MACQUARIE UNIVERSITY

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Doctor of Philosophy (Media and Cultural Studies)

Strange Country

Explorations through the territories of motherhood and child disability

Consisting of an EXEGESIS (60,000 words) and

a CREATIVE WORK of MEMOIR (40,000 words)

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CREATIVE WORK

**Strange country: True stories from the borderlands
of motherhood and child disability**

Summary

In this thesis, I explore the country of motherhood and child disability through research and creative practice. As the mother of an adult daughter with a severe intellectual disability, my lived experience underlies this work at the deepest level. To interrogate this territory, I have had to distance myself from its normalising processes, and so re-make it as 'strange'.

The 60,000-word exegesis investigates the stories that are told about mothers of children with disabilities. In the first part, I examine the ways in which these mothers are represented in the academic discourses of social science, philosophy and disability studies, and how these narratives both inform and are informed by dominant socio-cultural scripts, such as those found in the media. A current of marginalisation flows through much of this discussion, relieved by possibilities offered by feminist care ethicists, in particular the work of Eva Feder Kittay.

In Part Two of the exegesis, I turn to questions of self-representation. I delve into the ways mothers – and fathers – of children with disabilities narrate their own stories, and negotiate their own identities and those of their children, in their auto/biographical writing. Drawing upon relevant scholarship (Couser, Frank, and others) to analyse a sample of fifteen texts (solo works by mothers and fathers, as well as anthologies), I explore issues of generic expectations, authorship and entitlement, emplotment strategies, and the ethics of writing about one's own vulnerable child. A major consideration is to what extent these parental authors challenge – or comply with – prevailing representations. Of particular concern also is the effect of gender: how the stories told by mothers and fathers differ, and why those told by fathers have garnered more attention in both the public and academic spheres than those by mothers.

The 40,000-word creative work, selections from a memoir of my own journey through this strange country, consists of a collection of stories, essays, reports and dreams about my daughter, myself and our relational others, held together through the metaphor of the mosaic. As research, this work inquires into the way prevalent social scripts, research, other parental narratives, and lived experience combine, interact, interfere, and sometimes collide in the formulation of story.

Candidate's statement

I certify that the work in this thesis entitled "**Strange country: Explorations through the territories of motherhood and child disability**" has not previously been submitted for a degree, nor has it been submitted as part of requirements for a degree to any other university or institution other than Macquarie University.

I also certify that this thesis is an original piece of research that has been written by me. Any assistance that I have received in my research work and the preparation of the thesis itself has been appropriately acknowledged.

In addition, I certify that all information sources and literature used in its preparation are indicated in the thesis. The Macquarie University Ethics Review Committee has deemed that ethics approval for the research presented in this thesis was not required (see Appendix).

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My family has supported me tremendously during this expedition, especially my three daughters. These beautiful young women have been my inspiration. The eldest, Laura, has been keenly involved throughout, and I wish her well as she undertakes her own doctoral research into the social and political construction of intellectual disability, and what it means to be the sister of someone with a disability. Gabrielle, my youngest, has been, as ever, a constant source of energy and spirit. Both have kindly helped me out with proofreading. And of course, my thanks go to Amelia, without whom this research and this story would not exist.

Chapter One

INTRODUCTION

What is this strange country?

I am mother to three daughters, but it is my relationship with just one of these young women that is central to this project. Amelia, my middle daughter, has a severe intellectual disability.

Years ago, when Amelia had just started at a special unit for children with disabilities in a mainstream school, I attended a sign language class at the local technical college. I wanted to learn to sign so that I could use Makaton, the simplified signing system developed for use with children with intellectual disability. A woman in the group, a school teacher, asked me what type of work I did. When I answered that I was a lecturer in professional writing at the nearby university, she took my hand and looked at me intently.

'You know what you've got to do then, don't you,' she said.

'No,' I replied. 'What do I have to do?'

'Write about it, about you and your daughter. That's what you have to do.'

But the burden of destiny she had placed in my hands was too shapeless and heavy for me to carry back then. There were matters of identity and self-disclosure to consider, of privacy and consent regarding my daughter and other family members, of truth and memory, and more basically, of time to do the writing. But the bigger problem was that I didn't think my experience was narratable: I didn't have a coherent story to tell, nor did I wear the badge of entitlement to commit to such a task. I made a side-step instead and wrote novel for young adults, about a teenage girl who had a brother with a disability. The mother in that story – a nervy, shadowy character, almost a caricature – was, of course, based on me.

Now Amelia, at 24 years old, is grown up. While her sisters' lives have been shaped by achievements, and plans, and growing independence, Amelia is still as dependent on me as she was all those years ago. She, too, has achieved much, but on a smaller scale: she has learnt to run, to eat independently, and to communicate her wants and needs. She has clear likes and dislikes, and a stronger sense of both herself and the relationships that surround her. Her life continues to shape mine in fundamental ways: now, as she continues to need a high level of care and support, I find myself in a very different life-place to my peers, the mothers of typical grown-up children. But I am no longer absorbed in the foggy world of mothering a young child with severe disability;

the shapes are becoming clearer now, and snatches of meaning are emerging. There will never be a clear narrative plot to direct or contain my daughter, myself and our family, and no illuminating theme to identify our truth, because our lives together are a work-in-progress.

Now it's time to tell the story of our journey through strange country: strange, because it is atypical; strange also because, in order to write about it, I have had to estrange myself from it, and make it strange.

This thesis is about the stories people tell about mothers of children with disabilities, by researchers and theorists, by mothers themselves, and finally, in my own memoir.

I begin, in this introduction, with a brief discussion of what it means to be mother of a child with disability. I follow with a snapshot of the themes and tropes that surface in the media about mothers like me, not so much as a research investigation, but as a backdrop to the chapters that follow; to address these representations in media and popular culture in depth would require a different exegesis altogether. My primary aim in Part One is to investigate how mothers of children with disabilities are described, discussed, and theorised in relevant academic disciplines. I want to explore how these representations inform and are informed by the socio-cultural narratives (including those of popular culture) in which our lives are embedded.

In Part Two, I investigate the ways parents of children with disabilities self-represent in their autobiographical writing: how they negotiate this narrative landscape, and how (and if) they engage with the public and academic discourses that surround their experiences. In short, I want to know how parents tell their own stories. I consider here writing by fathers as well as mothers for two key reasons: firstly, it emerges that fathers are disproportionately over-represented in academic discussion of parental memoirs of child disability; and secondly, because significant differences are apparent in the stories that are, and may be, told by mothers as opposed to fathers about this experience of parenthood.

Part Three comprises my creative work, a set of true stories that chronicles my own passage through this strange country of marginalised motherhood.

But first, what is it about mothers of children with disabilities and the stories that surround them that warrants this exploration?

Mothers of children with disabilities: 'Distilled and magnified versions of motherhood'

How does mothering a child with a disability differ from mothering a typical child? Mothering in general involves intensive caregiving; Ruddick (1980) defines mothering practice as involving the normative demands of protection, nurturance, and development. For mothers of children with disability, and particularly severe intellectual disability, this experience is more intensive and longer-term, often continuing well into the child's adulthood. It is associated with higher levels of poverty and increased likelihood of marriage breakdown. It is also transgressive: giving birth to a child who will never become an independent citizen, who will never be a productive member of the workforce in an economy-driven society, is an aberrant act.

Motherhood in all its forms is subject to complex and contradictory ideologies: 'the mother is romanticized as self-sacrificing, life-giving and forgiving, while simultaneously being demonized as smothering, overinvolved and destructive' writes Reid (2000, 71). These representations are, Reid claims, especially hazardous for mothers of children with disabilities, because 'the demands placed upon the mother-child relationship go far beyond what is expected of those between non-disabled children and their mothers'. As such, 'the ways in which mothers of disabled children have been characterized over time can be understood as distilled and magnified versions of motherhood more generally ... The stage is set for casting the mother [of a child with disability] in the role of self-sacrificing angel, over-possessive demon, or other, milder variants on the same theme' (2000, 107).

Mothers of children with disabilities, Reid claims, are isolated from the mainstream social world of motherhood, and hence experience a sense of 'ghettoisation' (2000, 116). Their task of negotiating and advocating for their child in an essentially hostile social environment 'becomes an almost inevitable and necessary part of their own and their children's lives' (2). Likewise, Home (2002) refers to the 'hidden oppression' of

these mothers: a double oppression, as women in a patriarchal society, and as mothers of disabled children in an ableist world. This oppression, Home contends, often seems hidden from the mothers themselves because the ideology of caring – of presenting oneself as 'the good mother' – condones this marginalisation.

Until the 1980s, the mother as a subject of inquiry had been virtually ignored by researchers (Reid 2000, 70; Held 2006, 26-28). Reid describes how, after the Second World War, the popularisation of psychoanalysis and its derivatives led to a plethora of prescriptive messages about mothering, which typically emphasised the critical nature of the mother-child bond, and delivered instructions and 'rules' for effective mothering. Motherhood was deemed to be 'natural', and mothers were exhorted to immerse themselves in their role with 'extraordinary devotion' – while at the same time acknowledging the authority of scientific experts over their practices (Reid 2000, 73).

In the 1960s and 70s, the new discipline of women's studies launched a challenge, with feminist scholars arguing that mothering was not 'natural' per se, but socially and politically constructed within a patriarchal social system (Reid 2000). Feminists sought to differentiate between the bodily processes of reproduction and the socially constructed nature of mothering. Motherhood and the family were regarded by second-wave feminists such as Firestone (1970), Millett (1970), and Mitchell (1974) as institutions of patriarchy that entrenched the oppression of women. In reaction, branches of women's studies emerged in the 1980s that sought to describe the lived experience of mothers and the family more positively. Black British feminists, for example, drew attention to other factors (class and race) that contributed to their marginalisation in the public sphere, and claimed that, 'the black family has functioned as a prime source of resistance to oppression' (Carby 1997, 46). In the US, a branch of feminist philosophy known as the ethics of care developed that placed issues of dependency and care at the centre rather than the margin of human experience (Gilligan 1982; Noddings 1984; Held 2006). But there was as yet no place available for mothers of disabled children in this reconceived vision of idealised and empowered motherhood.

Motherhood research since has evolved to acknowledge the experiences of a more diverse range of mothers. For example, *Mothering against the odds: Diverse voices of*

contemporary mothers (eds Garcia Coll, Surrey and Weingarten, 1998), brings together perspectives from mothers who are single, adoptive, immigrant, homeless, lesbian, imprisoned, HIV-positive, poor African-American, and deaf, as well as mothers of a children with severe disabilities. In a more recent anthology, *Disability and mothering: Liminal spaces of embodied knowledge* (eds Liewicki-Wilson and Ciello, 2011), the experiences of mothers of children with disabilities and mothers who themselves have disabilities are explored through the lens of the humanities and cultural studies, with attention to the intersection of these identities with issues of race, ethnicity, class and history. But discussion of disability continues to be quarantined from mainstream literature on motherhood: for example, a recent collection of essays, *The good mother: Contemporary motherhoods in Australia* (eds Goodwin and Huppatz 2010), includes no reference to mothers of children with disabilities nor mothers who have disabilities themselves.

As traditional conceptions of the family are challenged and transformed by new configurations, motherhood in general is today being re-imagined in various ways. But in spite of these developments, ideas – and realities – about the lives of mothers of children with disabilities are slow to change. The way these mothers' lives are socially constructed could be said to have more in common with the lives of mainstream mothers forty years ago. As the following chapters will reveal, the themes that permeated the literature then, particularly those around 'extraordinary devotion', and 'natural' (and normalised) ideas of mothering persist.

While most mothers today may enjoy a wider range of options for performing identity, some recent developments may undermine these broadening agenda. Landsman (2009) discusses the increased technological surveillance of pregnancy, and how the themes of choice and personal responsibility in contemporary discourse about pregnancy reinforce messages of mother-blame; these are internalised by all mothers, but particularly by mothers of children with disabilities (Knight, 2013).

Trauma, identity, and mothers of children with disabilities

When her child is diagnosed as having a severe disability, a mother's vision of herself as an effective mother and her child as the imagined perfect child is likely to be

shattered, in a socio-cultural environment where disability is aberrant and mothers are deemed responsible for foetal health and safety. She experiences a 'disruption' to '[her] global interpretation of life's events' (Trute et al, 2010). Ryan and Runswick-Cole describe this disruption as a turning point 'in which mothers may experience an anomic period in which the ways they have made sense of the world and dominant norms and values that guide their understandings are no longer relevant' (2008, 203). Another way of expressing this crisis is that the woman's life narrative has dismantled.

This experience of disruption and disintegration is tantamount to trauma. 'Trauma, from the Greek meaning "wound", refers to the self-altering, even self-shattering experience of violence, injury, and harm' writes Gilmore (2001, 6). The violence experienced by the mother of a child with disability is embodied as her own transgression against the cultural expectations of motherhood. Few of the narratives available to her, as we will see in Part One, acknowledge the intensity of this violence; it remains unspeakable. Along with this psychic crisis, the mother of a child with a disability experiences the grief of losing the imagined child, but this grief, too, is unspeakable because her child is not, in fact, lost: the child is there, to be loved and nurtured and *worked on*; the mother is exhorted to recover the lost child, the socially valued child, through her compliance with medical interventions and her own efforts of care and remediation.

The dilemma of voicelessness as a symptom of the trauma response, and the simultaneous need to mobilise language in order to make sense of the source of trauma, is described by Gilmore:

> Crucial to the experience of trauma are the multiple difficulties that arise in trying to articulate it ... Something of a consensus has already developed ... that trauma is beyond language in some crucial way, that language fails in the face of trauma ... Yet ... language is pressed forward as that which can heal the survivor of trauma. Thus language bears a heavy burden in the theorization of trauma. It marks a site where expectations amass: Can language be found for this experience? Will a listener emerge who can hear it? (2001, 6)

In spite of this dilemma, the mother of a child with disability faces the tasks of both articulating her trauma and integrating her experience into a new framework of meaning that offers her the promise of valued identities for both herself and her child.

Finding a story: interpellation and resistance

'Getting a life means getting a narrative, and vice versa,' write Smith and Watson (2001, 81); the formulation of story is a fundamental aspect of performing identity. Stories, Frank argues, are also active agents; they have the capacity to determine, not merely reflect, how our lives unfold. He cites Mattingly in this regard: 'Experience is, at best, an enactment of pre-given stories' (Mattingly, 1998, cited in Frank 2010, 21).

The telling of our own stories is enabled but also constrained by those narratives that populate the socio-cultural landscape in which ours take shape. As Frank explains: 'People tell stories that are very much their own, but they do not make up these stories by themselves' (2010, 14). Frank borrows from Bourdieu's concept of 'habitus' in coining the term *narrative habitus* to describe the repertoire of possible scripts or stories that someone is disposed to: those that call to, or interpellate, the person; those that both resonate with them and can be mobilised (52). Narrative habitus is 'the unchosen force in any choice to be interpellated by a story' (53). These scripts are powerful; they encode and rehearse the accepted parameters of identity; and we may be drawn to take up particular stories in spite of ourselves. These narratives hail both tellers and listeners: they determine what will be listened to, as well as what may be told.

When a woman becomes a mother, she is necessarily interpellated by the repertoire of narratives of motherhood. However, when her child is diagnosed with a disability, her entitlement to appropriate these narratives is threatened. Other stories of borderland motherhood replace those from the mainstream; she may try to resist these as they direct her to take up marginalised identities for herself and her child. According to Frank, storytellers have the capacity to resist the prescribed narratives, and refuse interpellation: 'Vital, breathing stories can break through the filters and grids. Stories can make themselves heard whether or not they fit a narrative habitus' (2010, 59). This process of disruption Frank calls 'narrative ambush'. But such resistance is difficult, because the pre-existing scripts are so firmly entrenched in the narrative landscape; there may be no alternative roadmap for the storyteller to follow; and divergence from the trail may be deemed transgressive.

For the mother of a child with disability, the capacity to resist interpellation by these cultural scripts is compromised by the psychic impact of her trauma and subsequent

self-alienation. Struggling with difficulty to speak of her experience, she will be diverted towards the sanctioned stories of the narrative habitus. To understand the marginalisation of these mothers, it is critical to have knowledge of these various narratives that operate to contain her experience and her identity. Her first encounters with them will likely come long before she becomes the mother of a child with disability, through the discourses of the media and popular culture. Her new identity will be informed by, but also undermined, challenged, and reshaped by these media representations.

Media narratives: Saints and heroes, fallen angels and demons

In popular culture, families with a child with disability seldom appear, but when they do, it is always a marked presence: the child's disability becomes the problem around which the news item or story is conceived. The mother occupies a central role in the unfolding drama, and she is invariably positioned as an outsider to normal family life. I offer here a snapshot of the ways in which mothers of children with disability are represented in popular culture both as an indication of the limited options for performing identity that confront her, and as a prelude to the detailed exploration of the narratives of motherhood and child disability in academic discourse that follow in subsequent chapters.

While the angel and the demon figure in portrayals of all mothers, these archetypes emerge as central in the popular representation of mothers of children with disabilities. At one end of the spectrum is the saintly, virtuous mother who dedicates herself to the caring role and in so doing embodies the highest moral qualities of sacrifice, selflessness and devotion. The two mothers described in the following news article[1] exhibit these qualities.

Suburban mothers of disabled children face relentless challenges[2]

By Anna Madrzyk, *Daily Herald,* 5 Oct 2011

Diane Carpenter will host her family for Mother's Day at her Winfield home again this year. It's work, but it's so much easier than taking her 25-year-old daughter out.

"I have to watch her every second," Carpenter said, "so it's never relaxing for me to take her anywhere."

Debrina Moore will be home too, perched on one small corner of her 5-year-old son Christian's hospital bed in their Glendale Heights home. Daughter Cabri, 11, will climb on the other side. Together, the little family will watch a church service on TV.

"I wish we could go out to dinner," Moore said.

She's sad for a moment, then shakes it off.

For both of these extraordinary women, even Mother's Day is no vacation from the relentless challenge of caring for severely disabled children.

The figure of the self-sacrificing mother who appears in this news story is pervasive not only in popular culture, but in other public communications, such as the item overleaf (Figure 1.1), from the newsletter of a disability service provider. These examples are reminders of the deep mythical associations between disability and spirituality that Snyder and Mitchell describe:

> [D]isability ... promises a longed-for access to the otherworldly, because bodily aberrancy has been historically interpreted as the material signature of the divine order. (Snyder and Mitchell 2001, 379)

The attribution of the qualities of especial goodness to these mothers means that on the one hand, the mainstream social world is effectively absolved from responsibility towards them; and on the other hand, these mothers are discouraged from speaking out: they should, instead, embrace their special otherness.

The Special Mother

God is hovering over the earth, selecting his instruments of procreation with great care ... He instructs His angels to make notes in a giant ledger.

"Armstrong, Beth: son, Patron saint: Matthew
Forrest, Marjorie: daughter, Patron saint: Cecilia
Rutledge, Carrie: twins, Patron saint: give her Gerard, he's used to profanity."

Finally He passes a name to an angel and smiles. "Give her a child with multiple disabilities." The angel is curious. "Why, Lord? This one is so happy."

"Exactly," says God. "How could I give a child with disability to a Mother who does not know laughter? That would be cruel."

'But does she have patience?' asks the angel.

"I don't want her to have too much patience, or she'll drown in a sea of self-pity and despair. Once the shock wears off, she'll handle it."

"But Lord, I don't think she even believes in You."

"No matter, I can fix that. This one is perfect. She has just enough selfishness."

The angel gasps. "Selfishness? Is that a virtue?"

God nods. "If she can't separate herself from her child, she'll never survive. Yes, here is a woman I will bless with a child who is less than perfect. She doesn't realise it yet, but she is to be envied. She will never take for granted the spoken word... When her child says "Mummy" for the first time, she will be witness to a miracle. When she describes a tree to her blind child, she will see it as few people ever see My creations.

"I will permit her to see the things I see – ignorance, cruelty, prejudice – and I will allow her to rise above them. She will never be alone. I will be at her side every minute of every day of her life because she is doing My work."

"And what about her Patron Saint?" asks the angel, his pen in mid-air.

The Lord smiles.

"A mirror will suffice."

Figure 1.1: 'The Special Mother', reproduced from a respite service provider newsletter

Still on the positive end of the spectrum of representations is the hero-mother who articulates her adversities and mobilises her energies for the good fight. Her aim is to bring public attention to the injustices faced by her family and others like hers. She will be celebrated for her honesty and courage, as this news item illustrates.

Jane Raca: fighting for life support for her disabled son[3]

By Amelia Gentleman, *The Guardian,* 15 Jan 2013

The only book Jane Raca found to read when her son was born at 24 weeks and diagnosed with severe disabilities, was one written by the mother of a child with cerebral palsy, which began with a poem: "Fly, my darling, fly out on your wings!"

"I remember thinking: 'Oh God, no! It's not for me,'" she says. "It was all terribly soppy." Thirteen years later Raca has written an account of her own experiences, which cannot be described as remotely soppy. The book describes her misery, her fury, her suicidal thoughts, the damage to her marriage, her prolonged depression, without even a cursory attempt to splash the narrative with a saccharine-coating.

The result, *Standing Up for James*, is an incredibly honest and powerful description of one family's experiences. Alongside the gripping human account of bringing up a disabled child is a searingly angry portrayal of the state's failure to support her family properly in the years following his birth.

This brave mother-figure recounts her battles, but also her survival. The media is more likely, however, to relate the stories of those whose performance of this marginal version of motherhood is more problematic. In these cases, personal failings are laid bare, and the private world of the family is opened to public scrutiny.

The first of these types, the good but flawed mother – the fallen angel – typically appears on tabloid television programs or in the press, at the limits of endurance. She has struggled, but without adequate services to support her in the present, and with no possibility of relief in the future, she relinquishes her caring role. It is likely that she has called upon the services of the media to bring her plight to public attention, and the sympathy that this generates is often enough to trigger action from the authorities. The news item below exemplifies this emplotment.

Feeling the Strain: the Battle for Care that's Pulling Families Apart[4]

By Isabelle Archer, *Marie Claire*, 2 Feb, 2010

When news broke that Australia's only boarding school for disabled kids was set to close, it exposed once more the heartbreaking lack of support for their families.

Like many Australians, Anita Cain adjusted her clocks on April 1, 2006, to reflect the end of another Sydney summer. In Anita's case, though, this was a task that had to be completed with military precision: her 11-year-old son, Niall, was born with a range of disabilities that included obsessive-compulsive behaviour - and timekeeping was one of his obsessions. After touring the house, the single mother of one was convinced she'd put back every timepiece, but had forgotten to adjust the spare watch Niall kept on his bedside table. When he noticed the next day, he lost control...

As she stood in the wreckage of her kitchen, her son's inconsolable wails filling the room, something in her snapped, and she came to a realisation that filled her with shame and guilt: she could no longer share a home with her son...

The next morning, Anita left her confused and vulnerable son at a respite centre, abandoning him to the care of the NSW Department of Community Services (DoCS). A month later, she would formally relinquish her parental rights.

Finally, at the farthest extremity is the rare mother who violates every principle of motherhood by committing the unspeakable: she kills her child, and possibly herself as well. The public responds with horror and fascination, but also typically with sympathy for this mother who has been pushed too far. She functions as a powerful agent of catharsis for mainstream mothers.

Beverley May Eitzen acquitted of killing disabled son Peter[5]

By Sean Fewster, *Adelaide Now,* June 16 2011

A mother who killed her severely disabled son has been acquitted of murder due to her mental incompetence.

Beverley May Eitzen, 46, wept in the dock as the Supreme Court this morning found her not guilty of murdering her 16-year-old son, Peter, in July 2009.

Handing down his findings, Justice John Sulan said Ms Eitzen was suffering from "a major depressive episode" when she fatally stabbed Peter in the back seat of the family car.

Justice Sulan said Ms Eitzen had lived a long and difficult life as Peter's primary carer.

Underlying these representations is the persistent message that caring for a child with disability is not only burdensome but well outside the parameters of normal family life. Gibson (2012) discusses how a feature article on 'Stress' in a Canadian metropolitan newspaper singles out mothers of children with disabilities as exemplars of the impact of stress: 'One study of mothers who care for disabled children found the length of their telomeres [DNA molecules that protect chromosomes from fraying or fusing] tied to how much stress they were under. Each year of child care caused roughly six years of aging.' The options that the media makes available to these marginalised mothers Gibson describes as 'murderer, oppressor, martyr, or saint'. 'Once you are a mother caring for a disabled child,' she observes, 'your story is written.'

In their review of Australian print media articles about autism, Jones and Harwood found that the proportion of stories that conveyed negative impressions of autism was increasing: 'Between 1999 and 2003 "positive" stories outnumbered "negative" stories, however, this pattern was reversed in 2004 and 2005, with a predominance of articles focusing on "negative" stories' (2009, 9), typically about parents in crisis, abandoning or harming their child.

This picture of gruelling family life reinforces the public perception of mothers of children with disability as 'distilled and magnified versions of motherhood' (Read 2000). These stories emerge as isolated shouts and cries that break through the social silences. But they also contain these mothers' experiences within standardised scripts, and mould these lived realities into items for public consumption and catharsis for mainstream families. In so doing, they perpetuate the marginalisation of mothers and their children with disability. By their pervasiveness, they limit the emplotments available to mothers for telling other kinds of stories. They support Ware's observation that: 'Most contemporary accounts of disability in the media are typically uninformed by history, literature, art, or any perspective other than psychology and medicine' (2002, 144).

While media representations impact the way mothers see themselves and others see them, they are just one set of stories about our experience. In order to explore this terrain more fully, I needed to explore other narratives, to go further and deeper. I needed to find out about the stories that scholars tell, and how they interpret our lives.

I needed to move beyond the messages of the media, and draw on the authority of research.

Narratives from academic disciplines and rights discourse: Part One

In the three chapters that follow, I explore the ways in which mothers of children with disabilities are investigated, analysed, described and positioned within academic and rights discourse; in short, what researchers and disability activists have to say about this experience of marginalised motherhood. These narratives function as critical constitutive discourses that inform (and are informed by) social policy as well as popular cultural representations and the self-perceptions of mothers themselves.

While research into mothers of children with disabilities does not occupy major disciplinary territory in the academy, these mothers have been the subject of research for at least forty years. Review of this academic literature is critical to my project for several reasons.

Firstly, it represents the body of knowledge about these mothers and their families. Not only does it present valuable information about their lives, but it identifies the key questions and debates surrounding them, and the history of these investigations. It reveals why this research is conducted, which issues are on the agenda, which are ignored, and by whom.

Secondly, because this research on mothers comes out of different areas of the academy, a review such as this provides an opportunity to bridge disciplinary boundaries, and to move between the academic silos. It allows for drawing connections and highlighting contrasts between the different ways of knowing that characterise these disciplines. It provides a rich understanding of the complex ways in which these mothers are socially, culturally and politically constructed.

Thirdly, an interdisciplinary understanding produces a diversity of narratives. In contrast to the stories from the media and popular culture, these narratives are stamped with the authority of academic research. They inform policy and service delivery, generate public debate, and imagine the future. These stories reach out

beyond the confines of the academy to influence the lives of their subjects in many ways.

The disciplines that have been identified as specifically addressing issues pertinent to mothers of children with disabilities are the social sciences; philosophy; and disability studies.

The main site of research into families of children with disabilities is empirical social science research, particularly at the intersection of research into intellectual disability and family studies, and this literature is reviewed in Chapter Two. This substantial body of predominantly quantitative research deals with the impacts of child disability on families, and mothers are typically the subjects of investigation: 'the vast majority of "family" research might be better characterized as "maternal" research' (Bailey 2007, 292). Other relevant social science research, including ethnographic studies, is also reviewed in this chapter. The aim is to understand the evolving ways in which mothers have been positioned in the social sciences in recent decades, reflecting changing attitudes to motherhood, family life, and disability.

In Chapter Three, the focus turns to philosophy, and as such, to more theoretical and normative concerns. Five branches within philosophy and related areas are identified in which issues around intellectual disability and caregiving have been addressed: eugenics and bioethics, moral philosophy, critical theory and psychoanalysis, theological ethics, and feminist theory. In several of these areas, reference may be tangential, but nevertheless the narratives that these discussions give rise to are powerful. For example: in addressing eugenics, we are reminded of our recent history of state-sanctioned disavowal of the disabled body (and how some current practices reflect this still); and in considering the work of critical theorist Julia Kristeva, we confront how firmly embedded in our subconscious selves these prejudices and practices are. In other areas, such as feminist philosophy, and in particular theorising around the ethics of care, caregiving and disability are high on the agenda. New narratives are offered which have the potential to change this landscape.

Chapter Four explores the position of parents of children with disabilities in disability studies and disability rights discourse, as well as outlining some of the key debates in these areas that impact on parents and their children. In this literature, parents (i.e. mothers and fathers) are more commonly the subject of discussion rather than mothers

only, and they are cast in an ambivalent position: neither disabled, nor non-disabled by virtue of their intimate association with their children, they are deemed to be neither truly part of the disability experience, nor outside it. Also discussed is the often conflictual interaction between rights activists and parents, and how the carers' movement offers a possible, if contested, place for parents to speak and be heard.

These various discourses present a picture of a landscape that is not easy to navigate. Mothers of sons and daughters with disabilities may not be familiar with these theoretical debates and research outcomes, but their lives – and their own stories – will be impacted by them, as these discourses permeate the social and political world in which they find themselves. How they negotiate their way through this territory to give voice to their own experiences is the subject matter of Part Two.

Their own stories: Part Two

Increasing numbers of parents, and particularly mothers, are writing and publishing book-length accounts of their lives with children who have disabilities. These books play a critical role in the lives of families, in framing and validating their experience. But how do these writers carve out their stories in the contested spaces available to them? Do they fall back on the available cultural scripts, such as those that proliferate in popular culture, or do they take up Frank's (2010) call to enact narrative ambush? And who is doing this writing?

In Chapter Five, issues around the writing and publishing of parental memoirs of child disability are discussed. A sample of 15 books is introduced for investigation. These texts are analysed in Chapters Six to Nine according to key issues identified by researchers whose work focuses on narratives of disability, notably Couser (1997, 2004a, 2004b, 2009) and Frank (2004, 2010).

In Chapters Six and Seven, this analysis concentrates on the issues of genre and authorship. A consideration of genre provides insights into the shared 'communicative purposes' (Swales 1990) of these works, as well as conventions of form. The discussion of authorship addresses issues of class and race, and how these confer entitlement to take up the autobiographical project. Of particular interest, however, is the question of gender: how mothers and fathers deploy very different narrative strategies and modes of representing themselves and their child, and how their works

are differently received in scholarly discussion and the marketplace. These issues of gender permeate other topics in Part Two.

Chapter Eight addresses the emplotments mobilised by authors in the sample. These are discussed in terms of the rhetorical patterns widely employed in disability and illness life writing that have been identified by Frank (1999) and Couser (2009). Do these authors conform to these well-established scripts? Or do they enact 'narrative ambush' (Frank 2010) by producing what Couser identifies as 'counterhegemonic' (2009) narratives?

The concern of Chapter Nine is the ethics of parental writing about children with disability, 'those most vulnerable subjects' (Couser 2004, 56). How authors rationalise their life writing projects in ethical terms is addressed. Also discussed are the ways in which particular textual and linguistic elements in these works support – or undermine – ethical representation of the child with disability.

My explorations in these chapters have necessarily shaped the development of my own memoir, and in Chapter Ten, the focus turns to the creative component of this thesis. Drawing upon the work of Gilmore (1997, 2001), Friedman (1998), and Smith and Watson (2001), in particular, I reflect on my own creative practice, both as a female autobiographer and a mother of a child with severe disability.

Strange country: A memoir

This creative work addresses my lived experience as the mother of Amelia, my daughter who has a severe intellectual disability, from her birth to age 23. Simply by including aspects of life with Amelia as an adult, this account differs from the majority of parental memoirs which focus on the childhood years (see Chapter Five).

As research, this memoir delves into the way prevalent social scripts, research, other parental narratives, and lived experience combine, interact, interfere, and sometimes collide in the formulation of story. It also explores some of the textual strategies that may be mobilised in a representation of marginalised motherhood.

For reasons of length, the entire memoir could not be included in this thesis. Accordingly, the creative work consists of a selection of chapters taken from the full work (approximately two-thirds of the total word length).

Before moving on, several issues that are significant for the framing of this thesis need to be addressed. The first of these is the focus on 'mothers' rather than 'parents' in this thesis. The second is terminology: throughout the Anglophone world, different conventions apply for referring to persons with disabilities, and my choices of terminology in this thesis need to be explained. The third involves the seeking of ethics approval for this research involving creative practice through the Macquarie University Ethics Committee.

Why 'mothers' and not 'parents'?

In Part Two, narratives by fathers are considered along with those by mothers, but the focus of this thesis, and Part One in particular, is on mothers of children with disabilities.

Fathers, too, are closely involved in the raising of all children, including children with disabilities, and this needs to be acknowledged. But mothers are overwhelmingly the primary carers of their sons and daughters with disability, throughout their childhoods and into adulthood. As Kittay explains:

> 'Care of dependents is not inevitably nor exclusively the province of women. But it is *mostly* women who are dependency workers ... [T]o ignore the *fact* that most of the care of children is done by mothers, and to call this work of caring for children parenting rather than mothering is a distortion that serves women poorly' (1999, xiii, author's italics).

Read writes that in two-parent families 'it is well-documented that it is the mothers who carry the main responsibility for the care and upbringing of their disabled children ... Even when fathers are unemployed or at home for other reasons, the caring work and responsibility is not distributed equally' (2000, 52).

There is indeed a dearth of research addressing the impacts of fathering a child with disability. My family experience supports the proposition that these fathers, too, are a marginalised group, and that their exclusion is expressed in different but profound ways. As fathers of typical children are now more commonly embracing a hands-on parenting role, fathers of children with disabilities who do so face additional and different barriers to participation and acceptance from their peers. Further research into the role of fathers is definitely needed.

The most obvious reason for focusing here on mothers is, however, a simple one: I am mother to my daughter, and my experience has been informed in fundamental ways by my gender: bodily, socially, culturally, and politically.

People with disability: Terminology

The terminology used throughout this thesis to refer to people with disability reflects the 'people first' emphasis that applies within the Australian context of writing, where the terms 'people with disability', 'people with a disability', and 'people with disabilities' are used interchangeably. The rationale behind this usage is that emphasis is placed on the person rather than the disability. This 'people first' terminology is also preferred in the US and Canada.

In contrast, the terms 'disabled people' and 'disabled person' have currency in the UK. The argument is that people with impairments are subject to a process of disablement by a social world that fails to accommodate their needs: 'disability is not something emanating from individuals' bodily differences, but a social process by which inaccessible environments disable particular people' (Matthews 2008). This perspective derives from the social model of disability, which will be described in Chapter Four.

Australian researchers and advocates, however, also subscribe to the social model, and do not regard the 'people first' usage as undermining this political emphasis.

A recent concern, which will be discussed further in Chapter Four, is that a focus on the external disabling factors that take precedence in the social model has de-emphasised the lived, embodied experience of impairment. My use of 'people first', then, is consistent not only with my geographical location, but also with an

acknowledgement that impairment, as well as its social construction as disability, is experienced as intrinsically embodied by individuals.

As a result of these differences in terminology, quotes in the text reflect the preferences of the cited authors.

While the term 'intellectual disability' is used commonly throughout the Anglophone world, there are alternatives to this terminology also due to regional preferences. In the UK, the term 'learning difficulty' or 'learning disability' is commonly used. The out-dated term 'mental retardation' has generally been replaced universally by 'intellectual disability', but several major US-based journals within the medical and behavioural/social sciences continue to use it (such as *Mental Retardation and Developmental Disabilities Research Reviews* and *Mental Retardation*).

I use the term 'people with intellectual disability' throughout because this is the way people with intellectual disability in Australia choose to refer to themselves. I stray from this usage from time to time in Chapter Three to reflect the common application, within philosophical discourse, of the words 'cognitive impairment'.

Following 'people first' conventions, I use the terms, 'children with intellectual disability', and 'child with intellectual disability'. In many instances I have shortened these to 'children' or 'child with disability', given that the group I am referring to throughout consists of those with intellectual disability. This group also generally refers to those with more severe intellectual disability and complex care needs; in short, those who need and will continue to need help with daily living tasks throughout their lives.

 I avoid the terms 'child with special needs' or 'special child' that has widespread currency across the Anglophone world in service delivery and parent narratives, because this term is non-specific, it is used predominantly with young children, and most importantly, it has euphemistic overtones. Accordingly, I also refrain from using the term, 'special mother' to refer to the mother of a child with a disability.

Seeking ethics approval for research by creative practice

Approval from Macquarie University's Human Research Ethics Committee was sought for conducting this research involving creative practice. In my application I discussed the ethical sensitivities of this project, which involved the representation of family members, including my daughter who has a severe intellectual disability (aged 21 at the time). I submitted the documentation, incorporating draft consent forms (including a proxy form for my daughter who has a disability) and mechanisms for enabling feedback and review from those who would be represented.

I was subsequently informed by the Committee that the research activities listed in the application did not require approval because 'the involvement of family members in the research is not to provide Ms Knight with data (as defined in the *National Statement on Ethical Conduct in Human Research 2007*) but to corroborate Ms Knight's experiences'. A copy of this document is appended to this thesis.

This outcome was concerning to me as a researcher. It appeared that the Committee did not fully appreciate the ethical responsibility underlying autobiography as a research methodology. There was also the compounding issue of representing a person of extraordinary vulnerability, such as my daughter, who does not, and will never have, the capacity to consent independently.

This incident points to the need for further discussion and debate in order to support autobiography as a research methodology, and to emphasise the ethical responsibilities of autobiographers working within a university environment. In response to this outcome, I have nevertheless instigated the procedures outlined in my proposal regarding obtaining consent and enabling key participants to provide me with feedback.

Conclusion

This thesis addresses the experience of mothering a child with disability.

