Mead, Goffman understands the importance of social interactions when conceptualising the self, but he emphasises the *performative* nature of individuals in the construction of who they are: "[d]uring interaction the individual is expected to possess certain attributes, capacities, and information which, taken together, fit together into a self that is at once coherently unified and appropriate for the occasion" (1967, p. 105).

Adriana recognised that there are subject positions she occupies that are performance-based, and which draw on varying social circumstances and relationships. Yet, she identified one aspect of herself as her 'me' self - her 'private self'. Her 'private self' is

defined in contrast to her 'mother' and 'worker' self, and this signals a refocusing on her individuality. She 'likes' being by herself, and has a 'need' for 'that alone time.'

However, Adriana framed this reflection on her 'private self' through a focus on and critique of her physical appearance, and her attempts to "hold back the years." This comment, coupled with her statement that "a lot of women my age get freaked out about their age like 'oh crap I'm not 20 anymore'" is reflective of the troubling perpetuation of gendered and sexist expectations of what the female body should look like, and how women should behave. Therefore, while Adriana's assertion of her 'private self' can be understood as evidence of her agency and autonomy, this autonomy is still framed by constraining and restrictive assumptions that she has internalised because of her subject position as a woman.

***Sheryl – "... we've got a special needs child who really doesn't let us have a proper marriage"***

Sheryl also defined her sense of self as an individual through other subject positions besides that of 'mother'. While Adriana positioned herself firmly as a 'worker-subject', Sheryl strongly embraced the subject position of 'friend', with her social life and friendships affording her a multiplicity of subjectivities. Sheryl's friendships became an avenue for reorienting and contributing to a sense of self: "I think most of my friends don't even think of me as a mother," illuminating the ways through which others' interpretations of the self shape an individual's understandings of who they are. Through her friendships, Sheryl was able to assert her individuality and enjoy a context that was materially and psychologically distinct from her subject position as a mother – and all of the responsibilities and obligations associated with this subject position.

Sheryl reflected on how she thought those with whom she worked perceived her:

... everyone at work knows I have a child with a disability because I'm always raising money, raising awareness, raising funds, organising events, organising charity things, selling entertainment books, whatever. They all link me to that. But it's more of a money raising thing rather than who I am. But who I am is probably more of that person anyways –

I used to be a sales rep so I love all promotions and organising events ...  
so it fits in.

She deployed ideas of how others perceive her in order to articulate and affirm her sense of self. She found difficulty in situating herself within the subject position of 'mother of a child with a disability', while also within the subject position as "someone who is a sales rep and good at fundraising." She attempted to unite these two subject positions as a means of creating a coherent narrative of the self. The challenge Sheryl experienced is reflective of Stone's (2012) observation that women who are mothers can sometimes "experience difficulty giving meaning to the flow of their experience" (p. 294). This is particularly the case for participants if they draw on various subject positions besides that of 'mother', as these multiple subject positions may not always neatly cohere and harmonise. Often, these multiple subject positions may not sit easily together because the tension being played out between individualisation (assuming agency and autonomy) and hegemonic maternity (assuming self-sacrifice and obligation). This goes some way to explaining why participants who embody multiple subject positions may negotiate tension, conflict and/or ambivalence.

***Jill – "I needed to be something else besides Cindy's mum"***

Jill also strongly aligned herself with her subject position as 'worker' to both reassert some sense of agency, and to enable her to experience a multiplicity of subjectivities besides that of 'mother'. Jill identified a specific period of time in her life that has been foundational in shaping who she now. This period was when she was pregnant with her twins in the month of February: her mother died in May, and then her father died in July. Seven weeks later she gave birth to her twins. This intense period of grief and upheaval was then followed by a six-year search for a diagnosis for her daughter with a disability. The initial period of her twins' infancy and her parents' deaths became a reference point for Jill when reflecting on her sense of self:

... my change has occurred because of the death of my parents, and then the loss of a twin, so to speak ... like when I found out I was having twins, as sad as I was because mum and dad were dying, I was kind of excited and when I had them it was ok, it was good. But I still hadn't

mourned the death of my parents and then I was finding out that one of my children had big issues ...

When the girls turned three and they started going to preschool two days a week, I was hopeless. All of a sudden I had to find something to do, because I was lonely. And that's when I went back to uni ... Before I went back to uni I went to a counsellor because I felt like once the girls started to become more independent – when they started walking and when they could just sit there and play and you didn't have to sit there and feed them, they're feeding themselves... That little bit of time you have on your hands gives you time to think. And they go to bed, they sleep a bit better at lunchtime, you know what I mean? And I started to feel a little bit lost, and that sounds weird when you've got three children all at home, but I just felt like the walls were closing in. So I went and sought counselling myself, and it was good for me, but I've never sat down and bawled and bawled – I can't because if I did then I don't think I'd stop. I don't allow myself to be sad, I don't allow myself to go there, because I think it'd just be too hard to come back.

The way Jill managed her grief over her parents' deaths, and her child's diagnosis, clearly influenced how she constructed her sense of self. Her description of feeling consumed by occupying the subject position of mother, the feeling of being 'lost' when this changed or was disrupted, is a result of the way maternity and agency are positioned in opposition to each other.

The maternal subject position is not adequately recognised as a position of autonomous subjectivity: Jill's experience in caring for her children and then feeling a loss of 'self' once they began gaining some sort of independence is reflective of Juhasz's (2003) analysis that mothers can often experience "the contradictory and usually complementary feelings that the baby is (1) yourself and (2) something causing you to lose yourself" (p. 403).

The way that Jill managed these challenges to the self within her subject position of mother was to adopt a multiplicity of subject positions – particularly through her position as a student and a paid worker:

When I discovered going to uni, it gave me this sense of ... that was my treat and it was a massive treat. Getting a better education. So I've done an undergrad and I've done a masters and now I'm doing a PhD you know. And when I go to work I am somebody completely different to what I am at home, I try not to mix the two. I love what I do – love what I do! Don't know if that's because it's what gets me out of here? Don't know, couldn't tell you. But I have two different personalities.

Drawing on Mead's (1932) theory of self, Jill's sense of self was shaped by her 'me' role as a worker and student, according to the various contexts she finds herself within. Goffman's (1959) understanding of self is instantiated in Jill's experience, where her performance of 'self' was starkly different according different audiences and contexts. She went so far as to describe herself as having 'two different personalities', with the shift in physical context functioning as an important indicator of a change in subject position:

But being an academic and doing what I do, that's I think why I'm stalling so much, it's fantastic. It fits my lifestyle. It gives me the ability to be Jill over there and a mum here. I can be two different people. And I am, I'm definitely two different people. I drop Cindy off and I drive straight to work and the minute I get to work I don't give another thought about anything ... I don't know who I'd be or what I'd be if I didn't make that decision to go to uni.

This multiplicity of subjectivities was such that Jill deliberately demarcated each one, underlining Stone's (2012, p. 293) understanding of maternal subjectivity, where mothers cannot easily recognise themselves as unified agents. Rather, there is the assumption that "one must leave the maternal body behind to become an autonomous individual subject, a self-conscious and autonomous agent who is the source of normative authority and meaning" (Stone, 2012, p. 395). While Jill did not explicitly indicate a need to leave the maternal 'body' behind, she did indicate a clear need to leave her maternal subject position behind in order to fully occupy this realm of the autonomous, individual worker and student. Therefore, Jill's maternal subject position was somewhat fraught because of her difficulty in her apprehending a means for this subject position to harmoniously exist alongside her other subject positions:



But I needed a purpose, I needed to be something else besides Cindy's mum. Because that's what I felt like I was ... I felt like I needed to get my own identity otherwise I'd be just consumed by being her mum. I needed an outlet, and I thought well who's going to abuse me for going and getting an education and studying?

This reflection in some ways represents a choice to distance herself from the lone subject position of mother in order to establish and assert her subjectivity in other domains. If she did not do this in some way, Jill believed she would find it extremely difficult to sustain her maternal subjectivity. As Stone (2012) argues, our society fails to legitimise and recognise maternal subjectivity. This failure is linked to the way in which individualisation frames understandings of selfhood and agency, compared with the continual power of hegemonic maternity in perpetuating expectations of self-sacrifice and obligation.

Jill's choice to occupy the subject position of student is reflective of a relational understanding of the self – where the self is not regarded as homogeneous and therefore cannot speak in a single voice. Jill occupied these various subject positions: "I mean I wear different hats", but then reflected, "but my kids will tell you no. I'm a mum, they tell me I'm a good mum – they do." This experience chimes with Juhasz's (2003, p. 406) analysis that a

plethora of subject positions can be especially difficult to maintain, because the cultural consensus, usually well internalised by individual women, is that there is only one identity: Mother ... With a definition like that, the very possibility of subjectivity becomes problematic.

Jill verbalised the ways in which occupying a multiplicity of subjectivities as a woman who is a mother can be fraught and complex:

And I get anxious, I get really anxious and I don't know why I'm like that because it doesn't make sense to me ... And I'd hate to think someone would think I wasn't coping with both because then maybe I'd have to give up one. And I couldn't give up being a mother, I'd have to give up work.

Jill's experience is a compelling instance of how the obligation of hegemonic maternity and the expectations of choice and agency can precipitate anxieties about how multiple subject positions relate to each other, and how they can co-exist.

***Kelly – “I don't have the means to let myself just be me”***

Like Adriana, Sheryl, and Jill, Kelly was eager to situate and align herself with subject positions besides that of a mother – mainly through her position as a teacher. For Kelly, her job as a teacher was an important way of claiming a sense of self as a professional with agency and autonomy. This subject position was distinct from her subject position as mother: “I get to be myself, I get to be a teacher, I get to have my friendships with the other staff, and there's a very clear distinction between that and my home life and I think that's been hugely important.”

As Kelly reflected, “I think our experience has just been so full on, that it is really hard to find yourself in it.” This sentiment of feeling a sense of cloudiness or having difficulty in locating a sense of self within the experience of mothering recalls the “formless realm” that Stone (2012, p. 294) refers to. Therefore, occupying subject positions outside that of the mother assumed heightened significance for participants such as Kelly.

Kelly's experience also reflects Goffman's (1959) analysis of the performance of self and the importance of context in this performance: “I think that's why work is so important to me, because I get to be me, and not – it's another reason why I wouldn't have my children go to my school, because I wouldn't want to be perceived as a mum there.”

Bringing these two subject positions together would provoke an eruption of anxiety. The potential collision of these two subject positions is reflective of the lack of a specific maternal subjectivity (Stone, 2012, p. 397). Kelly did work to deliberately maintain a well-defined separation between her subject position of a mother, and that of a paid-worker. Yet, she pondered the ways that her position as a mother and as a teacher inevitably intersect:

Yeah they still intertwine, even in my work ... I still talk to my colleagues about my family, quite a lot, even though a lot of them haven't met Blake

since he was a baby ... They intertwine a bit, but I don't allow it to too much, because I just find that I don't have a – not an escape, escape's the wrong word – I don't have the means to let myself just be me.

This tension created in managing the boundaries between her self as mother and as 'other', is described by Benjamin (in Bassin et al., 1994, p. 15) as evidence of the paradoxes that riddle experiences of motherhood, where motherhood involves managing a sense of self and subjectivity as a complex and conflicted process.

The differing subject positions of the self are part of an oscillating process, reinforcing the individual who is a mother being an intersectional subject, where "structures of domination and subordination but also agency converge" (Willett et al., 2016). Kelly recognised herself as an individualised subject and agent, but was not able to do this through only aligning with her position of mother. She relied on her position as paid-worker and friend – and she connects these back to her family as the primary locus of her subjectivity:

work just helps to keep another part of me that's always been there – more ... like not let it get swallowed up by disability. Because you can feel like your whole life – your family is the most important thing – but there's other parts of me as well, and if I let them get swallowed and chewed up then that's it. And then when you go to relax a bit and get your mind on something else – there isn't anything, you can't.

Her explanation of the strained interdependence of multiple subject positions powerfully reinforces Juhasz's (2003,) view that: "maternal work is about not only caring for the child but also trying to organise or use these many aspects of self in such a way that they seem coherent, viable, or to possess continuity" (p. 406). Therefore, in Kelly's navigation of a multiplicity of selves, she was actually performing part of the maternal 'work' of emotional labour that is required in order to occupy her mothering role in a way that is viable and sustaining.

### ***Jayda – "I am starting to see myself as a professional"***

Jayda's experience of subjectivity largely reflects that of Adriana, Sheryl, Jill, and Kelly. Jayda did not reflect on her sense of self in a sustained way, yet clearly communicated a

shift in her subjectivity from seeing herself solely as a mother-subject in the past, to now a paid-worker subject. She constructed clear connections between these two subject positions.

