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Worlds of Care: Fathering Children with Disabilities

Aaron J. Jackson

0000-0001-9725-5373

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ABSTRACT

Worlds of Care: Fathering Children with Disabilities

Aaron J. Jackson.

This thesis, based on fieldwork in North America, explores worlds of disability, both personal and shared, as they are felt and come into being for fathers caring for children with disabilities. I argue that while disability gains meaning from social and cultural context, for parents it is lived as a bodily experience of disruption. The demands of caregiving, then, shake parents from their everyday, habitual worlds, and launch them upon a new subjective trajectory whereupon they struggle to remake a self in the context of care and disability that is biographically coherent. In this thesis, I engage existential themes of creativity, choice, facticity, tension, communication, and morality, and attend to the interwoven temporal and relational dimensions of existence, asking how it is that parents re-orient their lives after having a child that is neither expected nor typical and negotiate their day-to-day existence with and through others? This thesis adopts an auto-phenomenographic methodology to present a second-person phenomenology of disability. As such, I explore my own experiences of disability in the context of caregiving alongside those of my participants in contributing to our understanding of embodied care. This thesis builds an argument for understanding our shared embodied existence and the corporeal and existential grounds that constitute possibilities for giving care and impressing upon the world in new ways. This thesis presents disorientation and caregiving as experiences that have the potential to heighten parents' sensitivity to others and motivate a changed sense of relatedness to the world.

Keywords: Existential Anthropology, Care, Disability, Fathers, Caregiving, Embodiment, Phenomenology, Relationality, Existence, Temporality, Parents, Affect.

Declaration

- i. The thesis comprises only my original work towards the degree of Doctor of Philosophy.
- ii. Due acknowledgement has been made in the text to all other material used, and
- iii. The thesis is fewer than the maximum word limit in length, exclusive of tables, maps, bibliographies and appendices.

Aaron J. Jackson 14 November 2018

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Table of Contents

Abstract	3
Declaration.....	4
Acknowledgements.....	5
Introduction	10
Thesis outline	12
Chapter One.....	17
Aims of this Autophenomenography and Literature Review	17
Anthropology of Disability and Care: A Review	19
Caregiving and Disability.....	25
Caregiving and Masculinity	30
Communities of Care	33
Chapter Two	36
Theoretical Situation and Methodological Attitude.....	36
Theoretical perspective	36
Methods.....	47
Beginnings	47
Fieldwork.....	54
Writing Worlds	60
A word on definitions.....	67
Disability	67
Fathers, parents, and caregivers	68
Conclusion	69
Interlude: BBQ.....	70
Chapter Three.....	75

The Depths of Time: Past Becomings and Habitable Worlds	75
Wayne's arrival story	81
Ray's arrival story.....	82
Ethan's arrival story	83
Existential disruption.....	85
The presence of the past	89
Historicity	93
Temporal shiftings.....	97
Past hauntings	101
Narrative horizons.....	105
Conclusion	108
Chapter Four.....	110
Between Bodies: The Fleshy Work of Caregiving and Attunement.....	110
Routines of care.....	113
The body as a vehicle for care.....	118
Between bodies	127
To interiors.....	133
Attunement and interbodily resonance.....	137
Intercorporeal intimacy	144
Moral identities and imaginative horizons.....	146
Conclusion	149
Interlude: Greg's arrival story	150
Chapter Five.....	152

Conditions of Possibility: Patriarchy, Masculinity, and Moral	
(Re)Orientations.....	152
Patriarchy and modes of attunement	154
A discordant melody.....	161
An ethic of domination	165
A discordant melody (cont'd).....	177
Tokens of privilege	182
A discordant melody (cont'd).....	185
Existential and moral orientations	188
Moral breakdown and awakenings	193
Conclusion	202
Chapter Six.....	204
Part one: Asylum.....	204
Anomalous bodies	205
De-institutionalisation and community-based care	210
Dark Tourism	215
Interlude: Connectivities	218
Part Two: The between: Metastable situations & horizons of unsettlement.	220
Fears of incest	226
Enforcing normality	231
Incarnating the other	244
Conclusion	253
Interlude: An unpolished radio guest	255
Chapter Seven	257

The Axiom of Equality: Moral Lives and Communities of Care.....	257
Bigsby Street	261
Epistemic communities, parental ambivalence, and the existential demands of ethical life	269
An uncertain inheritance	282
Communities of care and corporeal diversity	289
Concluding Thoughts	296
Epilogue.....	302
References.....	305
Appendix A	340
Anthropology of Disability Review	340

Introduction

In 2011, when my son Takoda was four months old, he started having tonic-clonic (grand mal) seizures. Soon after, he was diagnosed with global developmental delay. And then, later again, declared profoundly intellectually and physically disabled. Flummoxed and disoriented, I found myself adrift in seas of strangeness: I no longer felt that I clearly understood my life. The shell of comfort my privilege as a white male afforded me moving within and between people and settings was cracked open. My son's body became a curious public spectacle and I felt this as palpably as though it were my own. Hearing the word 'retard' muttered by a stranger in public made my bones quake with a feeling I had never felt before. My son's disabilities revealed a hidden world that had been secretly nestled inside the one I had so blithely inhabited. I wondered how many of these realities are nestled inside one another, like nesting dolls, revealed or obscured in accord with how we exist in the world. I wanted to know how I was supposed to reconcile my life with this new one and the precarious and restricted future it hinted at?

This experience of disruption compelled me to carry out research into the daily lives of men caring for disabled children living in the United States. To better understand this phenomenon, I initially started out to explore the educative practices fathers engage in as members of a local support group—Which seemed the best way of accessing fathers. Ultimately, though, this thesis is not about how fathers share and exchange knowledge in relation to their lives as carers, for as fieldwork progressed these shared practices proved elusive. Instead, I found myself spending time with individual fathers across North America and learning about the new subjective trajectories the demands of caregiving had set them on. By participating in their lives and absorbing their actions and words, I was able to learn about parents' second-person

phenomenological experiences of disability, and from this research, I present three main arguments:

First, the demands of caregiving shake parents from their everyday, habitual worlds and launch them upon a new subjective trajectory whereupon they struggle to remake a self in the context of care and disability that is biographically coherent. In this thesis, I engage existential themes of creativity, choice, facticity, tension, communication, and morality, and consider the interwoven temporal and relational dimensions of existence, asking how it is that parents re-orient their lives after having a child that is neither expected or typical and negotiate their day-to-day existence with and through others? From this research it emerges that parents attempt to remake their lives and give them coherence on the background of an already intelligible world that is interwoven with others and influenced by larger historical meaning-structures. Their attempts at reorienting their lives, then, are coextensive with the lives they have lived and the biographical significances they bring to bear in creating meaning and coping with their new situations as carers.

Second, the body plays a fundamental role in what parents know about care and how they come to know it. Throughout this thesis I will build an argument for understanding our shared embodied existence and the corporeal and existential grounds that constitute our possibilities for giving care and impressing upon the world in new ways. Importantly, by focusing on care, embodiment, and our relational connectedness, I throw light on the ways children actively and uniquely inhabit their worlds and affect those around them. By being more attentive to these dimensions of existence and moral life we open the possibility to recognise disabled children as moral selves—beyond dominant understandings of personhood and sociality— with capacities to act on others in ethically significant ways.

Finally, through existential disorientation and the demanding practice of caregiving parents become more aware of the contradictions and dualities in

their lives. As such, I present disorientation and caregiving as important experiences that have the potential to contribute to parents' moral agency by making them more aware of oppressive norms and relations of power that marginalise the existence of their children. I argue that these experiences have the potential to heighten parents' sensitivity to vulnerability and refigure their sense of moral relatedness to the world. Through iterative concrete acts of care, then, and a desire for others to respect their children, the fathers in this study are shown to develop a heightened awareness of their own relationship to systems of oppression and privilege and a politicised concern for disabled individuals as a social group. As I will go on to show, these experiences not only motivate changes in the ways parents morally comport themselves in the presence of others, but can permeate their self-understanding and life projects. Harkening back to my first point, parents are not equal to the demands of care, because they find themselves already in the world, and therefore must create their lives in relation to others and the possibilities their worlds afford them. Therefore, parents' feelings, choices, thoughts, and actions across time must be understood in relation to their changing mediums of experience and the existential conditions they are rooted in.

Thesis outline

Each chapter reflects a focus on the different mediums of experience involved in the variety of ways parents experience disruption and create habitable worlds after the disorientation of having a disabled child. Each chapter, then, explores the ways parents continue along across time, acquire knowledge, and adapt to their changing circumstances as caregivers. The arch of my argument follows my own movement through these mediums of experience and layers of understanding which are interwoven with the lives of my participants.

Chapter One begins by describing my research aims and the reasoning behind my research approach. I go on to provide a critical evaluation of the scholarship in relation to my research and justify the relevance of my study. In this chapter, I also introduce the reader to my theoretical approach and outline concepts that I use to make sense of the data.

Chapter Two presents the methodological framework for the study, detailing my fieldwork activities, conceptual tools, and reflections on the research process. Additionally, I reflect upon my methodological choices and the impact these choices have had on my research.

Chapter Three, 'The Depths of Time', presents a series of introductions and background stories that describe the existential disruption parents experience upon arriving in to their worlds of disability. I attend to the body's historical density to illustrate the experiential character of this phenomenon, alongside key moments (diagnosis, etc.) and parents' differing responses to them. This chapter goes on to address the role memory plays in mediating the ways father experience their worlds of disability and reveals this type of experience as a crucial resource that enables and influences the ways carers are able to recreate their lives in the face of unexpected and changing circumstances.

Chapter Four, 'Between Bodies: The Fleshy Work of Caregiving and Interbodily Resonance', examines the intercorporeal dimensions of caregiving and how parents gain access to the inner lives of their children in the absence of verbal communication. This chapter begins by discussing key concepts of Merleau-Ponty's existential phenomenology, alongside his intercorporeal epistemology, which I then use in exploring the potential the body's plasticity, relationality, and affective capacity has for enhancing our connectivity to others, altering habits of consciousness, and refiguring parents' moral identities as caregivers.

Next, in Chapters Five and Six I pan out to consider larger historical and cultural meaning-giving structures while keeping my focus tightly on fathers' experiences. In Chapter Five, 'Conditions of Possibility: Patriarchy, Masculinity, and Moral (Re)Orientations', I turn my attention to a phenomenology of gendered embodiment and consider how fathers are morally oriented as caregivers in relation to their histories of gendered experience and norms of patriarchal masculinity. As we will see in this chapter, these personal histories attune fathers to what morally matters in their experiences of caregiving. I explore experiences of moral breakdown and their moral potential in unveiling tacitly held assumptions and intentions. As I explore the ways fathers become attuned to unjust aspects of their social and moral landscape through their activities as carers, it emerges they take personal and politicised steps towards creating and fostering more equitable relations with others and habitable worlds for their children.

Chapter Six is broken into two parts: 'Asylum' and 'The Between: Metastable Situations and Horizons of Unsettlement'. In the first section I consider the historical exclusion of disabled bodies from able-bodied spaces and culturally inherited ways of apprehending Otherness. This section sets up the following one by discussing the dehumanising practices that maintain able-bodied spaces and block our potential for relating to others. Specifically, I am interested in the way these historical and cultural horizons of disability both situate parents' 21st century experiences of caregiving and disability in Western societies, and circumscribe their possibilities for acting and interpreting themselves as carers.