In Part One, I attempt to map the ways in which mothers of children with intellectual disabilities are represented in the media, several academic disciplines and the social discourses of disability rights. These chapters cover wide ground, much like a narrow

track that wends precariously through vast and often inhospitable territory. My contribution comes in documenting these discourses of marginalisation from many perspectives, and in identifying any sites of resistance. Foremost in my mind is the lived experience of these mothers, who are too often silenced or spoken for.

My analysis of parent texts in Part Two investigates how parent writers imagine their lives and the lives of their children in the light of these discourses. My aim has been to interrogate and extend the work of other commentators of life writing about parenting and child disability. In approaching these texts, I have drawn upon my own 'insider' perspective. As a tribe member, I had anticipated that these parental narratives would cover familiar territory, but on occasions I have found myself estranged from these stories, and the versions of truth, experience and perception that emerge within them. There are many different stories to be told.

In my creative work I have sought to push some of the boundaries of this subgenre of memoir in terms of both content and form. Questions of self-representation and subjectivity, and the representation of my daughter Amelia are central concerns, as are issues around authenticity and testimony. My own journey unfolds in this landscape, from its beginnings in trauma, through the processes of identity re-formation, but with no real point of arrival.

Lewiecki-Wilson and Ciello use the term 'liminality' to describe the borderland territory in which mothers of children with disability negotiate their identities (2011, 7). Their words echo Friedman's work on geographics and identity, in which identity is perceived not as static and whole, but 'as a historically embedded site, a positionality, a location, a standpoint, a terrain, an intersection, a crossroads of multiply situation knowledges', in which there is no 'organic unfolding of identity but rather the mapping of territories' (1998, 19). This space is shifting and unstable. It is strange country. Commentators such as Freidman and Lewiecki-Wilson urge us to recognise the opportunities offered by frontier lands such as this, where 'resistance to cultural scripts and emergent knowledge can potentially arise' (Lewiecki-Wilson and Ciello 2011, 2). This space, they claim 'may be generative': it offers new understandings and pathways for self-representation; but, they warn, 'it is also fraught with risks'.

PART ONE

Stories from the Academy

Chapter Two

SOCIAL SCIENCES

The changing face of the 'good mother': trends in research into mothers of children with disabilities[6]

Introduction

The social sciences have been the main site for research into families of children with intellectual disabilities over the past forty years. This research has formed the basis for both understanding the impacts of child disability on family life and for the development of social policy. Over this period, and particularly in the past decade, this research has focused in particular upon the mothers of children with disabilities for reasons that are discussed below. In this chapter, I explore the narratives surrounding these mothers that have emerged from this literature.

The phases and ideological positions that this social research has passed through over past decades reflect changing attitudes to people with disability in society, changing paradigms in family studies, and changing research methodologies. In summary, these themes have evolved from an early *psychopathological* view of the family of a child with disability, prevalent in the 1970s; to a *stress-and-coping* model, evident in particular during the 80s and 90s (see, for example, Dykens 2005); and then to a *resilience* model, which has gained ascendancy in the past decade (Grant and Ramcharan 2001). Two additional themes have emerged recently: *adaptation* and *transformation.* While these latest developments present a much more positive picture of family life, I point to some major concerns underlying this optimism. While researchers concentrate on the resilience, coping mechanisms and adjustment of research participants, they risk losing sight of the political and social context in which caring takes place, as well as the power of socio-cultural scripts and narratives that inform the responses of their participants.

A constant in this literature over this time has been the overriding focus on mothers as research subjects and, as I will discuss, notions of the 'good' versus 'bad' mother continue to underlie this research. These culturally laden terms are used by both researchers and participants, and they influence significantly the way mothers perceive themselves and are perceived by researchers and the wider society. The microscope is very much directed back on the mother, and her own strengths and weaknesses, as the site of investigation.

This review began with a database search (Academic search premier), initially with the keywords 'mothers', 'children', 'intellectual' and disabilit*'; the search was then extended to include 'families' and 'learning disabilities'. My aim was to concentrate

on the most recent developments, so sources between 2000 and 2011 were specified in searches. The majority of relevant papers were published in key international journals dedicated to research on intellectual disability; others came from social science journals with broader agenda, and one or two emerged from the humanities. To augment these searches, I used cross-referencing to follow up pertinent leads. In the course of this investigation, it became clear to me that it was important to track back further in order to explore earlier research themes that have informed current positions, so I used cross-referencing to access relevant earlier books and papers.

The research phases mentioned above will now be discussed in further detail.

Family psychopathology

We do not really know what percentage of the population in Australia is retarded. In the United States, the President's Panel estimated that 3% of the population were mentally retarded, Bank-Mikkelsen estimated that in Denmark, the number of retarded is one half of one percent. He 'noted that Denmark had no slums, no poverty, no race problem' (Davies, 1968). (Jennings and Mills 1970, 115)

Jennings and Mills capture here the prevailing ideology of the 1970s, with its underlying message that mental retardation was primarily a problem of society's underclass. These authors describe six case studies in which the socially disadvantaged child, through appropriate education and remediation delivered by authorities, has managed to overcome the initial diagnosis of intellectual disability.

This *psychopathology* model focused not only on the problems inherent in families of children with intellectual disability (which were often regarded as intrinsically deprived, or deviant, or both), but also on the problems that would arise from the long term burden of caring for a child with disability that could infect 'good families'. Prior to the 1970s, children with intellectual disabilities were effectively absent from family and community life. Parents were generally advised by doctors to place their 'defective' children in state-run institutions; refusal to comply was regarded as aberrant. At the time when Jennings and Millis wrote this article, many of these 'homes' were being closed down, in response to growing awareness of both child and

disability rights. These authors address the perceived problems for these children, their families, and society at large.

This 'first generation research', report Shapiro, Blacher and Lopez (1998, 606) 'presented a bleak picture of stress, burden, depression, social isolation and psychological dysfunction.' In this context, mental retardation was regarded as 'probably the most dreadful diagnosis a parent can receive' (Fewell 1986, cited in Shapiro, Blacher and Lopez 1998, 606).

Stress and coping

Fifteen years later, an article by Cavanagh and Ashman exemplifies the 'stress and coping model' of family adaptation that was in ascendancy in the 1980s. These authors provide an inventory of the stressors faced by families of children with disability based on a review of the literature, and then propose home-based respite services as one strategy for reducing this stress. The authors encapsulate the key principles of this research orientation as follows:

> Nearly every study dealing with stress related to families with a handicapped child concludes with practical suggestions about how stress might be overcome. These recommendations highlight the value of professional counselling, financial help, intervention programs, and the establishment of various types of day and respite care services. (Cavanagh and Ashman 1985, 153)

At this stage of post-institutionalisation, government policy regarding provision of community services required research-based identification of needs, and authors such as these delivered this evidence. Researchers during this period commonly adopted ethnographic methodologies in order to capture an 'authentic' account of the caring experience. Bowman and Virtue (1993), for example, conducted in-depth interviews with Australian mothers of children and adults with intellectual disability from a range of different backgrounds. The authors claim that this interview material is personal, but also political – a way of enabling the voices of those who are 'too busy caring for others' to be heard.

> Too often women's experience as mothers of children with disabilities is either ignored or turned into human interest stories for mass consumption ... These stories make us feel better because we can abrogate any responsibility. Stereotypes of 'good mothers' who sacrifice and, by implication, 'bad' selfish mothers are reinforced. (Bowman and Virtue 1993, ii)

The sense of marginalisation faced by UK mothers of children with disability is described by Read:

> It is not only that the mother and her child are excluded ideologically and practically from such things as standard child care advice, information and provision, it is also that they and other members of the household may begin to experience a sense of social isolation and ghettoisation in both crude and subtle forms. (Read 2000, 116)

Like Bowman and Virtue (1993), Read alludes to the stereotypes of motherhood to which these mothers are subjected: the 'self-sacrificing angel' (the good mother), versus the 'overprotective demon' (the bad mother). These mothers, she claims, are 'under the microscope', open to the critical judgement of the community and of service providers who have access to the normally private spheres of family life.

In the period before the turn of the century, then, research generally reported not only on the hardships faced by families of children with disabilities, but also on the social isolation experienced by mothers, and the need for social services to address these problems. This emphasis was to change radically in the years that followed.

Resilience, well-being and quality of life

In contrast to this picture of marginalisation, and in spite of evidence that these families experience high levels of stress (see, for example, Emerson, Robertson, and Wood 2004; Minnes, Woodford, and Passey 2007; Gerstein et al 2008), researchers at the turn of the century were asserting that the negative aspects of family life had been overstated. Changing social attitudes to disability, and better social services were no doubt improving outcomes for families. The general consensus was that these families had been 'overpathologised' (Grant and Ramcharan 2001). Not only were families coping, but many were in fact going well and able to find rewards in their caregiving

experiences, and it was time to move into a new paradigm (Turnbull et al 2007). Researchers were also responding to discourses within the disability rights movement that challenged notions of disability as 'tragedy', and were reinterpreting the effects of disability on family life in this brighter light.

At the same time, the orientation in the broader area of family studies had shifted to a strengths based approach, emphasising adjustment and resilience (Grant and Ramcharan 2001). Terms such as 'well-being', 'adaptation', and 'family functioning', along with resilience, were replacing the earlier conceptions of stress and dysfunction. Research, overwhelmingly quantitative, began to emerge, focused on the development and application of instruments for the measurement of risk, as well as the protective factors that promote resilience and influence family quality of life.

In reviewing a corpus of studies published between 1999 and 2006, Turnbull and others (2007) found that only a small percentage of these studies addressed the availability of external supports to the family – a critical aspect of positive coping for all families of children with disability, as acknowledged in the earlier article by Cavanagh and Ashman (1985). Instead, the majority of studies focused on the families' *internal characteristics* as key variables. These authors concluded that, as such, these studies offered little opportunity for translating findings into more effective service provision for families.

Turnbull and others compare this 'microsystem emphasis' (i.e. emphasis on the internal characteristics of the family) to past research on people with intellectual disability that focused on remediating the deficits in individuals (see the reference to Jennings and Mills 1970, above). They call for wider appreciation of an ecological view that recognises the support needs of families across multiple levels. The authors also point out a number of methodological problems, in particular the overwhelming concentration of studies involving mothers of young and school-age children from mainstream families. They observe that 'the typical participant in this body of family research is a Caucasian mother of a child with ID [intellectual disability] between the ages of birth-18 selected through a convenience sample' (Turnbull et al 2007, 352).

Quantitative studies similar to those reviewed by Turnbull et al have also been published more recently (see, for example, Hastings, Beck and Hill 2005; Minnes, Woodford and Passey 2007; Neece, Kramer and Blacher 2009; Hills and Rose 2009;

Gerstein et al. 2009; Dempsey et al 2009; Werner et al 2009; Trute et al. 2010). This research, with methods that typically require participants to complete lengthy schedules and long interviews, places heavy expectations of a population that is time poor and already overburdened by paperwork. Such methods invite questions about who may be willing to participate in this research, and how representative these participants in fact are (Turnbull et al. 2007).

In contrast, a couple of papers have focused on the quality of service provision as a key component of family well-being (Dempsey and Dunst 2004; Dempsey et al 2009; Prezant and Marshak 2006; Caldwell 2007). Caldwell (2007) investigates the impacts of service cuts in a US state; he critiques the pervasive ideology of 'familism', with its messages that families should 'take care of their own' with little government intervention. Caldwell also (in a rare moment in this body of literature) refers to feminism, linking familism with the continuing economic suppression of women, and in so doing mobilises a political perspective. While other national social services systems have a stronger welfare ethos than those in the US, the shared experiences of mothers across national boundaries indicates that the ideology underlying familism may well be pervasive (see, for example, Knox and Bigby 2007).

Adaptation

A smaller number of recent studies have used ethnographic methodology to explore the adaptive strategies that mothers mobilise in their efforts to mediate for their child with disability and engage positively with the social world. Skinner and Weisner (2007, 305) refer to this process as 'renorming the normal': mothers work to reassert their child's personhood and their own identities as 'good' mothers within a social context that devalues them and their children (see also Landsman 2003). A theme that emerges from these studies is the mother's obligation to redeem both herself and her child.

Several papers describe the strategies mothers use to navigate through their stressful encounters with health personnel. Todd and Jones (2003) report that mothers of adolescents with disability, who commonly feel 'under surveillance', reinterpret the process of struggle and resistance on behalf of their children as a means of

establishing themselves as 'good mothers'. McKeever and Miller (2004) draw on the work of sociologist Bourdieu to account for the ways mothers of young children with severe disability work to increase the social value of their children and themselves in these stressful encounters, and thus are able to recover their place as 'good mothers'.

Activities associated with advocacy and activism, too, can provide mothers with a valued social identity while accommodating their need to project a persona of goodness, according to Ryan and Runswick-Cole: 'Activism allows mothers to ask for help while at the same time managing their image as the "selfless carer"' (2009, 51). Landsman (2005) discusses how mothers need to negotiate their way through the different models of disability (see Chapter 4). Firstly, when their child is diagnosed, they encounter the medical model, with its focus on impairment and remediation; then, as they enter the service delivery system, and the worlds of school and the community, they negotiate the social model, with its ideology of valuing difference. But the medical model holds stronger sway in the community, Landsman contends; drawing on her own experience as the mother of a child with disability, she describes how she is expected to be involved in raising money for medical research, but: 'Praise for being a good mother is much less forthcoming for my activism to get accessible buildings or my negotiations to get a different work schedule, enabling me to accommodate my daughter's daily needs' (2005, 132).

These redemptive efforts come at a high price. While researchers report that mothers derive significant positive benefits from their alternative mothering experience, there is continued evidence that they are under considerable stress. A number of women in the Ryan and Runswick-Cole paper reported taking antidepressants and feeling drained; 'the pressure on the mother of a disabled child is to be a "good mother", so much so that she may feel that her other identities (as friend, colleague, partner and others) are submerged' (2009, 51). Todd and Jones (2003) argue that in their efforts to forge an identity as 'good mothers', these women are silenced in terms of their own needs, and in fact may not even be able to consider their own rights. But, as McKeever and Miller describe, these mothers determinedly foreground the positive: 'while many women ... evidenced psychological and somatic distress, physical exhaustion, social suffering and economic disadvantage as a consequence of mothering a child with disability, the vast majority described the experience as richly rewarding' (2004, 1188).

This perceived need for these mothers to present as 'good' and 'selfless' persists as a key, enduring but problematic theme.

Transformation

Emerging from the resilience school, another stream of research has found momentum during the final years of the decade. The direction of this stream, which includes both quantitative and qualitative studies, is perhaps best expressed in the titles of recently published articles: 'Accentuate the positive to mitigate the negative' (Trute et al 2010), 'Happiness, wellbeing and character strengths' (Dykens 2005), and 'Children with intellectual disability: A gain not a loss' (Dura-Vila, Dein, and Hodes 2010). Influenced by the developing field of positive psychology, this stream is underpinned by the proposition that having a child with disability in the family is not so much a negative as a positive experience that leads to a richer and more meaningful life.

The term 'embrace of paradox', was introduced by Larson (1998) and described as follows:

> The embrace of paradox has several features: holding two oppositional thoughts about the child, loving the child yet wanting to erase the disability, hoping contrary to the received opinion of others and recognizing there was no cure all the while [sic]seeking solutions to ongoing problems. (Larson 1998, 870)

In her ethnographic study of six mothers of Mexican origin in California 'living at or near poverty level conditions' (1998, 867), Larson found that these women were able to reclaim the value of their child and their own family life, as well as deal with the negative prognostications of medical personnel, by making these psychological adjustments; it fuelled 'the energy behind their maternal work' (871). Unfortunately Larson fails to interrogate these findings in view of the marginalised status of these poor mothers, and their limited resources of social and cultural power.

Amongst the first to report on the transformational potential of parenting a child with disability were Scorgie and Sobsey (2000). These authors describe the process of 'disequilibrium' that precedes psychological transformation: 'The ability to find or create meaning out of events that might be considered by others to be catastrophic has

been well-documented in research on adaptation and coping' (2000, 197). The diagnosis of severe disability in a child presents as such a crisis. The three areas of positive transformation identified by these authors are personal growth, improved relations with others, and enhanced philosophical or spiritual values (2000, 195). But their methodology, like Larson's, is problematic: based on a very small sample of 15 parents (whether mothers or fathers is not made clear), pre-selected as 'good copers' by advocacy groups or service providers (198), these participants could not be regarded as representative.

Both these terms – 'embrace of paradox' and 'transformation' – are taken up by researchers in subsequent years. Hastings and others (2002), for example. report that resilient mothers develop 'positive reframing coping strategies', based on their survey of 41 mothers of school aged children in South England:

> A final intriguing finding is that mothers reporting higher levels of caregiving demands for their child with intellectual disability also reported more personal growth and maturity... Having a child with more severe disabilities may provide mothers with more opportunities to grow personally and develop a mature outlook on the world due to the increased challenges posed. (Hastings et al. 2002, 273)

Some years later, Trute et al. (2010) express a similar claim regarding the transformative potential afforded by having a child with severe disability:

> It seems that the more personally challenging the experience, the more opportunities are provided for personal growth, because of the greater disruption the experience provides to the individual's global interpretation of life events. (Trute et al. 2010, 37)

Dykens (2005) draws on positive psychology, which 'aims to more fully understand such positive states as hope, gratitude, satisfaction, flow, engagement, virtues, purpose, and meaning', as the basis for the following assertion:

> Although a stress and coping model is a better fit for family research than psychopathology, many families and siblings report various positive effects of having a family member with mental retardation. These families are not just coping, they are thriving and positively benefiting ... they are better people because of the experience. (Dykens 2005, 360)

This notion of the child with an intellectual disability as 'a blessing', and a pathway to greater understanding of the true meaning of life, is a pervasive theme in this research. Grant and others (2007) take this trend further by proposing a theorised account of what they refer to as 'transformational coping'. 'Under the most adverse conditions we are able to reinvent ourselves,' they write, '[by developing] cognitive coping strategies that allow individuals to reframe experiences around more acceptable or positive concepts' (Grant et al 2007, 564). These authors borrow Larson's (1998) term, and describe the 'embrace of paradox' as follows:

> Families are frequently depicted as facing caregiving dilemmas – for example between fulfilling their own needs and those of their child or relative, between wanting to avoid burnout, yet wanting to do everything possible for their child or relative, between wanting to maximise their child or relative's independence and growth yet also wanting to accept things as they are. (Grant, Ramcharan, and Flynn 2007,565)

By embracing these paradoxes, apparently, families are able to achieve positive transformation. These authors include three brief case studies to illustrate, however the source of these is not provided. In two cases, the mothers successfully 'embraced paradox': one became a more assertive and outgoing person as a result of the trauma she experienced around the time of her daughter's premature birth, exacerbated by the insensitivity of health professionals; the other, after 18 years of ongoing care for her son, participated in a carers' retraining scheme that enabled her to eventually re-enter employment that utilised her care-based skills. The third, however, failed to embrace the paradox effectively: she was overly protective of her son and consequently failed to plan for his transition to supported accommodation; now that she and her husband are ageing, she realises that she is caring 'out of time' for her son, and she holds deep fears for the future. To elucidate further, the authors quote Larson (1998):

> [T]he depth and profoundness of coming to terms with the child's disability, through the embrace of paradox, is powerful enough to generate an enduring commitment to *maternal occupational patterns* [my italics] and to generate profound internal spiritual and emotional changes. (Larson 1998, 873, cited in Grant et al 2007, 565)

Mothers of children with disability, these authors assert, are more likely to embrace caring as their long term occupation. The quality of love, too, plays a significant role in this caring equation:

> By their nature, rules and norms imply an element of conditionality, though in the case of parents of children and adult members with intellectual disability there may be an exception in the unconditional love and attachment toward their offspring that is often reported, but from mothers in particular. (Grant et al 2007, 569)

But as these authors point out, this boundless love that is a feature of 'good' parents can have a downside as well: it can be over-involved and over-protective (the 'bad mother'), as in the third vignette above. The line between the two is dangerously blurred.

Hubert (2011) takes up these ideas in her study of 20 mothers of young adults with intellectual disability and challenging behaviours, and provides the following quotes as evidence of exceptional love, positivity and resilience:

> 'If you took [my daughter] out of my life now, I'd have nothing left'
> 'I sort of wrapped my life around him'
> 'Everything I do has got Davey at the end of it and at the beginning of it' (Hubert 2011, 219)

Other interpretations may be possible for the degree of selflessness expressed by these mothers. My own sense is that the mothers in Hubert's study may be exhibiting some symptoms of co-dependence rather than resilience, in response to and as rationalisation of the limited life options available to them. And not all the statements of Hubert's participants were positive: for example, one father 'felt the life of his family had been destroyed by his son'; and tragically: 'at the thought of one of her other children giving birth to a similar child, [one mother] said: "I hope that I'd have the courage to put a pillow over her face"' (Hubert 2011, 222). But Hubert holds to her thesis, in spite of these counter-responses.

The 'good mother' who emerges from the transformational research is one, then, who is able to overcome personally the social and cultural constraints imposed upon herself and her child to find higher meaning in her family situation, and to provide a level of love to her child that is beyond the norm. The more severe her child's disability, the more likely she is to attain transformation. Her story is one of redemption and transcendence.

Narrative options and choices

As discussed in Chapter One, a woman faces a disruption to her life narrative when her child is diagnosed with a disability, and as a result she needs to find an alternative narrative that will enable her to integrate these events into her life story. By recognising that this claiming of narrative is a socially and culturally mediated process, we can understand that research participants may be giving voice to stories that both validate their experience and fit socio-cultural expectations. These needs may indeed be greater than the need to disclose their lived realities. Avery, for example, asks: 'Do parents of disabled children self-inscribe as victims? This is not revealed in the published literature, for such an admission would violate the 'good' and selfless parent role' (1999, 119). Frank argues as follows:

> [S]ocial scientists and various researchers using social science methods have been too exhaustively concerned with stories as self-reports that that provide more or less valid information about people's lives, and have neglected storytelling as a pervasive and crucially important form of human activity. (2010, 18)

Some of the narratives from the socio-cultural repertoire that are available to mothers of children with disabilities have been described above: the self-sacrificing mother; the resilient mother; the activist mother; the mother who is committed to enduring maternal occupational patterns; the mother who gives labour and commitment beyond what others could endure; the mother who can do the cognitive work of reframing an experience of marginalisation to facilitate the adjustment of her family.

For each of these models, the identity of the mother is taken up fully within the life-long caring role. It seems that it may not yet be possible to imagine other options. Where, for example, is the narrative of the woman for whom life is normalised: the woman who is able to pursue her own career and personal goals in tandem with managing family life – in spite of being mother to a child with a severe disability? Stories such these may be hidden in the literature on resilience, but these are not the stories that are currently heard or valorised by these researchers.

Alternative accounts

Two books published in the past few years – both by social scientists who are also mothers of children with disabilities – set out to challenge in some ways these prevailing representations. Kingston (2007) brings a feminist perspective to her ethnographic work with 18 Irish mothers of young children with intellectual disabilities: 'Mothers of children with special needs, I will argue throughout this book, belong to a marginalized group of women, whose self-sacrifices are taken for granted' (2007, 15). She explores the gendered nature of caring; the social construction of disability and mothering which legitimates the marginalisation of these mothers from normal social and economic life; and the particular cultural-political context of Ireland which entrenches this silence. Kingston rejects sentimentality: 'Living with a child with special needs is not easy and the narratives of my 18 participants were full of sadness and hopelessness,' she writes. 'They were exhausted, stressed, and often depressed' (2007, 85).

Landsman (2009), in her US based study of 60 participants, explores the process of identity reconstruction that is required of mothers of young disabled children 'in the age of "perfect" babies'. She provides a powerful examination of the mechanisms of social and technological surveillance of pregnancy, including the 'threat' of the mother to the (newly autonomous) foetus, and the impact of these cultural messages on women who (aberrantly) give birth to imperfect babies.

Both authors also describe how their participants rejected – often vehemently – the narrative of the 'special mother', and its religious equivalent, that 'God only gives special children to special parents'. A major concern for both authors is the issue of mother-blame: how it pervades medical and social discourse, and how it is accordingly internalised by mothers of children with disability. Landsman, in particular, gives examples of the self-blaming ruminations of her study participants. The ideological force of mother-blame, I suggest, plays a major role, not only in the marginalisation of these mothers, but in their compliance with prevailing social scripts. This issue was neither acknowledged nor addressed in the literature reviewed earlier in this chapter.

The mothering background of both authors provides them with an empathetic pathway into the lives of the mothers in their studies. Each also provides a brief narrative or autoethnography of her own experience of mothering a child with disability (Kingston in the prologue, Landsman in the epilogue). These pieces serve to legitimate the research process – as a shared, rather than objectifying, experience. They are placed as bookends to the research of these authors, but they are powerful and compelling testimonies in their own right. These researchers are 'wise' (after Goffman 1963) narrators: their autobiographical writing provides a critical contribution at the nexus of lived experience and academic knowledge.

Conclusion

Research on families with children with intellectual disability over the past 40 years has evolved through several clearly identifiable stages. Mothers have continued to occupy a central place in this work, and idealised accounts of the 'good mother' occupy considerable territory within this landscape.

While social attitudes to disability and social services to support families have improved over this period, people with disability and their families still experience considerable stress and disadvantage. At this point, however, this body of research on the whole appears to be moving along a trajectory that places undue importance on the internal characteristics of families (in particular mothers) to cope with the pressures of managing a child with disability, as well as the mother's capacity to interpret her own experience as uplifting and vocational, at the expense of addressing systemic problems at the socio-political level. While it is beneficial to families to identify the characteristics of resilience and well-being, a focus on internal family characteristics fails to acknowledge that these are the elements that families are least able to control. This research also fails to address mother-blame as a key discourse that serves to ensure the compliance of these research respondents.

The growth of interest in the 'transformation' narrative takes these concerns further; while researchers are promoting the spiritually compensatory and transformational aspects of the experience identified by some respondents, there is a real risk of these

narratives infiltrating the policy arena, in a context where services are already fragmentary, underfunded and difficult to access.

The preoccupation with versions of the 'good' mother in this literature provides evidence that this archetype inhabits areas beyond the media and popular culture. And while versions of the 'good mother' of a child with intellectual disability have changed shape in this literature over the years, her marginalised position has not altered significantly. Her halo is just a slightly different hue.

Chapter 3

PHILOSOPHY

People with intellectual disabilities and their mothers: Who cares?

Introduction

Ethicists and political philosophers seek to re-imagine the social world, to explore the nature of goodness, and to discuss and define the rights and obligations of citizens. The stories that philosophers tell about mothers and their children with disabilities might, then, be expected to envision an ideal world; Kittay, for example, contrasts the concerns of philosophy with those of the social science research described in the previous chapter: 'The issue is less how well parents cope and more what is fair and just to provide to disabled persons and their families' (1999, 178). But within the field of philosophy, the place of people with intellectual disabilities and their caregivers is not a comfortable one: they have been marginalised, ignored, and disavowed within mainstream philosophical thought, and it is only in the past decade or so that more positive and inclusive narratives have emerged.

In my explorations into the world of philosophy, I encountered four fields of discourse that have particular relevance for people with intellectual disabilities and their caregivers: eugenics and bioethics, moral philosophy, theological ethics, and the ethics of care. To these I add a fifth which does not specifically address issues around disability, but has discomforting resonance: the work by Julia Kristeva on the concept of abjection, which lies at the interface of philosophy and psychoanalysis, amongst other disciplines. These five discourses clash and contradict, but they also overlap, inform each other, and reveal unexpected allies. In at least one of them, relevance comes as much from absence in the debate as from presence; in others, people with intellectual disabilities and their carers occupy a more prominent place. Across the five, the narratives range from exclusion through marginalisation to inclusion and validation; or, as the headings below suggest, from negation through dismissal, abjection and submission to affirmation.

In this chapter, I discuss each of these discourses briefly, to map out the philosophical landscape and explore how the narratives about intellectual disability and caring generated within philosophy inform our cultural identities.

A narrative of negation: Eugenics

According to Jones (2011), 'Eugenics — the science of improving the race — was a powerful influence on the development of Western civilisation in the first half of the twentieth century... In this period all the institutions and practices of modern societies came into being and eugenics played an important role in moulding them'. Eugenics was not only a science, however: it was a social philosophy, and calls were made for the development of a dedicated 'eugenic philosophy' (Osborne 1937, 389).

The aim of eugenics was to improve the human species by selective breeding, and necessarily, this had enormous impact on the way people with disability and their families were perceived by society. The movement was finally discredited due to the gross excesses of Nazi practitioners, but the principles continued to have influence long afterwards. The attitudes toward disability in the 1970s described in the previous chapter – that disability was a problem of society's underclass – reflect these ideas. Vestiges remain in areas of bioethics and medical practice today, as will be discussed below.

In the US, the eugenics movement was a formidable force, and many prominent people, including Theodore Roosevelt and Alexander Graham Bell were active members, with financial support coming from sources as influential as the Carnegies and the Rockefellers, among others (Smith 2011, 10). While race was a target of the movement, so was disability. As far back as the 1880s, regional 'ugly laws' were enacted, which 'depicted "unsightly" individuals as threats to the health and equilibrium of normal Americans, requiring that they remove themselves from public sight' (9). Eugenics organisations were formed with the aim of identifying 'defectives' and controlling their reproduction, and state laws (e.g. in Connecticut, 1896) prevented the marriage of women of reproductive age who were epileptic, 'imbecile' or 'feeble-minded' (9). 'Feeble-minded' people were routinely institutionalised, and sterilised; social problems were commonly attributed to genetic defects. In 1911, the Eugenics Committee of the American Breeders Association identified and prioritised ten groups for containment and eventual elimination in order to improve the genetic stock of the population. First on the list were the feebleminded (Smith, 2011).

Able-minded (as opposed to degenerate) mothers were 'considered crucial to the prevention of feeblemindedness' (Carlson 2010, 69). Women were exhorted to adhere to 'hygienic rules' in order to manage the emotional and nutritional environment of the foetus. A woman's state during intercourse was identified as a potential risk factor. Women's magazines advised readers to investigate any possibility of 'defective stock' in their own family and that of their prospective mate. Expert (male) scientists warned that participation in higher education, and engagement with the stressors associated with the emancipation of women could lead to the birth of a mentally defective child. As Carlson summarises:

> [B]eing a good mother (i.e. preventing feeblemindedness) meant constant vigilance. Pregnant women were responsible for ensuring a healthy environment, physically and mentally, for the baby in the womb. Mothers of newborns were taught to watch for signs of idiocy, and were urged to give the proper love and attention to avoid adverse consequences. (2010, 72)

However, mothers, regarded as 'natural' nurturers, required the input of science to keep them on the straight and narrow, leading to 'the belief that vigilant mothers, *under the guidance of a male physician*, could prevent idiocy or at least mitigate its effects' (Carlson 2010, 70, author's italics).

Some early feminists employed the rhetoric of eugenics in their advocacy for women's rights, particularly reproductive rights. Carlson cites the case of Margaret Sanger, a leader in the birth control movement in the US, whose 1920 book, *Women and the new race*, included aphorisms such as 'We gather perfect fruit from perfect trees', and the following utopian vision, of a world where, when women have control over their fertility, 'child slavery, prostitution, feeblemindedness, physical deterioration, hunger, oppression and war will disappear from the earth' (Sanger 1920, 233-4, cited in Carlson 2010, 81).

Families with 'defective' children faced exclusion. Smith reports of a proposal by ophthalmologist Lucien Howe, in which couples who produced blind children should be required to pay a bond to cover the social costs incurred by these persons; this idea was extended to parents of insane or epileptic children. Families such as these were tainted, actively excluded from representations of the ideal (white, beautiful, fit)

families that were promoted through 'Better Babies' and 'Fitter Families' competitions run by the eugenics societies (Smith 2011, 12).

In Australia, the eugenics movement likewise attracted the interest of prominent figures. A key activist was Richard Berry, Professor of Anatomy at Melbourne University who, according to Jones (2011), exerted the influence which led to the establishment of the Eugenics Society of Victoria in 1929. Berry resettled in England where 'in 1934,' Jones writes, 'he would argue that to eliminate mental deficiency would require the sterilisation of twenty-five per cent of the population. At the same time he also advocated the "kindly euthanasia" of the unfit' (Jones 2011).

The world-wide eugenics movement lost momentum after World War II, discredited by the horrors of the Holocaust and other eugenic practices undertaken by the Nazis. But, as Smith (2011, 31) notes, it re-emerged 'in a more moderate and publicly palatable form', in which the 'focus on improving national and racial health was recast as a matter of improving human health by advancing medical and genetic knowledge' (235). Eugenic interpretations of disability persisted; Kerr and Shakespeare argue that the use of genetic counselling and prenatal diagnostic practices today contributes to the persistent belief that 'the birth of a disabled child is a tragedy best avoided' – a claim that could not be made about any other minority group with causing outrage (Kerr and Shakespeare 2002, cited in Smith 2011, 237). Practices such as compulsory sterilisation of those deemed unfit continued up until the 1970s, and debates continue in Australia and other countries today regarding the sterilisation of girls and women with intellectual disability, as the 2013 Australian Government Inquiry into the Forced and Coercive Sterilisation of People with Disabilities in Australia attests.[7]

While the eugenics movement itself has ceased to exist, the impacts of its legacy continue to be felt. Landsman's (2009) discussion of the intensive and increasing surveillance of pregnant women, and the ideology of mother-blame that accompanies it, was alluded to in the previous chapter. These practices carry strong echoes of eugenics in the guise of bioethics and medical advancement.

A narrative of dismissal: Moral and political philosophy

Philosopher and father of a daughter with disability, Roger Gottlieb, observes that: 'Neither secular moral theory nor religious ethics have had much place for persons in need of constant physical help and cognitive support, nor for those who provide care for them' (2002, 225). Carlson concurs: 'The topic of intellectual disability may be unfamiliar to many philosophers and is certainly not included in what might be considered canonical philosophical problems' (Carlson 2010, 9-10).

This historical absence of attention masks the problem that people with intellectual disability pose for the Western philosophical tradition at least since the Enlightenment, a tradition in which the autonomy of the individual is deemed to be a central feature of personhood (Kittay 1999). Modern philosophical theories are premised on the notion of the independent individual: the person who is able to make rational moral choices, is capable of participating in public life, and who is free (in terms of obligations) to participate. This preoccupation with autonomy as a defining characteristic of being human has meant that the very personhood of people with cognitive disability, and particularly severe and profound cognitive impairment, has been persistently undermined. Those who are caregivers are also devalued, both by their relationship to those with such disabilities, and due to their diminished capacity to participate in the public arena (Kittay 1999).

On the occasions when philosophers do address issues pertaining to people with cognitive impairment, the tone is either dismissive or overwhelmingly negative, underpinned by 'the normative assumption that intellectual disability is objectively undesirable, bad, and/or tragic' (Carlson 2010, 9-10). Carlson elaborates:

> Plato decreed that 'defective babies' should be left to die. Locke and Kant defined those who lack reason as less than human. And most troubling of all, when I looked for contemporary discussions about this group, most of the references I found were in discussions of animal rights, asking pointedly whether the 'severely mentally retarded' could be distinguished from nonhuman animals in any meaningful sense. (2010, 2)

McMahan (2003), for example, argues that the moral status of 'the congenitally severely mentally retarded' or the 'radically cognitively limited' should be demoted below that of other human beings, as this group may be more appropriately compared

with nonhuman animals. Singer (1996) describes an institution that he claims is for the 'mentally retarded' in the Netherlands; he then reveals that it is in fact a zoo for chimpanzees, not a residence for humans – with the implication that persons with cognitive disabilities and chimps share the same moral attributes (see Kittay 2009). Feinberg defines the capacity for autonomy as 'the ability to make rational choices, a qualification so interpreted as to exclude infants, insane persons, the severely retarded, and the comatose, and to include virtually everyone else' (1989, 28). Frey argues that 'severely impaired and defective humans' (2005, 332), who have limited capacity to exercise autonomy, have lives that are less valuable than all 'normal' adults and some animals; he proposes that if lives must be used in medical experimentation, then we should accept the prospect of using theirs (cited in Davy, 2014).

In response to the traction these voices have gained in the philosophical community and beyond, philosopher Kittay (2009) considers, with some desperation, abandoning the philosophical project altogether. Fellow philosopher, writer, and father of a child with intellectual disability, Michael Bérubé comments:

> So for some years now, I've been in the position of saying to my colleagues in philosophy, 'Your silence with regard to cognitive disability is most dismaying,' followed in short order by 'Actually, your undervaluation of the lives of people with cognitive disabilities is even more dismaying. I liked you all better when you were silent.' (2009, 353)

For political theorists as well as moral philosophers, the position of people with cognitive disabilities has been tangential, used sometimes to represent a 'marginal case' in testing the limits of a theory due to its 'problematic' nature. Kittay (1999) provides a critique along these lines of John Rawls, one of the twentieth century's most influential voices in moral and political philosophy. In Rawls's theory of justice and his revival of social contract theory, he imagines a democratic, just society in which all persons are treated as free and equal. Nevertheless, his theory also presumes that all citizens are capable of fully participating in public life. Kittay points out that Rawls bypasses the problem posed by those with cognitive disabilities and special health needs by claiming that they are 'morally irrelevant': these cases can 'distract our moral perception by leading us to think of people distant from us whose fate arouses pity and anxiety' (Rawls, 1975a, 96, cited in Kittay, 1999, 88). Where Rawls

does consider those with additional needs, he does so as a somewhat inconvenient afterthought:

> Since the fundamental problem of justice concerns the relations between those who are full and active participants in society ... it is reasonable to assume that everyone has physical needs and psychological capacities within some normal range. Thus the problem of special health care and how to treat the mentally defective are set. If we can work out a viable theory for the normal range, we can attempt to handle these other cases later. (Rawls, 1992, 272, note 10, cited in Kittay, 1999, 80)

This marginalisation impacts not only those with high support needs, but also those who care for them. Kittay argues that the obligations faced by those who care for such dependent persons place them in a position that is not equal with others who do not have the same set of obligations. In addition, these carers face social stigma as they fulfil their obligations to care for those who are devalued by mainstream society. Kittay reminds us that Aristotle, the father of philosophy, considered those who cared for others as morally lacking: 'A person who would do dependency work and would suffer ... diminished autonomy ... was viewed by Aristotle as the same person whose soul was defective in ways characteristic of a slave or a woman' (1999, 45). Feminist Joan Tronto puts it this way: 'Care has mainly been the work of slaves, servants and women in Western history' (1993, 113).