Jayda worked as a teacher before she had her children, and tried to keep working when her children were young. However, her daughter with a disability needed to be closely cared for, inhibiting Jayda's ability to continue her career in the same way. She instead opted for casual teaching, and then decided to undertake postgraduate studies, which eventually helped prompt her recognition of autism in her daughter. Her studies, and the diagnosis of her daughter, resulted in Jayda eventually starting her own business dedicated to helping other children with disabilities. She said that before she took these steps, she could not separate her sense of self from her subject position of mother: "but now I've stepped up into my own right now as a professional, and I am starting to see myself as a professional."

Jayda also spoke of the enjoyment and a sense of personal fulfilment she once experienced from her hobby of acting when she was younger: "acting was for me. That was a Jayda thing" but now her business is "definitely it [a Jayda thing] ... see [this business] to me is a reflection of my creativity." Jayda clearly sought to construct a meaningful and unified narrative of the self as a creative and self-directed individual by locating continuities in the roles of actor, teacher, business owner, professional and the mother of a child with a disability.

### ***Danielle – "I also have my own life too"***

Danielle's son has Down Syndrome, is in his late 30s, and has gained more independence as he has aged – although he does still require her care. Danielle tried to separate her role as a mother from her sense of self, and referred to her work, family, and sense of humour to situate herself within subject positions outside of that of mother.

I think that's [mothering] a big chunk of your life, but I do try and separate the two. I guess it makes it a little bit more difficult when you've got an adult child with a disability, because now if I get a phone call I'll take it, but I also have my own life too.

Danielle identified her 'own life', in parallel to her role in mothering her son. The disjunction between the two dimensions of her life required continuous a balancing of her own and her son's needs:

I go out, my son doesn't come with me everywhere I go, he will stay at home for a few hours. I couldn't leave him home on the weekend, I wouldn't do that, but I can leave him, and my husband and I will go out for tea on a Friday night. I encourage him to come but he doesn't want to, and I respect that because he likes his time on his own.

In occupying subject positions beyond that of her role as mother, Danielle still embodied understandings perpetuated by hegemonic maternity: that is, the interests of the child come before that of the mother. Danielle found rewards through subject positions other than that of 'mother', not through challenging hegemonic maternity and the connections between maternity and agency, but through having a son who is able to enjoy a level of independence.

#### ***Keira – "... my private, private stuff is here"***

Keira struggled to find meaning in her subject position of paid-worker since it seemed to conflict with her subjectivity as a mother. She sought to articulate the existence of a 'private' self distinctly separate from her role as paid-worker and mother. She described this private self as more solitary and sequestered from her other subject positions.

Keira trained in the disability sector and now teaches, using her expertise and knowledge that she has gained in caring for her daughter and advocating for her needs: "for years I was known as 'Anna's Mum'." Because her life was so defined by her role as a mother caring for her child with a disability, she came to draw on and utilise this knowledge and subject position in an empowering way by transforming dimensions of this position into a career.

In sharp contrast to previously discussed participants' experiences, Keira did not attempt to atomise her subject positions as paid-worker and mother. Instead, she perceived the two as interdependent and continuous. Yet, during the personal community mapping

exercise, Keira said: “my private, private stuff is here” and pointed to the centre of her map, where there was no one else but herself. Keira then pointed to the people on her map who represent her work, and then her daughters: “these two roles [my role as worker and my role as mother] do NOT invade this space [the space for ‘me’ in the centre].”

Stone (2012) argues that women who are mothers must in some way reject or recoil from their role as mothers in order to assert and establish their subjectivity, and if they do not do this then they find it problematic to establish their maternal subjectivity because our society positions maternity in opposition within subjectivity/individuality. Kiera’s experiences exemplify this conflict and her own strategies for challenging normative assumptions.

### ***Katherine – “I cannot believe what I have endured”***

Katherine emphasised the importance of her work as a school music teacher in allowing her to feel as though there is a “me out there.” Katherine’s understanding of her sense of self underwent enormous transformation since the birth of her child with a disability. After her son’s birth she went through an intensive period marked by memories of isolation and grief. As her son grew older and his condition improved – partly due to Katherine’s intensive commitment to his care – she recommenced working as a music teacher three days a week. She was only able to do this with the help of her eldest daughter, and occasionally her husband, in dropping her son at school and picking him up. She emphasised the importance of her paid-work role:

I mean I work three days ... I tried to work four days last year but just couldn’t. I mean last year I got the shingles, I just got so sick – I honestly physically could not manage ... it nearly kills me but it’s my creative outlet. Because I’m a creative person I’ve found it – I have found that I NEED that, I need something creative to be who I am and I lost all of that with [my child with a disability] ... as soon as I went back – when I did the flute – it was like oh wow, this is who I am, this is so instinctive to me, this is me.

This recollection is arresting in its lucid articulation of the significance of subject positions other than that of mother to this participant’s sense of self. Simultaneously though,

Katherine reflected on the profound and irrevocable ways in which being a mother to a child with a disability had changed every aspect of her life:

In many respects, I'm a different person. I don't think I understood ... I've always had a soft side to me but I didn't understand, fully, what it was like to have this situation in your family ... He doesn't fit in my life, I fit around his life.

Therefore, while Katherine inhabited a multiplicity of subjectivities, these subject positions were intricately related, complex, and required continuous negotiation. Her approach to navigating the competing expectations of hegemonic maternity and individualisation relied on philosophical pragmatism, self-awareness, resilience, and the capacity to tolerate internal conflict:

I just see the big picture all the time. One of my friends said to me, and I think this is true, that it exaggerates your emotions – so you feel the true depth of sadness or if you have a really happy moment you can really see it. Like I get the most immense joy out of a little milestone that he may make, but I'm generally walking on eggshells – I'm very fragile, I can burst into tears and I don't see it coming. I'm a changed person. I can be at work having a conversation with someone and they'll say something and it's like ca-chow – stab in my heart ... It could be anything, I could see a beautiful healthy child and ca-chow (cutting noise).

Although she had earlier emphasised the importance of her role as a teacher in shaping her sense of self, in the extract above she provided a poignant example of a key moment of change induced by her subject position as a mother, in the context of her role as a paid worker. In the context of her workplace – a place where she most fully inhabited a sense of self in distinction from her position as a mother – she demonstrated how her subject position as a mother can never be wholly quarantined from other dimensions of her life. The self as teacher and the self as mother, while distinct in Katherine's conceptualisation of self, are in fact mutually contingent and intermingled:

I think I'm strong, I think I'm so strong. I'm fragile all the time. But to do what I've done ... I cannot believe what I have endured. (whispering) It's unbelievable ... I've worked so hard. I've gone through hell.  
(Whispering) I've watched him suffer like you wouldn't believe. So I think I'm so much stronger. I don't look resilient, but seriously (tearful)  
... I don't think anyone knows – even my husband.

Notable here is the framing of her sense of self in terms of binaries – strong/fragile; resilient/vulnerable; and enduring/suffering – exposing the consequences of the competing frameworks of hegemonic maternity and individualisation for a woman's life. As Juhasz (2003, p. 403) explains it, "separation and connection orchestrate the trajectory of motherhood", and for some participants, a sense of "continuity or coherence is an illusion" when trying to find meaning and harmony in their sense of self. Katherine's fragility masks her strength, and her strength masks her fragility. It is within these multi-layered understandings of the self that maternity being positioned in opposition with agency can be challenged. Katherine was reflexive about the impact that becoming a mother to a child with a disability has had on her life, and articulated a deep awareness of both the ensuing constraints on her life, as well as the ways in which these constraints had galvanised her strength and resilience.

### ***Nancy – "I don't know who I am really ... outside of work"***

Nancy's sense of self was predominantly aligned with her position as a paid-worker, however since leaving paid work to care for her son with a disability on a full-time basis, her sense of self had been deeply challenged. Nancy's strategy for reconciling the disparate aspects of self was a reliance on her religious faith.

Nancy and I met in a prayer room at her church, and she brought with her to our interview a box filled with folders of awards, certificates, documents regarding her educational qualifications, letters of appraisal from her previous work places, and snippets of different pieces of her work. Nancy wanted to make sure it was clear to me how highly regarded she was in her profession, the milestones she had accomplished, the educational dreams she had carried since she was a child, and how much she had achieved in her career.



Nancy felt she needed to establish and promote her subject position as a successful professional in order then to highlight the significance of being a mother to a child with a disability on her sense of self: "I brought some stuff just so you could flip and see... you'll see the impact BANG you know ...". Her repeated use of the exclamation 'BANG' within the interview, represented the sudden, unexpected, and dramatic impact that having a child with a disability had on her life and sense of self.

Once Nancy established her subject position as paid-worker, and "career woman", she then discussed the difficulties of inhabiting this subject position while also situating herself within her role as a mother. She described feeling an increasing degree of stress at her last job that also involved travelling: "my health, I was getting older, tired, I was then seeing how I was missing out a lot on [my older child who does not have a disability]" She decided to resign from her position, and shortly after a job became available working for a disability services provider. Nancy took this position and said she was clearly suited to this role, yet: "I could see the wheels starting to fall off at home ... I thought, when I started to grieve more I thought, I'll be sitting on my rocking chair in here and I can pull out any certificate, but I've missed my kids."

Nancy made the decision to withdraw from this other position in paid employment to resume the role as full-time mother, but this decision left Nancy in a state of disorientation and flux. She struggled to reconcile her positions as paid-worker and mother of a child with a disability:

... last year I was trying desperately, and I still am, I'm hoping 2014 will reveal more, because I don't know who I am really ... outside of work. And outside of ... I don't want to be defined as just a carer. Does that make sense? That would horrify me, I don't mind being just a mother. A mother to me is doing stuff for herself, is getting out, being to the gym and then coming home and making a meal and listening to the kids ... I guess I see it more as a softer and rounder approach to a mother ... the future identity of me is that I would like to be more rounded... that it's not just all work or all ... when I say care for Oscar I mean Oscar is full-on and I want it more than that, because for me to keep doing that, I gotta keep doing that in 10 years, 15 years' time. I'm thinking 'oh my goodness I've got to be healthy, I've got to be not bitter, and I've got to

have mental strength. And the only way I'm going to do that is I've got to nurture myself with more friends, I've got to work at learning how to have more friends outside of a workplace, and supports, which we don't have'.

We're in danger zone as we're getting older – Aaron's going to go – so we need more. Because we can't rely on family so we're going to need to have more, I can see that. And just little, it might not be grand things but just little hobbies that I've never done because I've worked – I have to have something, there's only so much changing nappies and cooking meals I can do without having something else. Like I'm not into craft, I'm thinking fishing? Something ... But for me I know it's so important because I won't be a good mother or carer for Oscar if I don't find something in the next 5 years. I'll be okay for the next 3 or 4 but eventually you need something.

In this reflection, Nancy drew on the constructed image and associated discourses of the 'good mother' as a reference point as she sought to situate herself within another subject position. She posed this imagery and subject position of the 'good mother' in opposition to the subject position of 'carer'. In asserting that she does not want to be defined as "just a carer", but does not mind being "just a mother" Nancy interestingly juxtaposed what she perceives as a role (carer) with what she perceives as a subject position (mother). In drawing on the subject position of 'mother', she was searching for a path that would enable her to reconfigure and reassert her subjectivity and 'find herself'.

Yet, somewhat paradoxically, in order to situate herself within the subject position of mother, she felt as though she had to find interests and foster relationships outside of her role as mother. She believed she must do this in order to fully occupy the mother position. So, in a search for subjectivity and agency, Nancy aspired to meet the expectations of the role of the 'good mother', but felt she would only be able to do so by inhabiting additional subject positions outside of the role of mother.

Therefore, Nancy was somewhat cognisant of the illusory nature of good mothering ideology. In order to sustain her role as a mother-subject, she identifies her need to inhabit *other* subject positions, which can be linked with tenets of individualisation, privileging

and encouraging individual agency and autonomy. Nancy's reflections on her sense of self serve to crystallise the tension between hegemonic maternity and individualisation. Or as Juhasz (2003) describes it:

[f]or mothers, largely due to the cultural ideology of motherhood, this plethora of subject positions can be especially difficult to maintain, because the cultural consensus, usually well internalised by individual women, is that there is only one identity: Mother ... With a definition like that, the very possibility of subjectivity becomes problematic (p. 406).