In the following section, I focus on what I call *metastable situations*: moments when parents encounter ableist norms and practices that degrade their children. These unsettling moral experiences are inaugurated in social and institutional spaces and threaten parents' meaning-rich perceptions of their

children. I identify three orders of moral unsettlement: those that arise through navigating bureaucratic institutions, those that occur through the mortifying treatment of one's child, and those that emerge from witnessing others incarnate one's child. I examine the role these moments of unsettlement and their accumulation over time play in motivating parents to socially and politically contest the various ideas, practices, institutions, and social relations that marginalise and misrecognise their children. I argue that these attenuated understanding of disability that parents encounter come into play against a background of cultural and societal erasure that influence our imaginative associations and empathic responsiveness to one another. I suggest spaces of proximity are sites of possibility for engaging intersectional differences and fostering our sense of relatedness to others. Furthermore, I examine my own experiences with parents to throw light on ethically significant possibilities for acting and advocating that come into being through our relations with others.

In Chapter Seven, 'The Axiom of Equality: Moral Lives and Communities of Care', I examine converging and conflicting interpretations of life with disability that affect the ways carers feel positioned within networks of caregivers. This chapter serves as a mediation of fathers' everyday lived moral experiences surrounding care and the moral personhood of their children. It throws light on the existential conditions that ground moral life and motivate the varied nature of carers' committed actions, alongside epistemic communities and the complexities surrounding representations of family life and disability. Furthermore, this chapter explores the personal and politicised connections formed and subsisted between carers across group and geographical differences through the shared tremors of uncertainty and a positive ethos on corporeal diversity. Finally, I explore the role of existential hope and moral ambivalence, which we will see play important roles in making parents' lives liveable. The themes drawn out in this chapter have been underscored in previous chapters and augment a central conviction of my

thesis: that caregiving and experiences of disruption can open us to the world in new ways and illuminate more clearly the moral significance of our relationships with others.

Chapter One: Aims of this Autophenomenography and Literature Overview

Existential anthropology concerns itself with the conditions of existence and how people immediately experience the worlds in which they live.

Anthropologists in this field have focused on the body as the “existential ground of culture and self” (Csordas 1994: 4), the way culture is lived in activity (Jackson 1996), and how human beings exist (Piette 2015). The turn toward experience offers a corrective to anthropological approaches that elevate the conceptual and linguistic dimensions of human existence. In doing so, they illuminate the continuity of human existence in time (Piette 2015) and the ways people make worlds of meaning on the basis of and in relation to the social and practical life in which they are engaged with others. Some of this work explores the ways groups of individuals experience the immediacy of their worlds after some kind of disruption and the ways the forces of language, history, and upbringing are given meaning and find expression as individuals strive to regain a sense of equilibrium (see Becker 1999, Csordas 1994, Jackson 2013). For Jackson, disruption “lays people open to possibilities of behaviour that they embody as potentialities but ordinarily are not inclined to express” (2013: 63).

My study provides a unique example of how fathers perceive their existence in relation to their children and others within the framework of their own lives and the way caregiving permits them to experiment with and transform their lives with, through, and for others. By focusing on their felt realities, I describe how fathers negotiate their constantly changing, diverse worlds of disability as embodied subjects in time and space with others. I ask: How do fathers access the inner lives of their children in the absence of normative reciprocity? How do they achieve the level of responsivity needed in the non-self-interested labour that characterises caregiving? What do the roles of embodied memory, emotion, and self-understanding play in articulating their worlds of care? What do concrete acts of care contribute to habits,

knowledge, and their existential orientations as caregivers? Throughout the text, I describe the uniqueness of my participants' experiences of disorientation and caregiving, while also demonstrating the commonalities that allow them to come together around a shared understanding of their experiences caring for disabled children.

Additionally, this thesis extends the work of disability studies by documenting and describing how disability and care are lived and constructed intersubjectively. It explores aspects of care, stigma, and ableism that pervade the everyday experiences of caregivers. While parents may at times identify with a particular diagnosis and the practices and situations that correlate to the lifestyle it entails, the fathers in my study came together around their shared experiences of exclusion and difference that find expression in relation to the embodied particularities of the children they care for. Throughout this thesis, I address fathers' existential engagement with norms and practices that negate disabled human personhood and the possibilities these contestations inaugurate for disrupting the given social order, habitual behaviour, and extant cultural understandings that interpret and produce embodied difference in particular ways.

Finally, this study contributes to the literature on fathering, masculinity, and care by extending the boundaries of care to make visible men who assume caring positions to ask: How do their social identities as fathers and carers relate to their gendered embodiment and the historical and cultural assumptions around care practices that have become institutionalised? What possibilities does caregiving offer for ethical self-transformation and challenging oppressive social relations? A lot of attention has been given to the external contextual factors that affect the ways men construct and enact their roles as fathers. Such a focus, however, overlooks the existential context of men's lives which grounds the ways they press into their possibilities as caregivers. That is to say, the commitments, habits, motives, emotions,

capacities, actions, and everyday practices of relation that constitute fathers' moral modes of being in the world cannot be explained solely in relation to the structural conditions that favour them.

It is my goal throughout this thesis to tell the stories of fathers parenting disabled children with whom I spent seven months and to explore and describe the details of their lives and what they tell us about the role bodies, feelings, and other mediums of experience play in the way they experience and reflect upon their lives as carers, as well as the personal and intersubjective contexts that constrain or abet their possibilities for (re)creating habitable worlds. In doing so, I throw light on the ways caregiving shakes parents from their habitual everyday worlds and opens possibilities for impressing upon the world in new ways.

In the public and intimate everyday spaces of this thesis we see the ways parents' lives are intersubjectively grasped and individually created and recreated against a world of existential concerns and significances. By understanding the existential, affective, and bodily dimensions of caregiving we can talk about empathy, care, morality, and relationality, as being grounded in human bodily existence. These findings require that we recognise the body as the foundation of interrelatedness and care, and interrelatedness and care as the foundations of our humanity.

Anthropology of disability and care: A review

'Don't we need a benchmark to measure what we are?' a scholar once asked me. I had just delivered a paper on disability and caregiving at an annual academic conference. The paper was based on a recognition of the wide spectrum of human variation and an expansive notion of community and citizenship. It was largely inspired by my life caring for my profoundly disabled son and informed by what I have come to know of his sensorial experiences and how they shape

his being-in-the-world. I was engaged in what can be thought of as a cosmopolitan form of activism. I argued that the just treatment of those with anomalous embodiments should be based on a recognition of our interdependence as human beings. I wanted to shine a light on the Othering practices that foreclose our capacity to connect with and understand others. When it came time to the Q&A afterwards, however, my capacity for intellection and all of the linguistic powers I had been honing since childhood collapsed into a heap of visceral rumblings, and so it was with this scholar's follow-up question: 'Why should we do this moral work [valuing Takoda and those persons with similar embodiments as equal moral beings]?'

This line of questioning exemplifies a distinct tension between my dual role as an anthropologist and stakeholder in these wider debates around the moral personhood of those with intellectual disabilities, namely, as a carer. It's not always easy to discuss my son's moral personhood in detached and theoretical ways—after all, he is my child. Yet, my research is on parenting and disability, so I expect these critical rituals of argument and questioning—wherefore I am institutionally expected to indulge both reasonable and prolix, repetitious questioning. But it is also more than this: It is what Kittay calls a “public form of personal caring”, a part of the invisible labour that family members of disabled people do in enhancing “the social fund of knowledge about disability”, to borrow Rapp and Ginsburg's words (2001: 537) and socializing the world to meet their child (Kittay and Carlson 2010: 411). This thesis contributes to this broader project of enhancing the social fund of knowledge about living with disability.

As a philosopher and mother of a severely intellectually disabled daughter, Kittay (2009) writes about a similar experience of her own at a bioethics conference, describing the profound emotional challenges she

experiences responding to moral claims about the nonperson status of her daughter and those with cognitive disabilities like her. She writes:

How can I begin to tell you what it feels like to read texts in which one's child is compared, in all seriousness and with philosophical authority, to a dog, pig, rat, and most flattering a chimp; how corrosive these comparisons are, how they mock those relationships that affirm who we are and why we care? (ibid: 610).

Here, she is specifically referring to the views of Singer (1996) and McMahan (1996, 2003) who hold an instrumental view of human life and contentiously demote the moral status of those with cognitive disabilities because of their perceived lack of certain psychological and/or moral capacities. As Kittay acknowledges, while for theorists the wedge may be mere abstraction, these disendowments have historically permitted the abuse and neglect of those with cognitive disabilities—which continues unabated in certain regions of the world today—and have the potential to translate into horrific consequences on a practical level via bioethics into healthcare and policy decisions (2009: 613).

In addition to her role mothering a severely cognitively impaired child, Kittay's argument is refracted through the lens of feminist care ethics. I agree with Kittay's elaboration of an ethic of care which is based on a relational approach to personhood that defines our humanness in accord with our connections and intrinsic interdependence; a view that directs our attention to the claim that relationships are constitutive of who we are (see also Gilligan 1982). In *Love's Labor* (1999) Kittay offers one of the most cogent arguments I have read for the social inclusion and moral treatment of those with profound cognitive disabilities within the realm of distributive justice. She amends Rawls' theory of distributive justice to include care as a primary good by revisioning caregiving as a public good that promotes human flourishing. Kittay argues

that dependency is an inescapable dimension of human existence, which infancy, childhood, illness, advanced age, and disability attest to (1999: 29). The networks of giving and receiving that we are nested in, or our “nested dependencies” as she phrases it, make us all worthy recipients of care (ibid: 180). This argument calls us to recognise what should be a shared commitment to care and society’s obligation towards providing adequate provisions to support dependency relations. Throughout this thesis, though, I move beyond Kittay’s emphasis on dependence to illustrate the particular ways disabled children act upon their parents in ethically significant ways beyond dominant understandings of personhood and sociality. In doing so, this thesis contributes to the anthropology of cognitive disability scholarship by describing the alternate ways that those with cognitive disabilities are enmeshed in the world and affect those around them (see Jackson 2018; McKearney and Zoanni 2018).

In recent decades, care theory has been applied beyond the private sphere of intimate relations to social and political policies and practices also (see Held 1987, 2006; Kleinman 2012; Kohn and McKechnie 1999; Ruddick 1989; Tronto 1993). Feminist engagement with the topic of care proliferated throughout the 1980s and 1990s (see Hekman 1995; Manning 1992; Ruddick 1989; Tronto 1993). Noddings became one of the most well-known theorists of care ethics from the United States and made a significant contribution to philosophical discourse with her book *Caring* (1986), which stressed the value of a response-based ethic to education. Noddings later work provides a link between justice and care through her distinction of *caring about* and *caring for* (Hamington 2004).