The devaluation of those with cognitive impairment – and their caregivers – has meant that these groups have been exiled to the margins of mainstream moral and political philosophical thought throughout the last century. In tandem with the narratives issuing from the social research described in the previous chapter, this neglect has impacted not only on public perception but also on the provision of resources to support and foster their social participation.

A narrative of abjection: Kristeva and the semiotic

I take an aside at this point to delve into an area that offers an altogether different way of interrogating the representation of people with intellectual disability and their mothers. The influential thinking of philosopher and critical theorist Julia Kristeva on abjection does not directly address the marginalisation of those with cognitive impairment and their carers, but her work sheds light on the psychological and

cultural mechanisms that underlie this stigmatisation. As Liewick-Wilson and Cellio observe, 'the move to abject certain "others" has a long psychical and material history relevant to both mothering and disability' (2011, 7).

In *Powers of horror: an essay on abjection* (1982)*,* Kristeva describes *abjection* as that which does not 'respect border, positions, rules', and 'disturbs identity, system, order' (1982, 4). According to Creed, 'Kristeva is attempting to explore the different ways in which abjection works in human societies, as a means of separating out the human from the non-human and the fully constituted subject from the partially formed subject' (1993, 8). In this way, Kristeva's work is relevant for interrogating the discourses that construct people with cognitive impairment as 'non-persons'. This borderland territory of abjection is also expressed through the concept of *liminality*, which Lewiecki-Wilson and Cellio apply in relation to the stigma of disability:

> This liminal space ... is dangerous, dirty, threatening to all categories. In a society that values the whole body, the stable identity, the independent subject, the liminal state represents the erratic, the variable, the unstable. In sum, the liminal processes of interdependent and shifting self and other are threatening, stigmatized, and associated with the fear of disability. (2011, 7)

Kristeva's work focuses on the woman's body as a site of abjection, rather than the disabled body. But, as Lewiecki-Wilson and Ciello assert, these processes of abjection also apply to disability and, I argue, particularly to intellectual disability.

Kristeva describes how, within the patriarchal discourse of psychoanalysis, the mother is constructed as Other. 'The abject is placed on the side of the feminine: it exists in opposition to the paternal symbolic,' writes Creed (1993, 37). 'In Kristeva's view, the image of woman's body, because of its maternal function, acknowledges its "debt to nature" (Kristeva 1982, 102) and consequently is more likely to signify the abject' (Creed 1993, 11). Its boundaries are permeable and contestable, a play between inside and outside. The womb, Creed explains, is the 'utmost in abjection' (1993, 49), because it houses a new life form that moves from inside to outside, along with traces of excrement – blood, afterbirth, faeces.

The processes of abjection, Kristeva argues, are mobilised to subordinate maternal power to symbolic (phallic) law. She explains how, according to psychoanalytic theory, the process of coming to personhood and individuation requires that the young

child pass from dependency and the world of the mother, via the mechanisms of the Oedipus and castration complexes, into the phallic symbolic order of the father: the social world, governed by social rules, law and language. The universe of the mother, aligned with the natural world through her bodily processes of reproduction, must be abjected in order to be left behind (Kristeva 1982).

According to psychoanalysts, the pre-Oedipal child exists in a pre-linguistic mode, which Kristeva terms the *semiotic*. Creed explains: 'Kristeva's semiotic posits a pre-verbal dimension of language which relates to sounds and tone of the voice and to direct expression of the drives and to physical contact with the maternal figure' (1993, 14). Language is not the only feature of this process of transition to the symbolic; it is also about bodily control. Before the child can move forward, he or she needs to be in possession of the 'clean and proper body', and it is deemed to be the duty of the mother to deliver this purified body, in readiness for the transition to the symbolic, language-driven social order. But the child, and indeed the adult, who has significant cognitive impairment may not have the capacity to make this transition to the symbolic order. According to this framework, those with profound disabilities, whose communication remains at a pre-verbal level and who are unable to control their bodily functions, will always be fully entrenched within the semiotic.

If the body of the mother of a healthy child is deemed to be abjected, then how is the body of the mother of a disabled child regarded? She has failed in her duty to facilitate the child's 'clean and proper body' and provide the foundation for her child's reception into the symbolic world. Her compounded abjection (through association with motherhood and disability) remains largely unspoken, or perhaps unspeakable, except through the mythologies of saint and demon that were encountered in previous chapters. Creed (1993) provides many examples from horror films of mothers who give birth to demon children and become themselves demonised through this process; Smith (2011) refers to these filmic tropes as 'hideous progeny'. The parallels with mothers of children with severe disabilities are as disturbing as they are clear.

Kristeva discusses the ways in which the 'impure' (or abject) has been dealt with historically through the mechanisms of taboo and sacrifice (1982, 94). When a taboo is broken, and order accordingly breached, sacrifice is required; this provides the

ritual purification that permits order to be reinstituted. The saintly, self-sacrificing mother could be seen as a manifestation of this mechanism: she must atone for her abjection. The disruption brought about by the birth of a child with cognitive impairment means that the narrative of sacrifice is the only acceptable emplotment for mothers who have so violated the social order.

Kristeva's work, along with the related work of another feminist philosopher and critical theorist, Luce Irigaray (1981), have been applied to the broader social/cultural activity of caring. Hughes and others (2005) propose that 'the feminization of care in a culture dominated by the male imaginary makes the caring relationship and those involved in it necessarily subordinate' (2005, 262). Caring, they write, involves the containment of abjection: 'Those who care, who enter this world of waste, place themselves in a domain of peripheral value outside the masculinist boundaries that define proper productivity and, therefore, have no claim upon the values of success, dignity or respect. Care is a social sphere in which all participants are blighted because they live wasted lives' (267).

The concept of abjection provides the basis for a rich interpretation of the mechanisms underlying the marginalisation of people with intellectual disabilities, their mothers, and carers in general within a patriarchal social order. This theorising feeds back into the preceding discussions of both eugenics and moral philosophy, describing and accounting for the disavowal of those deemed unfit by virtue of their association with bodies neither 'clean' nor 'proper'.

At this point, I turn to more positive narratives about people with cognitive disability and their families. These arise from the discourses of theological ethics and the branch of feminist philosophy known as the ethics of care. While these two fields may seem to be curious allies, they both share a vision that challenges the view of the individual as autonomous and independent, and acknowledge that humans actually live their lives along a spectrum of dependency. Any convergence, however, ends here.

A narrative of submission: Theological ethics

The religious perspective emerges often in accounts of family disability. Gottlieb, philosopher and father of a daughter with a disability, finds the spiritual perspective both comforting and instructive for managing 'the exclusion or second-rate status of the disabled and their caretakers':

> I believe you cannot confront disability without spiritual resources ... In a spiritual perspective we concentrate on gratitude instead of entitlement, on devotion rather than publicly measureable achievements, on serving without limit... Instead of secular moralities ... we offer submission to the will of God and the recognition of the infinite worth of each soul. (Gottlieb 2002, 229)

In the broader literature of religious ethics, disability and caring are not high on the agenda. Several influential commentators, however, including theologians Hans Reinders and Stanley Hauerwas, challenge the way mainstream philosophers perceive the individual as independent and autonomous.

Reinders (2008) explores moral questions around personhood in depth, focusing on how these fail to account for the lives of people with profound cognitive impairment. He refers to the *relational* view of the person adopted by some Christian writers, summarising as follows: 'My humanity is not dependent on my capacity for self-consciousness, these authors argue, but it is constituted by the web of social relationships of which I am a part. In other words, personhood is not psychologically, but socially constituted' (2008, 36). But this conception, too, is inadequate, he argues; the human condition is characterised by *dependency*, even more so than by interpersonal connections. To elaborate, he cites the work of Hauerwas: 'As Christians, we know we have not been created to be our own authors, to be autonomous. We are creatures. Dependency, not autonomy, is one of the ontological characteristics of our lives' (Hauerwas, 1998, 147, cited in Reinders, 2008, 204). 'In Hauerwas's conception,' Reinders explains, 'the lives of humans with intellectual disabilities are paradigmatic for, rather than exceptional to, human existence' (2008, 204) due to this fundamental, shared experience of dependency.

The end point or *telos* of Reinders's theorising is the understanding that the gift of God's love provides affirmation of the humanity of all. In terms of how this relates to

carers of people with severe impairment, Reinders's invokes the themes of acceptance, submission, and spiritual transformation.

> The call to share one's life with a profoundly disabled person will not be properly heard until one is prepared to receive the presence of that person as a gift from God. Knowing how to receive that gift, however, is the subject matter of a spiritual journey of transformation. (Reinders 2008, 350)

Reinders' words echo those of Gottlieb above, regarding the call to re-imagine how one's life is morally constituted in order to embrace the caring role. These ideas have some parallels with the idea of 'transformational coping' subscribed to in the (secular) social science research described in Chapter Two. However, Reinders issues a warning about the temptation to see caring for a son or daughter with disability as a way of increasing one's moral worth; those who claim that caring has made them 'better people' are in fact operating from a core position of self-interestedness. Authentic caring, Reinders explains, is unselfconscious, and those who are doing it 'would be surprised to be asked why they are concerned about those they care for' (2008, 214). Authentic caring requires genuine submission to one's caring role. As illustration, he offers this quote from an exemplary mother's experience:

> 'For many, many years, I was confined to the house, alone and without the support of relatives or friends. My husband was at work all day and I was with Oliver [her child with profound disabilities] and the other five children. This enforced seclusion was difficult for me: I had a restless, seeking spirit. Through Oliver I was held still, I was forced to embrace a silence and attitude where I could "prepare the way of the Lord". Sorrow opened my heart, and I "died". I underwent this death unaware that it was a trial by fire from which I would rise renewed – more powerfully, more consciously alive.' (de Vinck 1990, cited in Reinders 2008, 136)

Mrs de Vinck's transformation occurs not through her choice, nor her desire for moral improvement, but through submission. Reinders acknowledges that this type of submission is anathematic to feminist thought: 'emancipatory feminism has rejected this kind of self-sacrifice precisely because ... it is a response to a role that is not voluntarily assumed' (136). But Reinders upholds that the spiritual rewards that come to Mrs de Vinck are far more valuable than those available through secular gender politics.

Reinders locates the site for overcoming the marginalising effects of disability and caregiving within the individual. Questions of gender and the marginalisation of caregivers go unacknowledged. It has been up to a group of feminist philosophers to bring a historicised and politicised perspective to this discussion. Political philosopher Eva Feder Kittay, in particular, has managed to situate people with cognitive disability and high support needs, and their carers, at the centre – rather than the margins – of moral theory.

A narrative of affirmation: Kittay and the ethics of care

Research on caregiving emerged in the 1970s, undertaken by feminist scholars who questioned the 'naturalness' of women's care work, the economic implications of this unpaid labour, and associated issues of social justice (Fine and Glendinning 2005, 603). As mentioned in Chapter One, this research was largely based on a critique of the family as an institution of patriarchy that condoned the oppression of women. In the US, however, a branch of feminist philosophy arose in which the socially positive features of caring were emphasised: care was recognised as an activity central to the lived experience of not only of women, but of all people: 'The ideal of care is thus an activity of relationships, of seeing and responding to need, taking care of the world by sustaining the web of connection so that no-one is left alone' (Gilligan 1982, 73). One of the catalysts for this movement was Sara Ruddick's (1980) essay, 'Maternal thinking'; Held remarks that:

> Ludicrous as it now seems in the twenty-first century, at the time [Ruddick's] essay appeared, the practice of mothering had been virtually absent from all non-feminist moral theorizing... The ethics of care now has a central, though not exclusive, place in feminist moral theorizing, and it has drawn increasing interest from moral philosophers of all kinds. (Held 2006, 26-28)

Care ethicists sought to redefine the basis of personhood by asserting that persons are not autonomous and independent, as mainstream moral and political philosophy asserts, but rather *relational*. They share this conception of the person with the theological ethicists described above.

> Care ethics takes the paradigm case of human experience to be embedded in familial and dependent relationships, rather than in those of autonomous individuals ... [it] postulates

the importance of a concept of self that is always in-relationship, a self with somewhat permeable ego boundaries that sees itself connected to others. (Martin and Kittay 2007)

As such, care ethicists draw distinction between this 'connection-based' equality and the 'individual-based' equality that characterises traditional moral theory.

Care theorists, including Gilligan (1982) and Noddings (1984), were generally concerned with the typical caring scenarios that characterise women's lives: the care of young dependents and ageing relatives. But the work that has most direct relevance for those who have long-term caring obligations for sons and daughters with disabilities is that of Eva Feder Kittay, philosopher and mother to a daughter with intellectual disability and very high support needs. Kittay's work offers a powerful narrative that replaces the themes of sacrifice and transformation with those of rights and social obligations.

Kittay's book, *Love's Labor* (1999) gives a theorised account of the caring role in philosophical and political terms, emphasising its gendered nature. Questions of who does the caring, and who provides support for the carer, the dependent, and the relationship of care itself are, Kittay contends, social and political questions (1999, 1). She argues that both the person with high dependency needs and the person caring for them experience diminished autonomy, and are currently excluded from enjoying the rights of full citizenship. Dependency work (as she refers to caring) is largely gendered work, arguing that 'to call this work of caring for children parenting rather than mothering is a distortion that serves women poorly' (xiv). It is also a class issue: 'at once sentimentalized and despised, dependency work has been unevenly distributed among genders, and even among women' (1999, 8), as high status women are able to offload this work to lower status women. Cultural messages naturalise dependency work by women: 'By so naturalizing the labor,' she writes, 'the coercion required for the *modern* woman to engage in dependency work has been covered in sentimentality' (95, author's italics).

Kittay argues that a political theory that valorises autonomy and 'excludes dependency concerns can be maintained only by the exploitation of those who do dependency work or by the neglect of the concerns of the dependents' (1999, 77). She takes the notion of the 'relational' person a step further than care ethicists by claiming – like Reinders (2008) – that 'dependent' is more accurate descriptor. And while

dependency is a universal experience, as we are all dependent at some time in our lives, the obligations owed to those who do the caring have not figured in moral, political or judicial discussions. She asserts that under traditional moral systems, the question individuals are encouraged to consider is: 'What rights are due me by virtue of my status as an equal?' But this question, reframed in terms of a 'connection-based' equality, would be: 'What are my responsibilities to others with whom I stand in specific relations, and what are the responsibilities of others to me, so that I can be well cared for and have my needs addressed even as I care for and respond to those who depend on me?' (28).

'Who is to care for the caregiver?' Kittay asks (65). She introduces the notion of *doulia*, derived from a traditional term used for a postpartum caregiver ('doula'), to describe the moral obligation of a just society to respond to the needs of the caregiver in order to support her in her caring role. This care, she proposes, should be delivered through 'the nested set of reciprocal relations and obligations' at the social and political levels (68). Full citizenship cannot be achieved until those who care for vulnerable others 'can fulfil these duties without losing our ability to care for ourselves, and in caring for another, the full burden of support as well as care for the one dependent on us will not fall on our shoulders alone' (131). The notion of *doulia* – care for the carer, embedded in social and political processes – offers a strong and compelling framework for re-imagining dependency work and its social value.

Kittay specifically draws attention to the case of those caring for persons with severe intellectual disabilities: 'the practice of caring for the severely developmentally delayed provides yet another paradigm of dependency work, distinguishable from the model of maternal care necessary for an "intact" flourishing child' (33); this type of care requires a life-long commitment to day-to-day physical care of the dependent person, as well as fostering their development, and promoting their social acceptance in the community.

Kittay's perspective cuts through some of the narratives that surround mothers of children with disabilities. For example, she would reinterpret the 'fallen angel' of popular culture – the mother who relinquishes care of her child with disability to the state because she can no longer cope – in political terms, in contrast to the

'transformational coping' proponents in Chapter Two, who would likely describe her as having failed to develop 'positive reframing coping strategies' (Hastings et al. 2002, 273). In Kittay's terms, this mother, who has been attempting to fulfil her moral goals in a society that fails to provide adequate support services, has exceeded her 'breakdown position' (1999, 43).

This concept Kittay borrows from Amartya Sen's (1989) discussion of the role of the dependency worker within the social technology of the nuclear family. She is in a position of 'cooperative conflict' with other non-dependents in the family who can provide access to necessary resources outside the family unit. Because she is obliged to sustain both herself and her charge/s, she is reliant on the resources provided by others (in particular, the 'provider'). She will therefore tolerate a worse situation than the provider before allowing the situation to breakdown; she is, therefore, in a 'worse breakdown position' (43).

Kittay's discussion of this cooperative conflict may seem unduly critical of family relationships when applied to typical contemporary scenarios, but for mothers of children with high support needs, it is highly relevant. In fact, as dependency workers (generally mothers caring for young children) in typical mainstream families achieve increased financial and ideological support for their social participation, those who care for family members with high support needs are being left behind.[8] The mother of a child with disabilities will typically perceive her own capacity for accessing external resources as extremely limited: her caring is more intense and long-term, and the cost of outsourcing care to paid dependency workers is generally prohibitive. She is also likely to feel a heightened need to demonstrate her moral worthiness as a 'good mother'. Hence her 'breakdown position' will be worse than that of mothers of typical children, meaning that she will be prepared to put up with more, and for longer.

In spite of this worse 'breakdown position', the rate of marital breakdown in Australia for families that have a child with a disability has been reported at 70% - 80%[9], twice that of other families. Without the support of a provider in the family, the dependency worker will necessarily rely upon the state as her de facto 'provider'; if this (inadequate) support fails, she finds herself in a potent moral conundrum. She has exceeded her 'breakdown point', and her only recourse is to relinquish her charge.

The repercussions for her child and for her own self-image as a mother are calamitous.

Kittay concludes her book with a personal narrative of mothering her 27-year-old daughter. Kittay emphasises that her daughter's humanity has never been in question: 'to us, she is simply Sesha, that unique individual whom we call our daughter' (158). Sesha is not merely a recipient of care; she reciprocates through her responses to caregivers, and her capacity for joy. This personal story provides a moving coda to the theoretical work, but more importantly, it grounds the discussion in the author's own lived experience. Commentators who cite Kittay's work invariably draw attention to the power of her story (e.g. Ruddick 2002, Gottlieb 2002). By bringing their personal testimonies into the public sphere, academic mother-authors such as Kittay (along with Landsman, 2009, and Kingston, 2010, who were discussed in the previous chapter), are opening the way for informed, critical examination of the lived experience of these marginalised mothers.

Critics of the ethics of care

A number of philosophers, including feminists, have criticised the ethics of care, and the relational concept of the individual that underpins it. These criticisms essentially maintain that this model goes too far in emphasising the interdependence of the individual, and that consequently the model may condone the oppression of women in fulfilling roles that place the needs of others before their own. Held, for example, cites Myers' comments that the self as relational may be 'too entangled in its relational web to achieve a distinctive moral identity' (Myers 2004, cited in Held 2006, 50). Care theorists counter this criticism with two major claims, amongst others: (i) that capacity for autonomy in a person is itself a product of interdependent relations; and (ii) that, in Held's words, 'it is deficient social assistance that makes so many of the commitments of the relational person so burdensome and hard to fulfil' (2006, 50).

Care ethics has also been criticised as 'depoliticized' because the emphasis tends to be on care as an attribute of female identities (Fine 2007, 100); Fine also points out that for US feminists, 'direct concerns for political programmes are relatively muted in favour of the deeper moral principles underlying the actions of individuals and their

society' (2007, 74), but he acknowledges that Kittay's work re-sets these issues firmly on the political agenda.

Others express concern about the imbalance of power inherent in the relation between the caregiver and the cared-for person. The spectre of the over-involved 'bad mother' emerges here, as the dependency worker necessarily takes the interest of the charge as her own. 'Projective identification, and self-loss, threaten to confuse or overwhelm the interests, the psyche, of the dependent,' writes Ruddick (2002, 220).

A further criticism comes from women with disabilities, who argue that by dividing women into 'carers' and 'dependents', the experience of women who require the assistance of their families (such as women with disabilities and ageing women) is further marginalised. Morris pleads for a shift in the theorising of care ethics:

> We need an ethics which is based on the principle that to deny the human rights of our fellow human beings is to undermine our own humanity ... We need an ethics of care which aims to enable people to participate in decisions which affect them and to be involved in the life of the community. Most importantly, we need an ethics of care which, while starting from the position that everyone has the same human rights, also recognizes the additional requirements that some people have in order to access those human rights. (Morris 2001, 15)

While much of what Morris calls for is consistent with the principles of care ethics, it is the shift in attention away from the caregiver towards the person with dependency needs that underlies her argument. This perspective anticipates the discussion of the disability movement in the next chapter; its implications for those who do the caring is a long way from Kittay's notion of *doulia*: the recognition and fulfilment of societal obligations, which implicate all members of society in the achievement of sustainable relations of care.

In spite of these critiques, the ethics of care, and particularly the work of Kittay, provides a robust theoretical framework for reformulating discourses of motherhood and child disability to foreground the philosophical, social and political dimensions of this experience. It offers positive, inclusive possibilities in an otherwise isolating and generally inhospitable landscape.

Conclusion

The five perspectives discussed in this chapter are situated across a spectrum of attitudes to persons with cognitive impairment and their families within the ambit of philosophical thinking. While there have been advances in the ways these subjects are addressed in moral theory, it is also fair to conclude that today the more positive, inclusive representations co-exist with rather than completely replace discourses of marginalisation and exclusion.

The discourse of eugenics is no longer a powerful social force, but its traces remain in contemporary bioethical debates. Mainstream moral and political theorists continue to effectively dismiss the cases of persons with cognitive impairment and their caregivers in addressing questions of personhood, and civic and moral responsibility. The concept of abjection offers a powerful interpretation of the mechanisms underlying this process of marginalisation from a psychoanalytic perspective.

Theorists working in the areas of theological ethics and care ethics refute the accepted conception of the moral subject as autonomous and independent. These scholars assert that as humans, we exist essentially in a state of relation to others, and several go further, by arguing that dependency is a feature of the human condition. Therefore, the giving and receiving of care must be a fundamental concern of our moral lives. Theological commentators, in contrast to feminist care ethicists, emphasise the transcendental potential of the care relation, based on acceptance and submission. This view is, as such, apolitical and ahistorical, and even while the religious perspective provides a useful framework for personal meaning-making, it requires that parents of children with disabilities adopt a moral code that is well outside that of mainstream society.

The care ethics articulated by Kittay and other authors is couched in moral terms, but it is also highly political, articulating as it does the devalued and gendered nature of care work, and its restriction to the private sphere where it is normalised. Kittay's work has been embraced by a passionate group of philosophical thinkers and writers, and its influence has extended to those working in the sociology of care. Responses in public discourse and the policy arena are slow to emerge, however, as will be discussed in the next chapter.

Philosophical theory may appear to have less direct impact on families of children with disabilities than media messages or social science research. But the ideas generated within philosophical thinking inform these public discourses, and are, in turn, informed by them. They reflect the concerns and priorities of the body politic, and they underlie the cultural landscape in which the lives of families are embedded. Personal narratives such as that of Kittay serve to undercut the prevailing narratives. As Gottlieb asserts, it is 'only when those who do the caretaking can also do the writing that this issue seriously comes to the fore' (2002, 226).

Chapter Four

DISABILITY STUDIES AND RIGHTS DISCOURSE

Parents of children with disabilities:
Are they 'in' or 'out'?

Introduction

The disability rights movement has achieved enormous gains over the past 40 years in challenging the barriers to inclusion that have faced people with disability across the globe. During the same period, the academic discipline of disability studies has established a robust presence in the academy. In the hierarchy of disability, however, people with intellectual disability (particularly severe cognitive impairment) continue to occupy a marginal position, as the movement foregrounds and valorises the individual and his/her responsibility as a full participant and claimant of rights. Parents of children with disability – without a disability, but nevertheless immersed in the world of disability – occupy an ambiguous position, and as such, are not always recognised as legitimate participants.

Any discussion of disability rights requires brief reference to the genesis of the movement and its central issues, and so I begin this chapter. Perhaps the key debate involves the *models of disability*. While these ways of understanding disability have informed advocacy and activism, and have played a critical role in framing contemporary narratives of disability, they are also the subject of negotiation and dispute. I then address the problematic position of parents of children with disabilities: in both the rights movement and disability studies, they are neither 'in' nor 'out', occupying what Ryan and Runswick-Cole call a 'liminal position'. Finally I consider the carers' movement, and how it may or may not offer a site of positive identification for parents of children with disabilities.

A difference between this chapter and those preceding it is the shift in focus from 'mothers' to 'parents'. Within disability rights discourse and disability studies, parents tend to be regarded as singular entity, surrounded by a particular ideology, with little differentiation in the roles of fathers and mothers. In current carers' movement discourse, too, issues around gender are downplayed. Some of the implications of this de-gendering are discussed below.

Disability rights, disability studies, and models of disability

The disability rights movement had its genesis in the 1960s, at a time when other minority and marginalised groups were emerging in the public sphere. People with

disabilities around the world were agitating against discrimination and for resources that would mitigate their exclusion from the social world. The first landmark outcome of international activism was the inaugural International Year of Persons with Disabilities (IYPD) in 1981, which brought about the widespread recognition of disability issues.

Along with improved access to public spaces such as transport, buildings, and employment, a major achievement of the disability rights movement has been widespread deinstitutionalisation of people with psychiatric, physical and intellectual disabilities. Narratives by people who had spent much of their lives in institutions, at a time when parents were encouraged by authorities to place their children with disabilities in homes and 'forget about them and get on with your own lives', played a major role in bringing the plight of this group of people to public attention.[10] While the process of 'devolution', or relocating residents into group homes and other community-based settings, has achieved significant goals, it has some way to go: almost 600 people with disability – the majority with intellectual disability and complex care needs – still live in large residential institutions in New South Wales (Kirkwood 2013).

The International Convention on the Rights of Persons with Disabilities, a human rights instrument of the United Nations, came into effect in March 2007. This convention was formally ratified by the Australian Government in July 2008. The most significant recent development for people with disabilities and their families in Australia has been the passing of The National Disability Insurance Scheme Act 2013 by federal parliament on 21 March 2013. This major initiative came about as a result of an Australian Government Productivity Commission finding that:

> The current disability support system is underfunded, unfair, fragmented, and inefficient, and gives people with a disability little choice and no certainty of access to appropriate supports. (Productivity Commission 2011, 3)

The broad aim of the Act is to make resources available 'to enhance the quality of life and increase the economic and social participation of people with a disability and their families'.[11] Roll-out of the National Disability Insurance Scheme (NDIS) commenced in 2014 in limited targeted areas across the country. The scheme promises much, but how much support, when, and to whom it will be available, is still uncertain; debates

persist about the government's capacity to finance the scheme, and at the beginning of 2014, the Prime Minister quietly replaced the word 'launch' for the roll-out with 'trial'[12].

In tandem with the rights movement, disability studies as an international academic project emerged; 'as an integral part of the emergence of the social movement of disabled people … it is also an intellectual struggle within the academy against dominant and unreflective paradigms of normality' (Meekosha 2004, 724). Disability studies has since established a strong interdisciplinary basis with wide influence. It is characterised by two distinct theoretical approaches: in the UK, disability studies comes out of a Marxist tradition that reflects 'the close relation between sociology, social policy and the politics of the welfare state in Britain' (Meekosha 2004, 729), whilst in the US, it has emerged from a very different intellectual background, as Ware describes: 'Humanities-Based Disability Studies is an interdisciplinary critical genre that draws from history, literature, philosophy, anthropology, religion, medical history, rhetoric, and first person narratives' (Ware 2002,143). Meekosha refers to these paradigmatic differences as 'the disability culture wars of the North Atlantic' (2004, 725). The contrasts between the UK and the US orientations can be summarised as follows: academics from the UK are more likely to focus on socio-political inequality, on issues of service delivery and access, and social change; US scholars are more likely to focus on the individual as the site for the valuing/celebrating diversity, and moral/humanist issues of equality. These differences are reflected not only in scholarly writing, but in public policy ideologies. They also play an integral role in the telling of stories of disability: who can do the telling, which stories are legitimate, and even whether it is possible to tell a story at all.

In countries such as Australia, 'on the "periphery" of the English speaking world', writes Meekosha (2004, 725), 'the approaches tend to be more eclectic, drawing on both metropoles'. Writers in Australia, such as Meekosha (and myself), consequently enjoy a vantage point from which to observe and critique these differences, and a less prescriptive intellectual environment which enables us to draw more freely from both traditions in our own work.

One of the key achievements of the disabled people's movement has been the development of the 'social model' of disability, originally by British activists from the Union of Physically Impaired Against Segregation (UPIAS) in the 1970s. Within this model, distinction is made between bodily impairment on the one hand, and the social oppression of those with impairment, which is experienced as disability, on the other. The social model was developed in response to the prevalent, medicalised view of those with impairment, which located disability within the individual body, and which became known as the 'medical model' of disability. In parallel with the social model, an additional perspective has arisen which reflects North American philosophical and political approaches (Shakespeare and Watson 2002); this is known as the minority group model or cultural model (Snyder and Mitchell 2006). Under this model, disability is, like race and sexuality, a concern primarily of identity and affirmation.

An appreciation of these models is critical for comprehending developments in disability rights and critiques of social policy, for engaging with theoretical and scholarly debates, and for understanding the social processes of disablement. It is also necessary for contextualising the ways in which people with disability self-represent. A fuller discussion of each of these models follows.

The medical model

Scholars attribute the emergence of what has become known as the 'medical model' of disability to the 'birth of the clinic' at the end of the eighteenth century (after Foucault 1963 [1973]), reflecting the ascendancy of medical science as the privileged source of explanations of the body. Before that time, disability was typically explained in supernatural or moral terms, with impairment serving 'as a trope for a moral or spiritual condition' (Couser 2009, 22). The following definition of the medical model comes from the website of Disability World, a US clearinghouse for rights information; organisations such as these provide a way of understanding these models that is publicly accessible and shared across the disability rights movement.

> The medical model is presented as viewing disability as a problem of the person, directly caused by disease, trauma, or other health condition which therefore requires sustained medical care provided in the form of individual treatment by professionals. In the medical model, management of the disability is aimed at a 'cure,' or the individual's

adjustment and behavioral change that would lead to an 'almost-cure' or effective cure. In the medical model, medical care is viewed as the main issue, and at the political level, the principal response is that of modifying or reforming healthcare policy.[13]

Disability activists argue that the medical model places the burden for adaptation squarely on the individual (i.e. to remediate and become 'normal') rather than on the society (to address the barriers that impede the inclusion of people with disability in the social world). It exposes people with disability to expressions of identity that focus on their impairment rather than on their personhood (e.g. 'the blind', 'the handicapped'); and it has historically entrenched their positioning as dependent recipients of medical and welfare services.

The medical model has also had particular ramifications for people whose impairments are not able to be remediated. In the past, these people were effectively removed from society; for example, the Weemala residential institution for people with disabilities at Ryde, NSW, was formerly known as the 'Home for Incurables'. Today, parental anecdotes continue to circulate about medical specialists delivering rude and pessimistic sentences on children who are diagnosed with impairments that cannot be remediated through their (often 'heroic') medical interventions.

This model continues to have significant impact on the lives of families of children with disabilities. The emphasis on remediation within the medical model means that the onus falls on parents to pursue all avenues for normalising their child. The options include surgical interventions, and highly demanding regimes of early intervention therapy that offer the hope of 'rescuing' their child from a lifetime of disability. If the therapy program does not deliver the desired results, the parents are likely to feel guilt that they have not worked hard enough or marshalled adequate resources to this end.

For mothers, these pressures are compounded by the medical discourses surrounding pregnancy. The medical surveillance of pregnancy has been addressed extensively by disability studies scholars and rights activists, regarding the termination of 'defective' foetuses, and the implication that babies who have impairments are universally unwanted (see for example, Kerr and Shakespeare 2002). The intrusion of the clinical gaze into the womb, and the status of the foetus-as-person has been discussed at length by scholars, including Landsman (2009), who critiques public health campaigns aimed at pregnant women and those planning pregnancy. These emphasise

the responsibility of mothers for preventing disability and producing 'perfect' babies. Once, the womb was seen as a safe haven for the developing foetus, Landsman argues, but today it is seen as 'permeable, vulnerable to the dangers delivered by selfish, careless women' (2009, 86). Landsman refers, for example, to the website of the US Center for Disease Control and Prevention (CDC): 'What YOU can do to Prevent Birth Defects'. While the importance of public education about health in pregnancy is incontestable, these overly simplistic messages promise a healthy, normal baby for compliant, 'good' mothers. They contribute to the sense of self-blame and failure felt by mothers who give birth to babies with impairments, and add to their marginalisation (Knight 2013b). They are also disturbingly reminiscent of the discourse of eugenics discussed in the previous chapter, with their implied messages that the birth of a baby with disability is a biological (and implicitly, moral) transgression.

The social model

According to proponents of the social model, disability is the result not of bodily impairment but of the social oppression faced by those with impairment. The following definition comes from the influential UPIAS document, *Fundamentals of Disability:*

> In our view, it is society which disables physically impaired people. Disability is something imposed on top of our impairments by the way we are unnecessarily isolated and excluded from full participation in society.... Thus we define impairment as lacking all or part of a limb, or having a defective limb, organism or mechanism of the body and disability as the disadvantage or restriction of activity caused by a contemporary social organisation which takes little or no account of people who have physical impairments and thus excludes them from participation in the mainstream of social activities. (Oliver 1996, 22; cited in Shakespeare and Watson 2002, 3)

The emphasis is on the social exclusion faced by people with bodily impairment. In this document, the emphasis, too, is on 'physically impaired people' – perhaps predictable due to its UPIAS provenance, but also indicative of a hierarchy within the disability rights movement that placed (and continues to place) those with cognitive

and mental health related disabilities somewhat differently from those with physical impairment.

This definition is extended on the Disabled World website to encompass the social responsibility that is also a major component of this model:

> The issue is both cultural and ideological, requiring individual, community, and large-scale social change. From this perspective, equal access for someone with an impairment/disability is a human rights issue of major concern.'[14]

Mobilisation of the social model has had enormous impact on the lives of individuals with disability and their participation in the social world, and as a consequence, people with disability are far more visible and active in mainstream culture than they were three decades ago. This, in turn, has helped to break down and challenge the mythologies and the prejudices that have surrounded disability and impairment. As Couser (2009, 27) notes, the social model diverts attention away from what *has happened* (i.e. what caused the impairment), to what *is happening* in the present for the person with a disability. It also moves focus away from the individual, to the social context: in the words of Shakespeare and Watson (2002): 'suddenly, people were able to understand that they weren't at fault: society was'.

But since the late 1990s, the social model has been under review and negotiation. Influential players in the disability arena, notably Shakespeare (*Disability rights and wrongs,* 2006), argue that it goes too far in dismissing both the importance of the personal experience of impairment and the value of therapeutic interventions, amongst other issues. In fact, Shakespeare and Watson have made the following bold assertion: 'Our claim is that the British version of the social model has outlived its usefulness' (2002, 9). Other scholars (in particular, women with disabilities) have criticised the social model for its de-emphasis of lived experience, and thus its de-legitimisation of their claims to represent their own gendered, embodied experience of impairment: 'As disabled feminists have argued, impairment is part of our daily personal experience, and cannot be ignored in our social theory or our political strategy' (Shakespeare and Watson 2002, 11). Mintz (2007) addresses this problem in her exploration of the personal narratives of eight female American disability scholars and writers: she examines not only the ways in which these writers challenge cultural representations of disability, but how they engage with the problem of representing their own embodiment within the framework of the social model. For people with intellectual

disability this problem is compounded, because the social model valorises self-determination and may indeed marginalise those who need others to advocate on their behalf, and who need a high level of support to express their choices and mobilise their autonomy.

Parents of young children with disabilities find themselves inevitably drawn into the competing discourses of the medical and social models. As mentioned in Chapter Two, Landsman (2003) describes this as a staged recruitment: when an infant or child is first diagnosed, parents are interpellated by the ideology of the medical model and its preoccupation with diagnosis and remediation. Later, their encounters with the social services system and advocacy, as well as their own experiences of marginalisation, draw them into the sphere of the social model. The ideologies behind the two models are clearly at cross-purposes. Parental narratives commonly involve these two models in a balancing act in which the author often adopts a position that privileges one (e.g. by focusing either on efforts to 'fix' the child or on activism to improve services). How these perspectives play out in parent narratives will be addressed in Part Two.

The cultural model

While the social model continues to hold ascendancy in disability studies and struggles for rights, in North America this model is interpreted through a very different lens from the Marxist orientation of UK scholars. Snyder and Mitchell refer to this different approach as the 'cultural model' of disability, 'primarily associated with social science-based and humanities-based discourses in the United States' (2006, 5).