Hegemonic maternity is analogous to an entangling web for participants such as Nancy who struggle to make sense of who they are, and thereby experience considerable inner conflict.

#### ***Charlotte – “You’re almost defined by the disability”***

Charlotte believed that her experience of mothering a child with a disability had not only fundamentally changed who she was as a woman, but it had imperilled her entire sense of self:

I think you change. I think you become – you lose yourself. You’re ... not a slave, but everything you do is for another person, pretty much. You’re cleaning up after people, buying food for people, cooking for people, washing for people. There isn’t much ‘me’ time, especially in the early years ... you learn to juggle lots of balls. You sort of feel like you get defined by it. I was thinking about this yesterday at school – like you sort of get defined by what your kid’s got. You’re almost defined by the disability.

This reflection exposes the intensity of care required in mothering a child with a disability, the nature of the role of primary caregiver for multiple children, and the gendered nature of care-work whereby Charlotte is presumed to take on most of these tasks even though she lives with and is married to the father of her children. Her sense of self was at risk of

being effaced under the weight of normative expectations and the sheer physical intensity of her daily life.

Charlotte was reflexive about this process of primary caring and conscious of finding ways to retrieve and reclaim a subject position outside of her mothering role:

Two years ago when things started getting really rocky I said, it was my goal to go for my 50<sup>th</sup> birthday and I never got there, so I said I'm going, I'm just going to go. So I took myself and a friend to Italy, and fell in love with the place. So we spent three weeks in Italy and now I've come back and I'm learning Italian so I can go back again ... and so for two hours every week I get to be 'Charlotta'! And speak Italian, and do something for myself.

As Bassin et al. (1994) argue "seeing the mother as a subject, a person with her own needs, feelings, and interests, is critical to fighting against the dread and devaluation of women" (p. 2). Charlotte's Italian classes were not only her way of challenging the limitations and orthodoxies of the role she feels has been imposed on her: this was also her way of retrieving and reclaiming a sense of agency. Her proclamation – "I get to be 'Charlotta'" – is vividly symbolic of the extent to which the act of addressing her own needs is not escapism or selfishness, but a vital strategy for self-care, wellbeing, and the maintenance of a coherent sense of self.

### ***Jocelyn – "I am a mum, and that's ... that's who I am"***

Jocelyn identified herself primarily as mother-subject, but underscored the importance of retaining and enjoying social connections that did not necessarily relate to her position as a mother-subject. She highlighted the importance of respite services in allowing time for women to occupy subject positions outside that of mother, and spoke about doing a fun run with her mum and sister: "which will be nice because it'll just be me time." Embracing 'me time' without guilt is an example of Jocelyn's capacity for agency, and for challenging normative expectations in the interests of her own needs as an individual.

While she described the different ways in which she was able to occupy subject positions outside of that of 'mother', she reflects:

I am a mum, and that's ... that's who I am. The kids are so important that ... but I do know it's important, I get a bit crazy if I haven't been active in a couple of days. I do have good support to be able to go and do those things and I really miss it if I don't.

Jocelyn was able to experience multiple subject positions, but in her descriptions of these different subject positions she did not explicitly articulate conflict or discontinuities. This perspective is in contrast to that of participants such as Jill and Nancy, who experienced clear tension between their mother-subject positions and other subject positions they may occupy.

***Jacinta – "I had to re-establish myself as a person"***

Jacinta identified herself as a primarily a mother-subject but was pragmatic in assuming that her subjectivity would be likely to change in the future when her son with a disability – now in his 30s – moved into out-of-home accommodation. She had been centrally involved in an organisation dedicated to setting up an out-of-home accommodation model for people with intellectual disabilities involving government lobbying and media campaigning, and at the time of our interview, the out-of-home accommodation was in the process of being built. Because Jacinta had dedicated herself so fully to her son's care and the running of the organisation, she was now apprehensive about constructing her sense of self and purpose once her son moved into the out-of-home accommodation:

And then what's my life going to mean? ... At the moment I'm so busy with everything, so [the organisation] is keeping me very busy but after he's [my son's] in there I'm going to step aside for a while – I'm the President at the moment – so at the end of the year I'm stepping aside for a while and I'm thinking, 'what the hell am I going to do!' I don't know.

Jacinta's position as a mother-subject was tightly aligned with her position as advocate. Once her son moved into out-of-home accommodation, not only her mothering role, but her role as an advocate may also shift and change. Jacinta had once before experienced this shift in a life-changing way, when she separated from her husband. When she was married she felt constrained in many ways, and experienced a lack of independence. The separation from her husband proved to be a liberating moment for Jacinta's sense of self: "I had to re-establish myself as a person ... But yeah, so as far as self-identity, I feel I had none before. And since the divorce, I'm me." Yet simultaneously, Jacinta also expressed a degree of equivocation about her sense of self as a mother:

I've often wondered who I'd be now if Dean hadn't been born with a disability and I don't really know. I don't know if I would be self-absorbed, because I'm totally not self-absorbed. Being a mother does that to you anyway, but being a mother of a child with a disability, I think you become more self-sacrificing – and it's willing, it's not something I regret ... who would I have been? I don't know.

The constraints on her sense of agency were due, according to Jacinta, to her marriage. Divorce allowed her to enjoy agency in ways she was unable to before, reflecting individualisation. Yet she continued to experience constraint because of her role as a mother in the context of hegemonic maternity. However, she framed this experience of constraint in a different way: she sacrificed herself "willingly" and this was not something she regretted. This sentiment aligns with representations of the 'good mother' of a child with a disability, who self-sacrifices for their child and places the needs and interests of their child above themselves, and all without hesitation, resentment or regret. The type of experience of self that Jacinta described represents a transformative notion of 'self', framed in opposition to the constraint she experienced in her marriage.

### ***Sally – "I'm still me"***

Sally defined herself primarily as mother-subject, devoted considerable energy to advocating for better support services for her child, and drew on assertive aspects of her personality to bolster her position as an advocate. She felt that she could not separate a sense of self from her role as a mother since her passions were all "rolled up in being a mum."

While Sally situated herself within the framework of hegemonic maternity and the subject position of mother, she also railed against the idealised version of this subject position:

I'm still me. Classic, I love it. The word is – there are a lot of mothers, I've seen them all – they have that 'oh I can't go to lunch that's when the baby sleeps' – I've had baby so baby will fit with me. That's why it's really hard with the Dom at the moment because he doesn't fit with me because he needs to be home in his own bed to sleep. We have to shut him in his room by himself to sleep – he needs that sleep. Whereas before, I've got a baby and say I'm going to Penrith they say 'why' and I say 'I wanna go shopping' and they say 'well you have a baby' and I say 'I don't care, he can have a bottle on the way'.

Here Sally compares the ways other women perform in their role as mothers in adjusting to their baby's needs, with the ways in which she was a mother with her other children. But she states that she is unable to do that with her son with a disability because of his additional needs. Sally was able to find a way of inhabiting a mother-subject position through devoting herself to advocating for her child's needs. She felt a tension through the limited agency she experienced because of the needs of her child, but attempted to assert agency within the parameters of her position of mother. In this sense, Sally experienced the subject position of mother in multiple forms, and even though she acknowledged the constraints she experienced, she still asserted the necessity of maintaining some sense of agency and independence of self.

### ***Jessica - "I have become 'Angie's Mum' – not Jessica"***

Similar to Jocelyn, Jacinta, and Sally, Jessica sees her sense of self as primarily being that of 'mother'. Yet Jessica does feel some conflict about whether she can identify herself as occupying subject positions outside that of mother, for example she says: "I still am Jessica, Jessica who loves a beer!"

However, in her acknowledgement of this, and the importance that she places on her friendships in her life she says: "I have become 'Angie's Mum' – not Jessica." This comment is telling of how Jessica understands and frames her sense of self. Yet she continues after she says this to say: "I think that's how you become, even with parents at school – they go 'this is Angie's Mum' and I go 'also known as Jessica'." Jessica's qualification in reply to the parents at school that she is 'also known as Jessica' when they refer to her as "Angie's Mum" is an important indication of Jessica responding to and reasserting her agency independent from her role as a mother.

### ***Tania – "I'm never going to be the same"***

Similar to Jocelyn, Jacinta, Sally, and Jessica, Tania primarily saw herself as mother-subject, with her role a mother being all-encompassing. While Tania worked part-time, she emphasised the impact that having two children with disabilities has had on her career and her ability to progress in her career. She ultimately positioned herself as a mother-subject due to the other aspects of her life being crowded out by the consuming nature of caring for her child. When I began speaking to Tania about her sense of self, and whether she felt as though she had changed because of her position as a mother, she recounted a story:

My big boss here is a neurologist, a stroke researcher. And he was chatting to us here one day about some research he was doing with fatigue in soldiers who've come back from battle who don't sleep at all – with MRIs, so it's quite obvious with an MRI that their cognition is affected, and it really comes back from this fatigue. And he's describing all these symptoms and I just thought – that's me ... that is SO me. And I'm thinking – finally I realise that I am the way that I am: coping with Marko, coping with exhaustion, coping with everything else. And I'm never going to be the same – which is okay.

For Tania, this provided a snapshot of the intense change in her life because of her position as a mother. It gave her an explanation as to why she felt unable to identify with any other position but that of 'mother' at this point in her life. Having her children changed every aspect of her life, and Tania found it difficult to situate herself in any subject positions outside that of 'mother'. However, during the interview she did place emphasis



on the affordances of her friendships in enabling her to build resilience, and added that 'humour', 'wine', 'fitness', and 'music' were important parts of her life that enabled her to continue 'coping'.

### ***Dana – “Scarlett’s Mum”***

When Dana responded to questions about how she understands her sense of self and her mothering, she said that they were 'intertwined'. She drew on perceptions of *others* to articulate her sense of self, reflecting relational understandings of self. She stated that her role of being a mother “is in me. I know that often Scarlett’s friends, ‘oh that’s Scarlett’s Mum’, like you become ‘Scarlett’s mum’, you don’t have a name.”

Similar to Jessica’s experience, others identifying Dana as her daughter’s mother, rather than as an individual in her own right, exemplifies the connections explored in previous chapters regarding the naturalised nexus between womanhood and motherhood. For Dana, womanhood and motherhood were conflated, effectively serving to efface her individuality as a woman. Dana’s recount of the way she is referred to as “Scarlett’s Mum” also indicated the ways in which others’ perceptions of the ‘self’ mediated normative expectations and manifested in participants’ narratives of self, underlining the importance of relationality in combination with hegemonic maternity, when understanding the ways participants construct a sense of self.

### ***Veronica – “I think I’ve lost, to a degree, my identity”***

At the time of our interview, Veronica’s children had moved out of home and she felt she was undergoing a period of change, rethinking and redefining her sense of self. She reflected on the importance of occupying other subject positions besides that of mother, yet also emphasised the difficulty in being able to achieve this because of the intensity of work that is so often required when you have a child with a disability. Veronica spent some time thinking before she spoke about how she understood and framed her sense of self:

You know, I think... to be really, really, really honest ... I think Veronica standing on her own is a bit scary. I think hiding behind the role of Mum

is a little bit more comfortable ... I think I've lost, to a degree, my identity.

This is a powerful reflection from Veronica, and is telling of how hegemonic maternity can shape a woman's sense of self. Veronica wholly positioned herself within the subject position of mother, because that had been what she had known for so long. She was reflexive about the impact of mothering a child with a disability, stressing the need to keep a balance between mothering roles and other aspects of life, but: "when you're going through it, it's hard to keep that balance." With temporal distance from the intensity of the mothering experience, Veronica was able to come to this more pragmatic perspective. The "balance" she referred to can be interpreted as her efforts in balancing and negotiating the tensions she experiences as consequences of hegemonic maternity and individualisation.

### ***Hannah – "There is no you anymore"***

Hannah expressed a sense of 'loss' of self as a consequence of her mothering role. She described herself as being "not here anymore." Her abiding sense of loss of her sense of self can be traced to a lack of time and opportunity to develop subject positions apart from that of mother. Hannah's summation of who she is, is a salient and poignant reminder of the immense impact that the maternal work of mothering children with disabilities within the framework of hegemonic maternity can have on individual women:

I'm kind of not here anymore, really. You don't have a sense of yourself, which is really sad, and they often say you've got to make sure to keep yourself as a person, but you often lose yourself a lot. So there is no me, anymore. So yeah, having kids, there is no you anymore, unfortunately ... I mean it is different, I must admit having a kid with a disability ... my friends that don't have kids with disabilities don't quite, I think, understand ... they seem to have so much time ... So when it comes to yourself (whispers) there's not that much time. Hence why I like work. Because my work involves sitting in an entry station where I can read a book, do my emails, get on Facebook, do some knitting, try and have a hobby (laughs) ... so work for me is very important in that sense ... I mean heck I've waxed my legs in the entry station. Simple things like that make you feel more like you.