In *Starting at Home* (2002), Noddings no longer sees care and justice as mutually exclusive approaches to ethics and argues that through *caring for* others (direct caring) we learn to *care about* others (indirect, conscientious

caring). Caring about others, then, in her view, provides the foundation for our sense of justice: “justice itself is dependent on caring-about, and caring-about is in turn dependent on caring-for” (2002: 6). In her view, the development of care and a relational self has its origins in the best homes and can enter the public realm through public policies of caring, establishing the conditions under which caring for others can flourish¹ (ibid: 23). As I go on to show, past emotional and affective experiences influence the ways parents identify as caregivers and empathise with others. Contra to traditional moral theories, then, affect and emotion take a central place in my care-based approach in understanding moral agency. While theories of distributive justice or its relationship to care ethics is outside the purview of my focus (see Noddings 2002; Kittay and Carlson 2010), my research suggests that these concerns motivate parents’ moral lives through a range of everyday, practical notions and questions, such as, what is fair and unfair? how we should treat one another and why? I have found that these ethical intuitions and understandings make up parents’ everyday lived values and emotions. They articulate the moral landscape. My thesis joins this community of inquiry into care by focusing on embodied care and how it emerges in bodily experience and is developed in bodily practice. In this sense, it is situated within a subset of the larger scholarship on care theory alongside theorists who treat the subject of care as more than a distinct moral theory and as something fundamental to human experience and moral engagement (see Hamington 2004, 2012; Kleinman 2008, 2012).

Towards these ends, Hamington explores the body’s role in care and suggests that embodied care “finds the human body at the nexus of the *is* and the *ought* (2004: 31, my emphasis). He argues that while morality can be informed by a sense of duty, caring habits, knowledge, and imagination should

¹ See also Joan Tronto’s (1993) moral and democratic political theory where morality and politics are reconciled in service of positioning care as a political ideal and strategy for recognising the achievement of equality as a political goal.

also be fundamental participants in moral consideration (2004: 31). In this thesis I focus on the skill and knowledge parents acquire through acts of care and the possibilities they open for changing parents' sense of relatedness to the world and the way in which they understand themselves as carers. I believe that many of my participants would find deep resonance in Kleinman's (2012) assertion that care is a true worthy object of ethical commitment.

Similarly, in *Fathering, Masculinity and the Embodiment of Care*, Ranson (2015) also mobilises the concept of embodied care, which has also been influential to my perspective on the role bodies play in care and, what Mattingly refers to as, "moral becoming" (2014: 207). Ranson purposes that hands-on caregiving can inaugurate moral transformation. She follows Hamington's claim that our moral imaginations are informed by caring habits, but narrows her focus to how men deepen their connections to their children and partners through the "grunt work" of intimate parenting. Caregiving, Ranson argues, affords men the opportunity to cultivate more reflective attitudes towards conventional gender roles. By speaking to the power of embodied caregiving and the potential it has to engender social transformation over time, Ranson's work foregrounds the value of caring masculinities (see Hanlon 2012) and core qualities associated with care, such as interdependence, relationality, reciprocity, that feminist care theorists have identified as being central to human survival. Ranson and Hamington's ideas come through in the way I approach moral agency and the body's role in motivating it.

If we look at caregiving descriptively, then, that is ethnographically in terms of what concrete caregiving entails and how it is experienced for families providing care, the embodied, situated, and emergent features of relational selfhood become central to understanding the significance of care and its articulation in moral life. In fact, much of the anthropological scholarship on family experiences with disability explores how relations of care are expressed

in local moral worlds and demonstrates the ethic of care informing parents' strivings for a good life—sometimes explicitly, often implicitly. Many of the texts discussed in the next section are addressed in terms of what they offer my understanding of the experiences of caring for disabled children. The literature on caregiving is far too broad to deal with in its entirety, so I have narrowed my focus to scholarship within the social sciences, particularly anthropological and sociological perspectives, and to literature concerning the experiential dimensions of caregiving (whether approached through an analysis of gender or disability, for instance). However, Appendix A provides additional review literature in relation to the broader anthropology of disability scholarship.

Caregiving and disability

Existential disruption/disorientation is my starting point in this thesis. Harbin classifies disorientation as “sustained difficult experiences that make it hard to go on” (2016: 17). “To become disoriented”, she writes, “is, roughly, to lose one’s bearings in relation to others, environments, and life projects” (ibid: 13). This thesis is about disruption. Having a child that is neither expected nor typical prompts an experience of disruption in the lives of parents, to which I address in the context of their individual lives. I interrogate two important questions. First, what are the conditions of possibility for reorienting their lives? And, second, what can existential disruption contribute to understanding their moral lives as carers? My interest in disruption has its origins in my own experience as a carer. It also has strong resonances with particular themes within existential philosophy; namely, the ecstatic, uncertain, contingent, and ambiguous nature of human existence and the role disruptive experiences play in revealing authentic existence: anxiety for Heidegger plays a disclosive role in bringing us face-to-face with our finitude and breaking us free from our everyday, public understanding of ourselves; Kierkegaard’s philosophy is

concerned with our everyday struggle to live an ethical life; Sartre's account of nausea focuses on the contingency and freedom of existence. As I will go on to show throughout this thesis, having a disabled child engenders an experience of disorientation for parents that makes visible aspects of their situation they once took for granted. As will also become clear, existential disruption precipitates other moments of unsettlement that engender critiques of the normative and generate new possibilities for acting and self-understanding. I refer to these throughout as moments of intersubjective moral breakdown and experiential/moral unsettlement.

Becker (1999) approaches disruptive experiences from the standpoint of embodiment to consider the process by which people living in North America attempt to create a sense of familiarity after their culturally-informed expectations around order and linearity are shattered. Like Becker, I am interested in the moral force of normalizing ideologies (around family, parenthood, and gender, for instance) and the creative biographical reconstructions participants make around them in their efforts to regain a sense of biographical coherence. As I will show, disruption opens possibilities for establishing new bonds of fellow-feeling with others in the context of care and acquiring new bodily habits that can be morally promising and help parents create a sense of existential continuity.

My thesis joins the social science scholarship exploring the intersection of disability and parenting. This growing body of work draws on four commonly used approaches to deal with ethnographic data of this kind: stigma (Goffman 1968), liminality (Turner 2011), anomaly theory (Douglas 2002), and the paradigm of embodiment (Csordas 1990); as demonstrated in the works of de Wolf 2013; Fisher 2007; Landsman 2009; Lewiecki-Wilson and Cellio 2011; Mattingly 2014; Shuman 2011. A key body of this research treats disability as an

“embodied, situated, and social experience in culture, constituted out of an ever-changing flow of relations among bodies, practices, institutions, experienced personally and socially constructed” (Lewiecki-Wilson & Cellio 2011: 3). My research reflects an embodied ethnographic approach, and at different times I deploy the theoretical concepts mentioned above in service of understanding parents’ experiences of disruption and caregiving. My research forms part of a trend within anthropology and the social sciences more broadly indebted to the works of continental philosophers like Merleau-Ponty and Heidegger, and given empirical support in the works of Csordas (1990, 1993, 1994); Kleinman (1998); and Jackson (1989, 1996, 1998). Within this scholarship knowledge is theorised as something embedded and arising in embodied action.

Kelly (2005), in her ethnographic study of parents raising disabled children in the Mid-South of the United States, describes the remaking of the self after the disruption of childhood impairment as the “conscious re-embodiment of the social category of parent”. Gail Landsman’s (2009) ethnographic study on mothering and disability in New York also springboards off this premise, entering the discussion of disability and mothering at the time of a child’s diagnosis. Landsman explores the ways mothers negotiate and (re)interpret motherhood and disability as they reckon with co-existing and contesting cultural rhetorics of tolerance and deviance, cultural discourse surrounding reproductive choice and control, and accompanying medico-techno-scientific interventions into reproduction that reflect the cultural desirability of perfect/normal babies. These two studies can be characterised by their focus on the ways subjectivity is shaped and reshaped through social interaction and mediated by cultural constructions of personhood, power, and agency in the context of disability and parenting.

Landsman incorporates her own experiences mothering a disabled child to describe and critique these processes. In doing so, she illustrates the ways personhood is established through our relationships with others. A “disabled child’s personhood, largely negated by society”, according to Landsman, “emerges in relationship with the mother, and so too a mother’s transformed self emerges in relationship with the child” (2009: 2011). This finds deep resonance with Kittay’s call for a social ontology based on an ethics of care: to reject the arbitrary hierarchy of identities as unjust (Landsman 2009: 204), and recognise the “distinctiveness of our particularly human relations to others and of the world we fashion” (Kittay 2001: 568). Like these above ethnographies, I also examine the ways fathers reckon with the cultural valuation of their children and what knowledge they acquire through intimate, everyday experiences of caregiving where corporeal and intercorporeal norms and practices play out. As will become clear throughout this thesis, I am interested in both formal and informal modes of knowledge and modalities of existence involved in this process of “conscious re-embodiment”, which sometimes bear no relevance to sociocultural generalisations (more on this in the next section). That is to say, parents’ attempts to reorient their lives are grounded in intersubjective life, but are also linked to their historical density and everyday lives.

It is worth acknowledging that the body of scholarship my study joins departs radically from the research literature particularly evident in the latter half of the 20th century that viewed disability as a burden on families: studies based on the medical model that frame disability as a tragic pall that families must attempt to ameliorate² (see Olshansky 1962; Solnit and Stark 1961). I also find that it departs from the changes in focus and methodology that Knight (2013) identifies in her typology of themes over the last fifty years: the

² See Blacher (1984) and Knight (2013) for a review.

psychopathology model of the 1960s, characterised by Olshansky's notion of 'chronic sorrow'; the stress and coping literature that dominated the 1980s and 90s (see Cavanagh and Ashman 1985); resilience models at the turn of the century (see Grant et al. 2007); to the growth and interest in adaptive (see Skinner and Weisner 2007) and transformative (see Hastings et al. 2002) models that promote the compensatory aspects of parents' experiences. In fact, I have found that parents' experiences of caregiving often reveal an intermixing of the themes Knight identifies. As Solomon writes, "There is no contradiction between loving someone and feeling burdened by that person" (2014: 21). In his book, *Far From the Tree* (2014), Solomon focuses on how parents shape family life around profound difference and how care is expressed through adversity. He examines the ways parents grapple with the profound emotional ambiguity of caring for children who are judged to depart from developmental and social norms. By addressing socio-political injustice and limits to self-definition, Solomon throws lights on another important theme in this body of work: the ways we struggle for self-definition and acceptance through the minds of others.

Towards these same ends, Doucet (2006a, 2006b) considers the practical and moral demands that arise in local contexts for Canadian men engaged in caregiving. Fathers and mothers not only make decisions in practical and relational terms, she writes, "but also in terms of how they think they ought to act in gendered social worlds" (2006a: 220). Doucet finds that under certain conditions, for instance, spaces populated by mothers, men feel their gendered embodiment taking more of a priority in their experiences of fathering as they come under the scrutinizing gaze of others from perceptions surrounding the social fit between male embodiment and other embodied subjects (2006b: 704/712). Like Doucet, I describe spaces and times where gender differences are intensely perceived and experienced, together with moments when gender markings or norms seem rather inconsequential. I find great value in Doucet's

study because she captures the shifting weight of embodiment and the nuanced ways fathers' identities and experiences change according to the moments and spaces they occupy with others. In Chapter Four, I focus on the situated doing of gender to consider moments when identity and gender expressions are negotiated. I take up Schwalbe's (2014) clarion call to expose gender expressions that are complicit in re-enacting unjust social relations, as well as resisting them.