According to the cultural model, disability is:

> a site of phenomenological value that is not purely synonymous with the processes of social disablement. Such an emphasis does not hide the degree to which social obstacles and biological capacities may impinge on our lives, but rather suggests that the result of those differences comes to bear significantly on the ways disabled people experience their environments and their bodies ... Cultural model approaches ... tend to recognize identity and body as constructed. (Snyder and Mitchell 2006, 6-7)

A such, the cultural model acknowledges the principles of the social model, but as Meekosha explains, it 'transcends' the 'impairment/social dichotomy' by foregrounding individual difference and the value of diversity and individual difference: 'the human body can appear in many forms, and it is implicitly a political act to judge bodies as "normal" or not' (Meekosha 2004, 728). The primary focus is on the construction – and politics – of identity. Disabled people are described as a minority group, a stigmatised group, a sub-culture, an under-class, or a subaltern group, and as such, have much in common with other marginalised social groups:

> [D]isability studies in the US have been influenced by identity politics and the corresponding academic disciplines emerging from the liberation movements of the 1960s—feminism, race and ethnic studies, gay and lesbian studies. (Meekosha 2004, 726)

As with other minority groups, the project for people with disabilities is the reclamation and re-affirmation of a socially devalued identity. However, this focus on valorisation creates a dilemma for those who want or need to tell a different story of their experience of disability, one that expresses difficulty, dislocation and social marginalisation. For example, parents of children with disabilities who experience lack of affordable health and social services within the US welfare system may find that this narrative is suppressed; their story is *expected* to reflect the values of the cultural model, one that validates both their child and their own transformed identity.

The different perspectives of the social and cultural models, and the transatlantic divide they represent, can be illustrated by comparing two books by and about mothers of children with disabilities that were mentioned in Chapter Two. One of the key themes in *Reconstructing motherhood and disability in the age of 'perfect' babies* (2009) by US author Gail Landsman is the process of identity re-negotiation that mothers in her study undergo:

> [A] number of mothers in the study describe a personal transformation in terms not only of rejecting the binary of normal/abnormal, but of embracing the very qualities in their child that are labelled by society as abnormal. (Landsman 2009, 207)

In contrast, Anna Karin Kingston's book, *Mothering special needs: a different maternal journey* (2010), was written in Ireland and published in the UK. In spite of

its somewhat sentimental title (which may have been required by the publisher), this work focuses on political issues around social marginalisation, as follows:

> [R]ights-based legislation does not automatically ensure that quality services for people with disabilities are implemented without a struggle ... This maternal struggle seems to take place regardless of social and cultural contexts and appears to be common amongst many mothers in the Western world. (2007, 47)

Both of these authors also address aspects of the alternative model: Landsman, for example, describes the social marginalisation of mothers in her study, and Kingston raises issues around the identities and social value of both children and mothers. Each work, however, is framed by the core values of the particular model that the author subscribes to.

Parents: insiders or outsiders?

As Ryan and Runswick-Cole observe, 'mothers of disabled children have occupied a complex, contradictory and marginal position within both disability studies and the disabled people's movement' (2008, 199). These discourses are based on the centrality of people with disabilities and as such, they inevitably exclude those without disabilities; in fact parents are often represented by disability activists as oppressive and overbearing forces in their children's lives. 'At best, parents of disabled children have been described as "allies" of their disabled children,' state Ryan and Runswick-Cole (2008, 201), and are placed on a par with participants in their children's lives such as professionals – a position which denies the commitment, emotional intensity and duration of their parenting role.

The shifting place of parents in the disability movement has been addressed by Shakespeare (2006), who contends that 'historically, research and policy was dominated by proxies for disabled people (parents, carers, professionals)' (186), before people with disabilities took these matters into their own hands and effectively removed intervention by these proxies. He concedes that now there may be scope for admitting relational others into the frame: 'I think there might be a danger of ignoring or undervaluing the role of parents. In stressing the negative aspect, there is danger of

giving an unbalanced picture' (188). The benefits of including parents are also pointed out by Casper and Tolley (2005):

> [D]isability studies has tended to emphasize how disability becomes meaningful for the disabled person but has not often attended to others present in the disability situation ... [T]he other side of the equation [is] how disability becomes significant for nondisabled persons in relationships with and in relation to disabled persons ... paying attention to all of the actors in the situation can serve as a route to real political change' (2005, 116-8).

But such inclusion is still a way off, and mothers today occupy what Ryan and Runswick-Cole refer to as a 'liminal position': they are not disabled, but they experience disablism through their intimate association with their disabled family member. These authors, mothers of children with disability as well as academics, describe their own experience: 'The liminality arises not only from the tenuous position non-disabled researchers have within disability studies ..., but also from the distance between the experience of being a mother and the experience of being the mother of a disabled child' (2008, 200). As such, mothers of children with disabilities are neither 'in', nor 'out', and this liminality is expressed on multiple fronts.

In recounting their experience of parenting, mothers (and fathers) therefore engage with the same issues of articulating marginalisation as authors who are themselves disabled, but they face another form of marginalisation – from the disability rights community itself. In this regard, the problems in representing themselves, their families, and their child with disability are (at least) twofold: (i) claiming and speaking their own experiences may be de-legitimised; and (ii) representing the lived experience of their vulnerable, disabled children may be viewed as paternalistic and invasive, and hence present an ethical dilemma (Couser 2004).

Two book reviews published in the international journal, *Disability & Society*, demonstrate some of these contradictions. The first is a review by Devaney, Swain and Harrison (2007) of *Becoming citizens: Family life and the politics of disability* by Susan Schwartzenberg (2005). Schwartzenberg's book provides an account of families' journeys to activism, and the reviewers complain about 'the lack of statements by the young disabled people themselves':

> Their primary presence in the book is in photographs, either smiling or being smiled at, rather than as active members of politically active families. This, in terms of the politics

of disability, offers an account of the role of parents within the disability movement in America. At worst, then, the voices of disabled people in the movement are themselves marginalized. (Devaney, Swain and Harrison 2007)

The question that begs is how many of these young people have the capacity to provide their own accounts? The emphasis on self-representation within the disability movement – on the claiming of rights by autonomous citizens – is here at odds with the lived experience of many people with cognitive impairments. Without the testimony of their parents, the stories of these young people would go unheard; I would argue that these parents are in fact enabling their children, rather than restricting them, as the final sentence implies.

The second review presents an altogether different perspective. *Between myself and them: Stories of disability and difference* (Krause, 2005) is reviewed by another group of transatlantic academics (Taylor et al, 2006). This book includes the autobiographical narratives of young adults who have a disability. However, one narrative from parents is included; their 21-year-old daughter is 'relatively non-verbal', and 'in order to have her story included ... her parents ... participated in a dialogue with the editor'. The reviewers describe this narrative as 'both inspiring and heartbreaking':

> [W]hile it is wonderful to read and learn about Jade and her family's struggle to create opportunities for independence for her, one cannot help but notice that [her parents] have lost their own independence and sense of identity through caring for their daughter, an uncomfortable fact of life for many involved in any caregiving role and one that is rarely acknowledged. (Taylor et al, 2006)

In contrast to the first example, these reviewers note that the contribution of parents is 'rarely acknowledged'. Jade's journey towards inclusion, they write, comes at the expense of the personhood of her parents. In the first book review, then, parents were seen to be *appropriating* the rights of their child; in the second, they are *sacrificing* themselves to these rights. These contradictory interpretations illustrate the dilemma faced by parents within the movement; after all, the parents in these two books were actually doing the same things. These two differing interpretations are reminders that the good/bad polarity that characterises the representation of mothers/parents may extend into the arena of disability studies.

This type of marginalisation of parents is unfortunately exacerbated by tensions that have existed historically between the disability rights movement and parents. Some parent lobby groups, for example, have adopted advocacy positions that are at loggerheads with disability activists; conversely, disability activists have accused parents who advocate for their own needs as being self-interested, and as regarding their disabled offspring as burdens.[15]

Such friction has surfaced frequently in the matter of supported accommodation for people with intellectual disabilities. As mentioned above, a major achievement of disability advocacy in Australia has been the widespread deinstitutionalisation of people with disabilities and their devolution to community care (primarily with their families, but also in state-funded group homes). While this has been an overwhelmingly positive development for people with disabilities and their families, it has also transferred responsibility for long-term care from the state back to families, while the availability of support services for families continues to be notoriously inadequate. In response, some parent groups have lobbied strongly for institutions to stay open, in spite of government commitments to close them in respect of the rights of people with disability. Two recent examples in New South Wales illustrate this tension.

In January 2011 the NSW State Government announced that Stockton Centre, an institution that had been housing people with intellectual disability for 60 years, would close in 2018; the 480 remaining residents would be relocated in community housing in the meantime. By February 10, this decision had been reversed because 'families of residents put a convincing case to the Minister', claiming that 'a lot of [the residents] have been there for over 50 years ... [and] the staff are the only family they know'.[16]

In August 2007, the *Sydney Morning Herald* reported that the plan to move long-term residents with severe disabilities from Weemala, an institution in Sydney, to community housing had 'horrified families'. Family members lobbied a high-profile political candidate in the federal elections at the time, as well as NSW state politicians, and the plans for closure were subsequently shelved.[17]

This backflip on the Weemala devolution plans was described by peak advocacy organisation People With Disability Australia Inc. as 'the most regressive disability policy to emerge in 30 years', which will 'establish a new generation of residential institutions that will ensnare future generations of persons with disability'.[18] This particular matter signified a low point in relations between disability activists and parents of people with intellectual disability. It also points to the concern of activists that many parents may be ignorant of the history of the disability rights movement and the struggles over decades that have brought about positive social change in the lives of people with disabilities.

The Carers' Movement

The mission of the carers' advocacy movement is to represent the interests of those who care for a person with a disability, mental illness, chronic medical condition or who is frail aged. This movement emerged a decade or two after the disability rights movement, and in Australia the rights of carers were recently formally recognised through legislation (the Carer Recognition Act was passed by the Australian Parliament in August 2010). One of the major concerns to government that precipitated this action is the ageing of the population, which will see a rise in the number of older people requiring care, and a corresponding reduction in the number of family members willing or able to care for them. Carers, a diminishing resource, will indeed need to be cared for in the future.

The Carers Association of NSW was the first dedicated not-for-profit to become an independent organisation for carers in 1980. Now all states are represented, and the umbrella organisation, Carers Australia, was formed in 1993. In the previous year, the first Carers Awareness Week was held, with the theme, 'Carers need care too!' Carers Australia reports: 'Since those early days research into caring has gone from strength to strength, and funding and programs have followed. Pensions for carers were introduced, programs were established, recognition of carers grew and more surveys and research from government and institutions were funded'.[19] Parent carers of children with disabilities have received some (in most cases very modest)[20] financial support since 1998. Prior to the 2007 federal elections in Australia, a Carers Alliance

was formed as a political party to contest a seat in the Upper House of the Australian Parliament. It was unsuccessful, but continues to exist as a political entity.

In the UK, the genesis of the carers' movement came a little earlier, attributed to the 1963 campaign led by Mary Webster, a former Congregational minister and carer of ageing parents, to bring to public attention the plight of 'dutiful daughters': those who were required to take on the care of ageing parents and effectively lived 'under house arrest' (Cook 2007). The focus was very much on these single women carers of ageing parents, but this was a time when most children with disabilities were still being sent into institutional care. From these beginnings, the carers' movement has evolved to represent lobby groups with different agenda from various caring scenarios, but the aged-care lobby continues to be by far the largest and loudest of these.

In Australia, the 'Every Australian Counts' campaign to lobby for the introduction of the National Disability Insurance Scheme (NDIS) has seen possibly the most successful co-operation between disability activists and carer groups. In 2009 the National Disability and Carers Alliance was formed by the Australian Federation of Disability Organisations and Carers Australia and National Disability Services to collaborate for improved services, including the NDIS[21]. The relationship between disability rights and carer groups, however, has not always been a close one, and at times relations have been openly hostile, as the conflict over supported accommodation discussed above illustrates.

Research into the social practice of caring began in the 1970s, with the work of feminist scholars who argued that community care policies of the time were 'effectively transferring responsibility from the state to the family, and within the family, to women' (Fine and Glendinning 2005, 603). These agenda were linked to debates of the time around gender and prevailing social attitudes that care of family members (including those who were elderly and disabled) was a 'natural' female activity. Today, the academic literature on caregiving comes largely through the disciplines of sociology and social policy, with the emphasis on aged care provision as the most pressing issue (see Rummery and Fine 2012). A review of this literature is accordingly out of the scope of this exegesis.

While disability studies as an academic discipline grew out of the disability rights movement, initiated by people with disabilities, there has been no parallel development in the area of caring, or caregiving (as it is known in the US). Academic work on caring is characterised by research 'on', rather than research 'from within'. Nevertheless, the carers' movement in the UK, Europe and Australasia has been able to achieve some recognition of the marginalisation of caregivers. Rummery and Fine compare this with the situation in the US, where 'the emphasis has been placed on demonstrating the burden of care through the ever finer measurement of the psychological construct of "caregiver burden" (Chappell and Reid 2002)'. The result is, they assert, that 'the carers movement has been less influential and has struggled to develop a strong national presence' (Rummery and Fine 2012, 326). This research orientation may be culpable in part for the failure of a carer's movement to gain traction in the US, but there is also a (perhaps stronger) cause: the cultural model prevalent in US disability studies, with its emphasis on affirmation and valorisation, effectively dis-entitles carers from taking up issues in support of their own rights.

Clements describes the current activism by carers for recognition of their rights as similar to the campaigns of the Disabled People's Movement in the 1970s. But problems arise within this struggle, because in human rights discourse, 'carers ... cannot be legitimately viewed as "rights holders"': caring is not an innate characteristic (unlike sex, race or disability), and an element of choice is seen to exist in a person's assumption of the caring role. Instead, carers are regarded as deserving of 'soft socio-economic rights rather than the hard negative civil and political rights' (2013, 4). But Clements argues that carers should, in fact, be entitled to claim status as rights holders, along with other marginalised groups, in view of the 'considerable national and international evidence that carers in general experience adverse social, economic, health and political consequences as a result of their caring role' (13).

Echoing the work of Kittay, Clements claims that gender lies at the heart of this injustice: 'Caring is not, of course, an exclusively female activity – it is just that the status of caring has been engendered by the fact that it is women who provide the bulk of it' (16). Its negative health impacts have been well-documented; he cites, for example, a longitudinal well-being study of Australians that found that 'female carers had the lowest collective wellbeing of any group' (Cummins et al. 2007, cited in Clements 2013, 14).[22]

The oppression of carers, Clements argues, is compounded the quarantining of care within the 'private' domain. 'What is being described here is a social model of exclusion – similar but even more subtle and "unconscious" than that we have come to associate with the experiences of disabled people (28) ... A carer's feelings of compassion, guilt and duty do not, however sanction adverse treatment, anymore than a woman's maternal feelings justify treating her less favourably' (36).

Yet reference to gender is absent in the current rhetoric of the both the carers' movement and social service policy. On the website of Carers Australia, the national peak body, gender of carers and the gendered nature of caring is ignored altogether, even in statistics provided on carer characteristics and demographics. In the recently released New South Wales Carer Strategy 2014-2019, the words 'gender', 'female' or 'women' do not appear: 'carers' are referred to in the plural, and the generic 'they' pronoun is used throughout. However, the two carer vignettes in the document focus on women in caring roles (one a mother caring for a teenage daughter with a disability, the other featuring two Aboriginal women), and each of the seven photographs in the document involves a woman in a caring role. In this way, I suggest, issues of gender are taken up 'by stealth' rather than clearly articulated: caring as a woman's role is normalised through these images.

Australian Bureau of Statistics data reveals that in 1999, of those self-identifying as primary carers of 15-44 year-olds, 21% were male; of 45-64 year-olds, 32% were male; and of over 65 year-olds, 35% were male (Australian Bureau of Statistics, 1999, cited in Fine 2007, 82). The clear majority of carers are women, with the total skewed slightly by an over-representation of men who self-identify as carers in the older age group (mostly caring for spouses). This lack of acknowledgement of the gendered nature of caring is so marked that it points to conscious policy intention, possibly in order to not alienate male carers. But it does not serve female carers well; it further normalises caring as a vocation for women, and it inhibits carers from mobilising a women's rights agenda in their advocacy.

The slogan of the Carers Alliance political party is 'Making the personal political', which replicates the catchcry of early feminists. However, in the party's policy statement, gender is ignored. This statement foregrounds issues of political and social inequality, as follows:

In a changing civil society, carers do not have the same rights nor the same life possibilities as the broader community, but they do have the expectation that, as providers of 92% of all disability services nationally they are entitled to recognition by government and to be supported to have input to policy, planning and the opportunity to participate in the direction of their own lives. (From the Carers Alliance website - Policies[23])

There are clear parallels with the arguments of Kittay (1999, see Chapter Three) regarding care relations, but no such no theoretical underpinning is claimed. This would appear to be a loss to the movement, because Kittay foregrounds issues of gender as well as equality, and emphasises the centrality of caring to human experience. Fine (2007) draws upon Kittay's work to emphasise that caregiving is an issue of rights and citizenship; and Rummery and Fine assert that:

Access to care, and the giving of care, can be seen as an important part of the resources which are both drawn upon and needed for social participation. Correspondingly, both the giving and receiving of care – if given, and received, out of choice, rather than out of obligation or because no other options are available – should be conceptualized as citizenship rights. (2012, 330-1)

Conclusion

This chapter has addressed the disability rights movement and the place that parents occupy within it.

The disability rights movement and the academic field of disability studies are characterised by tensions between the different orientations of UK based activists and scholars and their counterparts in the US. In the UK, the social model predominates, with its focus on disability as a function of society's failure to provide necessary accommodations to enable the full participation of people with disability. In contrast, commentators in the US typically work within the framework of a cultural model of disability that foregrounds issues of diversity, and the cultural construction of identity. Academic work in Australia is characterised by an approach that draws on both of these perspectives.

While families typically align themselves with the goals of the disability movement, the position of parents (and particularly mothers) is described as 'liminal'. They are neither included nor excluded, and relations between parents (or carers) and disability activists can be difficult, and at times, in open conflict.

In order to claim entitlement to tell their own stories, parents of children with disabilities must, then, negotiate a way through these hazardous zones. They may choose to seek respite in the carers' movement, but that landscape and its *narrative habitus* currently offer few opportunities for rich narrative exploration.

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In Chapters Two, Three and Four, I have taken a sweep across the landscape in which mothers of children with intellectual disability are represented in empirical research and theory, within the academic disciplines of social science, philosophy and disability studies. The picture that emerges for these mothers is contested, contradictory, and above all, marginal: on the fringes of theoretical and empirical research on motherhood and family studies, philosophical discussion, and the discourses of disability rights. The dimensions that underlie this academic work can be summed up by referring to the much-cited feminist dichotomy of the 'personal' and the 'political'.

In terms of the *personal*, several streams of this research ground their representations of these mothers in psychological characteristics, adaptation strategies, the capacity to transform, and in so doing, manage issues around identity re-calibration as a personal project. This process of re-formation, these researchers inform us, enables mothers to claim a socially valued role for themselves and their child, in spite of evidence that they may be socially isolated and depressed. This theme is evident in the social science-based empirical research, in theological ethics, and to a lesser extent, in the cultural model of disability, whereby the claiming of a re-formulated identity takes precedence over direct political concerns. This is the 'good' mother, whose identity is

conflated with that of her child, and while these researchers may protest against this analogy, she looks very like the saintly mother of popular culture.

Several researchers allude to the psychic crisis that a mother experiences when her child is diagnosed with a severe disability. This crisis is referred to as 'disequilibrium', 'disintegration' and 'anomie' (e.g. Scorgie and Sobsey 2000; Ryan and Runswick-Cole 2008), amongst other terms. This disruption is central to the mother's experience, and its impacts are interpreted in various ways. Some social scientists regard this crisis point as providing an opportunity for personal growth; and theological ethicists see it as a pathway to transcendence. On the other hand, critical theorists may regard it as a response to transgression and the processes of abjection. But it is never named for what it actually is: trauma. This failure to acknowledge and name the truth of this crisis may actually contribute to the self-alienation felt by these mothers.

As well as estrangement from self, these mothers experience isolation from society at large. They are excluded from mainstream conceptions of motherhood, and they typically face intensive surveillance from medical and social services regimes. They are implicated in the public and medical discourses of mother-blame, and socially and culturally constructed as abjected, compounded through their identities as mothers, mothers of children with intellectual disabilities, and carers. In disability rights discourse, they may be construed as inhibiting the autonomy of their child with disability, or as putting their own desires to alleviate their own burden of care ahead of the needs of their child.

In terms of the *political,* sites for productive identification have been slow to emerge for these mothers. During the first half of the twentieth century, the eugenics movement sought to eliminate 'feeble-mindedness', and in so doing, effectively demonised people with intellectual disability and the parents who bred them. In moral and political philosophy, persons with intellectual disability have been disavowed as 'non-persons', and their caregivers marginalised. In feminist theory, limit cases of motherhood, such as mothers of children with disabilities, have not figured in much of the discussion. In disability rights discourse, parents are neither insiders nor outsiders; they have been at cross-purposes with rights advocates over key issues, and their motives are often regarded with suspicion.

More positive possibilities for these mothers at the socio-political level have come through the ethics of care as a philosophical project, and in particular through Kittay's work which positions caring as a political as well as philosophical issue. Sociologists such as Rummery and Fine (2012), Fine and Glendinning (2005) and Hughes et al (2005) have recently sought to move Kittay's ideas into the mainstream agenda of sociological research on caregiving. Clements (2013) brings a human rights perspective to this discussion. But the carers' movement, another site for potential positive political engagement, has not yet articulated a theorised political/philosophical underpinning such as this. The wide reach of this movement, with its strong aged care constituency, tends to place parents of children with disabilities outside its primary focus; and its failure to foreground the gendered nature of care work emerges as a disservice to these mothers.

These discourses and the narratives embedded within them form a mosaic, a multi-faceted construction of contrasting and colliding shapes and colours. For a mother of a child with an intellectual disability such as me, the effect is dazzling and confusing, but also alienating. Except for a couple of isolated elements within this collage, all these pieces are *about* us mothers, rather than *by* us, told by third party observers who seek to mould our lives to fit preferred patterns. When mothers' own voices are heard as research respondents, these are mediated, censored by the power dynamics of the investigative process, and interpreted to fit into some paradigm or someone's particular agenda. As Atkinson and Poletti observe, 'most testimony is congruent with common belief and is collected, in a sense "processed", in the service of a range of institutional and discursive regimes' (2008, 1). To have one's truth interpreted in the authoritative voices of others is deeply confronting; it condones silence; and confers voicelessness; it might even be seen as a form of violence.

Several mother-researchers have been able to bring their own personal stories to this discussion, and in so doing, they cross the divide between observer and observed (e.g. Landsman 2009, Kingston 2007, Kittay 1999). There's a risk here, in relinquishing the safety of distance and turning the researcher's gaze upon oneself, in treading the softer ground of the autoethnographer (Denzin and Lincoln 2011, 2), and in publicly acknowledging one's own membership of this frontier tribe. The story of each of

these authors is a powerful testimony, and yet each consigns her own story to the borderlands of her text: Kittay and Landsman at the end, as postscripts; and Kingston at the beginning, as an introductory passage. For Kingston and Landsman, their research *on* Others is the primary matter of their writing; for Kittay, it is her theoretical discussion and critique. Their own lived experiences remain on the periphery.

How do mothers find the language to write through this experience of trauma and identity re-calibration? How do they – indeed, how can they – lay claim to their own stories in the midst of all these competing narratives? These questions are the subject matter of Part Two.

PART TWO

Their own stories:
Parent narratives of child disability

Chapter Five

BOOKS AND AUTHORS, TEXTS AND METHODS

In the case of a person like [my son] with a mental disability, it isn't the individual himself but rather his family that has to pass from the 'shock phase' to the 'acceptance phase' ... I have had to learn through concrete experience to answer such questions as how a handicapped person and his family can survive the shock, denial, and confusion phases and learn to live with each of those particular kinds of pain. I then had to find out how we could move beyond this to a more positive adjustment, before finally reaching our own 'acceptance phase'—in effect coming to accept ourselves as handicapped, as the family of a handicapped person.

(Oe 1996, 46)

To members of marginalized groups, autobiography may be the most accessible of literary genres. It requires less in the way of literary expertise and experience than more exalted genres, like fiction or drama; it seems to require only that one have a life – at least, one considered worth narrating – and sufficient narrative skill to tell one's own story.

(Couser 2009, 31)

Introduction

Over the past two decades a significant number of parents of children with disabilities have taken up the challenge of writing their life narratives. These authors are not Nobel Prize winners, unlike Kenzaburo Oe, and while a few are established writers, most are not. All, however, are compelled to tell their stories, to bear witness, to find meaning where there appears to be none, and 'to guide others who will follow them' (Frank, 1995: 17). These stories generally 'tell tales of struggle and heartache' about 'overcom[ing] adversity' (Calton, 2010, 849), as the excerpt above from Oe's memoir, A Healing Family, exemplifies.

Oe's words evoke the definition of 'memoir' proposed by Vivian Gornick:

> A memoir is a work of sustained narrative prose controlled by an idea of the self under obligation to lift from the raw material of life a tale that will shape experience, transform event, deliver wisdom. Truth in a memoir is not achieved through the recital of actual events; it is achieved when the reader comes to believe that the writer is working hard to engage with the experience at hand. What happened to the writer is not what matters; what matters is the large sense that the writer is able to *make* of what happened. (2001, 91)

How parent-authors do this work of memoirising, of making sense of their lives within the social, political and cultural context of their experience, is the concern of this and following chapters. Writing about one's life with a child with disability may seem to be a relatively straight-forward task, as Couser's words above imply; but as Oe's explanation of this process suggests, it is in fact extraordinarily difficult.

One of my first encounters with this subgenre of life writing was with *The Child Who Never Grew,* a memoir by Pearl Buck, another Nobel Prize winner, but from an earlier era. At the time (1990), my daughter had just been diagnosed with severe intellectual disability, and I was struggling to comprehend this unintelligible turn in my life's path. Without others around me who could share my experience, I was looking, like Susan Kamata, 'for deep and sustaining stories to guide me' (2008: ix). But Pearl Buck was not the source to go to; her book, published in 1950, described a world and a set of attitudes that only served to alienate me further. In the memoir, her child is unnamed, and seems barely human; there is no mention at all of the child's father, so it is impossible to understand her personal circumstances; and then, after seeking

medical opinion in the US, Buck places her young daughter in an institution where, as Buck contends, she would be better off 'amongst her own kind'. Buck kept her 'defective' daughter a secret for 30 years before finally coming out with the publication of this book, by which time Buck was a celebrated author. Much later, her daughter was diagnosed with phenylketonuria (PKU), a condition that is today routinely tested for at birth and remediated through dietary therapy.

While I bristled with indignation as I read this book, it was declared to be 'a groundbreaking account of raising a mentally retarded child' *(Publishers Weekly)* when it was published; and according to *Library Journal,* it was 'The volume [that] broke the taboo against raising the subject in public and laid the groundwork for the literature on the disabled that followed.'[24]

Since that time, life writing of all kinds has proliferated, particularly in the past decade: in 2007-2008 seven out of the ten bestselling non-fiction titles in the UK were memoir, and in the US, sales of memoirs increased 400 per cent between 2004 and 2008 (Yagoda 2009), many of these self-published. The digital age has also made self-representation possible in other forms – the blog, the online diary and YouTube – with what Couser calls 'a powerfully democratizing effect on life writing' (2009, 12-13). Parent blogs of child disability are relatively infrequent in countries other than the US and Canada, where a number are associated with a particularly active support groups. An association for families of children of the rare condition, 1p36 Deletion Syndrome, for example, has generated a significant number of blogs, including the long-running 'Adventures in raising a disabled child'[25], in which the parents of one young girl have documented intimate details of her development and their family life over many years. No doubt emerging out of a desire to help and share, open source blogs such as this one necessarily raise significant ethical concerns.

But my aim is to focus on books rather than blogs, for several reasons. Firstly, the life narrative or memoir remains a genre associated with the book, and the growing number of memoirs published annually in book form is testament to the reading public's fascination with this genre. Secondly, blogs tend to fall outside the generic conventions of the memoir: in diarised form, they are on-going and open-ended, in a constant state of reinvention. As such, a blog typically does not allow for the author to step back, reflect, and make sense of experience. This is as much a function of readers

as it is of writers, as Couser explains: 'The Internet seems to discourage extended linear narrative because, as is generally acknowledged, the attention span of the Web surfer is quite short' (2009, 14). The book form, in contrast, allows for the development of a shaped story. Thirdly, the social function of the blog diverges from that of the memoir, as González points out: 'Life writing in the public domains of the internet may differ significantly from traditional life writing in that it is not steered by the desire of registering an unconventional life, but by a quest for shelter and identification' (González 2013, 64). The blog, then, may offer a means for tribal membership rather than self-interrogation and meaning-making.

This chapter began with a quote from Kenzaburo Oe, a father author, and at this point in this exegesis, fathers of children with disabilities join mothers as the subjects of discussion. Fathers, too, write about life with their children with disability, and to bypass them would compromise this discussion. But importantly, including fathers opens up the opportunity for engaging with critical questions around how gender informs the storytelling of these parent authors.

In Part One of this thesis, my persona was as one who speaks with and for the collective; but now I need to distance myself from my tribe, and turn the researcher's gaze upon my peers. How am I able to engage objectively with these stories? Even as I endeavour to construct a framework of objectivity around my analysis, I cannot be free of my emotional entanglement with the content. While this may be regarded as a disadvantage, indeed a *disability*, it is also an advantage: as a 'wise' (Goffman 1963) interpreter of my tribe's texts, I have access to an enhanced set of meanings and responses that may be unrecoverable by the uninitiated.

From this vantage point, in the following chapters I will be examining a sample of parent narratives, with attention to the following questions:

- Who is authoring? Who has access to the resources required for both writing and publishing their stories?
- What are the differences, if any, in the ways these stories are told by mother and father authors?
- Do these authors respond to the discourses described in Part One, and if so, how? Do they comply with these narratives, or engage critically with them?
- What are the narrative strategies deployed by these authors?

- Which models of disability are invoked by these authors?
- How do these authors manage the ethical concerns associated with representation of their vulnerable children?

Parent narratives: who, what and where

Books about raising a child with disability fall into two broad authorship categories: single author accounts by a mother or a father; and edited anthologies of short pieces by a number of parent contributors. These books are generally targeted to other parents, and may be distributed through advocacy organisations and disability service providers, or identified through internet searches or by word of mouth. Few can be found in municipal and university libraries. They are seldom cited, even by researchers of family disability (such as those reviewed in Chapter Two), although some may attract a secondary readership of medical and allied health professionals. From time to time, one of these titles will break through into the mainstream, usually because the author is a celebrity or a particularly skilled writer.

But for families, these narratives are critical sources of information and validation. They provide a sense of shared experience for isolated parents, by recounting the authors' emotional responses, their paths through the medical and service delivery systems, and their ways of making sense of the strange world in which they are immersed. Most books focus on the particular disability of the child, and in so doing they reflect a form of tribalism that has emerged (especially on internet sites) amongst parents regarding disability types. Most books deal with the more common conditions of autism and Down syndrome, and publishers respond accordingly. The UK publisher, Jessica Kingsley, for example, specialises in books on autism spectrum conditions: 'Our list of titles on autism and Asperger Syndrome is now amongst the foremost in the world, and our books are published for people with autism and Asperger Syndrome themselves, as well as for their families, carers, and the people that work with them'[26]. Parents of children with rarer diagnoses are unlikely to find books that are so specifically targeted.

To investigate the range of titles readily available to parents, I consulted my local municipal library, which held one relevant title; the library of my local disability

service provider, which held several; and my university library, which also held a small number. Calton (2010) appeared to have more luck with the selection of texts available at the University of Iowa library, and the Iowa City Public Library:

> The oldest memoirs I came across were published in the 1950s, and the number increased with each decade... Although I was able to find memoirs written by the parents of children with several different disabilities, Down's [sic] Syndrome dominated the literature. More recently, there have been an increasing number of books on autism. I was also able to find a memoir written by a parent of a deaf child. Memoirs by parents of children with physical disabilities were almost non-existent, as were memoirs of blind children. (2010, 851)

As Calton also notes, the increase in the number of parent memoirs over the years parallels both the rise in disability rights and the increasing popularity of all types of memoir. Her observation regarding the prevalence of books about Down syndrome and autism supports the point that these clear diagnostic categories cater to distinct target markets. She also notes that most books are about children with intellectual rather than physical and sensory disabilities, a situation that points to ethical considerations, which will be discussed in Chapter Seven.

In order to gain a better understanding of the scope of books available to parents, I audited the collection listed on the library web-pages of one of the largest local advocacy organisations, Down Syndrome NSW[27]. While I would expect a large proportion of these books to deal with issues relevant to Down syndrome, I anticipated that the books by parents held by this organisation would most likely reflect patterns of authorship and publication that apply more generally. At the time (2012), this library held 43 memoirs by parents, published in Australia, US, UK, Canada, India and New Zealand between 1978 and 2009. Information regarding authorship and publication of these books is summarised in the tables below.

Table 5.1: Authorship
Parent-authored books held by library of Down Syndrome NSW (2012)

Authorship	% total, *n*=43
Single author	**67.5%**
Mother	62%
Father	38%
Multiple authors (anthology)	**32.5%**

Table 5.2: Country of publication
Parent-authored books held by library of Down Syndrome NSW (2012)

Country of publication	% total
Australia	30.2%
US	49.0%
UK	13.9%
Other (NZ, Canada, India)	6.9%

Table 5.3: Publisher profile – Australian and US books*
Parent-authored books held by library of Down Syndrome NSW (2012)

Country of publication	Self-published	Disability organisation	Speciality disability publisher	Other	Trade
Australia	30.1%	23.0%	n/a	23.0%**	23.0%
US	4.7%	n/a	62.0%	4.7%***	28.6%

* Due to the small number of books from other sources, these two countries only were considered

* * Small independent publishers

* * * Christian publisher

As the tables above indicate, for the selection of books in the Down Syndrome NSW library:

- two thirds of books were written by a solo parent-author (rather than multiple contributors), and of these, there were around twice as many books by mothers than by fathers
- almost half the titles were by US authors

- Australian writers were more likely to self-publish their work than to publish by any other means; the majority of US authors, on the other hand, were published by speciality disability publishers

- around one-quarter of titles were published by mainstream publishers under trade imprints.

In terms of content:

- more than twice as many cover the only childhood years (birth to 18) as those which follow the child into adulthood

- more than 60% are about Down syndrome only, while the anthologies are more likely to include other types of disability as well.

The picture that emerges from this snapshot is of a market dominated by books self-published and published by niche US publishers; they are more likely to be written by mothers about young and school-age children; and they are more likely to address a specific disability type. A relatively small proportion of books are published on trade imprints by mainstream publishers. There may, of course, be variations in this breakdown according to the type of disability: for example, an autism association may indeed hold more titles by British authors, due to the presence of a specialist autism publisher in the UK.

Sample of parental narratives of child disability

Selection of books for analysis

My process for selecting a sample of books for analysis mirrored the way I, as a parent, would source these texts for my own use. As mentioned above, I began by browsing the shelves of three libraries: a municipal library, a university library, and the library of a disability services provider[28]. I identified other titles through book reviews in the press, and from internet sources such as blogs. Two titles came as a result of my meeting their authors (Robertson and McLelland). Works were published between 1994 and 2012, simply because this was the time span of the books in the libraries I consulted. I was also mindful that this sample should be reflective of the author profile shown in the tables above, and accordingly I included a representative

mix in terms of female, male and composite authors; the age of children with disability; and the ratio of Australian titles to those published in other countries. I also wanted to cover a range of disability types, from children with high-functioning autism to those with profound physical and cognitive impairment, in order to compare the stories told, but also to reflect my own experience of mothering a child with severe disability. The 15 selected books are listed in Tables 5.4, 5.5 and 5.6 below, in order of publication date.

Table 5.4: Memoirs by mothers

Author and profession	Title	Publication: Year, country, publisher	Child	Disability
Burbidge, Mary G.P.	*Forever baby: Jenny's story – a mother's diary*	1997, Australia; Pan Macmillan (trade)	Jenny, died at 21 years	Multiple
Edelson, Miriam Union organiser, communications	*My journey with Jake: a memoir of parenting and disability*	2000, Canada; Between the Lines (independent)	Jake, 10 years	Lissencephaly
Fitton, Pat Teacher	*Listen to me: Communicating the needs of people with profound intellectual and multiple disabilities*	1994, reprinted 2000, UK; Jessica Kingsley (specialist)	Kathy, died at 27 years	Multiple
Evans, Kathy Journalist	*Tuesday's child*	2007, Australia; Bantam (trade)	Caoimhe, 3 years	Down syndrome
Johannesen, Jennifer Web designer	*No ordinary boy: the life and death of Owen Turney*	2011, Canada; Low to the Ground (self-published)	Owen, died at 12 years	Hydrops fetalis (multiple)
McClelland, Kylie Not given	*Extreme parenting: Raising children who have disabilities*	2011, Australia; Xlibris (self-published)	3 children with disabilities	Autism, plus others
Robertson, Rachel Writer, academic	*Reaching one thousand: a story of love, motherhood and autism*	2012, Australia; Black Inc. (independent)	Ben, aged 10 years	Autism

Table 5.5: Memoirs by fathers

Author & profession	Title	Publication: Year, country, publisher	Child	Disability
Bérubé, Michael Writer, academic	*Life as we know it: a father, a family, and an exceptional child*	1998, US; Random House (trade)	Jamie, 7 years	Down syndrome
Naseef, Robert Psychologist	*Special children, challenged parents: the struggles and rewards of raising a child with a disability*	2001, (rev ed), US; Paul H Brookes (specialist)	Tariq, 21 years	Autism
Brown, Ian Journalist	*The boy in the moon: a father's search for his disabled son*	2009, Canada; Random House (trade)	Walker, 12 years	Cardiofacio-cutaneous Syndrome (CFC)
Macris, Anthony Writer, academic	*When horse became saw: one family's journey into Autism*	2010, Australia; Viking (trade)	Alex, 7 years	Autism

Table 5.6: Anthologies

Editor/s	Title	Publication: Year, country, publisher	No. parent contributors
Marsh, Jayne D.B.	*From the heart: On being the mother of a child with special needs*	1994, US; Woodbine House (specialist)	7
Klein, Stanley D. & Kim Schive	*You will dream new dreams: Inspiring personal stories by parents of children with disabilities*	2001, US; Kensington (trade)	63
Dowling, Cindy, Neil Nicoll & Bernadette Thomas	*Lessons from my child: Parents' experiences of life with a disabled child*	2004, Australia; Finch (specialist)	51
Kamata, Susan	*Love you to pieces: Creative writers on raising a child with special needs*	2008, US; Beacon Press (specialist)	27

For this sample, in brief:

- 47% of books are solo-authored by a mother, and 27% were solo-authored by fathers
- 40% of books were published in Australia; 53.5% were published in North America (with more from Canada than in the Down Syndrome NSW corpus)
- 27% of sample books are anthologies; contributions to these anthologies come almost exclusively from mothers (between 80% and 100%)
- in the solo-authored works, 73% are about pre-school or school-aged children; in 20% or 3 books the children were aged 21 years or over; in three books by mothers, the child with disability had died
- grown-up children are represented in 3 of the 4 anthologies, though not to the same extent as younger children
- children with severe and multiple disabilities are represented in 64% of the solo-authored books (7 books), and in all anthologies.