Although she felt, quite forcefully, the loss of a sense of self, she emphasised the importance of paid-work in allowing her some measure of time and space to re-connect with dimensions of herself that would otherwise be negated in the crucible of her mother-work. Hannah's experiences, like those of other participants, expose the extent to which mothers' "choices are constrained in ways that can be incredibly painful" (Jones, 2013, p. 293).

## Summary

Participants who negotiated multiple subject positions, *as well* as participants who strongly aligned themselves with the subject position of mother, each experienced some degree of ambivalence, conflict, and equivocation when reflecting on who they are as women who mother children with disabilities. All participants, to a greater or lesser extent, wrestled with the competing expectations, norms, and assumptions of hegemonic maternity and individualisation. It was highly problematic for participants to conceptualise themselves as unified 'subjects': "because our cultural tradition casts unified, individual selfhood in opposition to the realm of maternal bodily relations ... being a subject *and* a mother or as a mother is rendered problematic" (Stone, 2012, p. 397). In response to this opposition between maternity and agency some participants asserted their subjectivity through drawing on *other* subject positions besides that of mother. The *other* subject position most often occupied was that of paid-worker, from which participants reported deriving satisfaction. This is evidence of how participants negotiate and live within assumptions of individualisation – through their assertion of subject-positions outside of the mother-subject – that offer a sense of agency and independence.

It is worth noting that when participants reflected on their sense of self, their discussion rarely included reference to, or comments on, their primary intimate relationship (for those participants who had partners). When articulating the influences on their sense of self, participants spoke about their position as mothers, as paid workers, and sometimes as friends, but rarely as partners. This dimension of a woman's intimate partnership and the extent of its significance in shaping an individual's sense of self constitutes an area within research and theorising of maternity that needs addressing.

In participants' reflections, their attempts to construct a meaningful and authentic narrative of the self were clearly evident. All participants sought to create coherence from their life histories, find reasons for self-affirmation, self-worth, and self-acceptance through these narratives, even if they were constructed within the constraining parameters of hegemonic maternity and seemed internally contradictory or paradoxical. Each participant's story was redolent with evidence of emotional labour in actively constructing, negotiating, and articulating their sense of self within the highly fraught and oppressive demands of both hegemonic maternity and individualisation.

It is important to emphasise that the findings presented here are indicative of a *continuum* of experience and perspectives – from a determination to self-empower through drawing on multiple subject positions facilitating expression of participants' creativity, personal and professional attributes, and aspirations, to an abiding sense of 'loss' of sense of self. The affordances of being able to occupy subject positions outside that of mother reinforce the necessity of respite services, social support, and flexible workplace practices for women who are mothers of children with disabilities.

Thus, the evidence presented in this chapter reveals that the self is indeed shaped by social interaction as Mead (1932) theorises; it is constructed through 'performances' in the way that Goffman (1959) describes; and it cannot be understood in isolation from interpersonal relationships in the way that Chodorow (1981) argues.

In the next and final chapter of this thesis, I synthesise the findings and identify the significance of this study, and conclude with a series of recommendations for further research.



## CHAPTER ELEVEN

### Findings and Conclusions

*"Before it becomes a story, experience is chaotic.  
We tell ourselves stories, at the ends of long, confusing days  
or after frustrating experiences, to make ourselves whole"*  
(Johnstone, 1990, p. 128).

*"Unifying the apparently conflicting stories of sorrow and  
hope, of pain and enrichment, is the acquired knowledge that  
humanity is found in forms different from those that might  
once have seemed acceptable or bearable.  
This realisation suggests the need to examine not only how  
some mothers do or do not adapt to a child  
with disability but how mothers of children with disabilities  
reconstruct motherhood"*  
(Landsman, 1998, p. 93).



### Introduction

The purpose of this concluding chapter is to draw together the key findings of the study and identify directions for future research. The aim of this inductive research was to explore, interpret, and represent the experiences of 18 women who are mothers of children with disabilities, with a focus on how these women construct and navigate their role as mothers, their relationships, and their sense of self. The study responded to calls such as those from Ryan and Runswick-Cole (2008) who proposed further research was needed to explore "the ways in which mothers of disabled children negotiate, manage and approach their daily lives" (p. 199). In developing and conducting the study, the feminist phenomenological and social constructionist theoretical and methodological orientation were foundational, informing the analysis and interpretation of data, and the presentation of the results in this thesis.

The central research question informing the study was: "With a particular focus on their relationships and sense of self, what are the experiences of women who are mothers of children with disabilities?" From this central research question, three subsidiary research questions were developed in order to capture data pertaining to the three interdependent

themes inferred from the central question. These three themes – motherhood, relationships, and sense of self – provided thematic guidance for the structuring of the data analysis and interpretation chapters in this thesis.

Through the methods of in-depth interviews and personal community mapping, the study generated substantial, rich data from which emerged the conceptual framework of hegemonic maternity.

## **Key findings of the study**

### ***Findings in relation to the first subsidiary research question***

In addressing the first subsidiary question of this study – “How do participants experience the ‘institution of motherhood’ (identified by Rich in 1976); how do they resist, conform to, challenge, and/or navigate this constraining institution?”, Chapters Five, Six, and Seven presented considerable evidence of participants’ lived experiences, as they developed within the context of hegemonic maternity. This is summarised below, along with the implications of each finding.

#### **Participants were compelled to adopt and enact a range of roles as part of their mothering**

Participants constructed and sought to reconstruct their experiences of motherhood and mothering through adopting and enacting a range of roles, some of which are recognisable as archetypes. Predominant amongst these for a majority of participants were: the primary carer; the expert; the advocate; and the ‘modern day saint’. This evidence extends, adds depth to, and corroborates Landsman’s (2003) research regarding how women who mother children with disabilities are often forced into the position of ‘expert’ and ‘advocate’ in order to ensure the best quality of care for their child or children. The catalysts for participants being compelled to take on these roles included: a lack of adequate support services; the gendered and hierarchical nature of care-work, and a pattern of medical personal devaluing or dismissing their maternal knowledge. All are indicative of the pervasive, complexly rendered, and often internalised normative expectations of hegemonic maternity within which the ‘good mother’ concept is perpetuated (Arendell, 2000; Douglas & Michaels, 2004; Goodwin & Huppertz, 2010; Hays,

1996).

As women and mothers, participants' choices and behaviours were often driven, mediated, and regulated by normative frameworks over which they felt they had little control. The roles positioned participants in relational ways that inevitably framed and shaped their personal relationships, actions, perspectives, and life choices.

When judging their mothering against normative frameworks, participants often expressed a sense of failure: "Mothers of disabled children make their way within a society that devalues their children and in which their motherhood has 'failed' to follow the culturally appropriate trajectory" (Landsman, 2009, p. 10).

When they contested, problematised, and reconfigured these constraining parameters, however, they drew on tenets of individualisation to demonstrate their creative agency in attempting to construct their own coherent narratives and trajectory of mothering to invest their lives and their family's lives with meaning and purpose.

### **Implications**

In their discussions about the compulsion to adopt and enact a range of maternal roles participants provided substantial evidence of the impact of hegemonic maternity and the institution of motherhood on their lives. These encompassed:

- the deleterious affect on their physical and mental health and wellbeing;
- significant levels of anxiety about their potentially unending role as primary carer, particularly in relation to the absence or dearth of viable alternatives for support;
- the intense labour of maternal thinking (Ruddick, 1989);
- the personal cost of sustained emotional labour (Hochschild, 1983) in their efforts to both conform to, and resist hegemonic maternity;
- a sense of isolation and marginalisation due to perceptions of otherness and difference; and
- a material disenfranchisement from normative paradigms of motherhood.

### **Participants experienced heightened challenges in negotiating normative discourses and expectations of 'normality'**

All participants spoke of their difficulties in negotiating normative discourses and expectations of 'normality', especially with regard to the concept of the 'good disabled child'. Participants worked to situate themselves and their children within normative frameworks, and many sought to actively contest such frameworks. These findings are in support of Landsman's (1998) view that many mothers of children with disabilities seek to normalise their children and their own experiences, and many are compelled to redefine and indeed reconstruct "existing cultural understandings of what constitutes normality and perfection" (p. 93).

### **Implications**

The tension between the expectations inherent in hegemonic maternity and the participants' particular context-specific experiences of motherhood and mothering, gave rise to internal conflict and the inability of many participants to reconcile their practice and unique circumstances with perceived societal norms. Each participant wrestled with the task of seeking to 'belong' to some legitimised external context, whilst at the same time recognising that their children's disabilities appeared to automatically preclude them from attaining social acceptance within uncontested normative frameworks.

### **Participants experienced regulation and obligation in their role as mothers of children with disabilities**

All participants experienced significant forms of regulation and obligation as they are produced and sustained by hegemonic maternity. Regulation was manifested through: regulation by others; participants' self-regulation; and their regulation of other mothers. As Walkerdine and Lucey (2007) argue: "modern mothering has become one of the central aspects of the regulation of women" (p. 226). Yet, participants also challenged the regulation of hegemonic maternity and its ubiquitous set of obligations through contesting normative expectations around 'good mothering' practices and attempting to redefine the criteria for the 'good mother'.



### **Implications**

Each participant recounted experiences of the affect of regulation and self-regulation on their lives and their propensity to reproduce this regulation in their own transactions with, or judgments of, other mothers. The tripartite nature of regulation can be seen to perpetuate the constraints of hegemonic maternity, imprisoning women in an intractable cycle of surveillance and self-monitoring that confounds their capacity for agential living.

### ***Findings in response to the second subsidiary research question***

The second subsidiary research question probed the nature of participants' relationships: "In what ways do participants construct and navigate their relationships, and how are their relationships shaped and impacted by their role as mothers of children with disabilities?"

The data relevant to this question, presented in Chapters Eight and Nine, evinced the following key findings and implications.

### **Participants struggled with the concept and materiality of 'display'**

Participants sought to make meaning of normative structures and understandings of 'family' and family relationships through grappling with how to 'display' their family. These struggles often involved experiences of stigma and responses of grief, and revealed the extent to which participants resist and conform to frameworks of 'normality'. In constructing their families, analysis of data prompted a rethinking of Finch's (2007) concept of 'family display', since participants drew on a number of strategies to both situate their families within legitimised contexts of 'displays', and also build alternative – and at times, subversive – forms of display in order to represent their family.

### **Implications**

Despite participants' resistance to, and attempts to contest normative definitions of family and display, the record of their ongoing experiences of stigma, grief, and exclusion, pose a direct challenge to theories of individualisation. In the context of participants'

lived experiences, such theories are exposed as inadequate and partial in accounting for the nature and contours of personal relationships. The data reported on in this thesis points to the incompatibility of concepts of individualisation and hegemonic maternity when explaining the experiences of mothers of children with disabilities.

### **Participants' personal relationships can be both enabling and limiting**

Participants enjoyed and often depended on a network of personal relationships, which both included and went beyond their familial relationships. Participants identified the importance of a small number of close (typically female) friends; their partners and children; often their own parents; and other members of their extended network of support. Yet despite the persistence of important personal ties, participants consistently reported a sense of isolation, feelings of being misunderstood and marginalised, a lack of adequate support, and problematic connections within their personal networks.

The findings challenge Giddens' (1991) assertion that individualisation leads to greater freedom in structuring personal networks, and challenge Bauman's (2002) contention that individualisation will lead to a total fragmenting of social ties. Rather, the findings provide evidence to support Spencer and Pahl's (2006) research regarding the continued importance of personal networks and ties within the context of individualisation and in some ways does resonate with Bauman's (2003) pessimism about social ties, in that participants do suffer social isolation. However, by exploring their relationships holistically, it was evident that personal relationships for participants continued to be enduringly significant, attesting to the importance of theories of relationality.

### **Implications**

These research findings further underline to need to re-theorise notions of individualisation and the attendant assumptions of 'choice' and 'agency': for women who mother children with disabilities, "the notion of choice can seem to presuppose a level of control that is all too illusionary" (Landsman, 1998, p. 94).

### **Findings in response to the third subsidiary research question**

A key aspect of this study involved the exploration of an under-represented theme in the research literature: that is, "how do participants understand and express their sense of

‘self?’”

Grounded in feminist phenomenological and social constructionist theoretical perspectives, the analysis of how participants reflected on their sense of self, brought to the fore the utility of concepts of relationality (Jamieson, 2006).