Caregiving and masculinity

At this juncture, my work also contributes to the literature on caring masculinities (Hanlon 2012; Ranson 2015). Given the devaluation of the feminine in hegemonic masculine ideals and practices, and that hands-on caregiving of children is likely to challenge most dominant ideas of manhood, Doucet asks the important question: "What is the relationship between hegemonic masculinity and care? (Doucet 2006a: 38; see also Ranson 2015: 17). Connell's concept of *hegemonic masculinity* has been widely deployed in gender theory to expose the relationships of power between diverse masculinities and the configurations of gender practice that sustain an oppressive patriarchal gender system. It is important here for understanding recent theorizing on masculine identities and how identities of care, rather than domination, contribute to gender equality. After a brief overview of the relevant literature, I will explain how my research engages with this theorising.

According to Connell, hegemonic masculinity describes a culturally prescribed norm that embodies "the most honoured way of being a man" (2005: 832). Connell and Messerschmidt (2005) reformulated the concept in 2005, emphasising the interplay between local, regional and global levels of masculinity, and other issues that complicate the gender order, such as compliance, costs and benefits, and resistance. Highlighting the gaps in current

empirical research, Connell and Messerschmidt call for more attention to the ways masculinities are defined in contradistinction to models of femininity (real or imagined) (2005: 848). "Masculinities are configurations of practice that are accomplished in social action", they write, and, therefore, "can differ according to the gender relations in a particular social setting" (2005: 836). According to Connell and Messerschmidt, while models of hegemonic masculinity might not correspond very closely to the actual lives of men, they "express widespread ideals, fantasies, and desires" and provide "models of relation with women and solutions to problems of gender relations" (2005: 838). In other words, they provide cultural reference points for the ways we think and relate to others. Typical dispositions, then, such as competitiveness, individual initiative, physical vigour, self-control, emotional distance, and economic power, are seen as the quickest routes to gender and social ascendancy (Hanlon 2012). These images of masculinity and hegemonic masculine characteristics gain legitimation and find expression through the exclusion and/or subordination of women and what is perceived as feminine, and the debasement of other forms of masculinity, for example, those who embody different sexualities, abilities, social classes, and ethnicities, etc. (van Hoven and Horschelman 2013: 8). Much research over the years has given empirical substance to the concept of hegemonic masculinity and the various practices and social relationships that sustain men's dominance over women, and for a very few men, dominance over other men (see Eastman 2012).

In recent years, Connell's conceptualisation of the hierarchical gender order has been criticised for being "static and positional" (Seidler 2006: 51). For example, Seidler argues that Connell's theorizing of subordinate and hegemonic masculinities often renders invisible "the tensions men feel when obliged to live up to prevailing masculinities and their actual... emotional lives (2006a: 51). Seidler argues that thinking about masculinities exclusively in terms of relationships of power blinds us to the difficulties men face in their own lives

(2006b: 3), and the ways “power also works through emotions, bodies and institutions” (2006b: 71). Hanlon offers a carefully balanced reflection in the wake of these criticisms and suggests that Connell’s and Seidler’s diverging perspectives are “differences in emphasis rather than in kind” (2012: 88). He argues that both perspectives are important, whereas Connell’s focus is on large-scale macro aspects of gender relations, Seidler emphasises cultural, religious and historical constructions of masculine rationality (ibid: 87). Hanlon writes:

men’s lives are lived out in complex ways expressing both power and vulnerability, and men inhabit multiple relational identities and social locations. We cannot appreciate masculinities without understanding relations of power and dominance, but we cannot understand power and dominance without also appreciating men’s emotional lives...we cannot deconstruct male power without reconstructing the emotional lives of men (2012: 66).

As I will go on to show, how men experience and feel about caregiving can differ dramatically depending on the interplay between how they feel about prevailing cultural beliefs around masculinity and fathering and the degree to which they are perceived by others and themselves as embodying society’s gendered dispositions and habits. My ultimate focus, however, when the gendered dimensions of existence are considered, is on how gender norms and interpretations emotionally resonate with my participants in relation to their experiential pasts. In this thesis, I address experiences of intersubjective breakdown that unveil tacitly held assumptions and shift the ways men relate to notions of manhood and care (Chapter Five). These considerations have

received minimal research in the context of men fathering disabled children³ (see Doucet 2006a; Marsiglio et al. 2005; Aitken 2009). I find Mattingly's (2014) notion of "moral becoming" useful when considering the morally significant thoughts and actions that caregiving can motivate. I also focus on experiences of moral unsettlement when fathers rub up against able-bodied norms and cultural categories that degrade their child's personhood, and the moral promise these experiences hold for changing their everyday practices of relating to others. Therefore, my work also contributes to the moral anthropology scholarship which highlights the centrality of ethical practice, judgement, and responsibility in everyday life, or as Lambek puts it, an ordinary ethics grounded in practice rather than knowledge (2010: 3; see also Das 2010; Garcia 2014; Zigon 2013).

Communities of care

The disorienting nature of caring for a child whose personhood is often negated by society can have the effect of bringing diverse communities into contact with one another. This can be seen in the ways parents participate in communities that facilitate situated learning and/or to find a sense of belonging. de Wolfe (2013), for instance, in her study of parents caring for autistic children in Queens, New York, examines the ways established scripts of autism are re-written across different social sites and through parents' collaborative engagements with one another in support groups. Her theoretical approach aligns with Hacking's (1999, 2009) concept of an "interactive kind"; a term he uses to describe how ideas and discussions interact with objects and affect the ways we understand them. In this way, autism as a label can be seen as both

³ Ranson is a notable exception in that she briefly considers the non-normative repertoire of techniques embodied by fathers of disabled children (2015: 112).

'real' in a biological sense and socially constructed (Hacking 1999: 119). This concept offers a way to focus on how parents contribute to changing public conceptions of disability. For Rapp and Ginsburg, this is often accomplished by sharing intimate disability stories with the public that resist pathologisation. According to them, in these family narratives, embodied difference is represented within the context of domestic life and subjectivity (2001: 537; see also 2011).

In this thesis, it emerges that fathers participate in support forums for many of the reasons outlined by the authors above. These spaces offer support, acceptance, and opportunities to learn how to navigate social spaces controlled and maintained "by diagnostic procedures, therapies, regimens, stigmas', etc." (de Wolfe 2013: 12). They also allow for new forms of cultural expression, advocacy, and social activism. In this thesis, online forums emerge as cosmopolitan spaces where parents come together around the shared oppression of social exclusion they face as carers. In doing so, parents challenge extant cultural norms and perceptions around disability and caregiving, and work towards creating a more tolerant human community.

The subjective experience of disorientation and caregiving poses challenges to ethnographic understanding because among carers in the United States personal identity, biographical continuity, and stability of life trajectory are at stake in the demands caregiving makes. I argue that these demands act as a destabilizing force in the lives of individuals, shaking parents out of their habitual modes of everyday familiar existence. What is often missing in the above research on parenting and disability are approaches drawing on the theoretical perspectives of existential anthropology and what this perspective lends to our understanding of existence and the resources people draw on in creating habitable worlds.

Chapter Two: Theoretical Situation and Methodological Attitude

Theoretical perspective

Caregiving is an experience that encompasses multiple dimensions of a person's life: the body, sense of self, memory, emotion, thought, feeling, culture, etc; therefore, I address caregiving in a way that considers the interrelatedness of these dimensions and their role in the construction of reality. Considering these dimensions involve reflexivity and establishes the dialectic between living/knowing that defines our being-in-the-world.

"Crisis transforms the world", writes Jackson, "from an apparently fixed and finished set of rules into a repertoire of possibilities" (1996: 22). By focusing on how the normal and habitual is disrupted and experienced by parents after having a disabled child, and the links of disruption to complex processes of selfhood and identification, we glean important insights into emergent features of selfhood that arise through caregiving and interaction. We will also see throughout this thesis the existential force of care in relation to the potentiality of selves.

Caregiving and existential disruption emerge from this thesis as an embodied, intersubjective phenomenon, indeterminately couched in webs of social interaction and situated within material and organisational environments (Crossley 2015). As such, I privilege parents' modes of being and culture from a relational perspective. That is to say, from the perspective that we are always a being-with in relation to others: "Our lives, thoughts, feelings, and actions are always interwoven with those of others such that they cannot be understood atomistically" (Crossley 2015: 67).

For Merleau-Ponty (1995) the dialogic structure of subjectivity and experiential connection between self and other is present from the outset. This is now evinced by studies on infant imitation whereby newborns are shown to be in possession of a rudimentary ability to monitor their own gestures and

recognise and imitate the gestures and expressions of others (see Gallagher and Meltzoff 1996). These studies revise and refine Merleau-Ponty's earlier theorising by providing empirical support for the theory of an innate body schema⁴ that exists prior to birth that accounts for the possibility of a self in relation to others.

This relational mode of being is important to my thesis for several reasons: Embodied others play a complex role in the lifeworlds of parents. First, parents' identities as caregivers are reflexively negotiated alongside the multi-perspectival views of others, both in relation to their ever-changing memories of others and the information reflected back to them as carers in their interactions (Cooley 1902). The structural dimension of our bodily relation to others can be witnessed in the way disruption is experienced by parents as a changed lived relation to not only themselves but others also. Even if others are physically absent, parents perceive, judge, feel, and think about their situations⁵ as caregivers in relation to the perspectives of generalised and specific others, couched as they are in culturally furnished interpretive schemas⁶ that imbue experience with meaning. "Even in our most individual consciousness, even when we think we are most alone", writes Wahl, "we are not separated from others" (1971: 16). Second, our relation to others is thematic also: other people affect us through their bodies: looks, movements, and the language they use (Trigg 2013). In this thesis, this is captured by the ways parents' subjective experiences of disability are negotiated and altered through intersubjective encounters with their children and others (Chapter Three & Five).

⁴ Defined by Gallagher and Meltzoff as "a system of motor capacities that function without the necessity of perceptual monitoring" (1996: 3).

⁵ The term *situation* in the tradition of existential philosophy refers to the situated nature of experience. A situation, then, derives its meaning from the dialectical relationship between lived experience and environmental givenness, that is to say, the parameters of a situation will be marked out by the cultures, structures, histories, etc. we inhabit, alongside the way we accept and act upon these contexts.

⁶ Understood here as shared assumptions, expectations, values, and frames of reference (Rerup and Feldman 2011: 578)

Finally, and perhaps most importantly, relationality accounts for the ways parents recognise the self-awareness of their children through their intercorporeal engagements and communications with them. I argue that through corporeal intersubjectivity parents grasp their child's intentions. Through a feeling awareness of their agency, parents become attuned to their children and internalise their perspectives (Chapter Four). As Daly argues, these affective interactions are integral to the body schema, affirming the importance of emotion and affect in our engagement with the world and the way we orient ourselves in intersubjective space (2016: 213). In this way, the body's active engagement and relation to its surroundings and others is central to the worlds parents develop around themselves.