Brief summaries of books in the sample

Books authored by mothers

Forever Baby: Jenny's Story – a Mother's Diary by Mary Burbidge, a Melbourne GP, is a diarised account that focuses on the time surrounding the drowning of Jenny, Burbidge's 21 year-old daughter with profound disabilities, in their home swimming pool.

My Journey With Jake: Jake (aged 10), the son of Canadian trade union activist Miriam Edelson, was born with smooth brain syndrome. Edelson addresses Jake's hospitalisation during infancy; the decision to place him in a group home; her intense fears as he comes close to death several times; and her activism.

Listen to Me, by Pat Fitton, is part personal account, part 'how to'. The author provides advice illustrated with her own experience of mothering Kathy, her daughter with complex needs who died at age 27.

In *Tuesday's Child,* Melbourne-based journalist Kathy Evans narrates her story from the birth of Caoimhe, her third child, until three years. She discusses topics such as

grief; the medicalisation of her child; causes of Down syndrome; social attitudes to disability and her own marginalisation; and sibling and family issues.

Canadian blogger Jennifer Johannesen recounts her years as mother to Owen, a child with multiple disabilities, in *No Ordinary Boy*, including her harrowing pregnancy; her son's months in hospital; his high medical needs and profound disabilities; their journey through the medical, educational, and therapy jungle; and Owen's death at the age of twelve.

In *Extreme Parenting,* Australian Kylie McClelland likens her experience of parenting three children with disabilities to extreme sport. In the first third, she recounts life with her children as a single mother on a limited income; in the next third, she deals with questions of gender and caring, and disability rights; and in the last section, she provides practical therapeutic guidelines.

Rachel Robertson's (Australian) book, *Reaching One Thousand,* is a meditation on her relationship with her young autistic son, Ben. She reflects on themes as diverse as the ethics of writing about her son, her son's personhood and neuro-atypicality, and challenges to her own identity.

Books authored by fathers

Life As We Know It, by US writer and academic Michael Bérubé, is a memoir of parenting Jamie, who has Down syndrome, from birth to seven years. It covers much wider territory, with discussions on sociology, political theory and philosophy.

Robert Naseef (US) author of *Special Children, Challenged Parents,* describes his journey with his son, 21, to arrive at a place where 'I am experiencing more fulfilment than I ever knew existed'. He combines personal anecdotes and reflections with his experience as a psychologist, focusing on the experience of fathers.

Canadian journalist Ian Brown's book, *The Boy in the Moon,* is about life with Walker, his young son who has the rare condition of cardiofaciocutaneous syndrome (CFC), his family's hardships and his search for meaning and community.

When Horse Became Saw, by Australian writer Anthony Macris, recounts the regression of two-year-old Alex into autism, and his parents' efforts to restore him to normalcy through intensive therapeutic interventions. Macris describes his frustrations with the health system and the social isolation of himself and his family.

Anthologies

From the Heart (ed. Marsh) consists of contributions from seven mothers in a US parenting program, organised under topics including 'Being heard', 'Feeling understood', and 'Coping'.

You Will Dream New Dreams (ed. Klein and Schive) includes over 60 personal stories from a diverse range of US parents. Included is the much-quoted 'Welcome to Holland' piece by Emily Perl Kingsley[29].

Lessons From My Child (ed. Dowling et al), an Australian book, was nominated 'a favourite' on the Down Syndrome NSW website, with reflections by over 50 parents (mainly mothers) organised under stages including 'Grief', 'Denial', 'Anger', 'Acceptance', and 'Love and joy'. Each section begins with a psychologist's explanation of the stage's relevance to the recovery process of parents.

Love You To Pieces (ed. Kamata) is claimed to be the 'the first collection of literary writing on raising a child with special needs'. It contains a selection of fiction, poetry and memoir by writers who are also parents.
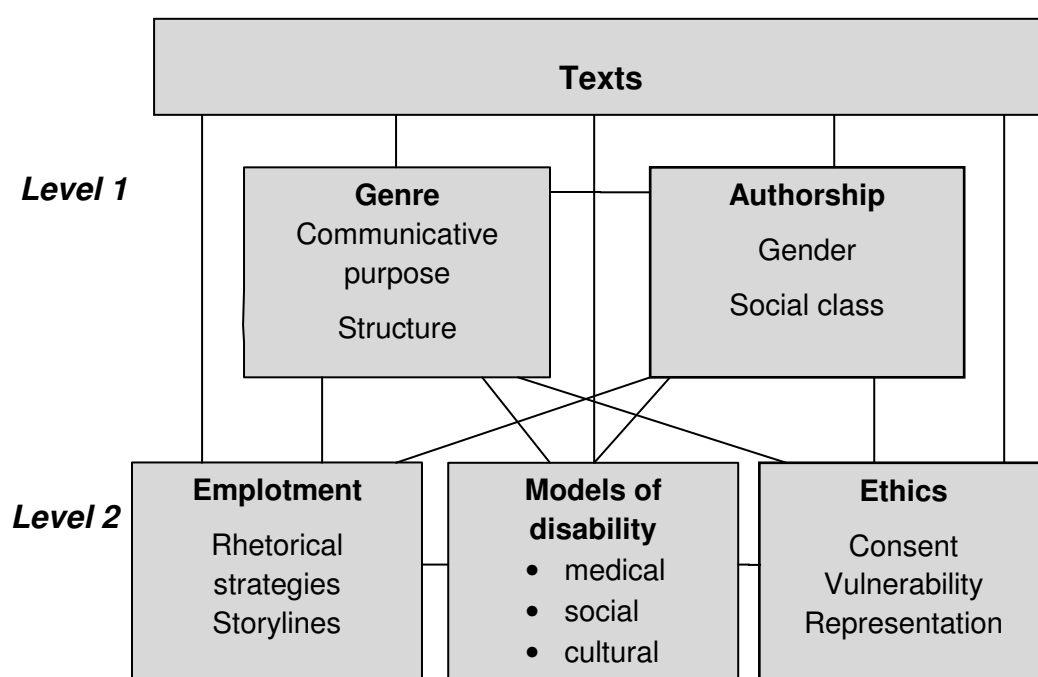
Framework for analysis of sample texts

In order to engage with the questions listed above, my first step was to establish a structure for analysis that would enable me to compare and contrast the strategies adopted by parent authors in terms of a number of contextual and narrative factors.

In the small literature on parent narratives of child disability, the typical approach is the case study, consistent with literary studies approaches. Frank (2004) and Couser (2004a), for example, take respectively an exemplary and a problematic text to analyse in detail issues around morality and ethics in parental accounts. Based on three texts, Robertson (2012) compares the way mothers of children with and without

disabilities self-represent and represent their children, and the public response to these narratives. Where a larger body of texts are considered, for example by Calton (2010) and Piepmeier (2012), researchers focus their discussion on a single issue: Calton examines the nine texts in her sample in terms of the social class of their parent authors; and Piepmeier, in her study of 19 memoirs, describes how these authors privilege grief in their narratives, and in so doing, she argues, undermine the value and personhood of their child.

In these analyses, scholars typically come to a particular point of view that is then extrapolated to the wider body of parental narratives. My own sense is that the texts in my sample are complex in the way that authors attempt to engage with the narrative options available to them as they negotiate through the contested positions described in Part One and the constraints of the autobiographical project. In response, I have adopted a multi-factorial framework for this analysis. The first level deals with the broad questions of genre and authorship that inform text development; and the second addresses emplotment strategies, the deployment of the models of disability (see Chapter Four) by authors, and questions around the ethical representation of the child with disability. This framework is outlined in Figure 5.1.

Figure 5.1: Framework for analysis of parent narrratives

This approach has both advantages and limitations over a case study orientation: it lacks the depth that the case study method can bring to the analysis of one or two texts; but it allows for a fuller a discussion of the issues raised by scholars in their analyses of texts by parents authors of child disability, and how these apply to the sample of 15 texts.

The categories on the first level of the framework reflect theorist Leigh Gilmore's observation that, 'autobiography is a practice of language, a signifying system charged with the representation (and construction) of identity through the organizing modes of genre and gender' (1994: 61). *Genre* is a term is applied variously within autobiographical writing to refer to:

- text types that may be distinguished as either 'autobiography' or 'memoir'[30]
- the established forms and formulas that autobiography/memoir generally assume[31], or
- the specific subject matter of the autobiographical text, for example, 'disability life writing' (Couser 2009).

In this analysis, I follow this definition of Couser (2009), and that of Frank (2004), who refers to parental narratives as a 'subgenre' of disability life writing.

Linguist John Swales has asserted that 'the principal criterial feature that turns a collection of communicative events into a genre is some shared set of communicative purposes' (Swales 1990, 46). These purposes are shared – or rather negotiated – between writers, readers and the discourse community within which the text is produced and distributed. The properties of genre guide what can be told by writers, but also what readers expect to find. Genre is a dynamic concept; genres respond to but also act upon the social world, as Thwaites and others observe: 'a genre develops according to social conditions; transformations in genre and texts can influence and reinforce social conditions' (Thwaites et al. 1994, 100). Hence the conventions of genre can work to normalise the ideologies and values that underlie texts, but also to reinterpret them. How these issues play out in parental narratives will be addressed in Chapter Six.

Issues around *authorship* are critical in any discussion of autobiographical writing, and in this analysis the chief concern that emerges regarding authorship is gender.

Much has been written about the vexed position of women in autobiographical writing (see for example Gilmore 1994, 2001; Friedman 1997; Smith and Watson 2001; Baisnée 1997), and essentially, this thesis is about *mothering* a child with disability. But because a large proportion of parent authors are fathers, there is an opportunity here to consider how gender impacts on the telling of these stories: how subjectivity is realised according to gender; which narratives are available to and mobilised by fathers in contrast to mothers; and why particular gendered accounts achieve more recognition than others. A comparison of this type has not yet appeared in this literature. Also addressed in this section is the social class of authors: an issue that has been specifically addressed by commentators of parental narratives of child disability.

The second level of the analysis considers how these narratives are shaped by the authors' engagement with problems of storytelling, self-representation and representation of their child. The first box – narrative *emplotment* – is a concern of all storytellers. For parental narrators of child disability, decisions around emplotment can indicate to what extent authors are complying with or resisting stereotypical, or what Couser (2009) refers to as 'hegemonic', narratives. Couser and Frank (1996) propose schemas that have traditionally characterised disability life writing; both these theorists call for authors to challenge these prevailing scripts. Do parent-authors take up this mission? Do they condone or critique the representations and cultural scripts that were identified in Part One?

The second box addresses an issue that is both specific to and inextricable from any instance of disability life writing: how do authors frame their experience of family disability in social and political terms? Which model of disability – medical, social, cultural – do these authors privilege in their narratives? Along with these questions, another begs, but it may not be so easily answered: just how conscious are parent authors of the philosophical, social and political messages that both inform and emerge from their narratives? In Chapter Eight, issues of emplotment and deployment of the models of disability is addressed.

Questions of *ethics* are central to all autobiographers; as John Paul Eakin has written, ethics is 'the deep subject of autobiographical discourse' (2004, 6). While questions around privacy, consent and the representation of others are common to all autobiographical endeavours, they are particularly salient for parents writing about

their children with disabilities. As such, questions around the legitimacy of parents telling their child's story – particularly when that child does not have the capacity to consent independently – arise often. The ways in which authors in the sample rationalise this project, and the ways they represent their child are explored in Chapter Nine.

While the issues for exploration have been placed in boxes in Figure 5.1 and will be addressed separately, these questions are interdependent and the boundaries between them are fluid. There is much crossing over, as the intersecting lines suggest. Gender, for example, informs the way all categories are realised. Emplotment emerges as a response to genre; and questions of ethics are implicated in the formulation of story as well as its textual realisation. As such, some restatement and repetition will be unavoidable in the following chapters as I attempt to map this complex territory.

Conclusion

Parental narratives have played a critical role in the lives of parents of children with disabilities over the past sixty years. These narratives, written individually by mothers or fathers, or collected into anthologies, also inform prospective parent authors about the 'lay of the land': how their own stories may be imagined, and how they are published and received in the marketplace.

In order to investigate, a sample of 15 books was selected, and a framework described for analysing these works. Of particular interest in this analysis are the strategies that parent authors negotiate their way through this narrative landscape, and whether they comply with or resist the prevailing socio-cultural messages that emerged in Part One.

For me as a mother-author, these questions are vital: I want to know what other parents are writing, and how they are doing it. I need to know how they engage with the scripts that surround them, and if they can, and do, challenge them. I approach this critical task with some apprehension: as a tribe member, I understand the fears and the constraints, the compulsion to disclose along with the warning to hold counsel. I find guidance here, but also cautions; I find allies, but also adversaries. Our stories may be parallel, but they are different, and it is these similarities and differences that I am seeking to explore.

Chapter Six

GENRE

**Moral non-fiction or advice from the battlefield?
The functions and forms of parental narratives
of child disability**

Introduction

'Disability has become one of the pervasive topics of contemporary life writing,' writes Couser (2009, 3), and parental narratives of child disability sit within the ambit of this genre. He describes the rise of 'nobody' memoirs – life writing by individuals who are unknown to the public – as opposed to books authored by 'somebodies': eminent or celebrity authors who are the colonisers of traditional autobiographical territory. A large proportion of these 'nobody' memoirists, he claims, are in fact writing about 'some body', and typically, that body is inscribed by illness or disability.

Couser uses the term 'relational' life writing to describe those 'narratives whose primary subject is not the writer but a proximate other' (2009, 12). These 'oscillate between biography and autobiography', he writes, ascribing to them the term, *auto/biography* (2004a, 56). The term 'relational' when applied in this way has strong echoes with the feminist philosophical concept of the relational self described in Chapter Three. As Smith and Watson state, 'the self-inquiry and self-knowing of many autobiographical acts is relational, routed through others ..., those whose stories are deeply implicated in the narrator's, and through whom the narrator understands his or her own self-formation' (2001, 64-5).

Narratives about life with one's own child who has a disability are salient examples of relational, auto/biographical, disability life writing. Frank identifies parental narratives as the 'subgenre of fully abled parents writing about their seriously disabled children' (2004, 182), and while a large number of these have been published, Piepmeier observes that 'this particular subgroup – the parent memoir – has received limited scholarly attention, including scholars from disability studies and scholars who focus on life writing' (2012).

This chapter focuses on questions about how memoirs by parents about their children with disabilities realise genre: what the generic conventions are, what the possible variants may be, and why. These questions are posed in terms of solo-authored works as well as anthologies in the sample. In addressing them I am reminded that, according to Swales (1990), the defining feature of genre is a 'shared set of communicative purposes', negotiated by writers and readers, and other stakeholders such as publishers. I begin with a discussion of the properties of this genre that have

been proposed by scholars, and explore whether books in the sample reflect these. I then identify a particular feature of this group of books: generic hybridity, and how a number of books in the sample stray from straight memoir into other forms of text. I conclude with a discussion of anthologies in the sample, and their particular generic properties.

Parent narratives as 'moral non-fiction'

Frank describes personal narratives of disability and illness as 'moral non-fiction' (2004, 175), arguing that illness and disability present challenges that call upon the writer to become morally engaged, to explore competing values and seek moral purpose. He contends that in our present moral climate, narratives of illness and disability are both necessary and *difficult*; they require the formulation of counterstories that do the work of 'remoralizing' the identities of subjects who have been socially and culturally devalued (as discussed in Chapter Three). 'Life writing about illness and disability upsets the conventional identities assigned to these groups' (Frank 2004, 178).

Frank uses three parental narratives of child disability to illustrate. 'Parental narratives are acts of justification: the parent-writers justify their children's right to exist' (Frank 2004, 184). These authors, Frank argues, challenge the devalued status of their child 'by emphasizing the dialogical relationship between parent and child: how parents' lives are better for having been shaped by their children' (183). He focuses on Sam Crane's book, *Aidan's Way*, about life with his son who was born without a corpus callosum, the tissue connecting the left and right hemispheres of the brain. This book qualifies as moral non-fiction, and achieves 'moral excellence', Frank argues, because the author's narrative of his personal transformation, from anger to compassionate service, 'expresses a better way to live' (187); it is this transformation that makes Crane's parenting experience narratable (189).

Whether this moral responsibility amounts to justifying the child's 'right to exist' is, however, debatable. Other scholars identify issues of citizenship as the primary purpose. 'In a culture such as ours, which is at once fixated on and dismissive of bodies, narratives of anomalous somatic conditions offer an important, if not unique,

point of entry for inquiry into the responsibilities of contemporary citizenship' writes Couser (2009, 15). Rapp and Ginsberg assert that parental narratives can motivate the rethinking of family and civic relationships by not only providing 'a model for the body politic as a whole, but also.... [by] constitut[ing] a broader understanding of citizenship in which disability rights are understood as civil rights' (2001, 545). Piepmeier (2012) concurs: 'Parents of children with disability have a significant role, that of changing the cultural meaning of disability, and therefore the broader understanding of citizenship and civic identity'. The aims clearly indicate alignment with the cultural model of disability (see Chapter Four).

Parent narrators, however, may have a different purpose that centres on advocacy and activism, and is closer to the social model of disability. Rapp and Ginsberg describe the balancing act that parents face as they negotiate the differing ideologies of the social and cultural models: 'the parenting literature ... is fraught with the tensions between efforts to normalize the experience of disability and the need for advocacy and special resources to accommodate those who cannot enter mainstream American society through the same pathways or trajectories as most others' (2001, 539). How authors in the sample engage with models of disability will be discussed in Chapter Eight.

For parent memoirists, then, the task of making of their own and their child's lives narratable is underwritten by these moral imperatives. These are lofty goals; they may not only be difficult to realise, but also somewhat restrictive in their insistence.

Sample texts and the 'morally good' story

How do authors of sample texts position themselves in relation to this 'morally good' story? To investigate, I examined back cover blurbs as the site where such a purpose might be articulated. Back cover blurbs provide indicators for books in terms of genre, but also they provide, in summary, evidence of the particular stance on the issues that authors foreground. As Pickford explains, 'the paratext, the cover blurb in particular, is extremely important, as it enables the publisher to position their product on the market' (2007, 90). Matthews cites Genette's observation that book covers (including blurbs) operate as a 'vestibule' or 'threshold' 'that offers the world at large the possibility of either stepping inside or turning back' (Genette 1997, 2, cited in

Matthews 2007, xi). This 'peritextual packaging' not only constructs an audience by situating the narrative, but it invites 'a particular politics of reading' (Smith and Watson 2010, 101).

These blurbs suggest that authors (and/or their publishers) recognise this imperative for 'remoralisation'. Assertion of personhood is foregrounded in several; the book, we are told, 'affirms the right of all people to live a full and meaningful life' (Fitton); 'reclaim[s] Caoimhe as an individual' (Evans); 'explores the value of a single human life' (Brown). These blurbs also affirm the child in relational terms, providing tributes to 'the influence that Jenny had on those around her' (Burbidge); to 'those who are profoundly different but have so much to give' (Macris); to 'the struggles and triumphs of those who speak their own language – or don't speak at all – and those who love them' (ed. Kamata).

Closely related is the child's role in facilitating the moral development of the parent and, in some cases, wider society. Books are described as the parent's 'chronicle... of love, spiritual growth, self understanding, acceptance and maturity' (Johannesen); or 'quest to understand autism and build a new kind of relationship with her son' (Robertson); which 'enriches our understanding' (Macris). These books show us 'how learning to see such a child can in turn change our vision of society and ourselves' (Bérubé); and help us appreciate how the child 'delivers to the world moments of joy so intense they seem supernatural' (Brown). Love is prevalent: 'a story of loss, love and courage' (Burbidge); 'loving someone who needs more than we think we have to give' (McLelland); 'the strength of love' (ed. Dowling). This is expressed in lexical variations: 'heart-felt' (Evans, Dowling); 'from the heart' (ed. Marsh, ed. Klein and Schive); 'heart and soul' (Naseef); 'devoted' (Edelson).

Other generic expectations, including veracity, figure strongly: 'real-life' (McLelland; ed. Klein and Schive); 'honest' (McLelland, Brown); 'eye-opening' (ed. Marsh). The modifiers, 'extraordinary', 'compelling' and 'wrenching' feature in more than one, along with words such as, 'powerful', 'intense', 'inspiring', 'deeply moving' and 'poignant'. These words express the passion and emotional depth of these stories, and hence their narratability.

Suffering, too, emerges. Frank asserts that 'Suffering has always animated life writing' (2004, 174), because suffering requires a re-evaluation of the way lives are

lived and made sense of. Indicators of suffering include the following phrases: 'pleasure and pain' (Burbidge); 'complex problems' (Fitton); 'bombshell of diagnosis' (Evans); 'perpetual crisis management, crushing disappointments and dashed hopes' (Johannesen); 'turmoil and pain' (Brown); 'rage, disappointment, and guilt' (ed. Kamata); 'initial shock, through grief and on to acceptance' (ed. Dowling); 'intense, sometimes painful, emotional terrain'(ed. Marsh); 'wrenching disappointment' (ed. Klein and Schive).

Several blurbs encode agenda that are more political: 'a hard-hitting, well-researched look at health care for Canada's children' (Johannesen); 'the ongoing ethical debate about genetics, as well as ... the minefield that is prenatal testing' (Evans); how 'government refused to fund the therapy his son so desperately needed' (Macris); 'an insightful critique of society's assumptions about the disabled' (Brown). These books typically straddle the double purpose of bringing the personal story together with a political statement, echoing Rapp and Ginsberg's observation above.

Through these blurbs, authors express their 'morally good' intentions, but they also risk falling into what Couser calls the 'stock-in trade narratives' of normalising and overcoming disability, with their 'giveaway blurb terms' of 'inspiring', 'uplifting', and 'the human spirit' (2009, 30). The line between the morally good and the sentimental appears here as perilously fine.

Memoirs, hybrids and crossovers

The communicative purpose of these texts is one key element of genre, and another is the structural properties that identify them as a set. In order to investigate how authors negotiate these conventions, I refer to Gornick's words, cited in the previous chapter, as a point of departure: 'A memoir is a work of sustained narrative prose controlled by an idea of the self under obligation to lift from the raw material of life a tale that will shape experience' (2001, 91). Not only should a memoir recount events, but it should deliver meaning; in short, it should tell a story (and one that is 'morally good').

However, these authors also face an obligation of a different kind, and from a different source – the marketplace. To illustrate: the submission guidelines for the

Special-Needs Collection of Woodbine House, a specialist US disability publisher, stipulate the following:

> Our current needs include, but are not limited to:
>
> - Practical parents' guides to raising children with specific disabilities
> - Guides to specific issues related to a given disability (e.g., communication skills, social skills)
> - Practical guides to issues of concern to parents of children with disabilities in general (e.g., special education, sibling issues)
>
> We are deluged with parents' personal accounts of raising their child with a disability. Although we consider submissions in this genre, be forewarned that we publish very few. We do not publish adult fiction, poetry, or books expressing a religious viewpoint.[32]

This speciality publisher is looking not for memoir, but for guides and self-help books.[33] In response, parent memoirists may feel the need to re-imagine their life writing, either by writing a guidebook, or by combining their personal narrative with instructional material. The latter becomes the hybrid form of memoir/self-help book, a hybrid that appears in other contexts, particularly in works by survivors of illness (for example, breast cancer[34]). It may not be just the requirement of publishers, however, that underlies this decision; this form also responds to parents' need to find *entitlement* to tell their stories. The notion that others will benefit from one's own experience is a powerful enabler, reinforcing the moral imperative that informs parent writers.

Of the eleven solo-authored books in the sample, seven can be categorised as conventional memoir (Burbidge, Edelson, Evans, Johannesen, Robertson, Brown, Macris)[35], while four deploy a *hybrid* genre (Fitton, McLelland, Naseef, Bérubé). The straight memoirs typically narrate episodes of family life, and most proceed chronologically from birth or just before, through the shock of diagnosis and the ensuing period of grief, to medical and/or therapeutic interventions, and other life events. One title (Robertson) proceeds thematically rather than chronologically. Authors incorporate a discussion of particular ethical, social, political and/or economic issues, and these commentaries are relevant to the disability type. For example, authors who have children with Down syndrome (e.g. Evans) address the ethics surrounding prenatal foetal testing for genetic abnormalities; authors whose

children have undergone 'heroic' life-saving procedures in the perinatal period critique these medical interventions in respect of quality of life issues (Johannesen, Edelson); and authors who have children with autism (McLelland, Macris) argue for more early intervention services to maximise the potential of, or 'recover', the child. The 'shaping of experience', and the finding of meaning – no matter how elusive, is the ultimate goal of these stories.

An outlier amongst these seven is Burbidge's diarised account of her daughter's death. Most of the book is devoted to the months before, during and after Jenny's drowning in the family swimming pool. As such, this work is an example of *thanatography,* or narrative of a death, rather than a life story, although the preoccupation with the death is not articulated in title or blurb. And in its unedited, diary format, it fails to 'shape experience', and indeed may have more in common with today's blog form than a conventional memoir.

Of the four hybrid works, three combine self-help with personal narrative (Fitton, McLelland, Naseef). Fitton's book sets out the guidebook aim in the blurb with a set of 'how to's: '*How to* cope with the complex problems of someone with this level of disability ... *How to* enrich that person's experience' (my italics). In the preliminary pages, however, she re-negotiates this objective:

> THIS BOOK IS NOT ... a complete guide to caring for and supporting people with profound intellectual and multiple disabilities ...

> THIS BOOK IS ... an affirmation of the right of people with profound intellectual and multiple disabilities and their carers to lead a full and meaningful life. (ix)

Fitton uses the marketability of self-help on the cover, but switches to advancing the 'morally good' purpose once the reader gets inside. In the body of the book, her recounts of personal experience function to illustrate her general points, and these examples are mostly told with more emotional distance than is encountered in the other texts. Naseef, in contrast, begins with a richly emotional narrative, and shifts to instruction/advice mode later in the book. He makes this transition by mobilising his persona as an 'expert' psychologist. McClelland deploys a different strategy, by dividing her work into three distinct sections: 'The Personal', 'The Issues', and 'Skilling Up Techniques and Strategies', and so combines memoir with what might be

called 'manifesto', through her strong assertions about the needs and rights of families of children with disability, before shifting into instructional mode.

By bringing together memoir and self-help, these authors are mobilising possibly the two most popular contemporary genres of non-fiction writing. The popularity of the memoir has been addressed by a number of commentators; Yagoda (2009), for example, calls the genre 'ubiquitous'. Regarding the genre of self-help, McGee argues that these books have moved in the last few decades from a niche position to being a 'postmodern cultural phenomenon' (2005, 11).

One author in the sample, however, explains how she set out to follow the marketplace demand for self-help, but found memoir more appropriate to her purpose. Johannesen writes in the Preface:

> Before Owen's death, I had planned to write a guidebook – an *Advocacy for Dummies* sort of book. I started the project many times, each effort ending in frustration. I eventually realized: I have no universal advice to give. No tips or tricks. My successes and failures in advocating for and raising Owen were largely dictated by my surroundings, my experience and my personality... If I wrote a guidebook, I thought, it would be relevant only to people exactly like me. (2010, 8)

Instead, she claims her book will 'illuminate the ethical and emotional challenges of caring for one so deeply vulnerable and dependent' (2010, 9). By self-publishing, she avoids the constraints that a publisher might impose, and elects to take up the 'morally good' mission that has come to define these parental memoirs.

The outlier amongst these hybrids is Bérubé's book, which is identified by Frank as 'part memoir, part disability advocacy, and part treatise on moral and civic responsibility to the vulnerable' (2010, 75). While most of the authors in the sample take up advocacy and activist issues (in particular, Edelson), and others venture into the overtly hortatory (such as McClelland), Bérubé extends the boundaries further with his melding of the personal with philosophy, sociology and political theory. His authoritative voice gives gravity to what is essentially a narrative of parenting a child with a disability. He ensures that his son's story – and his own – cannot be devalued.

The anthology: Collective voices, mediated stories

A number of anthologies of short parent narratives of child disability have been published, but these have escaped the attention of scholars. Indeed, little theoretical work has been undertaken to shed critical light on narrative anthology in general, as Lockard and Sandell write: 'The anthology qua genus has remained relatively untheorized' (2008, 227).

The small amount of research that has been done has emerged from women's studies. Lanser, for example, describes the role of 'communal voice' in women's narrative as 'a spectrum of practices that articulate either a collective voice or a collective of voices', which 'seems to be primarily a phenomenon of marginal or suppressed communities'. This communal voice, she argues, is 'a category of underdeveloped possibilities that has not even been named in contemporary narratology' (1992, 21). Franklin, in her discussion of feminist deployment of the anthology form in the 1970s and 80s, describes how editors of these collections succeed in creating identity-based communities through the sharing of story (1997). Lockard and Sandell concur:

> Contemporary anthologization practices have generally focused on establishment of a discrete literature that emerges from a cultural group that has been denied citizenship or its full equal rights, has been economically and socially marginalized, or has been suppressed by law. (2008, 248)

In terms of structure and process, Lanser distinguishes three techniques of communal narration: 'a *singular* form in which one narrator speaks for a collective, a *simultaneous* form in which a plural "we" narrates, and a *sequential* form in which individual members of a community each take a turn to tell their story'. This communal voice 'shifts the text away from individual protagonists and personal plots' (1992, 22), with the purpose of constructing community. In this way, anthologies share the properties of blogs as sites for 'shelter and identification' (González 2013, 64).

Anthologies in the sample exhibit these characteristics: they emerge from a marginalised group; they take up the task of community building; and they privilege Lanser's 'sequential' form. They also reflect the gender issues raised by Lanser and Franklin: while purporting to address 'parents' and 'families', these anthologies are

largely the domain of mother-authors. Contributors to these books (and in fact all anthologies of parenting children with disabilities except those specifically by and for fathers[36]) are overwhelmingly mothers. Of the 63 contributors to *You Will Dream New Dreams,* 55 are mothers (87%). *Love You to Pieces* includes 22 contributions by mothers (85%). In *Lessons From My Child*, 89% of contributors are mothers. *From the Heart* is the only book in the sample that specifically addresses mothers, and accordingly all seven contributors are female.

But these anthologies are different in one very significant way. In those works referred to by researchers, the voices of marginalised identities and the consequent establishment of community has a primarily *political* function, as Lockard and Sandell explain:

> Anthologies of writing by women, African Americans, Latinos, Native Americans, Jews, Asian ethnicities, queer communities, working-class people ... have created their own voices through anthology publishing...The cultural work accomplished by these volumes lies in their use of the genre to assert participation in the public sphere and citizenship-by-anthology. (Lockard and Sandell 2008, 246)

While the parental memoirs may take up issues of citizenship, the anthologies by parents of children with disabilities typically have a different purpose. The sense of community they give rise to has a *social/psychological* function rather than a political one. For example, *Lessons from My Child,* nominated a favourite with parents by Down Syndrome NSW, is organised into sections that reflect the recovery phases in grief counselling, including 'Grief', 'Denial', 'Anger', 'Depression', 'Acceptance'; and each of these sections is introduced by a psychologist/ editor. Many of the pieces are highly emotional, even desperate, for example:

> Her multiple disabilities have taken me out of a life where I'd achieved comfort, success, independence ... and plunged me into a world of chaos, hospitalisations, orthotics, therapies, surgeries, anger and grief. (64)

But these narratives are contained within a structure that ensures a final destination of acceptance and indeed, personal transformation. In *You Will Dream New Dreams,* many of the contributions end with affirmations, such as:

> I wouldn't trade that for anything (175);

> At the end of the day, you'll close your eyes and realize that you love your child – *this* child – more than anything. And when you sleep, you will dream good dreams (167);

> I know my life with my son will be a roller coaster ride of emotions. But I am prepared and knowledgeable – strapped in and enjoying the ride (185).

This book does the moral work of validating the child and the atypical parenting experience -- but with strong doses of sentimentality.

In contrast, *From the Heart,* which came out almost a decade before the others, includes more raw emotional disclosure and fewer accounts of positive personal outcomes. Examples include:

> ...the gut stuff that comes out in two minutes [when you are with other mothers] because of what you've been through .... It's like you are war veterans (p 43)

> What do we do with our anger? ... I need enough anger to motivate me ... but I'm reaching a point where I'm going to be ineffective... People can just dismiss you when you cry. (p113)

A possible explanation is that, published in 1994, this book predates the shift in family studies research to an emphasis on resilience and positive coping (see Chapter Two); another possibility is that it was written before the impacts of disability rights discourse had permeated through to challenge prevailing beliefs of disability as 'tragedy' for families.

Editors of these anthologies are either parents (*Love You to Pieces*), health/community professionals (*From the Heart*), or a combination *(You Will Dream New Dreams, Lessons From My Child*). How editors mediate content is a key question, which is articulated by Lockard and Sandell:

> But since what an anthology omits is often as significant as what it includes, this collective voice can never hope to be fully representative. The paradox of the excerpt is that by hiding as much as it reveals, it is simultaneously representative and not representative of the larger narrative from which it comes. (2008, 228)

Even when parents are editors, there is the possibility that they will select contributions that fit into their particular schema.[37] When editors or co-editors are

health professionals, another layer of mediation intrudes. *From the Heart*, for example, opens with a Foreword by a paediatric geneticist, titled 'What doctors think patients want from their doctors', in which he relates his own journey toward understanding the needs of families of children with 'congenital malformations'. This doctor effectively appropriates the subject position, and the families are relegated to a position of Otherness. In the Afterword to this book, a social worker writes that when dealing with these families 'I enter another culture of sorts: I cannot assume that I will understand the emotional terrain of their lives' (1994, 140). Parents are consequently placed in an ambiguous position regarding subjectivity: is this book by and for them, or about them? In this anthology, authorship is also mediated: contributors are named on the title page, and brief biographies appear at the back of the book, but the separate autobiographical pieces in the text are unattributed. This decision may have been made in an effort to ensure privacy, but it has the impact of de-authorising these mothers.

The newest anthology in the sample, *Love You to Pieces* (2008), sets out on a different mission: its blurb describes it as 'the first collection of literary writing on raising a child with special needs'. It includes short fiction, poetry and memoir by creative writers who are also parents of children with disabilities. These writers mobilise literary strategies to find ways of expressing what might otherwise be silenced. Some use fiction to obtain the distance needed to shape their experience, reflecting Gilmore's observation that 'a writer's turn from the documentary to the fictional marks an effort to shift the ground of judgment toward a perspective she has struggled to achieve' (2001, 23), as the following examples illustrate.

In 'Without strings', Hanna Holborn describes the tension between accommodating a child with disability and realising a dream of social mobility. While her working class mother can accept a grandchild with a disability, her 'pretty college boy' husband cannot. In 'Magic affinities', by Evelyn Sharanov, Emma struggles to connect with her autistic daughter as her marriage flounders; in one frightening scene, she bangs her daughter's head against a wall in frustration. Catherine Brady's story, 'The life of saints', critiques the mythology of mothering a child with disability. On one level it recounts a mother's struggle to hold things together in a family that includes an adolescent son with spina bifida. But the author weaves through this the religious symbolism associated with elevation to sainthood as the mother, Theresa, makes her

way through the stages of this journey. It is Theresa who manages her son's therapy, never her husband: 'Ian doesn't change Danny's catheter or work his atrophied muscles. This is my job, as it was to knit Danny whole when he was growing inside my body' (62). Her aloof husband is, significantly, a carpenter, and Brady describes the meticulous way in which he crafts his custom-made furniture. Theresa reaches a final crisis: she brings a saw down on a completed cabinet, creating 'one long smooth scar, one searing consequence'. There is a parallel with the damage to her own creation – her son, Danny, who has a scar down his back where his exposed spinal cord was surgically repaired in infancy. The story ends with Theresa's imagined words to her husband: 'Then I will tell him that suffering brings us closer to God' (p 79). This story interrogates powerfully the myth of the saintly mother.

While this anthology validates the literary potential of writing about the experience of raising a child with disability, these pieces also illustrate how fictional and quasi-fictional modes can be mobilised within this genre to create powerful and memorable stories.

Conclusion

The conventions of genre are like roadmaps: they provide signposts and guide writers along pathways that lead to desired destinations. They mark out the features of the landscape; they make for a smooth passage over difficult terrain and normalise disruptions. They favour highways and steer away from alternative routes. They show readers who come along for the journey what they can expect to find. They are useful, essential even, but they may be limiting.

Writers venturing into the subgenre of parental narratives will find guidelines for the privileged stories that 'remoralise' the devalued identities of their children with disabilities. But there are obstacles here: if they take a wrong turn they may be diverted into sentimentality. Some may choose a route that combines the telling of their own story with a learning experience for their readers. That track offers them both a stronger entitlement to write and a surer footing in a marketplace where self-help texts are a marketable product.

Those who respond to a call for shorter pieces can participate in the community building work of anthologies. But their voice will be mediated by editors, and they may find their work contained within a framework that reflects someone else's agenda.