**Participants’ sense of self was constructed in relation to others, and involved the occupation of various subject positions, which were often in tension with each other**

Analysis of participants’ reflections on the self drew on the work of theorists such as Mead (1913) who emphasise the construction of self through social interactions. Mead’s (1913) understanding of the self focuses on the constitutive power of the ‘other’. However, for some participants, the ‘other’ was not *always* holistically formulative of the self. Goffman (1959) understands the self as a collection of different *learned* roles, performed and enacted in order to influence interaction with others. Goffman’s (1959) work regards the ‘self’ as unified, and this understanding accounts for some participants’ reflections on their sense of self, and the ways in which they ‘perform’ their various roles.

Other participants reflected on their sense of ‘self’ in fragmented and less coherent ways: Goffman’s (1959) view of the ‘self’ did not account for the type of complexities that some participants emphasised. Alternatively, while similar to Mead’s (1934) and Goffman’s (1959) ideas, Chodorow’s (1981) understanding of the ‘self’ is relational, but she connects the ‘self’ to specific cultural norms about gendered reproduction. In doing so, she “reclaims and revalues feminine mothering capacities” (Willett et al., 2015). Chodorow’s (1981) conception of the ‘self’ appears to address and overcome some of the seemingly dichotomous boundaries that Mead’s (1934) and Goffman’s (1959) conceptions of the ‘self’ establish, while still recognising the self as being inextricably bound to interpersonal relationships.

The research findings therefore build on these theorists’ works, each of whom emphasise in some manner the concept of relationality as pivotal in the construction and maintenance of the self. It was most useful to draw on the psychoanalytic work of Juhasz (2003) and Stone (2012), who theorise maternal subjectivity and recognise that women who are mothers can experience multiple, diverse ‘subject positions’. Many participants in this study experienced multiple subject positions in the way that Stone (2012)

describes. However, Stone (2012) identified a tension that can exist within and between such subject positions. This tension is the result of the opposition between agency and maternity: being an autonomous agent *and* a mother are not seen as compatible. This tension that Stone (2012) identified between agency and maternity is emblematic of the tension between individualisation and hegemonic maternity.

The research found that participants' reflections on their sense of 'self' do indeed demonstrate the paradox of agency and maternity identified by Stone (2012). Participants who drew on multiple subject positions negotiated this tension as they found it difficult to reconcile their various subject positions – for example their position as a 'mother', with their position as a 'paid-worker'. Those participants who less readily drew on other subject positions besides that of 'mother' found it difficult to reflect on their sense of self, and often reported feeling a 'loss of self', and/or feeling wholly identified by others as 'the child's mother', rather than as an individual in and of herself.

### **Implications**

Expanded opportunities to occupy subject positions outside that of mother can be seen to militate against a sense of 'loss' of self that many participants identified. An underlying struggle with feelings of ambivalence, failure, and marginalisation plagued those who identified predominately as mother-subjects. Furthermore, that participants who actively inhabited multiple subject positions continued to feel a sense of ambivalence about their sense of self, underscores a need to confront and challenge the oppositional framing of maternity and agency, and further question the operation and influence of hegemonic maternity and individualisation.

### **Significance of Findings**

The study has drawn on and combined two previously distinct areas of study: Motherhood Studies and the sociology of personal life. This combination has not only added to knowledge and theorising within these two separate areas of study, but has offered new insights into what it means to mother a child with a disability.

The analysis of participants' personal relationships and sense of self adds to the limited scholarly inquiry on the experiences of women who mother children with disabilities from

a woman-centred perspective, rather than mediating a discussion of their experiences through a focus on their child.

The adaptation of Connell's (1995) 'hegemonic masculinity' to motherhood has led to the development of the conceptual framework of hegemonic maternity. The lens of hegemonic maternity enables the type of complex engagement and analysis that is often required when examining experiences of mothering and disability. It facilitates an understanding of how care continues to be devalued and gendered. It also enables researchers to explain why women who are mothers can simultaneously reinforce and challenge the constraining structures that frame their lived experiences. It offers a new theoretical tool for understanding mothering as both oppressive and empowering.

An understanding of hegemonic maternity contributes to O'Reilly's (2015) concept of 'matricentric feminism' (O'Reilly, 2015). Matricentric feminism (O'Reilly, 2015) recognises the extent to which women who are mothers continue to face discrimination and inequality in ways that women who are not mothers do not face. Exploring the construction and impacts of hegemonic maternity in the context of women who mother children with disabilities, has carved out a further space to recognise the importance and need for matricentric feminism – a feminism for women who are mothers to call their own.

The results of this study challenge current understandings of individualisation and its consequences, as the way individualisation is currently conceptualised does not allow for the representation of participants' experiences. Exploring how participants negotiated the tension between agency and obligation prompted a re-thinking of Finch's (2007) concept of 'family displays' to accentuate how participants' 'family displays' are often positioned as illegitimate. These findings offer an important contribution to the sociology of personal life when thinking about the way individuals reflect on and structure their personal networks.

The study offers new insights into the ways these women experience and reflect on a sense of self and advanced Stone's (2012) evaluations through linking the inherited fabric of Western ideas about the self as agential to individualisation, and linking the contemporary parenting industry and maternity to hegemonic maternity. The application of this framework for analysis offered a significant contribution to research on motherhood and the self. In this regard, the study contributes to long-standing sociological

questions regarding the relationship between an individual and the society within which they live.

While there has been a consistent emphasis on the constraints that participants in the study confronted, it is important to stress the complex and dynamic ways that their relationships within such constraints operated. Participants did not frame themselves as ‘victims’ who are completely at the mercy of the social and institutional frameworks that they live within. Their experiences are far more richly layered and complex. As Landsman (1998) articulates:

Mothers speak with anger about having their enormous difficulties ignored or minimised; they speak of the agony of lost dreams, the pain of seeing other children and imagining what might have been for their own child, their fears and concerns for the future, and their frustrations with a system that places unnecessary obstacles in their path and forces them to become ever more assertive. Yet at the same time, most bristle at suggestions that their lives or the lives of their children are tragic or pitiful (p. 92).

In fact, participants often tried to build alternatives to the socio-cultural expectations placed on them of how to mother or how to represent their lives. Participants’ lives were framed, constructed, constrained, and challenged because of their roles as mothers. Yet they also resisted, reflected on, wrestled with, conformed to, reinforced, and built alternatives to the very thing that was framing their experiences, *through* their mothering and relationships.

The embedded nature of hegemony and normative assumptions woven into the fabric of social life illustrates the power of these frameworks. When a woman becomes a mother, and then discovers that her child has a disability, she is confronted by frameworks that have already excluded her and her child. Her agency and ability to *choose* has already been circumscribed. Arguably, this may be the case for *all* women who become mothers, depending on how much privilege and capital that woman has to draw on. But for women who become mothers to children who have disabilities, the constraints they confront are exacerbated. Understanding this consequence is significant. While some of the challenges

that disability ushers in may never be eliminated, the challenges that raising a child with a disability entails can be alleviated through social and policy change.

### **Implications for Future Research and Policy**

There are numerous avenues for future research and policy development based on the findings of this study. Broader research could employ, challenge, and extend the concept of hegemonic maternity when examining the experiences of women who mother, or alternatively to explore how hegemonic maternity operates in social, cultural, political, and other contexts.

Further research on understandings of the self and subjectivities could investigate or challenge the multiplicity of subjectivities, and the tension between agency and maternity. More generally, researchers could further explore the tension that exists between individualisation and hegemonic maternity, and how this tension operates and impacts on everyday lived experience, as well how it operates in cultural and political institutions.

Any discussion of women who provide care inevitably raises implications for broader thinking about the gendered and devalued nature of care-work that persists. It is hoped that this research will prompt changes to see care-work remunerated and politically and socially valued, and thereby further address the implications of essentialised assumptions of gendered caring.

This research was conducted in the context of the roll-out of the National Disability Insurance Scheme (NDIS) in parts of NSW, Australia. This scheme is the first, nationally funded scheme to facilitate a person-centred approach in supporting people with disabilities, allocating them individualised funding packages that they can use to orchestrate their care and support. However, the NDIS, so far, does not adequately address the needs of carers for those with disabilities, and participants in this research had mixed responses as to how the NDIS would change their lives and the lives of their children. The caring contributions of 2.6 million family members for those with disabilities in Australia is worth more than \$42 billion annually, and without the ongoing work provided by caregivers – such as the participants in this study – the NDIS would fail (Tops, 2014).

Both care-work and market-work are fundamentals for the stability of our society and growth of our economy, and those who are primary caregivers deserve to have the opportunity to engage in both if that is what they choose. In order to facilitate this choice, care-work must be financially valued, and alternative arrangements for quality out of home care, respite, and ongoing support must become more readily available and accessible. Additional research is needed into this important and emergent area of policy development and implementation, and social change.

Related to the NDIS and the positioning of care-work, are the ways participants experienced formal structures and institutions. This was a significant sub-theme that emerged from the study and included the ways participants experienced schooling systems, hospitals, medical staff, respite centres, out-of-home accommodation and care, and the NDIS. Although this sub-theme has been discussed throughout this thesis, the limitations of space precluded a more detailed coverage. However, there are a number of areas of concern that emerged from this sub-theme, which are important to consider in any discussion of the implications of the findings for future research and policy. These include but are not limited to the following.

- Parents being equipped with *knowledge* about the existence of support services in order to then be able to *access* to such supports.
- The financial burden that disability imposes. This includes not only the lost income of the primary carer if they are unable to engage in paid work, but the lost accumulation of superannuation for this carer. This is particularly important to consider if a primary carer separates from their partner who was their primary source of income support. The actual and potential prospect of long-lasting caregiving obligations has serious financial and other implications for families.
- The importance of out-of-home accommodation care options for those who cannot or choose not to continue providing in-home care for their children for the remainder of their lives. Equally, the importance of respite services to enable caregivers to continue providing care within the home if that is what they choose.
- Improving the delivery of support services. These services and medical institutions operate on the assumption that mothers of children with disabilities have, or will acquire, expert knowledge, but then routinely invalidate or dismiss such knowledge.



- The development and utilisation of a health systems database that medical professionals can access and contribute to in order to streamline the amount of information and discussion generated about a child's condition, often across multiple sectors. At the present, parents are often compelled to remember, record, and manage this complex amount of information to ensure each health worker is fully informed regarding their child's disability.
- Further encouragement for employers to offer flexible paid-work arrangements for those with caring responsibilities.
- A need for medical professionals to be particularly cognisant of the way that diagnosis of disability is delivered to parents who have a child with a disability. Immediate support needs to be offered to families after the diagnosis of disabilities. This may involve more systematic use of online communities.

### **Concluding Comments**

This study has applied the lens of hegemonic maternity to examine “not only how some mothers do or do not adapt to a child with disability but how mothers of children with disabilities reconstruct motherhood” (Landsman, 1998, p. 93). The voices of the participants as they share their lives and experiences while mothering children with disabilities constitute compelling stories that are rarely told publically. While sometimes fragmented, and sometimes more coherent, each is always remarkable and absorbing. Collectively, these narratives of individual women's lives tell of resilience, heartache, courage, resistance, adversity, transformation, hope, and, most of all, love.



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## Appendices

### APPENDIX A: Organisational Recruitment Letter



**SSPS Office**  
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Web: <http://www.sydney.edu.au/>

To who it may concern,

My name is Sophie Brock and I am a PhD student at The University of Sydney. I am currently conducting research into the experiences of mothers of children with disabilities as a part of my studies. My research is interested in how having a child with a disability impacts upon mothers' lives, and how mothers' social networks and sense of family is affected. I am also interested in whether mothers feel pressure to parent their children in particular ways, and what their experience of the health system and institutions may be. Ideally I would also like to speak to some mothers whose children are currently included in the Disability Care Australia scheme.

In order to include mothers of children with disabilities in this study, I am contacting organisations that may have some form of contact with these mothers. It would be greatly appreciated if you were able to assist me in distributing information about this study, so that any mothers of children with disabilities can choose to take part if they are interested. Mothers who are interested in participating will need to contact me by phone or email, so they feel under no pressure to participate if they do not wish to. I have attached the flyer advertising the details of the study with my contact information, and a 'participant information statement' with more details about the research, to this email.

Confidentiality in this study is paramount, and no identifying details of participants will ever be shared. Participation in this study would help provide a voice for mothers with children with disabilities that has so often gone unheard. Involvement in this study is completely voluntary and participants can withdraw from the study at any stage.