For Merleau-Ponty, the experiencing subject's orientation in space and apprehension of the world are directed by what has become embodied knowledge or skill through the lived body's daily engagement in physical situations (1995: 139). In contrast, then, to Cartesian thinking, for Merleau-Ponty consciousness is "not a matter of 'I think that' but of 'I can'" (ibid: 137). The body schema connects the lived body to a world with meaning and potentiality through the body's situational understanding of space and spatial features. However, as Daly recognises, affect and emotion also direct our attention to what is significant in perception, which can be seen in the way "the intersubjective field becomes peopled with friends, enemies, and strangers" (2016: 214). I use Merleau-Ponty's concept of the body schema in this thesis to consider the potential new skills have in reconfiguring the boundary conditions of conscious awareness. By considering the relation between affect and the body schema, I will also throw light on the respective ways parents affectively and viscerally apprehend their realities of caregiving in relation to certain biographical significances and past interactions (Chapter Three, Four & Five).

My embodied epistemology finds deep resonance in Hamington's (2004) theory of embodied care. As Hamington puts it, caring habits inform the caring

imagination which tempers our reflections in regard to the central concern for relationship (ibid: 75). Throughout this thesis, I focus on the potential embodied care habits and actions have for (re)orienting parents' cognitive and affective intentionality and permeating their moral identities as carers. This focus invites us to think about the corporeal and affective grounds upon which we relate to others and exercise our imaginative abilities to empathise with those outside our sphere of experience (Hamington 2004) (Chapter Four, Six and Seven).

This does not preclude, however, a focus on the individual and human singularity. As Jackson and Piette write, the task of existential anthropology is to explore the various contexts and circumstances upon which individuality and relationality, modes we oscillate between, make their appearance in consciousness (2017: 10). Piette (2015) has made the empirical individual the focus of his existential anthropology. Small physical, gestural, and cognitive signs, according to Piette, attest to the presence of minimal modes of existence that have no direct significance with regard to the social and cultural models of existence that researchers try and understand, but that are necessary for understanding the way individuals manage their own singularity (ibid: 39). "People are skilled at...managing the collective aspect necessarily implied by the interaction in which they are participating", he writes, while simultaneously "managing their own singularity through gestures, movements, and thoughts that are specific to each of them" (ibid: 40).

For Piette, the aim of existential anthropology is to capture the "minor mode" of reality, the "human stratum that lightens, defuses, and frees human presence from the imperatives of...rationality" (2015: 41). The presence of these minimums or leftovers live and change, he says, so that every situation contains within it the traces of other situations and actions that speak to the ways

humans reckon with ambiguity and uncertainty (ibid). Modes of ‘repose’⁷ are central to his analysis of the minor mode of reality which can be understood as our aptitude for ‘mental loosening’: our ability to interpret actions and modulate “strangeness and tension through familiarity and tranquillity” by putting trust in or resting upon an ensemble of skills, experiences, thoughts, and reasons for acting (ibid: 81). This cognitive loosening, according to Piette, enables human beings an “economical way of being present in perception and thought” (ibid: 72). The ability of individuals to rest upon these embodied skill and capacities entered my own research by observing how parents accomplish acts of care with regard to this minimal substratum. In fact, Piette’s notion of ‘repository’ is useful here for considering Merleau-Ponty’s concept of the figure-ground structure.

While the perspective one takes up toward a situation is resolved through one’s interests and attention, according to Merleau-Ponty’s figure-ground structure, it hinges upon the body’s capacity to rest upon the kinds of supports Piette describes. For example, the subject’s body has the capacity to withdraw from explicit attention into transparency during habitual action so attention can be focused elsewhere. Also, the experiential flow between moments and actions is created on the basis of past experiences and situational rules and norms that are implicitly grasped and enable the subject to set aside certain details not deemed situationally relevant (Piette, 2015: 38). Piette uses the term “cognitive economy” to describe the importance of automaticity in generating appropriate actions (ibid: 74). In my thesis, this can be seen in the ways parents are able to negotiate and synchronise their attention and movements within situations calling for simultaneous and different demands. For example, this mode of presence can be seen when parents attend to their

⁷ Piette writes: In French, the word “reposité” fits well to designate the dual act of “se (re)poser”, of “poser” and of “poser à nouveau (re-posser)”. Repository directly implies an economical way of being present in perception and thought (2017: 19).

children through acts of care while simultaneously dealing with the main activity in an encounter (Chapter Four).

Importantly, this framework invites us to think about the being of disabled children and their modes of presence. Denizeau asks, how are we supposed to consider the mode of being a baby? (2017: 232). “The baby is presence”, he writes, “outside of the strategies presupposed by social relations, or the interplays of meaning that belong to one’s own culture...a baby is not able to apprehend the world, to read within it a prism of representations...The baby is not yet the rational subject of theories of action” (2017: 232). Disabled children and adults are not babies, but because many of these individuals are without language and/or the cognitive capacities to think in culturally variable ways, they force us to reckon with forms of human difference that go beyond our defining assumptions (McKearney and Zoanni 2018; Jackson 2018). In this thesis, I attempt to illuminate how children exist beyond particular cognitive capacities thought to define us by focusing on the distinctive ways they inhabit the world. I will go on to show how disabled children act upon those around them, often in ethically significant ways, through emotional and bodily modes of agency. This focus speaks more to the entirety of our “volume of being”, to use Piette’s expression (Jackson and Piette 2017: 180), and the distinct presence of individuals (Chapter Four, Six & Seven).

Furthermore, as Gail Weiss points out in relation to the figure-ground structure of perception, “the perspective one takes up towards objects, other people, and the situation as a whole” unfold in relation to a range of varying contextual levels that are not a part of the sensory field at any given moment (2008: 19). Within the framework of minimality described above, I understand these contextual levels as modes of minimal being that are vital to sustaining a subject’s sense of existential continuity across time and after disruption. With regard to the parents in my study, by observing and describing their habits and

routines and past experiences as ‘more or less remote in time and space’ (Piette 2015: 102), I throw light on various modalities of meaning with which they grasp and orient their lives, bringing strangeness into familiarity and creating a sense of existential continuity from situation to situation. As Piette explains, however, when one senses a restriction or tension these peripheral details can leave the minor mode (2015: 43). As will become clear throughout this thesis, these skills, habits, and experiences can become the catalyst for critically reflecting upon the present act or situation, inaugurating reflexive modes of self re-making.

During the development of this thesis, Merleau-Ponty offered crucial tools which I found important for exploring the way parents’ worlds are given shape through everyday bodily experiences of caregiving. Also, as mentioned above, Merleau-Ponty’s project appealed to me because it allowed me to give relevance to parents’ lived experiences of intersubjectivity. In this text, embodied, sympathetic perception emerges as the basis of ethical life and is key in making care possible. Through Merleau-Ponty’s concept of embodied subjectivity, I also hope to throw light on the agency of disabled individuals who are without certain cognitive functions. However, in order to understand where I have arrived at in terms of this thesis, we must now turn to the work of Heidegger.

As Jackson and Piette write, concepts are like tools that one takes up and deploys in relation to one’s project (2017: 7). Midway through conceptualising and writing this thesis, the interpretive influence of temporality revealed itself: that is, the extent to which the temporal features of the phenomenal self influence parents’ relationships with others, disclose what emotionally matters to them and, ultimately, what the world affords them in its making. Therefore, I supplement Merleau-Ponty’s focus on the lived body and existential spatiality

with a reading of Heidegger that focuses on self-generating temporality and lived personal history as important elements that also ground parents' experiences over time and after disruption.

Heidegger's notion of temporality provides a useful resource for comparing individuals in their existences in and through situations across time with regard to certain historical and biographical significances. This warrants a slight detour. Let me explain: In Heidegger's view, we are beings who are concerned with our own being, we therefore have an understanding of ourselves which is constitutive of how our worlds are disclosed; that is, what is present and relevant in experience, and who and what we are (Heidegger 2010: 42; see also Blattner 2005: 32). 'Being-in-the-world', then, means that we are entangled in a familiar world, disposed in a particular way towards things that matter to us. Leaving aside Heidegger's greater ambition with relation to his thesis of the Temporality of being, I believe his account in *Being and Time* provides a useful hermeneutic existential phenomenological account of the structure of experience.

In *Being and Time*, Heidegger draws on the ontological concept of 'care'—which is grounded in the non-successive, three-fold constitution of temporality (having-been, the future, and the present) – to describe the temporal manifold that gives unity to attunement (also referred to as thrownness), projection (also existence/understanding), and falling⁸ (2010: 203/334). Heidegger's term care designates "the being of a possible being-in-the-world": a sort of being that takes up a relation to the world (ibid: 57). The temporal unity of the care structure finds expression in Heidegger's maxim: being-ahead-of-oneself-as-already-in (the world) as being-together-with others taking care (2010: 179/180). According to Heidegger, these three interrelated phenomena disclose the kind

⁸ Sometimes discourse is added to these disclosing-structures (2010: 212).

of being we are. In summary, then, we are always in direct relation to the world and others. We are always ahead of ourselves, pressing ahead into the future and in relation to a particular understanding of ourselves which is always embedded in conditions not of our choosing (place and time, and my body and past, etc.). I have found these ekstastic movements useful in making sense of the findings that have grown out of this study, which I will now elaborate on.

Facticity is the term Heidegger uses to describe the involuntary thrown aspects of our existence (Heidegger 2010: 56). In attunement, he writes, Dasein finds itself, “not as perceiving oneself to be there, but as one finds oneself in attunement” (2010: 132). In other words, we find ourselves disclosed in a historical and cultural way, situated by ethnicity, religion, place of birth, gender, with a particular past and body, caught up in everyday life and tuned in to situations. As such, we act and exist in accord with the ways the world is made meaningful to us in our disposedness. Blattner explains that according to Heidegger’s notion of attunement we are affected by our own abilities and possibilities for being that already matter (2005: 51). We are “attuned”, Blattner tells us, “to what makes certain ways of being worthwhile, fun, desirable, scary, noble, exhilarating, and so on” (ibid: 52). Our ability-to-be, therefore, is governed by what it’s like for something to be the way it is. Attunement reveals or makes concrete our thrownness.

This concept is related to distinct phenomena in this thesis and offers a way to bring into focus the ways parents’ feelings disclose different aspects of the world and the personal histories that motivate them. This can be seen in the following way. First, a child’s disability prompts an embodied sense of disruption for parents through a changed sense of relatedness to all things, including themselves, or through a “diminishing of practical significance and belonging”, to borrow Ratcliffe’s words (2008: 73). When parents enter their

worlds of disability they experience a changed sense of reality in the degree to which they are situated in the world. The concept of attunement is useful for thinking about the role existential feelings play in relation to the disclosure or concealment of individual possibilities (Ratcliffe 2008). Second, it is also useful for considering the role embodied knowledge and memory play in defining their situations of meaning. Through recourse to memory and embodied knowledge various situations are anchored in other situations, facilitating the passage from one situation to the next or an existential sense of rupture and a new course of action.