For me, as a mother-author, these observations deliver opportunities as well as constraints. The properties of this subgenre, as 'moral non-fiction', are noble, but they could also be as restrictive, because there are other stories to be told as well, about a mother's marginalisation. And the prospect of fashioning one's story into a form that complies with marketplace demands – particularly by daring to advise and instruct others – is downright worrying: these are personas that I am unable to assume. Instead, I'm drawn to the last anthology, the one with 'literary' premises and promises, and stories written by authors who can turn their ragged lives into sculptures. There's opportunity here, for forging a path that may be less well-trodden.

Chapter Seven

AUTHORSHIP

Mothers, fathers, entitlement and identity

Introduction

'Life writing has always been, and will always be in some degree, controlled by the powerful', writes Couser (2004b, 200). The two indices that are most likely to identify 'the powerful' are class and race on the one hand, and gender. Scholars including Couser (2004a), Calton (2010) and Piepmeier (2012) have addressed how parent memoirists of child disability, like autobiographers in general, are typically of privileged social status. But as yet, gender and the questions of which stories are, or may be, told by mother-authors as opposed to fathers have not been addressed by researchers.

Auto/biography, writes Couser, is 'far from a gender-neutral genre', and has traditionally been 'more available to men than women' (2009, 12). In spite of this, more mothers are in fact writing about their lives with children with disabilities than fathers (see Chapter Five). These books are about raising children, which is traditionally female territory; it is significant, then, that a considerable proportion of fathers are taking up this project. My aim in this chapter is to shed some light on how the gender effect plays out for the writers in sample texts: if, and how, the narratives of mothers and fathers differ in the themes that emerge and in the voices mobilised.

But I begin by attending to the effects of class and race which, researchers assert, effectively disenfranchise those who lack social capital from bringing their stories into the public sphere. Their voices continue to be under-represented, and go largely unheard. Class and race effectively overlay gender as a marker of entitlement, so I address these first, but my discussion focuses to a greater extent on the impact of gender.

Class and race

> Those who produce narratives of illness and disability are not diverse in terms of race and class. They tend to be white and upper middle class. Before they became ill or impaired, many were already professional writers or worked in professions where writing was part of the job. (Couser 1997, 4)

In terms of race, Ferri comments that the concentration on privileged 'White' texts applies not only to authorship, but to commentary and analysis as well:

> [T]he proliferation of disability life writing continues to privilege White bodies, demonstrating the need to seek out narratives that can address the politics of race and disability. In fact, even authors like Mintz and Couser, who have written extensively on disability memoir, continue, with very few exceptions, to focus on texts written by White authors. (Ferri, 2011)

Parents who write about their lives with children with disabilities, and those who critique their works, are no exception. Piepmeier (2012), for example, found that all authors in her sample of nineteen parental memoirs of child disability were white and middle class. Calton (2010) specifically addresses the issue of authorship and social class in her study of nine parent narratives published between 1950 and 2007; all authors were white and either upper or middle class. These writers, Calton claims, 'use the resources available to members of the middle and upper classes ... to more easily accomplish the modern ideals of disability in America: deinstitutionalisation and inclusion' (2010, 849). She concludes that that these memoirs 'obscure ... the effect of class', and as a consequence, the experience of lower class families goes unrepresented. Some attempts have been made to extend the range of voices: in their recent anthology, *Disability and mothering: Liminal spaces of embodied knowledge* (2011), editors Lewiecki-Wilson and Ciello include diverse stories of women who are from the Caribbean, in a mixed race marriage, living in poverty, or those who have an inter-generational history of disability.

While Couser recognises the effect of social class, he does not dismiss the value of storytelling by socially privileged authors: 'to acknowledge their relative privilege is not to discount their authority to write from a position of disability' (2009, 190). The sense here is that because narratives of disability need to be told and heard, those who can do the telling, should. The social construction of disability places disabled persons in a very different position from those associated with other minority groups, he argues:

> Part of what these individuals [who write memoirs] have discovered as disabled people is that their other statuses (of race, ethnicity and class) carry them only so far; in some ways, disability trumps these other privileges. (2009, 190)

The memoirists in the sample fit the profile described by scholars above. Six are writers (Bérubé, Brown, Edelson, Evans, Robertson, Macris); one is a secondary

school teacher (Fitton); two are health professionals (Burbidge, Naseef); one is a blogger/web designer (Johannesen); and for one, no clear work related identity is given (McClelland). All are white and middle class (although McClelland reports that her social status has been downgraded with her entry into the territory of marginalised motherhood). Their narratives necessarily reflect this status; but in Couser's terms, these are the writers who have the resources to produce their own stories. Calton's call for less privileged voices to be heard is incontestable; but at present, the only site where these may be encountered is in the social science literature, as subjects in someone's controlled research project.

Gender

The culturally problematic place of women in autobiography has been explored by many commentators (Smith 1987, Gilmore 1994, Baisnée 1997, Egan 1999, Gilmore 2001, Smith and Watson 2001, Mintz 2006, amongst others), and until recent decades both its study and practice had been the province of male writers (Baisnée 1997). Mother-writers face the same lack of entitlement to write as all women, with the additional compounding effects of both disability and motherhood (as discussed in Part One).

Couser (2009, 12) refers to the 'autonomous (and even atomistic) individualism more available to men than to women' that is required of the would-be autobiographer. This notion of the 'autobiographical self ... as a conscious and unique human being who is able simply to transcribe his/her own story' (Baisnée 1997, 8) is interrogated by feminist scholars who propose that the idea of the unified autobiographical self is indeed a myth, that identity is provisional and contested, as well as socially and culturally rather than individually constructed (Smith and Watson 2001). As Baisnée summarises:

> Woman's sense of self is mediated by the identity the dominant male culture imposes on her, and it is more difficult for a woman to express the strong sense of individuality often displayed in male autobiographies ... If the modern male self is fundamentally divided and decentred, for women division and decentring can become total absence (Baisnée 1997, 9).

Gilmore argues that there is no space for women, and particularly marginalised women, in traditional autobiography, and 'unless the space is changed, the newly-remembered subject will disappear, as usual' (1994: 90-91). And yet women are narrating their stories of motherhood and child disability in increasing numbers, navigating an autobiographical territory that inhibits their voices, as well as a social and moral terrain that marginalises them. For male authors, narratives of fatherhood and disability are also well outside the 'normal' range of autobiographical subject matter; their pathway, then, is also neither easy nor privileged. What, if any, are the particular characteristics of texts by mothers in contrast to those by fathers?

When parent writing about child disability is investigated by researchers, gender is either ignored, or texts by male authors are typically discussed. Couser (2004a) provides an in-depth analysis of a memoir by a father (Dorris 1989), and he cites four 'more positive examples of parental narratives', all by men (note 18, 209). Of the four memoirs and two anthologies cited by theologian and ethicist, Hans Reinders (2008, 9, note 4), all memoirs are by fathers and just one of the anthologies is co-edited by a woman. While Frank (2004) cites books by Sam Crane, Bérubé, and Eva Kittay, he does not allude to Kittay's work at all in his discussion. In her 2010 study, Calton addresses issues of class, but not gender. Regarding the nineteen books in her study, Piepmeier comments that: 'Most were written by women, although a significant minority—seven—were by men, and this gender difference did seem to affect the content and tone of the memoirs' (2012), and yet these variations are not examined. Robertson (2011) discusses memoirs by mothers of children with disability, but her analysis relates specifically to memoirs of motherhood. There appears to be the curious effect that when the gender-inclusive term 'parent' is used, fathers are better heard than mothers. As Lewiecki-Wilson and Cellio comment: 'the voices of fathers on parenting a child with disability ... have been better represented in recent disability studies scholarship than voices of mothers' (2011, 3). So while the social process of parenting a disabled child is firmly entrenched as mother's work, as discussed in Part One, this story appears to garner enhanced social value when it is told by a father.

Mother-authors

Of the books by mother authors in the sample, four were published in Australia, two in Canada, and one in the UK. Two of the seven were self-published (Johannesen and McClelland). Johannsen blogs about this decision:

> My friends and acquaintances sometimes assume that I self-published because I couldn't get a publisher to take it on. In fact, I didn't even bother trying to find a publisher. Felt like a waste of time and an unnecessary hurdle.[38]

McClelland gives a similar rationale[39]. These mothers are bypassing the publishing industry, and in so doing, possible rejection and compromise. The two books published on trade imprints, by Burbidge and Evans, followed on from newspaper articles (for which Evans won a Walkley Award[40] in 2004). Robertson won the Australian 2011 Calibre Essay Prize for one chapter of her memoir, and her book was subsequently short-listed for the 2013 National Biography Award. Canadian Miriam Edelsen has developed a high profile for her activism, writing for newspapers and magazines, and media appearances. Several of these mother-authors have, then, been publicly rewarded for their writing.

The key theme that emerges in these works by mothers is *identity*. Identity is expressed through various modalities – embodied, relational, and socially constructed. Associated with this is the dichotomy of the *private* versus the *public self.* The private world of mother and child is encroached by the public sphere, through the medicalisation of the child, and the appropriation of mother and child by therapy and services regimes, as well as the social world in general. The mother's preoccupation with the private and personal, including her emotions of grief and loss, typically give way to the 'bigger picture', as she shifts gear to address social issues and advocacy on her child's behalf.

Identity for these mothers is powerfully *embodied*. Edelsen, Evans and McClelland open with narratives of their birth experiences. Evans writes, 'At various stages in pregnancy my body has been objectified, invaded, scrutinised, monitored' (227). From the outset these mother-bodies are represented as transgressive, and their babies are marked as 'other'. Edelson and Johannesen are quickly separated from their newborns, who are whisked away into the high-tech medical world; Evans receives a curt diagnosis of her child's syndrome, and is subsumed into the parallel world of

disability. McClelland immediately recognises her first child's physical disability, but she resists the interpellation of herself and her child into the world of abnormality. Burbidge, a medical practitioner, refuses to acknowledge her newborn baby's disability, and responds with 'four weeks of denial' (3).

Whatever the initial response, the bodies of these mothers are fundamental to the genesis of their stories. Evans's body, in delivering a disabled child, has betrayed her: 'I have become afraid of my own body, cut off from it' (102). Robertson, who does not narrate Ben's birth, nevertheless writes: 'To me, the bond between mother and child seems the closest relationship one could ever write about. My own body was my son's first home' (136). From this embodied self, guilt emerges. Writes Evans, 'something deep inside, something from my own past, tells me *it is my fault'* (102). Edelsen recounts the overwhelming feelings of guilt that haunt her: 'I dredge up harrowing scenarios from the pregnancy, like needing urgent dental work when a filling came out, or slipping on the ice one evening outside my office building' (45). Burbidge's self-blame takes the form of guilt over her daughter's death, for not watching her carefully enough; she counters this with, 'No-one has blamed me' (72). Robertson, in contrast, raises the blame issue from a more objective perspective: 'The family blame game is an alternative to the vaccination, birth-trauma or toxic-chemical blame routines ... Robert and I have never played this game' (16). Elsewhere, however, she confesses to a different form of self-blame: 'the guilt of it, of being an older mother' (82).

Smith describes the body as central to female subjectivity: 'The autobiographical subject carries a history of the body with her as she negotiates the autobiographical "I"' (Smith 1993, 22-23). For these mother-writers, the body has become not only problematic, but a site of betrayal. As discussed in Chapter One, the self-shattering experienced by the mother of a child with disability comes as a result of the transgression of cultural expectations of motherhood, and the source of her trauma is her own body. The scenarios of pregnancy, birth and the delivery of a disabled baby described by these authors reveal a deep sense of abjection (after Kristeva 1982 – see Chapter Three). This abjected self is effectively the starting point for the narrative of identity disintegration and transformation, and the journey proceeds away from the body into social, moral and psychic reconstruction. Evans describes this undertaking

as follows: 'This book is really nothing more than my attempt at rebuilding myself from the pieces [Caoimhe] has cracked apart to expose the truth of who I am' (250-1).

For all these authors, the relationship with the child with disability is central, and as such, all enact a *relational* identity. Robertson reflects in this way:

> If I were to summarise my past twenty-five years, what would I say? I finished my literature degree, went overseas, came back, had three different careers and several failed relationships, had a child, separated from the child's father, ran my own business, gave up the business, started writing a book ... It's a mess; it doesn't hold together. It's just a list of things that have happened, not a story... [T]he narrative that would encapsulate my identity would have to be about Ben and autism. (5-6)

Robertson's identity is not only bound up with the child, but with the disability as well, as if this were a character in its own right.

Each author manages the representation of this interaction between self and child differently. Robertson weaves together elements of her own history with anecdotes and reflections on her life with Ben; but her relationship with her son is always the point of departure. Burbidge writes of her daughter: 'She was my identity. She gave me my special place in my world' (216). For Johannesen and McClelland, their identities are fully taken up with the mothering role, and they mobilise highly assertive voices that perform affirmation of their own lives and those of their children. 'My children's needs and my love of being their parent have led me to reach deeper into my capacity than I believed possible. It has ... exhausted and exhilarated me, and I count my good fortune in every waking moment', McClelland writes (15). For other authors, there is more tension between the subjectivities of the self as individual and the self as mother. Evans, vacillating between the negative faces of guilt, grief and the weight of social expectations, and the joy and love she finds for Caoimhe, admits: 'I felt my life was held hostage by hers; the glitter of any future career must tarnish so that hers could sparkle' (175). Edelson focuses on her political activity and activism, but she experiences deep depression as she attempts to combine career and mothering, describing the difficulty of reconciling a confident, goal-directed work persona with the patience and acceptance needed as a mother of a child with a severe disability.

These authors reflect on their changed identity as *socially constructed*. 'It was a shock for me to find myself a woman of low status,' writes McClelland (91). Robertson

describes her resistance to interpellation as a 'carer': 'to use the term carer about the mother of a young child is to mark her out as different from other mothers' (95); and this is echoed by McClelland: 'somewhere in there, I stopped being treated as a mum and became a carer' (91). 'Sometimes I am aware that I inhabit a kind of parallel universe,' Edelson writes (82). All raise issues of social exclusion. Johannesen recounts her rejection by a local mother's group; Evans describes being questioned by acquaintances about whether she underwent prenatal testing. 'Caoimhe is my stigma,' she writes, 'one I must bear alone' (117). Burbidge takes her daughter along to writers' group meetings, and is surprised that 'Almost without exception they ignore her completely, step over her without seeing her – she is 'not there' to them' (28). McClelland, with typical wryness, responds to the stares of people in public places: 'Nothing in my experience stirs a person to ponder the meaning of life like a visible, stigmatising disability in a child. I would like them to do their pondering in the privacy of their own homes and not all over us' (23).

These authors enact *resistance* against these socially constructed representations. Evans begins wearing very bright clothes as a means of resisting the shadowy world into which she is cast. Johannesen rejects her disempowerment as a service recipient, and takes direct control of her son's funding to contract her own team of educators. Edelson mobilises her advocacy skills to spearhead a massive campaign against disability services funding cuts. McClelland claims resistance through her unconditional appreciation of her children and her life with them in spite of its enormous challenges. Robertson focuses on her son Ben's creativity and irresistible quirkiness, and the reciprocity of their relationship, to assert the personhood of them both.

Authors narrate their grief with different levels of intensity. Burbidge's book is essentially a recount of grief and loss following her daughter's death. Evans describes her solitary moments in the shower when grief overtakes her. Edelson compares her emotional response to that of her husband: 'Jim is distressed by Jake's condition but it doesn't seem to shake his very foundation as a person, as a man. I keep functioning because I must. But inside, I am shattered' (46). Other authors (McLelland, Johannesen) use language that is more restrained. Bewilderment and uncertainty are also common themes. Johannesen spends months commuting between her home and the neonatal care unit: 'I learnt to live from day to day without knowing when, or even

if, Owen was coming home' (39). Fitton summarises the cocktail of emotions that swamped her in the early days:

> First, I was trapped in the web of exhaustion that seemed to rule our life ... Second, although we seemed to spend a lot of time at clinics and hospitals, I did not feel that I was getting very helpful advice ... Third, I was beginning to lose all confidence in dealing with Kathy or anybody or anything. Fourth, Kathy and I did not seem to have a relationship; I felt great love for her but I wasn't getting any of the normal responses you get from a baby. This and the exhausting round of care sometimes made me very angry, sometimes at her. (8)

This confession of anger against the child is the only instance in the mothers' texts. Instead, anger is typically directed inwardly (in the form of self-blame), or outside the family, toward the service delivery system, where it takes the form of 'the good fight'. In an exception, Johannesen alludes very briefly to 'the night the silence got so bad I punched a hole in the wall beside the guest bathroom' (97), but she does not disclose further, except to say that this incident was a precursor to her marriage breakdown. While feelings of grief and loss, bewilderment and uncertainty are acknowledged, the journey is about managing these emotions, 'coming to terms', and finding value in life's new and unexpected direction.

For five of the seven mothers, the marriage relationship with the child's father had broken down. As Johannesen writes: 'Some research reports that as many as 80% of couples who have children with disabilities eventually break up' (96). Edelsen and McLelland cite similar statistics. Johannesen claims the reason for the relationship breakdown was the boredom of relentless caregiving, and not Owen's disability. McClelland writes that, 'Somewhere quite early in the calamity of all this, my version of a thirteen-year marriage dissolved. I barely noticed. He assures me he said good-bye' (41). Edelson wonders 'how much the exhaustion from six years of public and private battles for our child's care contributed to the undoing of our marriage... our life as a couple was slowly losing ground to the war room against injustice that had set up camp in the basement study' (171). She acknowledges the personal cost of advocacy and activism – ironically, the very activities that social scientists in Chapter Two claim is a way for mothers to reclaim social value. These families have all in some way exceeded the 'breakdown point' described by Kittay (1999, see Chapter Three).

But for these mother-authors, there is also the possibility that the loss of the marriage has opened up a space that enables writing, freeing the woman from another of the relational ties that intrude into her subjectivity. So, too, the death of the child has provided an opening for the telling of story. The children of three mothers (Burbidge, Fitton and Johannesen) had died prior to writing. In each case, the child's death emerges as an impetus for narrating and making sense of the experience; in practical terms, perhaps, these mothers now had the time available to manage this task. The ethical implications of this scenario will be addressed in Chapter Nine.

In terms of their public lives, Edelson is the only author who devotes significant space to her career and occupational identity. Others allude, if briefly, to their working lives. Evans describes some of her earlier career achievements, addressing the impact on her self-esteem: 'Up until her birth I had been a successful journalist; now I was a nobody, the mother of a disabled child' (175). McClelland states that: 'Before I had children ... I was living overseas, and I banked and was taxed on a healthy, six-figure salary.' Now, she writes, 'I live by begging, to supplement a Centrelink carer's pension' (89-90). Burbidge refers to her work as a part-time GP as well as other health services jobs she has, and at the beginning of the book she briefly describes the birth of Jenny when she was a young medical officer in a regional town. Robertson makes little reference to her professional life, implying that this is less fundamental to her identity than her relational world. Johannesen never refers to her career before Owen.

The writing personas of these mothers are diverse, and provide clues about how writing becomes a medium for constructing and performing a re-imagined identity. McClelland's assertive voice enables her to wrest control and a sense of mission; she refuses to yield to the 'tragedy' narrative. Johannesen's writing focuses on doing and problem solving, on enacting her identity through her advocacy for her son. Edelsen, in contrast, vacillates between emotional vulnerability and ethical certainty; between depression and social activism. Burbidge recounts her performance of various identities: a chaotic melange of doctor, writer, singer, flute player, community member, and wife, as well as mother. Robertson and Evans both find a literary voice with which to express their performance of marginalised motherhood. Robertson mobilises metaphor, dreams, and academic references to re-imagine her son's identity; she renegotiates the narrative of her son's (dis)ability and his obsession with numbers

in terms of her family's history of mathematical talent and difference. Evans uses literary language to paint the canvas of her story and claim a creative self.

Father authors[41]

Of the father authors, two are American, one Canadian, and one Australian. Three are writers (Brown, a journalist; Macris, a fiction writer; and Bérubé, an academic and writer); and one is a psychologist (Naseef). Three of these titles were published on trade imprints (Bérubé, Brown and Macris); and one was published by a speciality disability press (Naseef).

Just as Kenzaburo Oe writes about his son with disability in *The Healing Family* (see the quote at the beginning of Chapter Five), so the four fathers in this sample write about their sons. The father-son relationship, loaded as it is with social, cultural and even mythical potency, is effectively cloaked in silence when sons do not or are unable to meet social and parental expectations. In writing about this relationship, these fathers break this silence, and as such they stand in as proxies for those others unable or unwilling to speak. Tension emerges between the emotional responses of these fathers and the traditional rational male perspective. As such, a key theme that emerges in these books is the opposition between the poles of *emotion* and *intellect*.

Naseef's main purpose is to share his *emotional* journey as the father of Tariq, his 21-year-old autistic son, from the vantage point of his occupation as a psychologist. Naseef opens his book with a personal letter to his son:

> Truthfully, I was crushed for a long, long time when I found out you have autism. It was as if a house had collapsed on me, but I stayed alive at the bottom of the heap of rubble. I have fought through it, and over time, the weight has lessened ...
>
> Take my hand ... I am near ... I love you,
>
> Dad. (xix-xxi)

The book ends with another letter to Tariq. Naseef's direct address to Tariq expresses his intense relationship with his son, and his son's value as a person. Throughout, he acknowledges the emotional power of his experience and his own vulnerability.

Macris and Brown also explore their emotional responses; these are angrier, and more externally directed than those of Naseef. In a painful episode, Macris attempts to explain his son's diagnosis over the phone to his Greek mother:

> I tried to calm myself down, but by the time I opened my mouth, my anger was volcanic. 'Alex is fucked,' I shouted. 'He's completely fucked. His brain doesn't work. He's not normal. He'll never be normal.' The phone was no longer pressed to my ear. I was holding it in front of me like a microphone, shouting out my bitterness, my rage, my disappointment. (90)

Similarly, Brown pulls no punches as he describes his response to Walker's disability: 'After Walker was born, the future was unchanging, sad, full of obligation, until we died, which only raised the gloomy prospect of what would happen to him then' (44). These examples, in which the fathers identify the child as the site of their anger and pain, contrast with mothers' responses. The fathers express their loss of both the imagined perfect child and their plans for the future. Naseef expresses his disappointment as he invokes the American father's dream, and his own alienation from it: 'One of the little things that remains difficult for me is passing a little league baseball game on a summer's night' (39).

Naseef addresses those potent emotional cousins, guilt and shame:

> Whereas *guilt* refers to uncomfortable feelings attached to violating an inner standard or taboo, *shame*, however, is much broader and involves a failure to live up to one's ideals. There is a way out of guilt because a person can make up for things done wrong. Shame leaves us wanting to hide, with no easy way out. (30-31)

Naseef asserts that shame is more difficult to absolve oneself from than guilt. But this comes very much from the father's perspective; mothers, it could be argued, are more directly implicated in the violating of taboo that gives rise to guilt. For fathers, however, the emphasis is on loss of the ideal. They may describe feelings of guilt, but these come not from biologics of the child's disability, but rather from their capacity to do all that is needed to help the child. Macris is committed to taking up the most intensive therapy options available. Brown expresses his guilt over the family's decision to seek a residential placement for Walker; he also acknowledges the different role that guilt plays in the lives of mothers of CFC children: 'there was no escaping their guilt: it lived deep in them, deep in the germline of the maternal' (182).

He touches on the toxic impact of this socially induced guilt, which is 'a swamp of irrationality that has afflicted social thinking about disability for millenia' (185).

In contrast to these emotional responses, Bérubé's book deals in *intellectual* currency. It is a virtuoso work of argumentation and reasoning, as he traverses the landscape of medical science, philosophy, sociology, and politics to provide a treatise on the rights of people with intellectual disability. When a nurse finds Bérubé and his wife in the ICU by their baby's cot 'babbling about meiosis and monoploids', she makes a note in her report that 'parents seem to be intellectualizing' (14). Comments such as the following pepper the pages: 'Toddler I was not quite a Hobbesian state of nature, mind you; there was no brutal competition for playthings in which the race went always to the swift' (172). The tone throughout is didactic: Bérubé is teaching us, challenging us by bringing such a sophisticated discussion to the (devalued) topic of a disabled child. There is no shame here. Naseef also rescues himself from the intensely personal by mobilising a didactic tone as a psychologist, by generalising and theorising and counselling others, and in so doing, taking control.

Another major theme in the books authored by fathers is the opposition between *fixing the child* and *the broken child*, particularly evident in the books by Macris and Brown. Macris's book opens this way:

> When my son Alex was one and a half years old he entered into an autistic regression so severe it seemed to wipe away all he had known, diminish everything that he might one day be. At the beginning of 2003 he was, for all appearances, a normal, buoyant toddler. By the middle of the year we barely recognised the child he had become. (1)

Alex is a changeling, and Macris's mission is to restore the 'real' child they had known. Determined to *fix* Alex, his parents embark on an intensive and very expensive therapeutic program that promises positive outcomes – even restoration – for their child that throws them into financial difficulty, and jettisons their dreams of a creative lifestyle.

This will to fix emerges as a trope in the fatherhood experience.[42] Naseef writes that 'I was so passionately determined to change Tariq and make him the boy I wanted him to be.' It takes him some time to realise that 'instead ... I was forced to change myself' (254). Bérubé closes his book with a wish for his son's elevation to full personhood:

'For I have no sweeter dream that to imagine – aesthetically, ethically and parentally – that Jamie will someday be his own advocate, his own author, his own representative' (264); in short, a man in the image of his father.

But there is not always the possibility of fixing. Brown opens his book about life with Walker as follows:

> Tonight I wake in the dark to a steady, motorized noise. Something wrong with the water heater. *Nngah.* Pause. *Nngah. Nngah.*
>
> But it's not the water heater. It's my boy, Walker, grunting as he punches himself in the head, again and again. (1)

Unable to be fixed, Walker is represented as less than human, a 'lost and broken boy', 'an unsuccessful random human mutation', who delivers exhaustion and relentless care obligations to his family. By the end of the book, however, it is Brown who has been *fixed*: he finally acknowledges Walker as his 'teacher'.

These characterisations of the child as 'broken' or needing to be 'fixed' express an objectification of the child that is absent from mothers' accounts. These representations are clearly at odds with disability rights discourse: the disabled body is presented as unacceptable, in need of remediation. They also reflect the concept of autonomous personhood that prevails in the Western liberal philosophical tradition (see Chapter Three). As such, these representations privilege a view of the idealised self as independent, in contrast to the relational self that emerged in the mothers' narratives.

Fathers do not invest their identities in their child to the same extent as the mother-authors in the sample. Each has a clear sense of self beyond the parenting role: Bérubé as intellectual; Naseef as psychologist; Macris as writer. Brown intrudes his journalist-self to a lesser extent. Unlike the mothers in the sample, only one of these fathers has experienced marriage breakdown: Naseef, who has re-partnered and is now 'experiencing more fulfilment than I ever knew existed' (11-12). Bérubé and Macris pay homage to the dedication and selflessness of the mothers of their children, with the implicit message that these qualities have also supported the telling of their father-stories. Brown offers a different narrative: he writes about the strains on his marriage, and attributes these to the pressures of caring for his son: 'Instead of

bringing us together, Walker scatters us ... the grit of resentment lay like a fine dust over everything. But the prospect of leaving each other was unthinkable: there was no way we could care for Walker if we didn't do it together' (97). This account contrasts starkly with those of mother-writers (Johannesen and Edelsen), who deny that their child is the reason for their marriage difficulties.

All these father authors have, like two of the mothers, achieved success with their books. In fact, the acclaim has been considerable: Bérubé's book was named a *New York Times* Notable Book of the Year in 1998; Brown's book won both the British Columbia's National Award for Canadian Non-Fiction and the 2010 Charles Taylor Prize for Literary Non-Fiction; and Macris's book was short-listed for the Melbourne *Age* 2010 Nonfiction Book of the Year. Naseef's book, though not similarly awarded, comes with a host of endorsements. In terms of support for the writing process, Bérubé acknowledges the services of a research assistant, and Macris received writing grants from three separate sources. (Compare this with McClelland's experience as a single mother on a pension, funding the self-publication of her book.) The fathers have, indeed, outshone the mothers in receiving support and public recognition.

Conclusion

Parents who write about their lives with their children with disabilities fit into the traditional pattern of autobiographers in terms of their social status and ethnicity. While some researchers decry the absence of alternative voices, others support the view that those who can, should write, in order for these stories to be heard.

Parenting is predominantly women's work, and mothers write more books about parenting a child with disability than fathers. And yet memoirs by fathers are over-represented when parental memoirs of disability are discussed by scholars, and their books have achieved more traction in the public sphere. One reason for this could be that men have traditionally had a greater access to the autobiographical project than women. While this situation has been challenged in recent decades by feminist scholars and women writers in general, work by male authors – particularly those with strong identities in the public sphere – may still have enhanced legitimacy. But within this genre, the reasons may be more closely related to the subject matter at

hand, and indeed, the stories told by fathers are significantly different from those told by mothers.

When venturing into the private world of child and family, the father's story may be more novel, and hence more narratable. He is also not generally engaged to the same extent as mothers in the tedium of day-to-day care or the battleground of social services. At a remove from the relational entanglement of mother and child, he can bring greater emotional distance to his story, even as he dares to disclose his own marginalisation. His story may therefore be more sympathetic to readers. But perhaps most importantly, the father's experience is not framed as *embodied*. His story may be a socially marginalised one, but it is not *transgressive*, unlike the mother's story, in which her very body is implicated in her baby's disability.[43] This may give him greater access to the 'morally good' story, or versions of it. It may also mean that the standard linear narrative emplotments are more available to him, as will be explored in the next chapter. The mother's story, on the other hand, is more contested: her story – and this is my story – may be both harder to tell, and harder to receive.

Chapter Eight

EMPLOTMENTS AND MODELS

Strategies, plots and politics

Introduction

While *genre*, as discussed in Chapter Six, refers to the shared communicative purpose of a set of texts, and the structural forms that characterise these texts, *emplotment* describes the unfolding of story: what happens, and what sense the author makes of it. 'Lived experience that lacks a master narrative is precarious at best, impervious to examination, analysis, or understanding. At worst, such experience is invalid – incredible, invisible, unreal,' writes Egan (1999, 226). Emplotment, then, determines whether a story may be regarded as 'valid and valuable' (Couser 1997, 12), and its processes involve questions of both 'poetics and politics' (13): the rhetorical strategies that underlie and enable story, as well as the author engagement with the socio-cultural discourses in which lived experience is embedded.

Genres give rise to privileged emplotments, negotiated between writers, readers, publishers, and prevailing socio-cultural scripts. The typical plotlines or rhetorical patterns that characterise disability life writing have been described by researchers, in particular Frank (1995) and Couser (2009). Writers who adhere to these formulas produce what Couser (2009) refers to as 'hegemonic narratives', but even when writers choose to challenge these emplotments with counterstories, they cannot ignore their influence. To clarify, I draw on Ferri's allusion to Judith Butler's (1990/1999) work: 'even when we are resisting dominant scripts, we still must engage with them to be rendered intelligible. Thus, pushing against hegemonic scripts, we nonetheless call them into being' (Ferri, 2011). Atkinson and Poletti, refer to Ricoeur's (2004) term, *sensis communis*, to describe the process by which 'the legitimacy of testimony is determined largely by its capacity to articulate a perspective that is congruent with majority belief' (2008, 2). In order to resist, therefore, writers still need to acknowledge and engage with these dominant scripts so that readers will not be alienated from their stories.

In this chapter, I describe these dominant scripts in relation to disability life writing, and explore to what extent parent authors in the sample comply with or resist them. I then extend this discussion by considering how the authors engage with the models of disability that were described in Chapter Four. All contemporary accounts of disability are contextualised by these models: both dominant scripts and counterstories are framed by them. How they operate in parents' narratives provides

insights into these authors' engagement with disability rights, and indeed, their political perspectives.

Rhetorical patterns in disability life writing

Frank (1995) and Couser (2009) have proposed schemas that characterise the rhetorical patterns, or emplotment strategies, deployed by disability life writers. While illness stories are not the same as disability stories, there are parallels, and the three following formulas mobilised in illness narratives articulated by Frank (1995) provide a useful starting place. These are:

(i)   *restitution* stories, in which the illness is experienced, then resolved in a complete restoration of health

(ii) *chaos* stories, in which the troubles and difficulties brought about by the illness are never resolved or accommodated by the narrator, and

(iii) *quest* stories, in which the person comes to accept the illness, and seeks to find personal meaning in their experience. 'The quest narrative affords the ill person a voice as teller of her own story because only in quest stories does the *teller* have a story to tell' (1995,115).

Frank asserts that 'restitution' stories are about the triumph of medicine, and in this way, they may be aligned with the medical model of disability. In 'chaos' stories, the voice of the narrator is lost and unrecoverable, and therefore there is no real story to be told, whereas the search for meaning encoded in the 'quest' story serves to 'hold chaos at bay' (115).

Illness stories, unlike disability stories, may have the possibility of recovery as part of the denouement. A decade later, Couser identifies the following four rhetorical patterns that appear commonly in conventional life narratives of disability:

(i)   the rhetoric of *triumph*, in which the hero overcomes the obstacles of his/her impairment to achieve success (such as the champion athlete with a physical disability)

(ii) the rhetoric of *horror*, or gothic rhetoric, in which the author's experience of disability is represented as horrendous and intolerable

(iii) the rhetoric of *spiritual compensation*, or the conversion narrative, in which the challenges of managing disability are offset by the emergence of religious faith and the associated rewards of the spirit

(iv) the rhetoric of *nostalgia*, in which the disability 'provides not the *subject* of the narrative but only its *motivation* and, of course, its vantage' (2009, 33).

Couser refers to these as 'hegemonic' emplotments – those that reproduce and reinforce the dominant cultural messages of disability. He contrasts these with the rhetoric of *emancipation* , which 'contests received attitudes about disability' (33).

The schemas identified by Frank and Couser have similarities, but there are significant differences. Hegemonic scripts, Couser asserts, are imposed upon disempowered writers within the political economy of writing and publishing. Publishers of memoirs demand particular emplotments to satisfy the expectations of the marketplace. His use of the term 'hegemonic scripts' contrasts with Frank's term, *narrative habitus* (introduced in Chapter One): Frank's term refers to the repertoire of stories possible and available to individuals within their socio-cultural context (Frank 2010, 52). The difference is essentially that Couser views these scripts as 'imposed' on the individual, whereas Frank regards this as less an imposition than a process of uncovering and negotiating: of finding and then appropriating a culturally available story (albeit one that is often limiting).

Frank encourages storytellers to resist interpellation by these pre-existing scripts, and to enact 'narrative ambush' by breaking through the constraints of the *narrative habitus* to extend the range of possibilities with new stories (2009, 58-9). So too, Couser calls on life writers to take up the challenge of producing narratives that are 'counterhegemonic', that interrogate the well-worn emplotments and 'deviate consciously from ... failed or counterproductive formulas' (2009, 172). To illustrate, he cites feminist disability life writer Anne Finger, who describes her own project to write against the standard emplotment of:

> ..ascending into crisis... And then the hard-won ending, with its return to the empire of the normal...; the final chapters of the narrative, when not just the body but the self has been chastened, and from that chastening, grown... I do not want to give you just my story... I also want to write about the social experience of disability. (2006, 7-8; cited in Couser 2009, 178)

Finger here encapsulates not only the emplotment of the typical pathos-driven disability narrative, but its alternative, the counterhegemonic story in which the narrative of the individual becomes representative of the collective. This is making testimony, or *testimonio*. Beverley describes the difference between autobiography and *testimonio*:

> *Testimonio* represents an affirmation of the individual subject, even of individual growth and transformation, but in connection with a group or class situation marked by marginalization, oppression, and struggle. If it loses this connection, it ceases to be *testimonio* and becomes autobiography, that is, an account of, and also a means of access to, middle- or upper-class status, a sort of *bildungsroman*. (1992, 103)

This definition of *testimonio* gives writers a means of situating their lives within a constraining social order, even as they represent their own lived, embodied experience. Disability life writing, Couser argues, is a postcolonial phenomenon: writers who are 'colonized subjects' represent themselves in ways that challenge and test the prevailing cultural representations available to them (2009, 7). These texts are counterhegemonic; they take up this post-colonial agenda, in relation to content and form (i.e. in terms of both politics and poetics).

While the rhetorical patterns discussed above may apply to disability life writing in general, to what extent do they also characterise auto/biographies by parents of children with disabilities? And what might constitute a counterstory?

Emplotments and sample texts

It could be argued that each of the authors in the sample takes up a 'counterhegemonic' project, simply by writing about the lives of their children and themselves, by breaking their silence and bringing their stories into the public sphere. As Frank observes in relation to Bérubé's book: 'Stories *enact* realities: they *bring into being* what was not there before ... The core idea is that Jamie's life is effectively invisible until a story makes that life narratable' (2009, 75). Even Burbidge's book (which is somewhat unrealised as a memoir) achieves this goal: she was one of the first writers in Australia to bring her experience of mothering and child disability into the public domain.

But the types of stories – the master narratives – told by parents are the concern of this section, and I now consider whether or not these texts fall into the scripts identified by Frank and Couser.

The Quest

The 'quest' story is associated with the archetypal hero story (after Campbell 1949, see also Vogler 2007). It is outside the scope of this thesis to provide a full discussion of accounts of the hero story and its various manifestations, but a simplified outline of the journey (following Vogler) involves these stages: the protagonist is called to leave the ordinary world, and may initially refuse the adventure; he [sic] crosses into unfamiliar territory; with the help of allies, he faces trials that lead to a major ordeal, which he overcomes; he wins the reward or 'boon', and turns for home; he triumphs over yet another test, and is symbolically reborn, ready to deliver the boon and serve his people. This hero story has driven narrative across time and culture. Its application as a 'well-worn emplotment' to the story of disability is encapsulated in the words of Anne Finger above.