Please do not hesitate to contact me with any questions you may have: 0411 558 610.

Sincerely,  
Sophie

## APPENDIX B: Recruitment Advertisement/Flyer



**SSPS Office**  
**Discipline of Sociology and Social Policy**  
**School of Social and Political Sciences**  
**Faculty of Arts and Social Sciences**

ABN 15 211 513 464

**Dr Jennifer Wilkinson**

Senior Lecturer in Sociology

Room 140  
RC Mills Building A26  
The University of Sydney  
NSW 2006 AUSTRALIA  
Telephone: +61 2 9351 2650  
Facsimile: +61 2 9036 9380  
Email: [jennifer.wilkinson@sydney.edu.au](mailto:jennifer.wilkinson@sydney.edu.au)  
Web: <http://www.sydney.edu.au/>

### Advertisement/Flyer

*I am currently seeking mothers of children with intellectual and/or physical disabilities to take part in a project as a part of my PhD at The University of Sydney, supervised by Dr Jennifer Wilkinson. The study aims to investigate the experiences of mothers with children with disabilities from the mothers' own perspectives.*

*The study is interested in what the experiences of these mothers are in relation to things such as: their everyday life, the support they receive from institutions and organisations, their experience with the job industry, their social support networks, and how being a mother has influenced or impacted on their sense of who they are as women. Participation in the study is completely voluntary and participants can withdraw at any time.*

*Involvement in the study would involve a face-to-face interview of approximately 1-2 hours, and the possibility of a shorter follow-up interview later on. Participants will also be asked to bring a photograph/photographs with them to the interview that represents their journey as mothers, and will be asked to take part in a 'personal community' mapping exercise. Details of these activities will be further explained, and are completely voluntary.*

*Participation in this study would be greatly appreciated and would provide a voice for mothers with children with disabilities that has so often gone unheard. If you are interested in taking part, please contact Sophie either by phone (0411 558 610) or by email ([sbro5827@uni.sydney.edu.au](mailto:sbro5827@uni.sydney.edu.au)) for more information.*

*If distributed by email: Attached to this email is a participant information sheet that provides further information about the research and its purpose.*

*If displayed as a flyer: Please see the front desk for a copy of a participant information sheet that provides further information about the research and its purpose.*

## APPENDIX C: Participant Information Statement



**SSPS Office**  
**Discipline of Sociology and Social Policy**  
**School of Social and Political Sciences**  
**Faculty of Arts and Social Sciences**

ABN 15 211 513 464

**Dr Jennifer Wilkinson**  
*Senior Lecturer in Sociology*

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Email: [jennifer.wilkinson@sydney.edu.au](mailto:jennifer.wilkinson@sydney.edu.au)  
Web: <http://www.sydney.edu.au/>

### **Pulling Together or Pulling Apart: Investigating the Experiences of Mothers of Children with Disabilities**

#### **PARTICIPANT INFORMATION STATEMENT**

##### **(1) What is the study about?**

You are invited to participate in a study that aims to investigate the experiences of mothers with children with disabilities. It will examine and explore how having a child with a disability impacts upon mothers' lives, and how social networks, sense of family, and sense of identity are affected by having a child with a disability. The study is also interested in whether mothers feel pressure to parent their children in particular ways, and as well as in their experience of the health system and government mechanisms.

##### **(2) Who is carrying out the study?**

The study is being conducted by Sophia Brock and will form the basis for the degree of her PhD at The University of Sydney under the supervision of Dr Jennifer Wilkinson.

##### **(3) What does the study involve?**

*The study involves participating in a one-to-one interview with the researcher. There is also a possibility you may be asked to participate in a follow-up interview. As preparation for the interview you will be asked to gather photographs you feel represent your journey of motherhood. There is no need to provide copies of the photographs, as they will only be used as tools of reflection during the interview. During the interview you will also be asked to take part in a 'mapping' activity where you place people in your life on a diagram according to how important they are to you in your life. This will be explained further during the interview. If agreed upon, a*

*photo of this personal community 'map' would be taken to assist the researcher in reflecting on the interview – however the photo would not be reproduced or used in any other way.*

*The interview will be audio recorded and then transcribed. Once you have finished reading this information sheet, and if you agree to participate in the interview, you will be asked to read and sign a participant consent form giving permission for the interview to take place and be recorded. You can withdraw this consent at any time in the interview. The transcription shall be made available to you for review before being analysed in the context of the research study. You can choose for the interview to be conducted either on The University of Sydney grounds, in a public space, or in your home.*

**(4) How much time will the study take?**

The interview will take approximately one to two hours, however, depending upon the progress of the interview the actual time taken may be shorter or longer. If you agree to take part in a follow-up interview it will take approximately one hour.

**(5) Can I withdraw from the study?**

Yes. Being in this study is completely voluntary - you are not under any obligation to consent and - if you do consent - you can withdraw at any time without affecting your relationship with The University of Sydney.

You may stop the interview at any time if you do not wish to continue, the audio recording will be erased and the information provided will not be included in the study.

**(6) Will anyone else know the results?**

All aspects of the study, including results, will be strictly confidential and only the researchers will have access to information on participants. Real names will not be used and all clearly identifying information will be removed from the transcripts. As a participant, you will be provided a copy of the transcription for approval before any analysis takes place.

**(7) Will the study benefit me?**

Although we cannot and do not guarantee or promise that you will receive any benefits from the study, it will provide you with the opportunity to share your story with the researcher.

**(8) Can I tell other people about the study?**

Yes – if you are aware of other mothers of children with disabilities who would like to participate you can pass on our contact details.

**(9) What if I require further information about the study or my involvement in it?**

When you have read this information, Sophia Brock will discuss it with you further and answer any questions you may have. If you would like to know more at any stage, please feel free to contact Dr Jennifer Wilkinson by telephone 02 9036 9481 or by email at [jennifer.wilkinson@sydney.edu.au](mailto:jennifer.wilkinson@sydney.edu.au)

**(10) What if I have a complaint or any concerns?**



Any person with concerns or complaints about the conduct of a research study can contact The Manager, Human Ethics Administration, University of Sydney on +61 2 8627 8176 (Telephone); +61 2 8627 8177 (Facsimile) or [ro.humanethics@sydney.edu.au](mailto:ro.humanethics@sydney.edu.au) (Email).

This information sheet is for you to keep

## APPENDIX D: Community Map Instructions



**SSPS Office**  
**Discipline of Sociology and Social Policy**  
**School of Social and Political Sciences**  
**Faculty of Arts and Social Sciences**

ABN 15 211 513 464

**Dr Jennifer Wilkinson**  
*Senior Lecturer in Sociology*

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Telephone: +61 2 9351 2650  
Facsimile: +61 2 9036 9380

Email: [jennifer.wilkinson@sydney.edu.au](mailto:jennifer.wilkinson@sydney.edu.au)  
Web: <http://www.sydney.edu.au/>

Dear \*\*\*,

Thank you so much for agreeing to take part in this study. I really look forward to meeting with you.

This study aims to investigate the experiences of mothers with children with disabilities, and a part of what I am interested in is what kind of support networks you have in your life. Support networks refer to people who not only support you in caring for your child with a disability, but are also people who are important to you in your life. These could be people you see often, or rarely – they could be family members, friends, neighbours, co-workers, social workers – or anyone who you feel is significant to you in your life. They might have a central role in helping you care for your child, or they may have nothing to do with your role as a carer or mother.

Using post-it notes or sticky labels, I would like you to think about the people who are currently important in your life, and list each name on an individual sticky label. You may list as many or as little names as you like. For each label please fill out the following details:

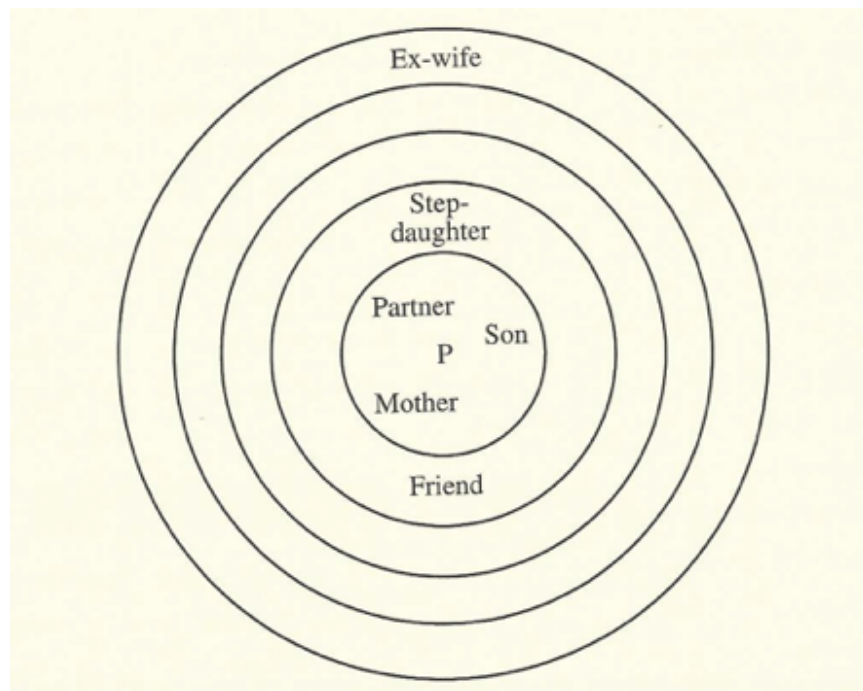
1. First name and initial of the surname if there is more than one person with that name
2. Age (or estimate)
3. Approximately how far away they live from you

If you cannot fit all the information on the label, don't worry, you can tell me during the interview. Here is an example of a completed label:

|                        |
|------------------------|
| Sally P<br>45<br>40kms |
|------------------------|

When I come to meet you I will bring a 'map' for you to place the sticky labels on. If you imagine yourself at the centre, each circle represents the relative closeness or distance you feel

from somebody. Those labeled closest to you in the centre circle are those deemed the closest, most valuable relationships in your life. Each ring outwards demonstrates a further distancing in the relationship.



Your views and experiences will be enormously valuable to this study. Please be assured though, that you or the names of people on your sticky labels, will not be named or identified in any way.

Please do not hesitate to contact me if you have any queries or questions. My number is 0411 558 610 and my email is [sbro5827@uni.sydney.edu.au](mailto:sbro5827@uni.sydney.edu.au).

Thank you again and kind regards,

Sophie

## APPENDIX E: Pre-Interview Questionnaire



**SSPS Office**  
**Discipline of Sociology and Social Policy**  
**School of Social and Political Sciences**  
**Faculty of Arts and Social Sciences**

ABN 15 211 513 464

**Dr Jennifer Wilkinson**

*Senior Lecturer in Sociology*

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Email: [jennifer.wilkinson@sydney.edu.au](mailto:jennifer.wilkinson@sydney.edu.au)  
Web: <http://www.sydney.edu.au/>

### Pre-Interview Questions

It would be much appreciated if you could please fill in this pre-interview questionnaire and return it via email to [sbro5827@uni.sydney.edu.au](mailto:sbro5827@uni.sydney.edu.au)

The reason for such questions is that as a part of my study I am aiming to speak to a variety of different women of varied ages, in a variety of relationships, and from a variety of different social, economic, and cultural backgrounds. Filling out and returning this questionnaire before the interview will allow more time during the interview to focus on your experiences of mothering, and will allow me to seek out interviews with a variety of other women from different backgrounds.

1. What is your age bracket?

|                   |  |
|-------------------|--|
| Under 25          |  |
| 35 – 45           |  |
| 45 – 55           |  |
| 55 – 65           |  |
| Over 65           |  |
| Prefer not to say |  |

2. Which best describes your relationship status?

|        |  |
|--------|--|
| Single |  |
|--------|--|

|                        |  |
|------------------------|--|
| Defacto                |  |
| Married                |  |
| Divorced               |  |
| Widowed                |  |
| Other (please specify) |  |
| Prefer not to say      |  |

3. How would you describe your sexual orientation?

|                        |  |
|------------------------|--|
| Heterosexual           |  |
| Homosexual             |  |
| Bisexual               |  |
| Other (please specify) |  |
| Prefer not to say      |  |

4. Which best describes your household income (before tax)

|                   |  |
|-------------------|--|
| Under 15K         |  |
| 15 - 30K          |  |
| 30 - 50K          |  |
| 50 - 80K          |  |
| 80 - 100K         |  |
| 100 - 130K        |  |
| 130 - 160K        |  |
| Over 160K         |  |
| Prefer not to say |  |

5. To which racial or ethnic group(s) do you *most* identify?

|                                    |  |
|------------------------------------|--|
| Aboriginal/ Torres Strait Islander |  |
| Caucasian/White                    |  |
| Asian                              |  |
| Hispanic or Latino                 |  |
| Arab                               |  |
| African/Black                      |  |
| Pacific Islander                   |  |
| Other (please specify)             |  |

|                   |  |
|-------------------|--|
| Prefer not to say |  |
|-------------------|--|

6. What is the highest degree or level of school that you have completed?

|                                                    |  |
|----------------------------------------------------|--|
| Less than Year 10 school certificate or equivalent |  |
| Year 10 school certificate or equivalent           |  |
| Year 12 higher school certificate or equivalent    |  |
| Vocational Qualification/TAFE                      |  |
| Associate diploma/degree                           |  |
| Bachelor degree                                    |  |
| Bachelor honours degree                            |  |
| Masters degree                                     |  |
| Doctoral degree                                    |  |
| Other (please specify)                             |  |

7. How many children do you have and what are their ages?

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8. What child has a disability and what is the nature of their disability?