Attunement also offers a way to focus on experiences of inter-affectivity rooted in caregiving. Fuchs (2013) uses the concept of interaffectivity to describe the ways our body schemas and feelings incorporate the perceived bodies of others. In this thesis, I consider the body's capacity for inter-attunement as a form of empathy constitutive of subjectivity/intersubjectivity (Daly 2016). In cases where parents are caring for non-verbal children, this emerged as an important medium through which they gain an intuitive understanding of their children's inner lives, and by which children express agency and act upon their parents (Chapter Four). Underlying this focus is a belief in the epistemological importance of bodily feelings and inter-affectivity, which I will in the course of this thesis argue can bring about changes to how parents are ethically and existentially oriented in the world.

Now, in terms of how the future and present structure experience, Heidegger draws on the concepts of understanding and falling, respectively. The first of these terms relates to the ways human beings press ahead into activities correlative to what they understand themselves to be. "An understanding of being is already anticipated in the projecting upon possibilities", writes Heidegger (210: 143). As such, understanding has in itself

the existential structure of projection (ibid: 139). What I am interested in is the way biographical meanings and future plans come into conflict with parents' new lives and situations as caregivers and the possibilities of forming a unified self that are brought about through these movements from future to past. In many instances throughout this thesis, we will see the ways biographical coherence is creatively achieved from the ways fathers press ahead into new understandings of themselves which are presupposed by past significances.

Fallenness, Heidegger's third ekstastic movement, relates to the ways we are absorbed in a world with others. I wrote about our relation to other individuals at the beginning of this section. Especially important here, however, is that I approach the phenomenal experience of disruption upon entering the nonnormative world of parenting a disabled child as a tendency to break with Heidegger's notion of everyday fallenness, that is, as Villa explains, "our tendency to give in to the "tranquilizing" understanding of everyday concern, a tendency that intensifies reification and causes us to lose sight of our original open or disclosive character" (1995: 145). As we will come to see, the familial practices and socio-cultural norms around bodily differences and behaviour that very often mediate the ways we think, feel, and act as parents, are thematised and reflected upon by the parents in this study. It emerges that the demands of care shake parents from the fallen averageness that Heidegger describes and launch them upon a new subjective trajectory whereupon they struggle to remake a self in the context of care and disability that is biographically coherent.

It is not just that parents can act how they like in their understanding as caregivers, however. Goffman (1961/1991) has explored the ways spaces are created and maintained by situational moral norms, rules, procedures, stigmas, etc. that govern the ways we behave and express ourselves in interaction. Self-understanding, in a phenomenological sense, for instance, is permeated by the cultural significance of certain social expectations and gendered dispositions.

The perceptions of non-disabled others, implicit normative evaluations of bodies, and mainstream domestic ideals tied to family happiness invariably shape how parents understand their situations. Hence, it may be socially frowned upon for a father to engage in certain intimate caregiving activities, such as bathing and dressing one's teenage daughter, and if this norm is broken, there are social consequences. These boundaries are pliable, however, and parents negotiate these spaces in relation to what matters most to them (for instance, their lives with their children, hopes, and fears, etc.). Kleinman uses the term "local moral worlds" to draw attention to the mundane practices that create and sustain meaning and give rise to things that emotionally and morally matter to us (2013: 3). Through these activities, contestations, and negotiations, carers make efforts to carve out lives that are worth living within the perduring but malleable framework of their long-term biographies.

As I go on to show in the next section, based on these philosophical assumptions and the reflexive nature of this research, autophenomenography is the best research methodology for this study.

Methods

Beginnings

I travelled to Phoenix, Arizona, for fieldwork with my partner and two children in June 2015. We arrived at the beginning of a record-setting heatwave that lingered over the sprawling desert metropolis for three weeks. We rented a place in Scottsdale, an affluent suburb northeast of downtown Phoenix, the same suburb that Ray lived in. Six months earlier, I had emailed Ray, the founder of Dads 4 Special Kids (D4SK), to explain my research and invite his assistance and support. At the time, Ray was on the cusp of retirement— a married white male in his late fifties who worked as an engineer paramedic with the fire department. He is also the father of an adult disabled son, Zachary,

who was born with a rare brain disorder. Ray established the support group in 2001 when Zachary was fourteen.

Early on, I thought a support group seemed like a sensible way to access fathers. From the preliminary online research I had conducted back home, I found support groups for men raising disabled children in Australia scarce to non-existent. Furthermore, a support group would enable me to focus on the educative practices men engage in as they learn from one another, express their experiences, and co-construct their understandings of disability. Over the phone, Ray invited me to participate in the support meetings and agreed to introduce me to other members of the support group, so I could begin recruiting participants for my research once we arrived in Scottsdale. As it turned out, the idea was a failure.

It first occurred to me that the impression I had received of the group's active and growing participation was erroneous at my first D4SK meeting on the 17th of June when only one other person, apart from Ray, attended. And, then again, during my second meeting a couple of days later on the 20th. On that day, there were four of us in attendance: myself, Ray, and two other guys he has known for over a decade. We sat around a long table on the outdoor patio of ⁹IHOP in the shade. Our conversations were friendly and roamed over a diverse range of topics, but no one ever talked about their children or home life.

At first, I attributed the atmosphere of reticence to my presence as a stranger. After a few months, it dawned on me that while my outsider status early on was enough to affect an attitude of reserve between the regulars, the group was mostly comprised of lifelong friends brought together over the shared experience of parenting a disabled child. This shared bond was rarely, if ever, thematised in discussion. Rather, I felt it to be present in moments of laughter and palpable in the knowing silences they shared. It seemed to me that

⁹ International House of Pancakes

members didn't attend this particular group to share advocacy tips and care strategies, or to ask for and give help and advice to one another. Instead, they attended the group for the diffuse feeling of connection and understanding it provided. This was later confirmed when one of the regulars casually explained to me that it was a good feeling to be around people you've known for a while and that you don't have to explain everything to. Also, the fathers of D4SK all had older disabled children, the youngest being thirteen years old. If there had ever been a time when they needed to communicate their experiences and educate themselves, that time had passed.

I began spending time with two other fathers that I met through D4SK: Wayne and Greg were both white males in their mid-forties. Wayne was divorced and shared custody of his two teenage boys who were both diagnosed with autism as toddlers. Greg was married and the primary carer for Mia, his teenage daughter who suffered a brain injury from a serious car accident when she was younger. One father declined participating because his partner disapproved of him sharing the more intimate aspects of their lives as carers. Given these meetings were attended by middle-aged white men, I often wondered how themes of race and privilege figured into issues around access and participation. However, the low attendance rates and close acquaintance between the members gave me little grounds for a sociological analysis of this kind. However, I do embed discussions of race, class and income in a vignette in Chapter 7.

After three weeks, I realised that D4SK's potential to connect me with others had been stretched to its limits. So, I contacted a council member from the Arizona State Planning Council for Developmental Disabilities I met during a meeting a week earlier. She put me in touch with Karen, the Director of Programs for Partners in Leadership, an organisation in southern Arizona that provides training programs for parents of disabled children. Karen provided me with a list of fathers who had been involved in their training programs and

also sent out an announcement about my research to those on their electronic mailing list. Raul contacted me shortly afterwards expressing his desire to participate. He was a self-identified Hispanic male in his late fifties. He had retired a few years back and was now the primary carer for his thirteen-year-old daughter, Mia, who was diagnosed with cerebral palsy. He lived with Mia and his wife in Laveen, an agricultural community southwest of downtown Phoenix.

There were others who reached out also. During the first couple of months I invited several fathers out to breakfast or lunch and interviewed them. However, these men didn't have time to spare beyond these meetings and so many of their stories have not made it onto the pages of this thesis. In those early months, I also reached out by phone to three fathers I was familiar with through reading their online blogs or published essays. All three agreed to participate. I looked up Scot, a white male in his late fifties, after coming across a published essay about his experience caring for his autistic daughter. He was living in Tucson with his wife. During our time together, they were still raw with grief from the loss of their daughter, who died the previous year from kidney disease at the age of twenty-seven.

I was familiar with Paul and Ethan because I had been reading their online blogs describing their experiences of caregiving since before I commenced graduate studies. I was excited to enrichen what I had already come to learn about their lives. Paul, a self-identified Jewish American male in his late-fifties, was living in Brookline, Massachusetts, the primary caregiver for his daughter, Pearl, who was now in her early twenties. Paul also had a son, close in age to Pearl, who was living in a residential school. His son and daughter had both been born with the same rare genetic disorder. Ethan, on the other hand, was living in Columbus, Ohio. He was a white male in his early forties living with his wife and two children. Ethan was a stay-at-home father for his youngest son, Jack, who was diagnosed with autism. While Paul and

Ethan lived in the Northeast and Midwest, a fair distance from my other participants, in the southwest, I was happy to make the trips back and forth, and for the intimate, extended stays with them that the distance between us encouraged. My movement between these locations was contingent on my participants' availability. I made several trips to the Midwest and Northeast, sometimes staying for a week or two before flying back to Phoenix.

While fathers were my primary focus, I also spoke with partners, wives, siblings, friends, teachers, home health aides and therapists who were present during different activities. They described their experiences with disability and talked about their relationships with my participants, which helped deepen my understanding of my participants' social world. It is worth noting that there are a range of other demographic and social differences among my participants not reflected in the above description. Some parents have undergraduate or graduate degrees, while others served in the military or pursued trade school. Some parents were living pay cheque to pay cheque, while others made 100,000 USD per year. Their backgrounds and experiences are very diverse.

Access to field sites is one of the greatest methodological issues written about in conducting ethnographic fieldwork. When I consider this, I think of Ethan's words to me on our last day together that if I wasn't a carer myself then he may not have been comfortable spending time with me. In my case, I feel like my status as a father of a disabled child helped mitigate many of the methodological problems described by researchers with regard to access and acceptability. In the case of Ray, Ethan, and Paul, I was welcomed into their homes and workplaces, and afforded the opportunity to shadow them for stretches of time, observing them individually across situations and activities.

At times, however, my insider status gave rise to limitations or problems. For instance, because I was younger than all the fathers and at the beginning of my journey as a caregiver, these relationships were sometimes imbued with paternalistic undertones. While my role as a young father fostered the kind of

intimacy that gave me access to the intimate spaces of their homes and lent itself to the kinds of emotional self-disclosures I was after, my shifts in identity from father to researcher sometimes jarred with their expectations at times, which had a cooling effect on relationships. Here's an example: Ray, who was crucial in facilitating my introductions early on, aligned his passion project (gathering testimonies from men that spoke to the power of positive fathering) with my research. He asked me to record my conversations with parents so that he could upload them to his website as a resource to help other fathers. When I reiterated that his agenda was quite different from my own and justified my refusal by explaining my methodological concerns with being followed by a cameraman and how I believed it would impinge upon the privacy and conduct of those I was spending time with, he withdrew from contact with me. At the time, I was reminded of Mead's words, "The fieldworker is wholly and helplessly dependent on what happens ... one must be continually prepared for anything, everything—and perhaps most devastating—for nothing" (1977: 25).