Several, if not all, books in the sample express elements of the quest journey: the narrator faces trials, then finally comes to accept the disability of their child, and through love, ultimately finds personal meaning, wisdom and compassion. Evans struggles to understand the turn her life has taken; she grieves, even as she loves her daughter unconditionally; she seeks information and therapeutic support; she explores aspects of her past as she processes her experience; she engages with social commentary on the disability experience; she accepts her child's disability and grows personally, even as she resists final closure in the face of the future's uncertainty. Robertson enacts a quest in each of her chapters as she reflects on a particular theme and finds meaning by drawing together the various aspects of her experience. Bérubé's book is a quest, on behalf of Jamie, to declare his son's rights to inclusion and reaching his own potential. But two texts in the sample, *The Boy in the Moon* by Brown and *When Horse Became Saw,* by Macris, provide particularly rich ground for exploring the quest narrative. Significantly, both are by male authors.

Brown and the unresolved quest

The Boy in the Moon has received considerable accolade (see Chapter Seven), but this book has also attracted criticism. McGuire, for example, explores how 'the life of cognitive disability is conceived of as an unliveable life' by Brown (McGuire 2010). Out of Brown's belief that his son is 'broken' comes the quest to *know* Walker. 'If he wasn't knowable, what was his value?' Brown asks (282), invoking one of the underlying preoccupations of Western liberal philosophical thinking.

The book begins with Brown already beyond the ordinary world, immersed in trials: relentless care obligations, hospital emergencies, sleeplessness, marital tensions, and a pervading sense of meaninglessness. In Chapter Three, Walker's birth, which signifies the crossing of the threshold, is described, and we are given a glimpse, via flashback, into the 'normal' world that Brown inhabited before Walker. Over the course of the narrative, Brown encounters various mentors who represent the discourses that inform his experience – medical, political, communal, spiritual. In this reading of this text as quest, we see how each of these characters tempts Brown to follow their pathway in his quest for meaning; how he responds to each is critical to his journey towards knowledge.

The first of Brown's mentors is Dr Norman Saunders, a paediatrician and emissary from the world of science, who attempts to diagnose Walker, to make him knowable (29). Brown then encounters another doctor who delivers a disturbing prognosis – 'moderate retardation is still catastrophic' (67) – but this man opens the way for a different way of knowing Walker. "The Buddhists say the way to enlightenment, to pure being, is by getting your mind out of the way," he says. "Walker already knows how to do that." This is the voice of the spiritual, made accessible (and acceptable) to Brown through the discourses of science.

Allies appear as advocates who assist Brown to recover his life by finding a residential placement for Walker. By this time, Brown has slid into temptation, going to bars and 'even strip clubs': 'I wanted a shred of my old life back,' he writes (103-4); like the reluctant hero, he has been resisting the call to action.

Almost halfway through the book, Brown's journey proper begins, signposted by, 'I decided to get in my car and start driving' (112). Brown seeks 'other people in the

world' like Walker – another way of *knowing* his son, but also a way of finding connection and community for himself. In the US and Canada he encounters those few families that have a child with cardiofaciocutaneous syndrome (CFC). These people provide him with lessons in valuing his son's life and about belonging to a community. But the underlying message proposed by several, of a God who gives 'special children to special parents' (135-6), fails to convince Brown, who is 'a fairly conventional atheist', and he makes the cynical appraisal that: 'The possibility that their lives had been touched by God's grace was at least one way to make sense of the otherwise senseless burden they carried' (141). Drawn back to the world of science, he meets a geneticist who has identified genes associated with CFC and can test Walker, but this process ends without a clear outcome: 'The latest round of genetic tests, alas, had only deepened Walker's mystery' (174).

The next encounter takes him again to the spiritual world, to L'Arche, a Catholic-based French organisation that operates communities around the world for people with intellectual disability. Brown visits a community in Montreal; he is inspired and subsequently travels to a village in France, where a priest tells him that 'the core members of L'Arche are our teachers' (198). These words offer another way of understanding Walker. He meets Jean Vanier, the founder of L'Arche: 'He had radical ideas,' Brown writes, 'frailty was strength, peace no longer lay in the tolerance of difference, but in the bridging of it through a mutual concession of weakness ... *I wanted to believe it* [my italics]' (210-11). Brown hovers on the cusp of faith, but his scepticism intervenes, and he is compelled back into the rational world of science: 'I tried one last time to find his mind' (275). He organises for Walker to undergo further MRI investigations, but 'his brain had even less to tell me about who Walker was and how the world appeared to him than I knew myself' (279).

Brown's story narrates what is, in effect, an unresolved quest. Brown cannot *know* Walker. There is no map, no code, and no cure. Brown's quest is also about finding *value* in Walker's life, and while several ways of enabling this emerge, they are all stymied by the clash of discourses. Each of the pathways that opens up – the scientific, the political, the communal, the spiritual – are found wanting. At the end of his quest, he finally acknowledges Walker as his teacher, but a sense of provisionality persists.

Macris and the displaced quest

The quest that emerges in *When Horse Became Saw* takes a very different form, involving Macris's journey towards acceptance of both his disabled child and changed expectations for his own life. The book opens with:

> When my son Alex was one and a half years old he entered into an autistic regression so severe it seemed to wipe away all he had known, diminish everything he might one day be ... By the middle of the year we barely recognised the child he had become. (1)

Alex is a changeling, and the story that unfolds is about Macris's quest to restore his child to his former, 'real' self, to save him from disability and the cruel future that his father imagines:

> When Kathy and I die, Alex would be completely dependent on the state for his welfare. He would live in shabby, supervised accommodation and dress like a tramp. Or a buffoon. At best he would be marginalised and misunderstood. At worst, despised and maltreated. (50)

Macris and his wife Kathy are frustrated in their attempts to obtain a diagnosis for Alex, and then by the long waiting lists for early intervention therapy for children with autism. His fears for Alex – and himself – mount as he contemplates the catastrophe of their immersion in the world of disability.

Macris and his wife decide to follow the Applied Behaviour Analysis (ABA) approach to treat Alex's autism, but this privately accessed therapy is hugely expensive. The dreams of this couple – one a successful emerging writer, the other a dancer – for a creative, non-materialistic lifestyle are jettisoned as the need to acquire money becomes the priority. Macris becomes preoccupied with his role as provider for his family, and is forced to take on more work to supplement his salary, while Kathy becomes Alex's full-time therapist. Their lives become a study in survival, entailing financial difficulties, sleep deprivation, and overwork, all centred on Alex's recovery program. As Alex begins to make gains, Macris writes, 'My son was coming back to me' (266).

Towards the end of the narrative, Macris receives some unexpected financial assistance. Then suddenly he is offered a prestigious job as head of a university department: 'Overnight, I had a secure job with more hours, a dramatic increase in

salary and a stronger career path' (272). The tide has turned. Macris's financial problems are solved, and his social position recovered – in fact, enhanced – after the long ordeal. But when Alex is given another intelligence test soon after, the results are sobering: 'Alex may have done well for a child of his level of functioning, but he was still severely autistic' (291). Alex has not been restored; this is, in effect, a failed *restitution* emplotment. But another, parallel quest has emerged along the way: Macris's own journey. He emerges with a transformed identity, as a mature man and father, a provider and protector.

Triumph

The 'triumph over adversity' emplotment described by Couser has parallels with the quest story. It also resonates with the social science 'transformational coping' literature, summarised in this quote from Chapter Two: 'These families are not just coping, they are thriving and positively benefiting ... they are better people because of the experience' (Dykens 2005, 360).

Naseef's book is the clearest example of this emplotment: he relates his journey from grief and loss to a place 21 years later, where 'I am experiencing more fulfilment than I ever knew existed' (2001, 11-12). His journey has re-formed him as a psychologist, adviser, and teacher. McClelland also produces a variation of the triumph over adversity emplotment, as she rejects the negative representation of her children and herself, and claims value for their lives and her own, even as she recounts her struggles. 'I never gave up,' she writes; 'I never walked away blaming them for their shortcomings, I never let our family life be less important just because it was different. I never wished their needs away, rather, I wished for my capacity to grow' (37); 'I had to get stronger, braver, more skilful' (57).

The books by Edelson and Johannesen, contain some elements of triumph that emerge out of the hardships. Edelson recounts her intense fears as Jake comes close to death several times; and she narrates her battles with depression and her sense of alienation: 'In truth, I am barely able to endure social times with friends and family I know well. Intimacy with relative strangers is beyond my reach right now' (29). Her triumph comes in the form of social activism: she produces a radio documentary series, and

organises a national press campaign against cutbacks to disability services funding. As an experienced union activist, she writes: 'We demonstrate and raise hell for a living. Others may have to reach deep inside themselves to find the strength to make such a ruckus' (147). Johannsen, in contrast, recounts her adversities as obstacles to be overcome: her gruelling pregnancy; Owen's severe disabilities and high medical needs; her negative encounters with the social world; and her dealings with the schools, therapists and government authorities. She navigates her way through with resilience and resourcefulness, and she finally takes charge of her son's program herself. This is her triumph.

Chaos and horror

In these two narrative types (the former proposed by Frank, the latter by Couser), the narrator never reaches a place of resolution: 'chaos' stories refuse a constructive narrative thread, while 'horror' stories focus on the destructive and negative aspects.

Elements of chaos and horror figure in each of the books. In several, horror plays a role in the formulation of plot. Johannesen begins by recounting her horrific experience of pregnancy and Owen's birth, and Owen's complex health problems effectively drive the narrative, despite the matter-of-fact tone with which they are recounted. In other books that begin with threats to the child's life in the neonatal period (e.g. Edelson, Bérubé), the details of the medical/hospital scenario serve as a narrative hook. (Bérubé, however, deflects any temptation for horror through his researched discussion of Jamie's condition.) The horror of Alex's regression provides the narrative impetus for Macris's book. Both chaos and horror play out large in Brown's book, as Walker's disability and their arduous family life take on gothic proportions.

Chaos and horror of a different kind inform Burbidge's book. Burbidge recounts somewhat breathlessly a lifestyle that includes three part-time professional-level jobs, hobbies, community and church activities, as well as boarders living in her home, a menagerie of pets, other family members, and Jenny, her daughter who has severe disabilities. There is a simmering sense of over-compensation in this frenetic activity that is not interrogated. Chaos turns to horror when Jenny drowns in their home

swimming pool. With relentless detail, Burbidge describes her intense grief and guilt over this tragedy.

In these parental accounts of child disability, grief emerges as more significant to emplotment than chaos and horror. Piepmeier (2012) criticises the way parental authors foreground grief:

> Excessive grief ... functions to dehumanize the child by identifying the child as the source of almost unbearable sadness ... Although it figures more or less dramatically depending on the book, in general, the first half to three-quarters of many [parental] memoirs is misery. (2012)

But this grief, Piepmeier acknowledges, motivates the narrative arc, which usually ends with 'the parent-author recognizing and affirming the humanity of the child'. (2012). For Burbidge and Brown, grief is central. Others –Johannesen, Naseef – downplay it, and several – McLelland, Bérubé and Robertson – work against it. In this subgenre, however, grief may indeed need to be narrated: the story of how grief over the birth of an imperfect child is socially and culturally constructed needs to be told. The problem is the extent to which grief dominates over other interpretations of the experience.

Another problematic element emerges: death. In the books of three authors, the child has died (Burbidge, Fitton and Johannesen). As mentioned in Chapter Six, Burbidge's work is in effect *thanatography*: the narrative revolves around Jenny's death at age 27. The first section includes excerpts about Jenny from Burbidge's diaries before the drowning; but Burbidge writes: 'Looking back, I am dismayed and chastened to find so little of Jenny in the diaries I've kept since 1990' (4). Jenny's death makes her, as a subject, *narratable*: Jenny now takes centre stage in her mother's world, and her death brings the opportunity for re-evaluating her life:

> What a lot she gave to us – our roles, our images, our importance, and love and warmth and comfort and laughter, an excuse to do things or not to do things, to be different. (175)

Of Jenny's funeral, Burbidge writes:

> I'd always imagined [it] as a rather sad little affair – set as it was at the end of years of hermithood for the retarded lady and her mad old mother, and then dying together like that... But not at all – this was a funeral worthy of anyone. (166)

Jenny's death in many ways resolves the uninterrogated chaos of Burbidge's life. In contrast, Fitton mentions her daughter Kathy's death at 21 in passing, curiously in a chapter called 'Things Can Only Get Better':

> When Kathy died, we felt utter despair at the prospect of life without her. We were angry that her last days in hospital had not been managed better, and that we were not prepared for her approaching death. (188)

Readers learn nothing more of the circumstances of Kathy's death, except that she had escalating health problems. In assuming an instructional voice in her hybrid genre text, Fitton disobliges herself from disclosing critical details such as this, even though many other episodes are recounted in detail. Johannesen's book, on the other hand, is subtitled 'The Life and Death of Owen Turney', so the child's fate is clear from the outset. In the brief penultimate chapter, Johannesen recounts the tragic phone call she receives from Owen's father, where her son was sleeping on the night he died. 'I had been thinking about this moment for months, years,' she writes (141). She describes the imagined final moments with her son: 'I assumed it would happen when he was with me, in my house, possibly in my bed and in my arms'.

Such an imagined death scenario is described in three other books, but in these, the child is still living. In Edelson's book, Jake comes close to death on several occasions, and the final chapter serves as a kind of requiem for her living son. Edelson describes plans for her son's funeral in simple declarative clauses in the future tense:

> Close friends will take part in the service ... Leo will say a few words about the meaning of Jake's life ... Jim and I will scatter his ashes on the lake in the Gatineau Hills. (186-7)

In the final paragraph of his book, Brown also envisions his son's death:

> [T]his is what it will be like, if he dies ... I didn't fear it. I was already as close as I could be to him; there was no space between my son and me ... I held that sweetness in my arms, and waited for whatever was going to happen next. We did that together (288).

Macris, in contrast, imagines his own death:

> On this particular night, my death took on a shocking immediacy. I suddenly found myself imagining what it would be like to die ... And my last thought would be, Who will look after Alex? He would be left to the mercy of the state.... I would die a broken man, frantic with worry ... (230)

He then ruminates about Alex's future death, and his family's present:

> The tender young face I so loved was old and ravaged. His teeth had rotten... He was dying alone, in great agony, unloved, after decades of neglect...

> In the moment that I had looked upon the imagined face of my dying son, the distance that separated me from my own death, from Kathy's death, from my son's death, vanished. We were all alive, but we were also already dead. (231)

For Macris, life in the realm of disability is a kind of death. For other authors, the death of the child, real or imagined, represents an end to the chaos, and provides a sense of narrative closure. But the notion of death-within-life functions as a worrying inversion of the typical parental narrative of imagining the child's future. By focusing on the deaths of their children, these passages undermine these authors' attempts to affirm their identities.

In contrast, several authors assert a more positive future: Bérubé closes his book with a dream of Jamie's blossoming autonomy: 'For I have no sweeter dream that to imagine ... that Jamie will someday be his own advocate, his own author, his own representative' (264). Robertson's closing message is more categorical: 'I don't want to predict Ben's future because that isn't my role. Ben will determine his own future' (2012, 212). Evans writes: 'I will speak for her until she finds her own voice' (288). Death simply doesn't figure in these authors' imaginings of their child's future.

Nostalgia

While nostalgia is not a primary theme in sample texts, several authors provide glimpses into their lives before the intrusion of disability. Evans describes her travels, her career achievements and her former loves with a sense of freedoms foregone; Macris must put behind him his old dreams of a creative lifestyle; Naseef and Macris both fondly recall their lives with their sons before their autistic regressions; Robertson revisits her childhood home with a mission to reconnect with her early self;

Edelson devotes a chapter to her personal history and her life before children. These memories act as points of departure for the subsequent narrative and its unfolding of challenges. Rather than coming across as regretful, these recollections enable us to place these subjects, and to evaluate their journeys. Two authors, Johannesen and McClelland, provide minimal information about their personal histories; their motive in doing this is surely to focus on the present, on the child and on the topic at hand. But as readers, we feel an absence; perhaps we need some connection with their previous selves in order to contrast normality with its converse, and to imagine ourselves in their predicaments.

Spiritual compensation

The proposition made by several theological ethicists and social scientists, that disability provides a pathway to spiritual transcendence, was discussed in Part One. To recap: Reinders, for example, writes of the 'spiritual journey of transformation' that comes from the understanding that the presence of a profoundly disabled person in one's life is 'a gift from God' (2008, 350).

Most texts in the sample are, however, determinedly secular. Bérubé explores the experience of disability from a number of theoretical positions, but he bypasses the religious; Edelson refers to Jake's *bar mitzvah* as a significant rite of passage*,* but this is cultural rather than religious; Evans is dismayed by the number of memoirs that she finds containing religious associations and the word 'angel' in their titles. Brown is ambivalent: early on, when he learns that his wife has taken Walker to see a shaman, he sees this as a sign that they had reached their lowest point; but later, he is drawn to the spiritual perspective of the L'Arche community. Burbidge is the only active church-goer amongst these authors; she describes, for example, a church service following Jenny's death in which the preacher reads from First Corinthians to demonstrate the value of Jenny's life, but even so, she refrains from the 'gift from God' motif.

Most authors find other ways to derive meaning: Naseef experiences emotional awakening; Macris finds his place as a mature man and father; Brown eventually acknowledges Walker as his teacher; Evans embraces her child's difference.

McClelland defends her devalued status, focusing on political and social issues, as do Edelson and Johannesen.

Several authors reproduce the cultural messages of disability as tragedy, even as they struggle to find a way through them with their love for their child. Others foreground social and political issues, and so counter these scripts with their calls for change. Still others work to affirm their child's identity in spite of the marginalising forces of the social world. Whatever the plot that carries their story, each author necessarily comes face to face with the models of disability that were described in Chapter Four.

Models of disability

The models of disability, in parallel with the socio-cultural scripts, are an undeniable part of the landscape in which disability life writing takes shape. In this section, I explore which models are privileged by authors in the sample. I propose that just as a master narrative is a requirement for these stories to be valid and accessible, so, too, an affiliation with at least one of the models of disability is necessary – in fact, unavoidable – as scaffolding for the author's particular personal, social and/or political messages – whether or not the author is actually aware of this connection[44].

To recap, the medical model of disability emphasises the defective body, the individual's obligation to normalise, and the processes involved in realising this outcome. The social model addresses disability as socially and politically construed, and focuses on the obligation of society to facilitate inclusion. The cultural (or minority group) model stresses that diversity and individual difference are intrinsically valuable, and therefore focuses on identity as the site of discussion. To these, Couser adds another model that he claims is invoked often in disability life writing: the 'symbolic (or metaphorical)' model, which predates the medical model, and for which an impairment 'serves as a trope for a moral or spiritual condition' (2009, 21).

Of these models, Couser asserts that it is the social model that 'can be *presumed* to advance the collective interests of people with disabilities' (2009, 30), because representation that deploys this paradigm acknowledges the social and political dimensions of disability over the personal. The social model positions disability as a *political* issue. But this very point brings about a dilemma for life writers: by focusing

on the limitations imposed by the external world, the social model may dismiss the importance of the lived experience of disability that is the very substance of auto/somatography; in short, it may be effectively 'stifling testimony' (Couser, 2009, 30). Other models, then, may need to coexist with the social in order to deliver a personal story.

Landsman (2005, see Chapter Two) discusses the ways in which the different models interact as mothers negotiate their way through the discourses of firstly, the medical model when their child is diagnosed; then the social model, when they encounter the services system, school and the community with their child. In her later (2009) work, Landsman also invokes the cultural model, to describe what might be the next stage in this maternal journey:

> Portraying their child as giver of a gift, not for which they were specially chosen but which they learned, through any normal mother's love, to receive, mothers reinstate their child's full personhood, situating it in opposition to the consumerism and social hierarchy that would devalue their children, their own motherhood, and indeed the lives of countless others. (2009, 170)

Affirmation of the child's value as well as the mother's own identity is the key message here, consistent with the cultural model perspective. However, in order to reach this goal, Landsman appeals to the discourses of 'transformational coping' (see Chapter Two) and 'submission' (Chapter Three) – discourses which potentially disempower mothers of children with disabilities by condoning their marginalisation. This example points to some of the ambiguities that arise from the cultural model, and these are discussed further below

Parent authors must negotiate their ways through these different models in their narratives. In Figure 8.1, the model that is privileged by each author is represented. (The symbolic model is not included because none of these authors mobilise this as the primary model, although there are vestiges in at least one text.)
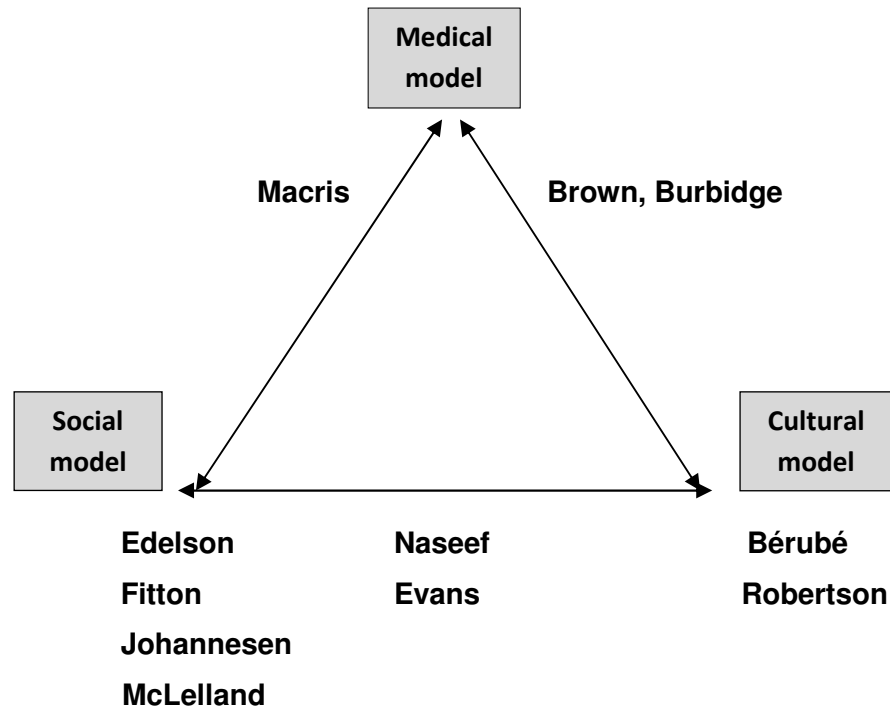
Figure 8.1: Models of disability and sample texts

The predominant model in the books of Brown and Macris is the medical model. Brown asserts that Walker is 'broken', and his narrative is largely driven by his determination to 'solve' the problem of his son; this premise situates the book within the medical paradigm. Along the way, he addresses issues of family stress and service provision (social model) and spiritual matters (symbolic model), but as he comes to understand that Walker is his teacher and his son's personhood is conferred, he embraces the cultural model (hence his position on the right-hand side of the triangle). Macris also privileges the medical model in that he foregrounds Alex's regression: much of the book is concerned with the recovery of his son's lost self. He addresses social issues, but it is this narrative of loss and recovery that defines this memoir. His position on the left side of the triangle indicates that the social model is secondary in this work.

Burbidge's book also sits on the medical-cultural axis, but her work is more difficult to classify. Of all the sample texts, hers is the most naive in terms of socio-political engagement. She doesn't medicalise Jenny's life, but she labours over the process of

her death in hospital. In purportedly affirming her identity, Burbidge manages to infantilise her daughter; she quotes from a newspaper article that she has written:

I have a darling baby... I've had my darling baby for nearly 20 years now, and, unless something happens, I guess I'll have her for another 20 years. She's been at the lovely seven-to-nine month stage for a long time, so I don't expect much change. (27)

Now, less than twenty years later, such a portrayal comes across as mawkishly sentimental, and the vision of innocence that Jenny represents here calls up the excesses of the symbolic model.

On the other hand, Edelson, Fitton, Johannesen and McClelland all mobilise the social model. That four of the six mother-authors prioritise this model is significant. Mothers, more than fathers, operate at the interface between the public and private spheres, and it is often up to them to take up the day-to-day struggles in the social world. Fitton concentrates on her negotiation of the social and medical worlds as an example to other parents. Edelsen addresses her negative encounters with the medical world, questions of bioethics, and her advocacy and activism. While Johannesen opens with a medicalised account of herself and her son, she focuses throughout on her engagement with the social world and her navigation through the minefield of disability services. McClelland rejects the medical account of her children, and in part two of her book, 'The Issues', she debates issues around support, inclusion, and value for herself and her child. She is the only author to address directly issues of gender and care from a political perspective. But these mothers also draw on another model, the cultural, to tell their complementary stories of relationship with their child, and to affirm their own and their child's identities.

The books by Naseef and Evans sit somewhere further along the axis between the social and cultural models. Naseef frames his own grief response to his son's diagnosis as socially constructed; he describes his own battles to obtain services, and his subsequent move into counselling and advocacy. But he also sets out to affirm his son's identity, as well as his own life, and what he can bring to others – especially other fathers. Evans begins with the medicalisation of her child, but she critiques this: 'the violence of [the medical world] appalled me' (2004, 70). She reflects on the marginalisation of herself and her child: 'The truth is that while society is tolerant of children like Caoihme, nobody wants them' (184-5). Caoimhe is never described as broken, however, and her identity is always affirmed; it is Evans's own response and

the response of others, products of the social world that devalues disability, which are culpable.

The works by Robertson and Bérubé are located firmly within the cultural model. Robertson recasts her son Ben's disability as an example of diversity and quirky individuality:

> Ben's love of numbers is both mystical and pedestrian. It's unrelenting ... The literature on autism describes Ben's love of numbers as 'a preoccupation with a stereotyped and restricted pattern of interest that is abnormal...' (*DSMIV*). Psychologists have described his behaviour as 'obsessional', 'compulsive' and 'ritualised'. I prefer to call him 'passionate'. (11)

Likewise, Bérubé refuses a label of abnormality for Jamie:

> As a form of emotional exercise I have tried, on occasion, to step back and see him as others might see him... It never works; Jamie remains Jamie to me. (xi-xii)

These authors also use textual structure to realise a counterhegemonic purpose. Robertson rejects a linear narrative trajectory in her storytelling, explaining that:

> This narrative can't be a simple chronological story, though, because my life is one of disruption and disjunction. The 'soaring curve' of the imagined life has been broken and re-made in a different shape. (6)

Her writing reflects such dislocation: chapters are organised around themes, and the narrative shifts through time and space. But in spite of these disruptions, the work flows gently and coherently, suggesting, perhaps, that while her story may have been broken, its new shapes fit together smoothly. In interrogating the social and cultural construction of disability from many perspectives, Bérubé interweaves personal recount with essay, pushing the boundaries of both genres, always with the clear goal of affirming Jamie's intrinsic value. Both authors invoke the social model as well, as they discuss to different extents the social construction of disability, the marginalisation of their child, and the responsibility of the state regarding disability services provision. But the medical model also emerges in these works: Bérubé provides a lengthy explanation of the biochemistry of Down syndrome, and Robertson describes the physiology of autism in some detail: 'I am thinking that autism is to disability what cancer is to illness', she writes; 'a special status' (50).

The cultural model provides a strong framework for the narrative of affirmation, but there are problems with its mobilisation that need to be recognised. The 'specialness' that Robertson refers to is a case in point. Both Robertson and Bérubé focus on their child's specific disability: autism and Down syndrome, respectively,[45] and this focus reflects the 'minority group' emphasis of the cultural model. By concentrating on the particular disability, these authors and their children become, in effect, members of 'special' disability tribes rather than the broader population of families of children with disabilities. Such a tribal consciousness encourages hierarchies of disability types: autism or Down syndrome, for example, may be perceived as having more social currency than other disabilities, particularly those that are more obscure or without a clear diagnosis. A focus on the specific needs of those with one type of disability also has a depoliticising effect, by fragmenting the constituency of all families of children with disabilities. In addition, by concentrating on diagnostic criteria, authors run the risk of aligning themselves with the medical model.

In contrast, the authors in the sample who write from a social model vantage begin with a diagnosis of their child, but tend to move to a generalist disability perspective. Fitton, McLelland and Naseef, in particular, write little about their child's specific condition; instead, they focus on the broader disability experience, consistent with Snyder and Mitchell's observation that in promoting a social model of disability:

> scholars largely refused to define those bodies and conditions that were disabling, opting in favour of an understanding of disability as: *That in the body which exceeds determinate efforts to predict a life trajectory.* (2001, 377, authors' italics)

By expressing a shared experience of disablement, these authors are offering a more inclusive message that, in Couser's words, is able to 'advance the collective interests of people with disabilities' (2009, 30).

The cultural model poses additional difficulties. Its insistence on a positive framing of experience may inhibit those other stories of grief, trauma, hardship, and social isolation. Those who subscribe to it may find themselves utilising culturally problematic discourses in order to promote messages of affirmation and value, such as those invoked by Landsman in the example above. And it may more readily accommodate a story from a socially privileged source; as Calton argues, the 'modern

ideals of disability in America: de-institutionalization and inclusion' are more easily accomplished by those from the middle and upper classes' (2010, 849).[46]

This brief analysis suggests that the use of models of disability in parental narratives occurs at the intersection of social privilege, gender, and level/type of disability. There is, of course, scope for wider investigation of how these models combine, repel and sometimes form uneasy alliances in narratives such as these.

Conclusion

As a member of this tribe of parent authors, and one who faces the same difficulties and dilemmas, I'm loath to name any of these emplotments as 'hegemonic'. To borrow McGuire's (2010) words, 'Like disabled people, parents of disabled people have often been marginalized in the search for moral clarity ... I do not want to reproduce these (inherently ableist) tactics of moral surveillance'. These authors have struggled to find a way to tell their stories that straddles trauma and dislocation, that engages with but also disengages from the dominant scripts. Their stories are motivated by the shared experience of grief and marginalisation, and all attempt in varying ways to mediate this story with one of acceptance and affirmation of their child. They deal with death, real and imagined, and in so doing call up matters of ethics, that will be addressed in the next chapter. Only a few of them, however, could be referred to as 'counterhegemonic', in the sense that they manage to reframe the experience of parenting a child with disability in a new ways that undermine prevailing interpretations.

Rhetorical patterns are a function of gender as well as genre. The hero narrative that is associated with the rhetoric of the quest, for example, is more available to fathers; it requires a sustained expression of subjectivity that is, as Couser observes, based on an 'autonomous ... individualism more available to men than to women' (2009, 12). The quest can take other forms, however: mothers' narratives in the sample typically take up an emplotment of displacement and identity recalibration, followed by advocacy for social change, with the mother's subjectivity closely bound to that of the child. This reconstructive capacity of stories is addressed by Frank: 'What begins as disruption is thus reconstructed into continuity – perhaps a contingent continuity, but

nevertheless a single narrative trajectory that holds different aspects of a life together as a whole' (2009, 115).

As key elements of the socio-cultural narratives, the contrasting ideologies of the models of disability underlie these narratives. Which models emerge gives insights into how authors might envision their project as 'counterhegemonic', and clues about the author's level of engagement with the wider world of disability rights.

The emplotments of these stories provide me with models and templates, but they also issue warnings. 'Stories,' Frank writes 'have a capacity to work in ways their tellers did not anticipate' (2010, 35). Once told, they are out of the teller's control: 'As often as stories are conscripted to advance some cause, they do that work only for a while and then turn against those who conscripted them' (36). It's a hazardous business, this making of life stories. Frank cites Canadian storyteller Thomas King: 'For once a story is told, it cannot be called back...So you have to be careful with the stories you tell' (King 2003, cited in Frank 2010, 35).

Chapter Nine

ETHICS

Rights and wrongs, vulnerability and subjectivity

Introduction

Ethics, Eakin argues, is the 'deep subject' of autobiographical discourse (2004, 6).
Parent writers face a particular type of ethical challenge: they are telling not only their
own story, but that of their child, about whom they have intimate knowledge and to
whom they have privileged access. 'The closer the relationship between writer and
subject, and the greater the vulnerability or dependency of the subject,' Couser writes,
'the higher the ethical stakes and the more urgent the need for ethical scrutiny'
(2004b, xii). But in spite of this urgency, parents typically assume rather than request
the right to narrate their children's lives. When these children have severe disabilities,
these issues are compounded because, as Couser asserts, disabled children are 'doubly
vulnerable subjects – triply so if their impairment compromises their competence or
diminishes their autonomy' (2004a, 57).

 In this chapter, I discuss some of the ethical issues raised by scholars of parental
narratives of child disability, and explore how these are addressed by the authors of
sample texts. These issues underlie parents' writing projects, they form part of the
difficult and unstable foundations for our stories, but the questions that surround them
are seldom asked; McDonald (2010), for example, observes that 'apart from Couser's
work, there is surprisingly little in the academic literature about the ethics of writing
nonfiction about one's own children'. My exploration delves into the ways parent
authors represent their children, and how (or indeed if) they rationalise their writing
projects in ethical terms. I also investigate how these authors either support or
diminish the personhood of their vulnerable child through their choices at the textual
level.

'Unauthorized biographies': parental memoirs as appropriation

Couser (2004a) refers to parents' narratives about their children's lives as
'unauthorized or *self*-authorized' because the consent of the child has generally
neither been sought nor granted. As illustration, he critiques Michael Dorris's
account of raising his adopted son, Adam, in *The Broken Cord* (1989). Adam, a
Native American child, has cognitive impairments associated with fetal alcohol
syndrome (FAS). Dorris confronts the reality that his son's 'most significant kinship

group' is not the Native American nation of his biological parents, nor the multiracial world of his adoptive parents, but 'the "family" or "tribe" of victims of fetal alcohol syndrome' (Couser 2004a, 59). This discovery, and the realisation that his son's incurable condition was indeed preventable, leads Dorris to take up the mission of fighting against FAS and alcoholism within the Native American community.

In so doing, Couser argues, Dorris's son effectively ceases to be his own child, with whom he is intimately connected, and becomes an anthropological case study, 'a synecdoche for a damaged generation' (61). In distancing his son as 'other', Dorris uses language 'that echoes that used by colonizers to describe recalcitrant "primitive" people'; and that 'threatens to characterize mentally impaired people as a literally inhuman, unredeemable population' (Couser 2004a, 67). As such, Dorris's passionate advocacy regarding FAS and the Native American community has come at too high a price: the respectful and humane portrayal of his son.[47]

Not all scholars share Couser's assessment of Dorris's work. Theological ethicist Hans Reinders, for example, lists Dorris's book as first 'among my own favourites in the Anglo-Saxon literature' (2008, 9, note 4) when addressing 'stories in which people give an account of their firsthand experience of living life with a disability or sharing their lives with a disabled person' (9). Conflicting opinions such as these illustrate how unsteady the ground is on which these conceptions of ethical representation are built, even amongst expert commentators.

Couser observes that most writers of parental narratives are 'generally wholly amateur in their credentials and experience and thus not necessarily conscious of ethical constraints'[48] (Couser 2004a, 54). As a consequence, parents may indeed misinterpret the vulnerability of their child as licence to represent them, and the fact that most parent memoirs of child disability are about a child with intellectual disability – those most vulnerable subjects – supports this view. Calton (2010), for example, found that almost all parental narratives of disability in her study were about raising a child with cognitive impairment; in fact, she comments on the absence of writing about children with sensory and physical disabilities. Unlike children with severe intellectual disabilities, children with sensory and physical disabilities are more likely to be aware that their stories have been told; they are more likely to understand privacy issues; and they may be able to provide consent independently. They also have the capacity to tell

their own stories, if and when they choose to do so. Parents may consequently feel less anxious about bringing their stories about children with severe disabilities into the public sphere. This quote from a review of Lisa Nops's memoir of raising her autistic daughter, *My Life in a Pea Soup* (2012)*,* illustrates: 'But as Lisa said, "if [daughter Sally] was normal I wouldn't have been so truthful" and from that truth telling Lisa's gift to us as readers is the gift of empathy' (Jaffe 2012).

This contradiction between the ethical appreciation of vulnerability and its (often unwitting) exploitation is explored by Robertson (2011), in her discussion of the ethics of motherhood memoirs. Robertson describes the public outcry that followed the publication of Julie Myerson's memoir, *The Lost Child* (2009), in which Myerson relates her anguish over the drug habit of Jake, her teenage son. Myerson was accused by the press of selfishness and exploitation, and was referred to disparagingly as 'writer first, mother second' (2011, 3). Robertson compares this to the positive reviews of Charlotte Moore's memoir, *George and Sam* (2004), about her two autistic sons, which includes anecdotes about 'naked teenagers smearing poo on the walls' (2011, 5). Moore was praised for her honesty; her ethics were never questioned; and the effect on her sons went unmentioned, even though her sons are more vulnerable as subjects than Jake Myerson. Unlike Jake, however, her sons would never be able to voice outrage over their mother's representation of them. Roberston observes that a double standard exists in the public perception of ethical risk to children: it is more acceptable for parents to write about children who are severely disabled – in spite of their vulnerability.

Robertson suggests that the real reasons for the fierce response to Myerson's book go beyond ethics alone, and intersect with gender, politics and culture. 'Myerson,' she writes, 'has transgressed not just ethical boundaries but also the boundaries of our social construction of motherhood' (2011, 4), and it is in fact the 'seriousness' with which she addresses loss and motherhood that is the reason behind the negative responses. On the other hand, 'Moore falls into the exceptional mother category. Her uncomplaining, unemotional and matter of fact tone elicits admiration' (6). 'Is it acceptable for a *mother* to publish a memoir about her child?' Robertson asks (4). If so, she should do so with stoic detachment, as Moore does; or she should use the light-hearted tone, replete with irony and self-deprecation, favoured by the many 'mommy bloggers' who populate cyberspace (7). In Robertson's discussion, the

spectre of the good versus bad mother (discussed in Chapters One and Two) re-emerges.