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## APPENDIX F: Participant Consent Form



**SSPS Office**  
**Discipline of Sociology and Social Policy**  
**School of Social and Political Sciences**  
**Faculty of Arts and Social Sciences**

ABN 15 211 513 464

**Dr Jennifer Wilkinson**

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Email: [jennifer.wilkinson@sydney.edu.au](mailto:jennifer.wilkinson@sydney.edu.au)  
Web: <http://www.sydney.edu.au/>

### PARTICIPANT CONSENT FORM

I, .....[PRINT NAME], give consent to my participation in the research project

TITLE: Pulling Together or Pulling Apart: Investigating the Experiences of Mothers of Children with Disabilities

In giving my consent I acknowledge that:

1. The procedures required for the project and the time involved have been explained to me, and any questions I have about the project have been answered to my satisfaction.
2. I have read the Participant Information Statement and have been given the opportunity to discuss the information and my involvement in the project with the researcher/s.
3. I understand that being in this study is completely voluntary – I am not under any obligation to consent.
4. I understand that my involvement is strictly confidential. I understand that any research data gathered from the results of the study may be published however no information about me will be used in any way that is identifiable.

5. I understand that I can withdraw from the study at any time, without affecting my relationship with the researcher(s) or the University of Sydney now or in the future.

6. I understand that I can stop the interview at any time if I do not wish to continue, the audio recording will be erased and the information provided will not be included in the study.

7. I consent to:

- |                      |     |                          |    |                          |
|----------------------|-----|--------------------------|----|--------------------------|
| • Audio-recording    | YES | <input type="checkbox"/> | NO | <input type="checkbox"/> |
| • Receiving Feedback | YES | <input type="checkbox"/> | NO | <input type="checkbox"/> |

If you answered YES to the "Receiving Feedback" question, please provide your details i.e. mailing address, email address.

**Feedback Option**

**Address:** \_\_\_\_\_

\_\_\_\_\_

**Email:** \_\_\_\_\_

.....  
Signature

.....  
Please PRINT name

.....  
Date



## **APPENDIX G: Interview Schedule**

### **Interview Schedule**

#### **Introduction**

- Introduce self and research interests
  - Interested because grew up in family with disability – Dad's MND = demands of disability and the intense care that often has to be provided by the family, and what impact this has not only on the primary caregiver but the family as well...
  - During University study, became very interested in motherhood as a topic for academic interest, and the roles and expectations that come with motherhood that are reinforced by our society and government
  - Came to discover there was very little research done on mothers of kids with disabilities in this context
  - Importance and significance of study – shed a light on experiences, particularly in light of NDIS
- Restate the aims of this project –
  - Investigate the experiences of mothers with children with disabilities;
  - Examine the concept of 'good mothering' for these mothers;
  - Explore the personal community and networks of support for mothers of children with disabilities;
  - Investigate the ways your role as a carer and a mother can impact on your sense of self, identity, personal relationships and sense of family
- Reaffirm confidentiality, voluntary nature of project, go through PIS and PCF – ask to read and sign consent form
- At two points throughout the interview we will undertake the personal community mapping exercise you've prepared for, and discuss the photos they've brought

#### **Checks – warm up**

- Confirm information from pre-interview questionnaire
  - Children number and disability
- Find out more about child and disability
  - When did you first learn about the disability/diagnosis?
  - What are the consequences of the disability – how much care do you need to provide in day to day living?

#### **Informal networks of support/personal community/ relationships**

- Personal community mapping exercise
- DEFINING RELATIONSHIPS
  - What was your experience of drawing up the list of people you consider important to you?
  - Did you have to leave people out? Who? How many? Why?
  - So why is this particular person placed here?
  - What is the difference between relationships in the different circles? What made you put this person in a closer circle and this one in the outer circle?
  - How would you label or describe these different circles?
  - Discuss the presence or absence of child with a disability on map

- COMPARING RELATIONSHIPS (family)
  - What is the significance of this family member in your life? Why do you think you're closer/more distance to them than to another family member?
  - How important has family been in coping with having a child with a disability
  - Would you say that you've had strong support from family in caring for your child, or a lack of support? Why?
  - Do you get something from relationships with family members that you don't get from relationships with friends?
  - Do you feel that becoming a mother has changed your relationship with family members? Why and how so?
- COMPARING RELATIONSHIPS (friends)
  - What has been the significance of these/this friend/s in your life?
  - Do you have a best friend or would you describe friends in this way? Why or why not?
  - How has your experience of friendship changed from before you had a child with a disability to now?
  - How important have friends been in coping with having a child with a disability?
  - Would you say that you've had strong support from friends in caring for your child, or a lack of support? Why?
  - Do you get something from relationships with friends that you don't get from family?
  - Do you feel that friends understand your life situation better than family or the reverse?
  - Do you think your role as a mother has changed your relationship with particular friends?
- OPTIONAL: QUESTIONS FOR EACH INDIVIDUAL ON MAP
  - How often do you see each other?
  - How often would you speak?
  - Who usually initiates contact?
  - What do you mainly talk about?
  - How understanding do you feel they are of the demands you face in your life?
  - Has the relationship changed since you've become a mother, or since you've become a mother with a child with a disability?
  - Have there been any particular turning points in your relationship?
  - In what situations would you turn to this person for support? Do they turn to you for support in their own lives?
  - Do you feel the relationship is reciprocal – is there the same amount of give and take?
  - How important is this relationship to you?
  - How much of an influence does this relationship have in defining how you see yourself as a person/mother/carer?

### Formal Networks of Support

- Institutional support
  - Are you receiving any support from government or non-government organisations? What type?
  - Who initiated the support – did you have to seek out the organisations or did they find you?
  - Are you aware of any programs available from the government to support you in your care giving role?

- If you've used support networks either from government initiatives or support groups, how has this help (or lack thereof) impacted on your mothering experience?
- How readily available is information on support available to you? Do you have to actively seek it out?
- Is there any sort of respite offered to you and do you take avail of it? How important is this respite for you? How do you think using this respite impacts on you as a mother to your children? Or does it?

#### **NDIS QUESTIONS**

- *How did the process work? Have you been assigned a case worker? If so how effective do you think the case worker is? Do you feel like they're prioritizing the needs of your family*
- *Do you feel that the system of working out your needs and then being allocated funds that are under your control is an effective way for the scheme to work?*
- *What's been your overall experience of the system – is it easy to navigate, do you feel you have your questions and queries easily answered?*
- *If you had the power to create a system/institution for people with a disability in an ideal world what would it look like?*
- Experience of the health system – hospital visits, experiences with doctors, nurses, speech pathologists, physios etc
  - What has been your overall experience of the health system? Positive and supportive or negative and distressing?
  - Is there a difference in the way that specialists, nurses, government representatives, social workers or counselors treat you and your child?
  - Do you feel empowered as a mother of a child with a disability and have confidence that you know what is best for your child?
  - Based on your experience, do you feel the medical profession is respectful of your expertise, knowledge and experience in mothering your child with a disability?

#### **Employment**

- Are you currently in paid work?
- Do you work full time/ part time/ casually?
- Has your work position changed since you've had children or your child with a disability? How and why?
- What have been (if any) barriers to participating in paid work because of your position as a mother and carer?
- What have been your experiences with the paid employment industry?
- In your experience, have employers been understanding and/or supportive of your position as a mother of a child with a disability?
- Has your role as a mother of a child with a disability influenced in any way the type of work you're involved in or would like to be involved in?
- Is being in paid employment an important factor to you in your life? Why or why not?
- How important is your position in the paid work industry in defining your sense of self?

#### **Photo elicitation**

- Would you mind taking me through the photos you've selected to show me?

- When was this photo taken?
- Where was it taken?
- Who are the people in this photo?
- How old are you in this photo?
- Why is this photo significant?
- At what stage of your life were you when this photo was taken?
- How does this photo represent your journey through motherhood? What stage does it represent?
- How have your values/priorities changed since this photo was taken? Have they changed?
- How does it make you feel reflecting on these photos? Nostalgic? Proud? Sad? Joyful? Thankful? Etc
- How would you describe the process of selecting photos for this interview today? Were there particular photos that you deliberately left out?
- Before having children, what did you think motherhood would be like?

### The Concept of the 'Good Mother'

- Do you feel pressured to parent in particular ways?
- Do you feel that expectations of mothers with children with disabilities differs at all to mothers of children without disabilities? In what ways, and why do you think this is so?
- Where do you feel expectations of what motherhood should be like come from? (Media images, friends, own mother/family?)
- How has being a mother of a child with a disability challenged or changed your expectations of what it's like to be a mother, and how to parent?

### Motherhood and the individual

- Do you feel as though your role as a mother, and other roles you play in your life can be separated?
- What type of impact do you think mothering a child with a disability has had on your close relationships?
- Do you feel it is important to maintain parts of yourself separate from your role as a mother, or is being a mother inherently central to who you are as a person? Is your identity dependent on motherhood?
- How has being a mother of a child with a disability impacted on the way you see yourself?
- Has having a child with a disability had a transformative impact on your life?

## **APPENDIX H: Safety Protocol**

### **(Minimal) Safety Protocol**

Risk management strategies and interview safety have been discussed between Sophie Brock [the researcher] and Dr Jennifer Wilkinson [the Supervisor] and both parties are clear as to procedure. Dr Wilkinson considers that the safeguards provided in this safety protocol are sufficient to manage the safety risks.

If the research participant opts to nominate their private residence as the desired location to conduct interviews, the following safety protocol will be observed.

- The address of the location and the time of each interview shall be communicated to Dr Wilkinson prior to the interview.
- The researcher shall communicate by mobile phone with Dr Wilkinson before the commencement and upon the conclusion of each interview.
- Where possible, interviews will be conducted in daylight hours or in the early evening.
- Where an interview takes place in a private home, the researcher will take steps to ensure that she is able to leave at any time. This includes only entering 'public' areas of the house where possible (such as kitchens and living rooms), ensuring that the exit route is clearly known, and watching to ensure that the door is not locked after entering.
- In the case of an adverse event occurring during the interview, the researcher shall terminate the interview and exit the private residence. If this does occur, the researcher shall contact Dr Wilkinson as soon as practically possible to advise her of the adverse event.

This safety protocol has been agreed and accepted by the researcher and the supervisor.

## APPENDIX I: Resources



**SSPS Office**  
**Discipline of Sociology and Social Policy**  
**School of Social and Political Sciences**  
**Faculty of Arts and Social Sciences**

ABN 15 211 513 464

**Dr Jennifer Wilkinson**

*Senior Lecturer in Sociology*

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Facsimile: +61 2 9036 9380  
Email: [jennifer.wilkinson@sydney.edu.au](mailto:jennifer.wilkinson@sydney.edu.au)  
Web: <http://www.sydney.edu.au/>

### Resources for Support

Salvo Care Line: 1300 36 36 22

- Trained counsellors at the Salvo Care Line are available 24 hours a day, 365 days a year. Our counsellors will offer a listening ear and help you work through a range of options which might include information and referrals to empower you to change your situation.

Lifeline Australia: 13 11 14

- Lifeline is a national charity providing all Australians experiencing a personal crisis with access to 24 hour crisis support and suicide prevention services.

Carers NSW counseling services: 1800 242 636

- Caring can be a rewarding experience, but it can also be stressful and difficult. Many carers experience a range of feelings related to their role as a carer. Emotions like anger, depression, anxiety, loneliness, loss and grief are very common. Your family and friends can provide important support but you may find it helpful to talk with a professional who is not emotionally involved with you or the person you are caring for. Our carer counselling program can connect you to a qualified professional who understands the problems that carers often face.