The tension between us lasted two weeks, during which I made the decision to reach out to fathers from outside the support group. This situation was anxiety-provoking for me and I found myself reacting strongly to Ray's micro-aggressions. I can remember my feelings of ambivalence—the anthropologist part of me wanted to reach out and reconcile things by offering to conduct interviews for his website—with the caveat that they were in no way related to my own—whereas another part of me felt wronged and mindful of the paternalism at play. This event was cause for further emotional introspection and made me realise that my feelings were irrevocably tied to my past, growing up under my father's paternalism and abuse, which I discuss more in Chapter Five. Thereafter, emotions became integral to my methodological inquiry for their epistemic value. I began journaling my feelings and discussing them with my partner, which helped deepen my understanding about how my emotions influenced my interpretations of others and separate

my own experience and concerns from those of my participants. Furthermore, contemplating these emotions during fieldwork gave birth to new lines of thought and inquiry. For instance, this episode with Ray drew my attention to gender-based styles of communicating and relating to others, which I also discuss in Chapter Five.

Individual-centred fieldwork in various North American cities also shaped the degree and intensity of access. There were stretches of intense and intimate contact where I shadowed my participants for hours or days, followed by quieter stretches of time punctuated only by coffee and lunch dates. I spent these quieter times writing, organising my notes, transcribing recorded conversations, and hanging out with my family in and around Scottsdale. My initial plan had been to examine how fathers share and exchange knowledge as carers in relation to a place-based community. My renewed focus on singular individuals, however, to borrow Piette's words when he writes about existential anthropology, involved a "shift away from socio-perspectivism" with a view of reincorporating details "into an anthro-perspectivism that seeks to describe human existence, its continuity in time, outside of the traditional sociological models of constraint, rationality, strategy or communication" (2015: 67).

My field slowly emerged through time around the individuals who invited me into their lives. Therefore, my field was found rather than something objectively existing (Hines 2015). As such, it is comprised of individuals who share a common history with relation to their children, a history that speaks to the negative cultural value ascribed to their children's embodied differences and their separation from able-bodied culture. My field consists of people who share identities as carers, identities that generate the kinds of motivations and loyalties that constitute communities, whether they are interacting with each another or not (Brunt 2007). It is not uncommon to hear people ask about men who cannot cope with the demands of caregiving and abandon their families. That so many are curious about this phenomenon is an interesting finding. I did

not, however, conduct research into this population because my research is tightly focused on how fathers create habitable worlds after disruption; a topic far less underexplored in my opinion than the former.

Fieldwork

I carried out fieldwork for seven months, from June 2015 until Dec 2015. During my second meeting at IHOP, as noted earlier, there was a moment when Ray was embroiled in an intense but friendly argument with another member of the group over the politics of whiteness and race relations in America, all the while feeding his adult disabled son a plate of pancakes, communicating and being attentive to him through minor gestures of care. This observation marked a theoretical and empirical turning point for me, and slowly and increasingly these minor details became the focus of my field notes. Piette refers to gestures and actions that fall outside the primary interaction and what is expected by other interactants as the “minor mode of reality” (2015: 40). According to Piette (2015), these are individual details that are particular and unfold against a backdrop of coordination, but are not generalisable to the social and cultural dimensions of existence. They “widen the field of details to be described and considered”, he says (ibid: 40). These early meetings prompted a shift in my focus, away from a concern about how fathers of disabled children support each other and share, exchange, and negotiate knowledge, to a focus on these minor details and what they inferred about the individual and their changing experience of caregiving and disability over time. That is to say, my focus shifted to an anthropology of human beings (Piette 2015).

I share existential anthropology’s commitment to exploring the empirical lives of ‘actual people in everyday situations’ (Jackson 2013: 9). Larger philosophical concerns motivate this research, and like other anthropologists within the tradition of existential anthropology, I hope to lend empirical data to

philosophical questions and ideas concerning human essence and existence, choice, action, and freedom. Like Piette (2015), I use the term phenomenography to describe my research methodology. According to his usage of this term, this process involves “a focus on human beings, their actions, gestures and states of mind, taken separately and tracked from situation to situation” (2015: 46). What is sought, Piette goes on to say, “is a balance between closer or more distant perspectives, in order to observe and write a description of existence, and not just of one activity, situation or event” (ibid). To get insight into how the men in my study continue and exist over time after the disruption of having a disabled child, I realised I would have to pay attention to particular moments and how they were anchored in and connected to other moments. Consequently, I shadowed my participants individually as a participant observer, attentive to individual’s moments of being, in addition to attending public events, support meetings, and parent-teacher conferences.

First of all, a few theoretical clarifications are needed. According to Piette, human presence is made up of a volume of details including those that are as unimportant to the people who carry them as they are to their fellow participants (2015: 39). He describes the “reality of action” as, on the one hand, “a body in the process of moving, accompanied by sideways glances and peripheral gestures, and on the other hand a state of mind that has nothing to do with the action in progress” (ibid: 40). These details make up the minor mode, he says, “which is neither a general action, nor a particular type of activity” (ibid). Instead, they are modes of “being present” in one’s action, as he puts it, that release individuals from the action without disengaging them (ibid). By paying attention to the minor mode, Piette makes the object of his study the lesser details that he says often fall outside of the socio-cultural dimensions of existence that researchers take to be the central conditions of belonging (2015: 232). Instead, Piette’s brand of existential anthropology recasts the focus away from the intersubjective dimensions of existence towards

observing singular individuals with a view to compare beings in the process of existing. For me, these particular details of existence hinted at personal histories of practice and people in the process of living with their children; not just to the kind of automaticity related to habits and practices, but also previous experiences, states of mind, feelings, and other aspects of consciousness, including self-experience, temporality, and memory, that comprise our unique existence moment to moment. I came to see silences, laughter, gestures, pauses, inconsistencies, affective dispositions, etc., as entry points into understanding the details of existence resident in experience and action.

I began writing fieldnotes everyday in my phone, which I found less obtrusive than carrying around a notebook. In the evenings, when there was time, I fleshed out my notes of the day into unfettered detailed portraits, including as much detail as possible so that I may go back later on and recover details that seemed unimportant at the time. I also took photos and collected other debris I found around me: like scraps of paper with jottings, etc. With permission, I recorded random conversations and augmented them with written descriptions of the finer details I observed. This has allowed me to represent longer conversations verbatim in some places throughout this thesis and describe interactions with their accompanying gestures, movements, speech idiosyncrasies and other individual peculiarities.

As mentioned above, shadowing also formed a crucial part of my methodology. This is when “a researcher follows a person as his or her shadow...throughout his or her different activities, to collect detailed-grained data” (Meunier and Vasquez 2008: 168). While this is typically carried out as an act of non-participant observation (Piette 2015), I performed this method as a participant observer with Paul, Ethan and Ray, at times, participating in their activities, at other times strictly observing. Shadowing took me into particular spaces and times I may not have had access to otherwise, for instance, their homes and workplaces, during night time and work meetings. As in all

fieldwork, I benefited enormously from people's generosity, and in Paul's case I was invited to stay in his home during fieldwork visits to Massachusetts.

Like other forms of participant observation, shadowing helped me, as the old anthropological adage goes, distinguish between what people say they do and what they actually do. Again, I believe my own status as a carer and father reduced some of the psychic discomfort that is sometimes identified with a sense of intruding on people's private lives (see Czarniawska-Joerges 2007). Having said that, fieldwork was not without its moments of discomfiture, such as when unexpected private details about my participants revealed themselves, or when my participants' feelings and perceptions threatened to negate my own self-perceptions. These experiences prompted productive moments of dis-ease: introspective moments that permitted me to explore my sense of unease, which helped deepen my understanding of myself and of other selves in interaction.

While my presence may have, at times, provided a distraction from people's usual involvement in things, shadowing enabled me to observe my participants across a range of moments and situations by themselves and with others. This permitted me to track people's actions, feelings, patterns of behaviour, motivations, dilemmas, and struggles from one situation and/or activity to another, across what they perceived as events to what they perceived as non-events. This approach has a couple of advantages. Importantly, as Piette identifies, it helped me develop insights into how the meanings of different situations fit within the longer-term framework of people's biographies (2015: 48). For instance, continuously tracking my participants individually from one moment to the next helped me understand their feelings of continuity and change between different moments and situations, and the meaning modalities that link them and modulate our existence.

In order to help me achieve this understanding, I documented my interpretation of people's moods, gestures, facial expressions, affective dispositions (affect-based responses to things) and supplemented these

observations with their retrospective commentaries on what I had observed. Sometimes, my interpretations of their reasons and intentions for acting were confirmed, while at other times these commentaries yielded surprising discoveries in relation to what people were thinking and feeling. Sometimes contradictory and/or inconsistent details emerged during these introspective explications speaking to changing self-states and what Beauvoir (2011) would see as the irreducible ambiguity of existence. This methodological detailism (a focus on the details of existence) has heuristic power: These presences, while seemingly inconsequential, i.e., feelings and thoughts that contain traces of other experiences, can appear as catalysts for later decisions and are “generators of various consequences” (Piette 2017: 183).

Let me give an example. One afternoon, I went for a ride along with Fire Station 607 in Scottsdale, Arizona. The crew was comprised of four men: two paramedics and two EMTs. I sat in the back between Ray and the other paramedic, Marty. The two EMTs rode up front, Addison steering the truck, Glen riding shotgun. I was listening to their banter through the headsets which allowed everyone to communicate over the hum and vibration of the tyres blazing over the scorched freeway.

‘My kid’s room looks like a homeless shelter’, Addison said. ‘The rest of the house is immaculate because I’m so fucking OCD, but his room looks like a homeless shelter. So, when I get home the first thing I do is close his bedroom door. I can’t look at it. That shit makes me anxious. He works his ass off at the Home Depot but doesn’t do anything at home. They told me he works hard, and I said, I’m glad he works somewhere because he doesn’t do shit at home’.

‘Right’, Glen joined in, ‘Damien just conserves as much energy as he can for work’.

Addison and Glen laughed together.

‘How old is he now?’, Marty asked.

‘Too old to be at home’, Addison said jokingly, bouncing up and down on the seat.

‘I’d like to move to Colorado when the time comes’, Glen announced.

‘Oh, Colorado is beautiful’, Addison said. ‘We’d like to move east, escape the heat, you know’.

In that moment, something that felt charged passed between me and Ray. Maybe I was waiting for something to happen, attuned to the conversation’s potential resonance with Ray; maybe I was aware of the way seemingly small things said and done can sometimes make implicit things matter. Ray cast his eyes downward and an expression of mild consternation flickered across his face. Then he looked up and smiled and said, ‘Say, did I tell you guys Congress called...’

Much later, I asked Ray about this day and he had trouble recalling it. But he told me that he finds it difficult to hear people discuss vacations and retirement plans when it’s unlikely that as caregivers he and his wife will be afforded the same freedom. Another year later, over the phone, Ray told me that Zachary was finally, at the age of twenty-seven, transitioning into a residential facility. He and his wife were thinking of moving to the east coast for a while.