Vulnerable subjects in the sample texts

Most of the child subjects of sample texts are very young (in eight books, they are under thirteen years old). Five (Jenny, Kathy, Walker, Owen and Jake) have profound disabilities with high medical needs; three (Tariq, Alex and McClelland's wild child) have severe autism; and two (Jamie and Caoimhe) have Down syndrome. These children are highly vulnerable, in fact 'triply ... vulnerable' (Couser 2004a, 57). Ben, Robertson's son who has high functioning autism, is the only child who might understand that he is being written about, and Robertson describes obtaining his consent: '[Ben] has allowed me to write about our relationship' (214), and to use his stories (140); nevertheless, he is a minor, a child of 10 years. Three of these subjects have died – Owen (at age 12), Jenny (21) and Kathy (27); it may be that the death of the child has mitigated the moral dilemma for these parent writers.

The issue of maintaining the privacy of their children is raised by two authors. Roberston explains that to protect her son, she changes his name. McClelland also chooses this strategy: her children are given the nicknames of 'firstborn', 'wild child' and 'lucky last'. Others appear to be more concerned about the responses of those outside the family circle; Macris, for example, preserves the names of immediate family members, but changes those of other characters for privacy reasons.

Several authors provide a clear rationalisation of their writing projects in ethical terms. Bérubé states that: 'My job, for now, is to represent my son, to set his place at our collective table' (264). When a TV interviewer asks Edelson what compelled her to go public with Jake's story, she writes: '"What choice did we have?" I respond. For me, and for other parents I have encountered in this movement, the answer is simple: our kids cannot speak for themselves' (146). Johannesen gives the following reason for writing her book: 'the stories illuminate the ethical and emotional challenges of caring for one so deeply vulnerable and dependent' (9). Fitton describes her book as 'an affirmation of the right of people with profound intellectual and multiple disabilities and their carers to lead a full and meaningful life' (ix). Robertson

recognises the dangers of writing about her son, but rationalises her decision in this way: 'I believe that I am the one person standing between him and a cruel, exploitative world' (135).

Whose story is it?

Parental auto/biographies are *relational* works, in which the 'primary subject is not the writer but a proximate other' (Couser 2009, 12). This poses a quandary for authors: whose story are they telling? Several authors in the sample manage this problem by identifying a shared narrative space in their book titles: *My Journey with Jake* (Edelston); '*a Father, a Family, an Exceptional Child*' (Bérubé's sub-title); '*One Family's Journey into Autism*' (Macris's sub-title). Burbidge sub-titles her book '*Jenny's Story – a Mother's Diary*', but it is clearly her own story she tells through her diaries, and this is the story of her daughter's death.

Scholars (Frank 2004, Couser 2004a, Piepmeier 2012 and Rapp and Ginsberg 2001) identify the ethically 'good' story as the one that foregrounds the child, that affirms his or her life and identity. But this may come at the expense of the parent's own narrative, as Robertson articulates:

> The thing that was bugging me was: this was my story and I wanted to write it my way, without censorship. I recognised that all scholarship and creative writing involves negotiating ideas of 'truth'. I also recognised that I would have to compromise in order to protect my son and that protecting my son was very important to me – but still, I wanted to be free to write whatever I felt and thought. (135-6)

Robertson recognises the fraught position that she occupies in terms of the 'morally good' story: how can she write *truthfully* about her own life, and, at the same time, *ethically* about her son? Evans, too, confesses a selfish reason for writing that could well be at cross purposes with the morally good: 'This book is really nothing more than my attempt at rebuilding myself from the pieces [Caoimhe] has cracked apart to expose the truth of who I am' (250-1).

Parents may need to tell their own story, to disclose the darker sides of their experience, but unless they 'compromise', they risk falling into deeper ethical waters.

In light of the Robertson's discussion of reviews of Myerson's and Moore's books (above), criticism is more likely to be foisted on mothers, subjected as they are to the social expectations – and also mythologies – surrounding motherhood. For mothers of children with disabilities, these constraints are compounded by their transgressive status, as discussed in earlier chapters.

Personhood, language and representation

Discussion up to this point has addressed the way the child's life has been framed according to the author's moral stance; how authors negotiate issues of privacy and consent; and how – and if – authors may tell their own story as well as that of their child. But also ethically important is the question of *how* to write about one's child with disability.

Frank discusses how Sam Crane realises a 'morally good' story in *Aiden's Way* not only through the content of his story, but through his use of language: 'his prose is far more lyrical as he describes washing Aiden than when he describes taking on the prime minister of Singapore' (Frank 2004,187). There are many examples of language that affirms the child's identity in sample texts. But language can, of course, serve the opposite purpose, and undermine personal value. Brown describes his son as 'a lost and broken boy', 'a typo', 'unnatural', and 'a genetic misfire', and he opens his book by comparing Walker's vocalisations to the sounds of a broken water heater. Macris explodes in anger that 'Alex is fucked'. Burbidge likens her adult daughter to 'a darling baby' who 'bounces happily and reaches out for a cuddle' and has 'lovely curls'. At one point Evans calls Caiomhe 'my stigma, one I must bear alone'. In these instances, these children are portrayed as problems, as infantilised, or as devalued, through these lexical choices. Eventually, through the arcs of their stories, these authors will come to recognise the intrinsic value of their child: to enact what is, in effect, narrative repair. Evans, for example, writes: 'I teach her the rudiments of intellectual thinking; she teaches me the ways of the spirit, gives me wisdom – and so we complement each other perfectly' (184).

Other textual strategies provide clues about how parents respond to their children. The use of dialogue is highly significant because the ability to mobilise language is a

critical aspect of mainstream conceptions of personhood. The child with severe disability is typically unable to self-represent verbally, and so when a child's speech is represented, its inclusion is marked. Robertson's son, Ben, is the only child with well-developed verbal skills, and accordingly she frequently uses his dialogue to develop his character and affirm his personhood. Several chapters open with Ben's direct speech: 'How do I feel?'; 'Do you remember when I was in kindy?'; 'Mum, I need you,' sings a voice from the bedroom'; 'Mum, my main hobby is writing adventure stories, so I'll be doing that while you drive'. Ben's language enables him to self-narrate; he can contribute to the authoring of his own story; his humanity is underscored. Similarly, in the introduction to Bérubé's book, Jamie's developing language is a signifier of his emerging personhood. Evans, too, uses her daughter's verbal skills to emphasise her selfhood; Caoimhe speaks out to reject her childish petname: '"No Mammy. Not Ki-Ki. Caoimhe." She knows who she is' (253). In stark contrast, when Macris represents Alex's speech in his book, he does so in order to show his son's regression, through the example of Alex's declining verbal skills, and accordingly, his diminishing personhood.

For the child without the capacity for language, other strategies beyond the lexical need to be mobilised for affirming their identity. The author has to interpret the child as a character, to stand in for them, and imagine their subjectivity. By opening and closing his book with letters to his son, Naseef hails his child into the narrative with the second person form of address:

> When the nurse put you in my arms, I felt the electricity of that instant. You felt so soft and delicate to my fingertips. I cradled you next to my heart. Our eyes met and locked on to each other's for the first time. (xvii)

In this letter, Naseef then moves from the second person into first person plural ('our'), and so connects his son within his own authorial voice. He draws his non-verbal son into the conversation of the narrative, and thereby into personhood.

Other textual strategies have more negative consequences. By confining the child to the object position in the clause, for example, the child is denied subjectivity, and identity becomes a function of what is *done to*, and how *others feel about* him or her; as a consequence, the child becomes a passivised subject. In this example, Brown gives an explicit account of his son's toileting procedure:

I spin 180 degrees to the battered changing table, wondering, as I do every time, how this will work when he's twenty and I'm sixty. The trick is to pin his arms to keep him from whacking himself. But how do you change a 45-pound boy's brimming diaper while immobilizing both his hands so he doesn't bang his head or (even worse) reach down to scratch his tiny, plum-like but suddenly liberated backside, thereby smearing excrement everywhere? (4)

In this extract, Walker's body parts occupy the object position in almost every clause. Walker is not only objectified and disempowered, however; given the semantic content of the passage, he emerges as a study in *abjection*, without bodily control and defiled by excrement.

In the following excerpt, Johannesen describes Owen's therapy procedure, and in so doing, she opens up the voyeuristic clinical gaze for the reader's appropriation:

Owen's dystonic movements could be reduced somewhat with direct physical pressure and containment of the limb or body part. Pressure on the shoulder would stop the arm from shaking. Bending him at the hips and cradling him like a baby would relieve the overall, full-body thrusting. Effective, yes. But a whole lot of work. Owen's dystonia and spasticity would continue in his sleep. Movement and tightness would prevent him from falling asleep or would wake him in the night. (105)

Gerunds or nominalisations take the subject position in all clauses, and Owen ('him') appears only in the object position. He is effectively reduced to a series of bodily responses to actions that are *done to* him, and these actions are further distanced through the use of the conditional tense: these are *possible* actions. The action is also described from the narrator's perspective, evidenced in the sentence fragment, 'But a whole lot of work', to which could be added 'for me'.

In contrast, Evans works to assert the subjectivity of Caoimhe in this extract:

As the days passed, we stumbled into a rhythm; we began to fit back together. From her lips, the rest of her movements flowed downwards in a pattern predictable and punctual as chimes on a clock. Her limbs sprouted and stretched; her arms swiped the air, fists opening and closing like two small sea creatures. She kicked her legs and sucked her toes exactly according to the time scales in the baby manuals. She rolled from her front onto her back, then back the other way. At six months she was able to sit, and her world took on new dimensions (152-3).

At the beginning of the passage, Caoimhe is incorporated into the authorial voice, 'we'. In the next three clauses, her body parts are the agents of action, and in the following three, an integrated 'she' takes the subject position, producing the sense of an emerging subjectivity. There is only one nominalisation operating in the subject position, 'the rest of her movements', occurring at the outset of this process of individuation. In the final sentence Evans takes up her daughter's point of view. In this way, the child becomes an actor in the narrative, not just an object of narration.

Of course the child's degree of impairment is an issue: Caoimhe is able to 'do things', whereas Owen is not so capable. But no matter what the child's level of disability, the point is that language can indeed be mobilised at the level of grammar to re-position the subject in a way that affirms the child's personhood.

Conclusion

Questions of ethics confront the parent writer on many levels of textual formulation and development, from the right to tell the story of one's child, through to the language choices made in the writing of it. These questions cut across the lines of genre, gender, emplotments and models. They cover moral, political, social, interpersonal and linguistic grounds. They move from mission through to clause. They require careful weighing of the needs of self and vulnerable other.

Like Robertson, I want to write my own story in my own way. But this is my daughter's story, too, and so there are caveats. I am her proxy, the teller of her story. I am also its custodian: I have to ensure its safe passage. Any version of my story that I choose to narrate will find its place only in the context of hers. This must be my promise to her.

We need to tell the best stories that we can. We need to advocate for our children, and elevate their personhood. Our stories will not always be the sanctioned, 'good' stories; these alternative stories must be allowed to be heard, but not at the expense of our vulnerable others. That is yet another one of the challenges of negotiating a writer's way through this strange country.

Chapter Ten

FROM MAPPING TO WRITING

And why don't you write? Write!
Writing is for you, you are for you;
your body is yours, take it.

(Cixious 1976, 876)

I've travelled with these authors on their book-voyages, each journey different from my own, but similar, related; there's a kinship amongst us that connects us and separates us out. But relations with kin, whether by blood or by experience, are never rational; they are ruled by passions, and so I have found it with these books.

Some of these authors I love, for their ability to remember details and describe; to persevere, sentence by slow sentence; to retread all those steep steps, the ones we all hoped we might someday leave behind. Some I admire, for their ability to muster energy I don't have, for their resources, for their doing and their acting. Some I worry over and cry with, for standing so naked before their readers; for their identities, pressed paper-thin; for their certainties lost, maybe never to be recovered; for their exile in a strange land that might never become home. Some anger me, for their arrogance or their ignorance. And some I dislike, because their tales scrape against my own and wound me.

These authors and their books are like boats riding the seas: they've travelled far; they need to find ways to dock their stories, and have them heard. They fling out their ropes, thick coils of words that clutch at the wind; some find ways to land, while others flounder. The bigger boats, the ships, fuelled up with cleverness and accolades, make their passages easily, while the lonelier sailors falter and lose themselves in turbulent wakes. Out further, corralled by editors with dauntless themes, the smaller craft huddle into anthologies: canoes and dinghies that paddle their fragment-stories and fly their flags of women's words, that cry across their flimsy bows, with the sea shifting always beneath them, crashing them together so they collide like so many broken characters upon a page.

Now I need to pay heed to Cixious's call, to manoeuvre my own vessel into shore, and have my story heard. But first, I need to look back once more over the route I have travelled.

Charting the territories

In these past chapters I have endeavoured to chart the territories in which parents – particularly mothers – of children with disabilities find themselves, carve out their identities, and tell their stories. In Part One, narratives *about* them were described: how these mothers are represented in the media, and how, in the territories of academe, researchers and scholars objectify, categorise, and analyse them. In most of these stories, mothers of children with disabilities are outliers: marginalised, excluded, and sometimes sanctified. There are oases of respite, particularly in feminist philosophy, but these are, as yet, few.

In Part Two, the location of knowledge shifted to the domain of lived experience, with the focus on narratives *by* parents of children with disabilities. In these chapters, I considered books by fathers as well as mothers, to explore *how* the stories of mothers and fathers differed, and *why* books by fathers were more often cited by scholars. The focus was on how mothers and fathers use writing to make sense of their experience and to negotiate the borders between their own experience and mainstream parenthood. As Mitchell and Snyder write:

> To represent disability is to engage oneself in an encounter with that which is believed to be off the map of 'recognizable' human experiences. Making comprehensible that which appears to be inherently unknowable situates narrative in the powerful position of mediator between two separate worlds. (2000, 5-6)

Each of these parent writers set out in a different way to make their world knowable, to reclaim their own identity and that of their child and family, to chronicle their hardships and triumphs, and to advocate for improved services and resources. In so doing, each has had to undo the process of normalising the world of disability they inhabit (what Skinner and Weisner, 2007, have referred to as 'renorming the normal') and re-make it as strange, as Friedman explains:

> To themselves, people made peripheral by the dominant culture are not 'marginal', 'other'. But to counter the narratives of their alterity produced by the dominant society, they must tell other stories that chart their exclusions, affirm their agency (however complicit and circumscribed), and continually (re)construct their identities. (1998, 230)

In order to tell these 'other stories', parent writers have had to navigate through the socio-cultural scripts that interpellate them: the narratives that emerge from the discourses discussed in Part One, but also the 'hegemonic' rhetorical patterns that underlie disability writing, which were described in Chapter Eight. These scripts need to be acknowledged, scholars remind us, because if writers do not engage with them, their stories may not be heard. But they also need to be challenged and resisted. Parent writers have also had to negotiate a way through the models of disability; some have done this actively, from a position of political awareness, while others have made their way with less assurance, sometimes resorting to the time-worn formulas that betray a certain naïveté.

Parent writers have also needed to comply with the generic conventions of disability life writing, in particular that 'subgenre of fully abled parents writing about their seriously disabled children' (Frank 2004). These stories should be 'morally good', we are told; they should affirm the personhood of the child; and they should promote 'broader understanding of citizenship and civic identity' (Piepmeier 2012). And they should steer away from the overstatement of grief and any slippage into sentimentality. In terms of form, two main options are available to parent writers: either they produce a *memoir,* that is, a continuous first person narrative, and a plotline that will recount events across time (Smith and Watson 2001), and in so doing 'shape experience, transform event, deliver wisdom' (Gornick 2001); or they produce a *hybrid* work, one which typically brings together memoir with the genre of self-help, which extends the narrative by providing guidelines for other parents raising children with disabilities, and which, therefore, delivers social worthiness. These, too, are prescriptions which are sites for potential resistance.

In the sample books, mothers and fathers told different kinds of stories. For mothers, their identities emerged as always relational, inextricably linked with their child. Fathers, in contrast, came across as more individuated protagonists; their plotlines commonly followed the journey toward acceptance of, and their eventual joining with, their child. This latter narrative arc supports the 'morally good' story, because within it, the author moves from separateness to unity, and implied in that unity is the child in the image of the father. For mother-authors, the 'morally good' emplotment is more elusive: the need to 'justify their children's right to exist' (Frank 2004) becomes

irrelevant because the child's identity is not in question: as Kittay (1999) writes: 'she is simply Sesha, that unique individual whom we call our daughter'.

Mothers, too, as we have seen, occupy a space that is more transgressive than fathers: they are implicated bodily, medically, socially and culturally in the genesis of their child's disability, and in their child's place in the social world. 'Caoimhe is my stigma, one I must bear alone,' Evans (2004) writes. Whichever theme or emplotment a mother chooses to impart, it will necessarily have emerged from this core source of trauma.

As a mother-author, I have had to find my way through these conventions and scripts, to resist these orders and interpellations. I, too, have had to confront the spectre of speaking to, and against, my own transgression. I've had to question my entitlement to challenge the dominant scripts, and even my authority to write at all.

Finding – or not finding – the autobiographical 'I'

Gilmore summarises the vexed place of women writers in autobiography as follows: 'Many women writers ... experience their desire to write as trespassing' (1994, 63). These issues were addressed in Chapter Seven. For mothers of children with disabilities, this de-authorisation is compounded by the convergence of motherhood and disability, as well as trauma. If the 'stable *I* anchored within a relatively stable genre' (Gilmore 1994, 41) is elusive for women autobiographers in general, then it may be even less available to mothers of children with disabilities.

But mother-authors in the sample have been able to access an autobiographical 'I'. Those who write from a social model emphasis – Edelson, Fitton, Johannesen and McLelland – appear to appropriate it with more assurance, as if their agenda to expose and critique the system strengthens their subjectivity. Those others who invoke the cultural model – Evans and Roberton – convey a more fluid sense of subjectivity, a provisionality that seems to float over their work, even as they take up the singular 'I'. 'I laughed hollowly at the death of the control freak, my former persona,' writes Evans (47), and towards the end of her book, she reveals that having Caoimhe 'has exposed the dark and ugly bits of me' (250). For Roberston, time shifts within the chapters, and with it, her various selves; she uses metaphor rather than linear

chronological sequence to provide links. For example, in her opening piece, 'Pomegranates and life stories', pomegranates are associated with her son's pleasure in eating the fruit and making a mess, the red of blood, the symbolism of fertility, and her connections with her younger self. Gilmore describes the potential offered by this self-in-crisis:

> Autobiography provides a stage where women writers, born again in the act of writing, may experiment with reconstructing the various discourses – of representation, or ideology – in which their subjectivity has been formed...The subject is already multiple, heterogeneous, even conflicted. (1994, 85)

For myself as mother-author, these issues around subjectivity have been preoccupying and troubling. It struck me at the outset that the shifting ground of my selfhood across the years could never be pinned down to yield a coherent 'I', moving as it has through the disruptions of trauma to new-found certainty, then back again and forward, an iterative process with no end point. My path was, as Gilmore suggests, 'strewn with obstacles' (2001, 14); her observation that: 'To navigate some writers move away from recognizably autobiographical forms even as they engage autobiography's central questions' (2001, 6) provided me with a point of departure. I needed to go further afield than the mother-authors in my sample. I needed to find another way to make testimony and tell my story, and this search led me into questions about the nature of narrative itself.

Narrative disruption: resistance or necessity?

Not only autobiography, but narrative in general presents problems for women writers, according to feminist poststructuralists (in particular Kristeva 1974, Irigaray 1975, Cixious 1975). These scholars argue that narrative, in the same way as autobiography, privileges the speaking subject and the act of representation; it is a modality of patriarchy, linked to the symbolic order of the masculine (Friedman 1998, 228-9). I am reminded of Kristeva's work on abjection, discussed in Chapter Three, in which the dichotomy of the symbolic order and the feminine semiotic was explored. These poststructuralists assert that, in contrast to narrative, poetry and the lyric are 'tied to the repressed feminine, maternal and pre-oedipal' (Friedman 1998, 229). The

lyric can disrupt narrative; according to Kristeva, 'poetic language unleashes the semiotic's transgression of the symbolic order' (Friedman 1998, 232). Cixious writes that only poetry can enact this transgression, for 'poetry involves gaining strength through the unconscious and because the unconscious, that other limitless country, is the place where the repressed manage to survive: women' (1975, cited in Friedman 1998, 232). It is this mobilisation of the lyric mode that underlies Cixious's concept of *écriture feminine,* or 'feminine' and 'revolutionary' embodied writing (Atkinson 2014).

Feminist theorists such as Friedman argue, however, that 'identity is literally unthinkable without narrative,' (1998, 8). In addressing this dilemma between the need for story and the limitations of narrative for expressing the feminine, she argues that the poststructuralists do not advocate a refusal of narrative, but rather a disruption of it: 'Narrative may be necessary, inevitable, but its mode of discourse is to be resisted' (1998, 229). How this resistance may be enacted, then, is through the subversion of narrative, and its infiltration with the semiotic modes of poetry, metaphor, and the lyric. These disruptions can reflect and express the liminal position/s of the writing subject.

While this capacity for disruption has been posited as *resistance* to the hegemony of narrative, it was becoming clear to me that it was more than this: it was a *necessity*. How could my story of transgressive motherhood be told otherwise?

From constraint to opportunity

In her work on trauma and autobiography, Gilmore discusses how some authors seek strategies beyond the documentary: 'In swerving from the centre of autobiography to its outer limits, they convert constraint into opportunity' (2001, 14).

My task now was to identify and mobilise these opportunities for disruption. To do this, I've had to stray from the genre of parental narratives, into other sites of women's autobiography where these practices have been legitimated, where classic works such as Maxine Hong Kingston's *The woman warrior* (1975)*,* with its interplay of voices, time, truth and dream, and Sandra Cisnero's *The house on Mango Street*

(1984/2009), with its spare story fragments that sit on the edges of truth and fiction, stretch the boundaries of genre.

I've had to garner the support of theorists who articulate these possibilities, and the strategies that enable them. Smith and Watson (2001) discuss the complexity of the 'narrating "I"', 'split, fragmented, provisional, multiple, a subject always in the process of coming together and of dispersing', and the various potentials of voice, realisable in the second and third person as well as the traditional first person (60). These authors also describe how the representation of time can be used to interrupt the narrative, to challenge the linear sequence of events, and interrogate the subjectivity of the author: 'The conscious diffraction of times of telling and the fragmentation of chronological sequence are narrative means of emphasising that a subject is not unified or coherent' (72-74). These disruptions impact on the process of reading, as well as telling: readers, too, are dislocated: they need to renegotiate a position in regard to the author and the text, and hence become implicated in its message. Intrusion of other extra-generic elements, Smith and Watson suggest, such as fable, meditation, lyric sequence, or sketch, can also challenge and disrupt the flow.

Friedman draws upon Nobel Prize laureate Toni Morrison's assertion that 'narrative is not, and never has been, enough' (1984): it requires *other ways of knowing* – 'the metaphoric, the visual, the musical, the kinesthetic' (1998, 234). Gilmore (2001), in describing the use of fictional or quasi-fictional techniques in trauma narratives, suggests that: 'the writer's turn from the primarily documentary to the fictional marks an effort to shift the ground of judgement toward a perspective *she has struggled to achieve'* (23, my italics). These same techniques, it occurred to me, could also be invoked to mediate in the narration of grief, alienation, and guilt. These possibilities resonated with me; they excited me, and convinced me that my story was indeed narratable.

I've also learnt from the parent writers in my sample of books: Naseef uses second person address as a powerful strategy for hailing his son into the narrative; Robertson shows how narrative and essay forms can be combined in a single theme-based chapter, held together with the glue of metaphor; Bérubé models pushing the boundaries of genre, discourse and narrative with his intellectual *tour-de-force*. I've

learnt, too, from the contributors to one of the anthologies, that my life and my daughter's life are worthy subjects of literary writing.

The making of story

I have written a memoir about my life with my daughter, Amelia, that covers the period from her birth in 1990, up to early 2014, when she was 23 years old. Because we are part of a family, this work also incorporates much about her father and her two sisters, and mention is made of several important extended family members. Also included are friends, educators and service providers who have played a role in Amelia's and my life.

This memoir proceeds chronologically, but it is not a continuous narrative: each chapter is basically a stand-alone piece that addresses a particular theme, event or period. Chapters range in length from seven hundred to five and a half thousand words, and take a variety of forms: lyric pieces, recounts, stories, dreams, and essays. The metaphor of the mosaic underlies the work, with these various elements coming together to make a picture, or a story. While there are aspects of 'narrative transgression' here, the making of story has also been a chief concern: I wanted to shape the events of our lives, and somehow draw meaning from them; to use quasi-fictional techniques, but without ever compromising the truth.

The mosaic metaphor carries through into the narrative voice, which brings together first, second and third person points of view. In the majority of these chapters, I use first person, but this is liable to shift. On several occasions I take up the second person, particularly for the purpose of addressing Amelia directly, but also to address either the reader or a third party. In addition, I use the third person in several pieces to mobilise an alternative persona; I've done this as a necessity, not just for the purposes of storytelling, but as a way of finding affective distance, of 'off-loading' some of the intense emotional content. This persona is called 'Eliza' (my middle name is Elizabeth); family members also go by alternative names in these chapters.

Through these strategies, I address issues around genre and gender in terms of autobiographical writing. A key aim of this work, however, has been to take up the issues raised throughout this exegesis, to interrogate the socio-cultural discourses that

inform my experience. These issues include maternal trauma and family marginalisation; the representation of mothers of children with disabilities in public discourse; the 'transformational coping' social science literature; the place of people with intellectual disabilities in medical and philosophical discourse; motherhood and the concept of relational personhood; the vexed position of parents in disability rights discourse; discrimination; access to resources and services; issues of gender and caring; models of disability, in terms of their impacts on our lives as well as my use of one or other as framing devices for particular chapters; concerns around the ethical representation of my vulnerable daughter; and indeed, my efforts to produce what might be regarded as a 'counterhegemonic' work.

At 60,000 words, this memoir is too long to be included in its totality in this thesis. The creative work that follows consists of a selection of pieces which constitute two-thirds of the complete work. I have aimed to be as representative as possible in this selection, but readers may experience some discontinuities in the narrative as a result of this abridgement.

This writing has not been easy, but it has been necessary, and perhaps it may deliver some measure of value. For me, this exploration is concluding, but the journey continues.

Notes

Chapter One

[1] These extracts come from an informal survey of news items published on the internet.

[2] 5 October 2011. http://www.dailyherald.com/article/20110508/news/705089945/

[3] http://www.guardian.co.uk/society/2013/jan/15/jane-raca-life-support-disabled-son

[4] http://nz.lifestyle.yahoo.com/marie-claire/news-and-views/latest/a/6741343/the-battle-for-care-thats-pulling-families-apart/

[5] http://www.news.com.au/beverley-may-eitzen-acquitted-of-killing-disabled-son-peter/story-e6frfkvr-1226076286084

Chapter Two

[6] A version of this chapter was published as: Kathryn Knight. 2013. The changing face of the 'good mother': trends in research into families with a child with intellectual disability, and some concerns, *Disability & Society*, vol 28, no 5, 660-73.

Chapter Three

[7] The Parliament of Australia ran a Senate Inquiry into Involuntary or Coerced Sterilisation of People with Disabilities in Australia that commenced in late 2012, with the first report handed down on 17 July 2013, see http://www.aph.gov.au/Parliamentary_Business/Committees/Senate_Committees?url=clac_ctte/involuntary_sterilisation/index.htm.

[8] For example, rebates for the cost of care for pre-school aged children are available to parents, but no such rebate is available for the costs of care for adult children with disabilities and high support needs. The opportunities for these parents (generally mothers) to participate fully in the workforce is severely compromised as a result of the high costs of care.

[9] See, for example: Kuriaco, 2011, at http://everyaustraliancounts.com.au/i-need-a-man-and-have-decided-to-ask-women-how-do-you-do-it/

Chapter Four

[10] Examples are: *I Hear More Than You See* by Jan Daisley (2005, Dural NSW: Landers Publishing), and *Captives of Care* by John Roarty (1981, Sydney: Hodder & Stoughton). Both authors lived for many years at Weemala, the 'Home for Incurables' at Ryde, NSW.

[11] http://everyaustraliancounts.com.au/abousubmission_to_the_productivity commission/ downloaded 10 February 2012.

[12] Ryan, C. 2013. Tony Abbott tries in on with NDIS 'trial' instead of 'launch'. *Sydney Morning Herald.* 20 Dec 2013. http://www.smh.com.au/federal-politics/political-opinion/tony-abbott-tries-it-on-with-ndis-trial-instead-of-launch-20131219-2zo03.html

[13] Disabled World - Glossary list of definitions and explanations of the Models of Disability in society today: http://www.disabled-world.com/definitions/disability-models.php#ixzz1lkMh8bPl downloaded 8 Feb, 2012

[14] Disabled World - Glossary list of definitions and explanations of the Models of Disability in society today: http://www.disabled-world.com/definitions/disability-models.php#ixzz1lkN1sgur

[15] An example from my own experience: In a past role with a peak disability organisation, I was meeting with a professor of disability studies to plan a seminar to be led by a visiting scholar. This professor had just come from a 'Carers Week' event, and apparently left brochures about this event at the front desk. A colleague was irate about this: 'We are an organisation for people with disabilities,' he said to me. 'We don't support carers.'

[16] ABC news. 'Newcastle's Stockton Centre to close in 2018'. Jan 31, 2011 11:16am. http://www.abc.net.au/news/2011-01-31/newcastles-stockton-centre-to-close-in-2018/1923464; ABC news. 'Stockton Centre to remain open'. Feb 10, 2011 7:26am. http://www.abc.net.au/news/2011-02-10/stockton-centre-to-remain-open/1936748

[17] Natasha Wallace, 'Turfed from the only home they know', Sydney Morning Herald. 13 August 2007 http://www.smh.com.au/news/national/turfed-from-the-only-home-they-know/2007/08/12/ 1186857348366.html

[18] PWD E-Bulletin, Issue 50, February 2009. http://www.pwd.org.au/documents/pubs/EB50.html

[19] http://www.carersaustralia.com.au/about-us/history/

[20] A person who cares for a person over 16 years old is eligible to receive a non-taxable Carer Allowance (currently $115.40 per fortnight), and an annual Carer Supplement of $600. The same rate is available to carers of children under 16, with an additional Child Disability Assistance Payment of $1,000 pa. A Carer Payment is also available for full-time carers of adults with disability, but this is strictly means tested.

[21] http://disabilitycareralliance.org.au/

[22] Compare this acknowledgement of the health impacts of caring within the literature on the sociology of care with the research into mothers of children with disabilities described in Chapter Two, where these impacts are downplayed or even disputed.

[23] http://www.carers.org.au/carers/

Chapter Five

[24] http://www.amazon.com/Child-Who-Never-Grew/dp/0933149492

[25] http://raisingadisabledchild.blogspot.com/

[26] http://www.jkp.com/catalogue/autism

[27] http://www.downsyndromensw.org.au

[28] The three libraries were: the Blue Mountains City Library, NSW; Macquarie University Library, and the Nepean Area Disability Organisation (NADO) Library.

[29] Kingsley likens the experience of finding out your child has a disability to altered travel plans. You have booked for a trip to Italy, but suddenly you find yourself in Holland, a place you had not planned to visit. Holland may not be the Italy you dreamed of, but it does have its own positive features that you need to discover and acknowledge.

Many memoirs by mothers cite this fable, and it is referred to at least once in many anthologies published since it first appeared in 1987. Personally, I find the analogy inappropriate, and annoyingly dismissive of the challenges we face as mothers of children with disabilities. Our parenting experience has not been rerouted, it has been challenged at a profound level.

[30] Gore Vidal, for example, expresses the distinction in this way: "A memoir is how one remembers one's own life, while an autobiography is history, requiring research, dates, facts double-checked." (1995). *Palimpsest: a memoir*, Random House, p 5; Smith and Watson (2001) describe memoir as 'life writing that takes a segment of a life, not its entirety, and [focuses] on interconnected experiences' (274).

[31] Smith and Watson (2001, 70) give the following examples as typologies of life writing: the Bildungsroman (or Kunstlerroman), confession, memoir, conversion narrative, testimonio, quest for lost identity or homeland.

Chapter Six

[32] www.woodbinehouse.com/submission_guide.asp

[33] Examples of titles published by Woodbine House are: *Feeding your child with autism; The boys'/ girls' guide to growing up; When Down Syndrome and Autism intersect; Body talk;* examples published by specialist UK publisher Jessica Kingsley are: *The Asperkid's launch pad; When the school says No...how to get the Yes!;* and *Letters to the home front: Positive thoughts and ideas for parents bringing up children with developmental disabilities, particularly those with an Autism Spectrum Disorder.*

[34] Such as Pam Stephen. 2007. *Any day with hair is a good hair day: how to get through cancer and get on with your life (trust me, I've been there)* New York: Hachette

[35] In fact, the proportion would be much higher in a wider sample, because I have deliberately avoided the 'how to' style in favour of those that comply with the definition of 'memoir'.

[36] Examples are Donald J. Meyer (ed.). 1995. *Uncommon fathers: Reflections on raising a child with disability.* Bethesda, MD: Woodbine House; and Jill Harrison, Matthew Henderson and Rob Leonard (eds.) 2007. *Different dads: Fathers' stories of parenting disabled children.* London: Jessica Kingsley.

[37] An example from my experience: When Cindy Dowling and Bernadette Thomas were seeking contributions for *Lessons From My Child,* I proposed a story about my family's recent trip to Bali, which was challenging (and also triumphal) due to my daughter's disability. The editors were not interested, and asked me instead to write about my daughter's diagnosis when she was a baby. I wasn't ready to tread that ground again at that time, and so I was unable to contribute.

Chapter Seven

[38] http://lowtotheground.ca/

[39] Personal communication

[40] Walkley Awards are Australia's national awards for excellence in journalism.

[41] I do not hyphenate the phrase, 'father authors', because I wish to draw attention to the way in which the authorial identity of fathers is not bound up to the same extent in their relational parental role as it is for mother-authors.

[42] McClelland describes her ex-husband's response to their newborn first baby, born with a bone disorder that affected his legs and feet: 'Dad did not do so well. He ordered the midwife to bring a specialist to "fix it" before we left the birthing room' (2011, 21).

[43] It is important to clarify here that fathers do, of course, contribute equally to the child's genetic inheritance, and the role of paternal sperm mutations in genetically grounded disabilities is being increasingly acknowledged by science. But messages from the discourses of public health and popular culture continue to focus almost exclusively on the responsibility of mothers.

Chapter Eight

[44] My discussion of the privileging of a particular model in these narratives has some parallels with Couser's description of rhetorical patterns: 'These different rhetorics are often combined within single memoirs, but in most cases one pattern dominates' (2009, 33: note 1).

[45] Other authors focus on the child's specific disability. For Macris and Brown, this is consistent with their medical model orientations. Evans, whose work also reflects a cultural model perspective, focuses on her daughter's Down syndrome.

[46] Frank's discussion of Sam Crane's book, *Aiden's Way* (2002), provides a salient example: this book, Frank argues, demonstrates 'moral excellence'. But Crane's social advantages are clear: 'his prose is far more lyrical as he describes washing Aiden than when he describes taking on the prime minister of Singapore', Frank writes (2004, 187).

Chapter Nine

[47] Michael Dorris's own life has come under considerable scrutiny since his death by suicide in 1997. Allegations of physical and sexual abuse have been made against him by two of his three adoptive children and two of his three biological daughters. The disjuncture between his public persona and the reality of his personal life, in particular depression, alcoholism and mistreatment of his children, has drawn critical commentary. See, for example, Colvert, C. 1997. The anguished life of Michael Dorris. *Star Tribune*. 2 August, 1997. http://www.startribune.com/lifestyle/11473191.html

[48] This contrasts with Couser's assertion elsewhere that disability life writers typically have a background in professional writing (see Chapter Seven). In the sample, six of the eleven solo authors are in fact professional writers, and so *should* have an appreciation of ethical issues in writing.

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Websites

Carers Australia: http://www.carersaustralia.com.au/

Carers Alliance: http://www.carers.org.au/carers/

Disabled World: http://www.disabled-world.com/

Every Australian Counts: http://everyaustraliancounts.com.au/

Human Rights and Equal Opportunity Commission: http://www.hreoc.gov.au/

National Disability and Carers Alliance: http://disabilitycareralliance.org.au/

APPENDIX

Outcome of application for ethics approval

Outcome of application for ethics approval

From: **Ethics Secretariat** <ethics.secretariat@mq.edu.au>
Date: Fri, Sep 9, 2011 at 2:18 PM
Subject: Ethics application ref: 5201100682 - Ethics approval not required
To: Nicole Matthews <nicole.matthews@mq.edu.au>
Cc: kathryn.knight7@gmail.com

Dear Dr Matthews

Re: Exile on Main Street: mothering on the margins – the experience of raising a child with a disability

The Human Research Ethics Committee (HREC) considered the above application at its meeting on 26 August 2011. The HREC would like to thank you and Ms Knight for submitting a thorough and well-prepared application.

The HREC noted that the aim of the project was to produce a work of creative non-fiction (autobiographical memoir) based on the personal reflections of the co-investigator's experiences and also an exegesis that will inform and respond to the creative work. Item 2.2 and 3.2 of the application made it clear that no data collection activities will be undertaken in writing the creative work. The role of family members, extended family members and non-family members is to corroborate Ms Knight's recollections rather than to provide data as participants.

The HREC indicated that the activities described in the application could not be considered as human research under the remit of the HREC, as described in the National Statement on Ethical Conduct in Human Research (2007) and therefore did not require approval from the HREC.

Please retain a copy of this email as this is the official notification of the HREC's decision regarding the application.

Please do not hesitate to contact the Ethics Secretariat if you have any questions.

Yours Sincerely

Dr Karolyn White
Director of Research Ethics
Chair, Human Research Ethics Committee

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