Connecting Carers NSW: 1300 794 653

- Connecting Carers NSW (CCNSW) provides support to foster, kinship and relative carers across New South Wales. We offer carers 24 hour telephone support, ongoing education, peer support and advocacy to assist carers in their vital role caring for children and young people in out of home care (OOHC).

Helpful Links:

Association for children with a disability: <http://www.acd.org.au/information/links.htm>

Australian Institute of Family Studies:  
<http://www.aifs.gov.au/cfca/pubs/factsheets/a143428/index.html>

Carers NSW:  
<http://www.carersnsw.asn.au>

Find a carer support group near you:  
<http://www.carersnsw.asn.au/groups>

## Appendix J: Human Research Ethics Committee Approval



**Research Integrity**  
Human Research Ethics Committee

Monday, 16 December 2013

Dr Jennifer Wilkinson  
Sociology; Faculty of Arts and Social Sciences  
Email: jennifer.wilkinson@sydney.edu.au

Dear Dr Jennifer Wilkinson

I am pleased to inform you that the University of Sydney Human Research Ethics Committee (HREC) has approved your project entitled **"Pulling Together or Pulling Apart: Investigating the Experiences of Mothers of Children with Disabilities"**.

Details of the approval are as follows:

**Project No.:** 2013/1051

**Approval Date:** 16 December 2013

**First Annual Report Due:** 16 December 2014

**Authorised Personnel:** Wilkinson Jennifer; Brock Sophia Ashleigh;

**Documents Approved:**

| Date Uploaded | Type                       | Document Name               |
|---------------|----------------------------|-----------------------------|
| 12/12/2013    | Participant Info Statement | PIS                         |
| 15/11/2013    | Participant Consent Form   | 2. Participant Consent Form |
| 15/11/2013    | Interview Questions        | 3. Interview Schedule       |
| 12/12/2013    | Other Instruments/Tools    | Resource List               |
| 12/12/2013    | Other Instruments/Tools    | Participant Letter          |
| 11/12/2013    | Recruitment Letter/Email   | Organisation Letter         |
| 12/12/2013    | Questionnaires/Surveys     | Questionnaire               |
| 12/12/2013    | Advertisements/Flyer       | Advertisement/Flyer         |

HREC approval is valid for four (4) years from the approval date stated in this letter and is granted pending the following conditions being met:

### **Condition/s of Approval**

- Continuing compliance with the National Statement on Ethical Conduct in Research Involving Humans.
- Provision of an annual report on this research to the Human Research Ethics Committee from the approval date and at the completion of the study. Failure to submit reports will result in withdrawal of ethics approval for the project.

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- All serious and unexpected adverse events should be reported to the HREC within 72 hours.
- All unforeseen events that might affect continued ethical acceptability of the project should be reported to the HREC as soon as possible.
- Any changes to the project including changes to research personnel must be approved by the HREC before the research project can proceed.
- Note that for student research projects, a copy of this letter must be included in the candidate's thesis.

**Chief Investigator / Supervisor's responsibilities:**

1. You must retain copies of all signed Consent Forms (if applicable) and provide these to the HREC on request.
2. It is your responsibility to provide a copy of this letter to any internal/external granting agencies if requested.

Please do not hesitate to contact Research Integrity (Human Ethics) should you require further information or clarification.

Yours sincerely



**Dr Stephen Assinder**  
Chair  
Human Research Ethics Committee

This HREC is constituted and operates in accordance with the National Health and Medical Research Council's (NHMRC) National Statement on Ethical Conduct in Human Research (2007), NHMRC and Universities Australia Australian Code for the Responsible Conduct of Research (2007) and the CPMP/ICH Note for Guidance on Good Clinical Practice.

## **Appendix K: Summary for Participants**

There were 18 mothers of children with disabilities who participated in this research, from various locations within NSW, Australia. The results of this research are based on analysis of the most consistent themes within interviews.

It was discovered that participants occupy a number of different 'roles' as mothers of children with disabilities. They are compelled to do so because of a lack of adequate support services, the gendered nature of care-work that continues to expect women to be the ones to carry the primary load of caring, and because of experiences with medical professionals devaluing or undermining their maternal knowledge.

Participants experience huge challenges in presenting their mothering and their children as 'normal' to the rest of the world, and as a result of this, they often wrestle with a sense of belonging, and how to challenge stereotypes and preconceived notions of what is 'normal'. How they behave as mothers is not only influenced by other people's perceptions of them and their children, but they self-regulate their behaviour. Often, in doing so, participants experience a sense of guilt if they cannot live up to the idealized standards of what it means to be a 'good mother'. However, participants develop strategies to try and push back against these regulations, judgements, and perceptions, to redefine what it means to be a 'good mother'.

Many participants struggle with a sense of ongoing grief – grieving for the loss of their 'imagined child' who does not have a disability, and/or grieving for the pain and struggles that their child with a disability has endured. They also experience struggles with how to present their families to the world. Yet again, participants come up with strategies that present their families as existing within a framework of 'normality', while also challenging the very concept of 'normality' itself.

In terms of participants' personal networks of support and personal relationships, it was discovered that many depended on a fairly small circle of typically female friends, their own parents, and their partners. Concurrently though, most consistently reported a sense of isolation, marginalization, and a lack of support and understanding from others.

Finally, many participants grappled with how to understand and speak about their sense of self and how they view themselves as women and mothers. It was found that engaging in paid employment, or occupying a predominant role in their lives that was separate to their role as mothers was important. Those who did not occupy other roles often reported a sense of 'losing' themselves or their identity. However, even participants who did occupy multiple roles in their lives experienced tension and ambivalence in trying to reconcile how these various roles fit in with their identity as mothers.

The following provides a summary of the findings and implications:

### **Motherhood**

1. Participants adopted a range of 'roles' as part of their mothering including: the primary carer, the expert, the advocate, and the 'modern day saint'. What compelled participants to adopt these roles included: a lack of adequate support services, the gendered and hierarchical nature of care-work, and a pattern of medical personal devaluing and dismissing their maternal knowledge.

Implications include:

- Significant levels of anxiety about the potentially unending role of being a primary carer – particularly in relation to their own death and who would look

after their child. These feelings were exacerbated by a dearth of viable alternatives for support.

- The intensive 'thinking' and 'emotional labour' that they were required to engage in when looking after their children.
- A sense of isolation, stigma, and marginalisation due to perceptions of otherness and difference.
- A feeling that they are failing to meet social standards of what 'good motherhood' is.

2. Participants experienced huge challenges in trying to navigate social expectations of what is considered 'normal' – both in relation to their mothering, and their children. They described a stereotype that exists of how a 'good disabled child' should look and behave. Participants both framed their mothering within 'normalised' standards, but also challenged and contested this very framework.

Implications include:

- Internal conflict and the inability of many participants to reconcile their unique circumstances with perceived societal norms.
- A struggle in finding a sense of 'belonging', while also recognising that their children's disabilities appeared to automatically preclude them from attaining social acceptance within certain contexts.

3. Participants experienced judgement and regulation from others such as the public, family, and friends, about how they should behave. They also self-regulate their behaviour, and at times participate in judgement of other mothers' behaviours. However, participants also challenge the regulation they experienced through working to redefine what it means to be a 'good mother'.

Implications include:

- Participants can feel trapped, frustrated, and regulated by other people's judgements of their behaviour. Although, experiencing such judgements can also result in participants self-monitoring and judging their own behaviour.

## **Relationships**

4. Participants struggled with how to 'display' and present their families to the rest of the world. These struggles often involved experiences of stigma and responses of grief. They drew on a number of strategies to display their families within the framework of 'normality', and also to build alternative – and at times subversive – ways of representing their families.

Implications include:

- Participants experience ongoing stigma, grief, and exclusion as a result of trying to negotiate how their family is represented in public spaces.
- This finding directly challenges the rhetoric of individualisation that supposes individuals in contemporary society have freedom of choice in how they construct their families.

5. Participants often depended on a network of personal relationships which both included and went beyond their familial relationships. They identified the importance of a small number of close friends, their partners and children, often their own parents, and other members of their extended network of support. Yet despite the persistence of important personal ties, participants consistently reported a sense of isolation, feelings of being misunderstood and marginalized, a lack of adequate support, and problematic connections in their social networks.

Implications include:

- An emphasis on the importance of social support networks for mothers of children with disabilities with people who are not only there for participants to talk to, but are active in their participation in participants' lives and their children's lives.

### **Sense of Self**

6. Participants often constructed a sense of identity in relation to other people, and drew on a variety of different roles or 'subject positions' when reflecting on who they are. Participants may see themselves holistically as mothers, as paid employees in their jobs, as students, and so on. Many felt tension between these different positions. For example, it was often difficult reconciling the positions of being both a mother, but also a paid worker in a role completely distinct from the role of mother. Although, the participants who less readily drew on other ways of describing themselves besides 'mothers' found it difficult to reflect on their sense of self, and often reported a feeling of 'losing' themselves.

Implications include:

- Expanding opportunities for women who are mothers of children with disabilities to occupy different positions outside that of 'mother' – for example through paid work or study – can help prevent/overcome this sense of 'loss' of self.
- An underlying sense of ambivalence, failure, and marginalisation plagued particularly those participants who did not see themselves as occupying other positions besides that of being a mother.
- Those who did occupy other positions still continued to feel some sense of ambivalence about their sense of self.

### **NDIS and Support Services**

This research was conducted in the context of the roll-out of the National Disability Insurance Scheme (NDIS) in parts of NSW, Australia. This scheme is the first, nationally funded scheme to facilitate a person-centred approach in supporting people with disabilities, allocating them individualised funding packages that they can use to orchestrate their care and support. However, the NDIS, so far, does not adequately address the needs of carers for those with disabilities, and participants in this research had mixed responses as to how the NDIS would change their lives and the lives of their children. The caring contributions of 2.6 million family members for those with disabilities in Australia is worth more than \$42 billion annually, and without the ongoing work provided by caregivers – such as the participants in this study – the NDIS would fail (Tops, 2014).

Both care-work and market-work are fundamentals for the stability of our society and growth of our economy, and those who are primary caregivers deserve to have the opportunity to engage in both if that is what they choose. In order to facilitate this choice, care-work must be financially valued, and alternative arrangements for quality out of home care, respite, and ongoing support must become more readily available and accessible. Additional research is needed into this important and emergent area of policy development and implementation, and social change.

Related to the NDIS and the positioning of care-work, are the ways participants experienced formal structures and institutions. This was a significant sub-theme that emerged from the study and included the ways participants experienced schooling systems, hospitals, medical staff, respite centres, out-of-home accommodation and care, and the NDIS. There are a number

of areas of concern that emerged from this sub-theme, which are important to consider in any discussion of the implications of the findings for future research and policy. These include but are not limited to the following.

- Parents being equipped with *knowledge* about the existence of support services in order to then be able to *access* to such supports.
- The financial burden that disability imposes. This includes not only the lost income of the primary carer if they are unable to engage in paid work, but the lost accumulation of superannuation for this carer. This is particularly important to consider if a primary carer separates from their partner who was their primary source of income support. The actual and potential prospect of long-lasting caregiving obligations has serious financial and other implications for families.
- The importance of out-of-home accommodation care options for those who cannot or choose not to continue providing in-home care for their children for the remainder of their lives. Equally, the importance of respite services to enable caregivers to continue providing care within the home if that is what they choose.
- Improving the delivery of support services. These services and medical institutions operate on the assumption that mothers of children with disabilities have, or will acquire, expert knowledge, but then routinely invalidate or dismiss such knowledge.
- The development and utilisation of a health systems database that medical professionals can access and contribute to in order to streamline the amount of information and discussion generated about a child's condition, often across multiple sectors. At the present, parents are often compelled to remember, record, and manage this complex amount of information to ensure each health worker is fully informed regarding their child's disability.
- Further encouragement for employers to offer flexible paid-work arrangements for those with caring responsibilities.
- A need for medical professionals to be particularly cognisant of the way that diagnosis of disability is delivered to parents who have a child with a disability. Immediate support needs to be offered to families after the diagnosis of disabilities. This may involve more systematic use of online communities.

The women who participated in this research generously offered me their time when they often had little to spare, and shared with me their stories of resistance, struggle, tenacity, resilience, and love. Their poignant reflections, passion, and strength are at the heart of this thesis, and it was an immense privilege to have been given the opportunity to undertake this research. I will be forever grateful to each of the participants, and the essence of their stories will stay with me.