As Stuart writes, “Ordinary affects are the varied, surging capacities to affect and to be affected...that catch people up in something that feels like *something*” (2007: 2). At a phenomenological level, my description and observation of Ray’s presence – glimpsing his expression and experiencing it as meaningful – speaks to the experiential character of accessing and directly perceiving social others. Ray’s expression was expressive of experiential life, of feelings and states of mind that make up the act of existing. In this case, his sadness and longing were given in expression– invested with meanings wedded to an unexpressed context of mutual understanding of norms around retirement – and later verified verbally. After fieldwork when I learned of

Zachary's transition out of home and Ray's plans to travel east, I thought back to this moment on the firetruck and its connection to the present.

Another methodological and ethical aspect to the way I went about fieldwork for my project involving experiences with disabled children has to do with the way I approached the subject matter of disability. At one time, for instance, Ethan expressed his concern for how his son would be represented by me. I was not interested in casting disability as pathology or profiling the various impairments of individuals (although these are mentioned). Rather, I eschewed the medical paradigm because a view of disability which constructs the identities of children with cognitive and physical impairments in terms of particular deficits unwittingly ties the experience of parents and children to medical and therapeutic spaces. I wanted to focus instead on the relationships between parents and children and how children appear to their parents in perception and experience and how parents experience themselves with relation to their children. This focus was important for shedding light on the intimate personal knowledge parents acquire of their children through caregiving. It was also important for exploring parents' intuitions about their children's social experiences.

Writing Worlds

Up until this point, I haven't said much about my dual role as a carer and researcher. This autophenomenography is grounded in my own perspective and experience as a carer as much as it is in the concrete lives of my research participants. With regard to this focus on my own lived experience of disability and care, this form of research can be considered autophenomenography¹⁰. From its inception through to its conceptualisation and written form, my

¹⁰ In this form of research, Allen-Collinson says the researcher analyses their own experience of a phenomenon rather than their cultural or subcultural location, as is often the case in autoethnography (2016: 293).

presence pervades the details of this text. My familiarity with the lived world of caregiving gives me direct insight into the mundane activities that comprise giving care, as well as the pain, conflicts, and intimacy it brings into play. Through caregiving, I am aware of the way it can call us to be present in new ways and enhance life's meaning while at the same time, in the words of Kleinman, expose "troubling truths about what it means to be human" (2010: 17). I experienced the disruption that comes with having a child that falls outside of what is considered species-typical, an experience which served as the springboard for this research. But through caregiving, I have also come to know new meanings, emotions, and moral experiences that have changed the way I understand myself and those around me. These disclosures provided me with valuable insights and guided my approach throughout the various production stages of this thesis.

It seems to me that the lives of carers in the context of giving care to disabled children are often understood with relation to certain social, political and cultural contexts¹¹, as shown by so many studies in the social sciences already. Rarely, however, do these studies delve into the deepest centre of the human person and the personal and spiritual resources that enable carers to act on their worlds and sustain themselves in the face of disruption. I knew caregiving as a deeply human experience, freighted with discontinuity, competing desires and commitments, and established on the grounds of "choices already made, a past already lived, roles in which we find ourselves" (Frierson 2013: 243). In this thesis, caregiving also emerges as an experience profoundly connected to the existential possibilities that, to borrow from Heidegger (2010: 11), we choose, grow up in, stumble into, or develop over time. As I will go on to show, these possibilities are grounded in how carers

¹¹ I have in mind here the way public available discourses of disability and identity and various social and cultural expectations and practices are often taken by researchers to be the central features of parents' lives.

understand themselves across time, their affective ties to their children, and the full range of meanings, memories, perceptions, feelings, thoughts, and actions available to them. I believe these existential possibilities go a long way in explaining how responses to caregiving differ across individuals.

To my way of thinking, it is near impossible to stand outside the worlds we inherit and build ourselves into. That is to say, our observations, interpretations, and the theories we tend towards can never be neutral or value-free, “every effort of understanding must take off from our actual situation, the point at which we stand”, as Barrett tells us (1962: 4). Or, as Ratcliffe puts it, the philosophies we are geared into and propositions we assent to are driven by different existential concerns and feelings, therefore, our pre-reflective orientations make some lines of inquiry more enticing than others (2008: 253). For instance, I find moral and political theories that posit personhood on the grounds of certain psychological capacities especially troubling because they are not commodious enough to include my son and others like him in the spectrum of valued humanhood. Furthermore, I am suspicious of theories that posit our radical freedom in making the worlds we choose because they conceal our Other-regarding tendencies that serve our own interests and limit the freedom of others (Hatab 2000). In this thesis, we will see the ways parents’ projects, intentions, feelings, and desires exceed and transform the conditions upon which they are “thrown” in time, while always being situated by them (Jackson and Piette 2017). These thematised presuppositions partly explain my interest in existential philosophy and desire to explore those regions of human existence that go beyond the knowledge we acquire through reasoning.

This embodied, situated perspective problematises the key phenomenological method *epoché* developed by Husserl (2014). The *epoché* requires a shift to a reflective attitude wherein one attempts to suspend the everyday, engaged natural attitude towards reality, with a view to investigate and arrive at how the world and objects appear in our experience with the

meanings they have (Gallagher and Zahavi 2012). This raises the thorny question: If we always already live with understandings and interpretations, how can we suspend what is given in our experience? I don't believe this is entirely possible or even desirable, for the reasons I have mentioned above. However, to take matters at the practical research level, autophenomenography calls for critical, exploratory, and interpretive engagement.

From early on, I kept a reflective journal of my experiences and feelings. But unlike some researchers who may do this in an attempt to bracket their values and biases, so as to avoid imposing them on the research process, my own experiences and personal assumptions were key contributors to the interpretive process. I took notes of both a descriptive and reflective nature during fieldwork and post-fieldwork phases. In these notes, I focused on my own lived and interpretive experiences of disability and care, as well as those with relation to my research participants. These reflections and their relevance were continually brought into dialogue with my participants throughout our time together, which was helpful in identifying conceptual differences between our experiences which provided the basis for thinking about our different identities, pasts, and desires. In some cases these conversations (via email and text messaging) extended into the write-up phase. Therefore, the perspectives and insights that inform this thesis emerged through a process of co-creation between researcher and participant (Gadamer 1975).

This open-ended circle of inquiry and analysis remained an important part of the process during writing and revising this text also. So, while these inter-related interpretations, reflective writings, and academic concepts helped me understand human experiences of care (both my own and my participants'), my ongoing experience in the world post-fieldwork also deepened my understanding of these experiences and the theoretical concepts I draw on in this thesis. As Kohn writes, "ethnographic data may be perceived as a living and growing beast that travels the globe and is reframed, retamed, reanalysed

within the researcher's shifting consciousness that a growing maturity and changing relationship to 'the field' afford" (2010: 193). For instance, nearing the end of fieldwork I became seriously ill with Lyme disease. My experience of relational disability shifted to an intimate first-person perspective. Of course, the experience of disability is diverse and varied across individuals with relation to one's existential situation and the particular features of one's disability. My lived experience of suffering and medical marginalisation, however, gave me a new appreciation for what Jackson (2017: 171) describes as our existential imperative to act on the world, and what Kleinman describes as the "unequal struggle between where the world is taking us and where we aspire to go" (2007: 17).

As such, a new light was shone on my fieldwork material which allowed new threads and insights to emerge. During fieldwork, for instance, I found Merleau-Ponty's idea of the lived body helpful in understanding and describing parents' experiences and actions because, as we will see throughout this thesis, bodily knowledge and sympathetic perception play a central role in providing care. My experiences after fieldwork, however, gave me a more explicit sense of the ways we continually move from our future to our pasts in making meaning and creating lives that we deem liveable. Thus, I began to engage with Heidegger's thought concerning temporality and gained a deeper appreciation for its different articulations in experience. My ongoing experiences and reflections, then, helped shape the way I understand Heidegger and in turn, Heidegger helped me make sense of my experience with illness and caregiving. As Kohn notes, "Our [ethnographic] findings...are reframed by our own developing sensitivities and interactions with other people and other 'fields'" (2010: 197). Through a sharpened appreciation for the way earlier experience and acquired knowledge develop over time and serve as a continual background to experiential life, I began to see new threads in my fieldwork material emerge. I gained a deeper appreciation for parents' recollections and

memories, and the ways they act and interpret their lives in accord with the openings and connections they afford.

The stories told throughout this thesis are rooted in the details of actual experiences, and so I have tried to stay as close as possible to these details. That is, I have tried to describe “human beings as they exist”, rather than exploit the details of experience in service of theory (Jackson and Piette 2017: 25). In existential anthropology, Lucht writes, the dilemma is how to capture significant life events without “sacrificing lived reality in the lifeless embrace with one’s logical concepts” (2017: 123). This approach, I believe, justifies my descriptive approach and the creative techniques I use. Smith et al. describe creative nonfiction as a genre of writing that is “fictional in form yet factual in content” (2015: 59). This literary hybrid has resonance with what Geertz referred to as ‘faction’: “imaginative writing about real people in in real places at real times” (1988: 141). This genre of writing goes back to the New Journalism movement of the 1960s (Wulff 2015) and has been used by anthropologists as a strategy to tell emotionally compelling stories and make anthropology accessible to audiences beyond academia (see for instance Stoller 2009; Angrosino 1998).

Since the 1980s ‘writing culture’ movement, ethnographic texts are now widely accepted as “partial fictions”, that is, truths that are “inherently partial–committed and incomplete” (Clifford 1986: 6). Given the complex nature of truth, then, there is contestation over exactly what constitutes creative nonfiction in anthropological writing. While the genre of writing is sometimes seen as a spectrum that includes fictional texts (for instance Bandelier 1890), when I think of this genre of writing, I think of texts based on lived ethnographic experience that use creative techniques for purposes of evocation. This is what I mean by the term creative nonfiction. I employ this approach to writing in different ways and for different reasons throughout this text. In some instances, I have drawn on my fieldwork material to weave a creative narrative

that condenses large swathes of information and action into a digestible portrait. In these vignettes, I have taken more creative license than anywhere else in this thesis, and as such I use a footnote to alert the reader that they are reading an account that consists of certain creative flourishes and minor embellishments in order to protect the identities of those involved, as well as for purposes of narrative linearity and coherency—And also, if I may add, to reveal the heartbeat of the story.

In other instances, I render descriptions that are true to my participants' empirical lives and my own fieldwork experiences, but I use fictional techniques and storytelling for the interpretive openness this style of writing displays. Rather than pinning down moments by imposing a particular definition or analysis of reality, in these sections I focus on emotions, atmospheres, and states of mind to describe particular moments as they appear to and resonate with the people concerned. As Smith et al. note, creative nonfiction can offer embodied, sensuous, and relational accounts of human lives which invite readers to vicariously inhabit another lifeworld or spur them to see the world from another perspective (2015: 63). With relation to the disabled children in this study, I employ these literary devices in an attempt to do service to their lives and the dignity of living without language and other capacities that are often taken to be the hallmark of humanhood. Of course, by not providing the reader with an explicit analysis there is a degree of control I surrender over how the text will be interpreted by the reader. In my view, however, what is potentially gained through this style of writing exceeds the corresponding possibilities of misinterpretation or over-simplification.

Autophenomenography, as mentioned above, refers to a focus on the researcher's lived experience of a phenomenon, in contrast to a focus on their location within a sociocultural context – even though, as Allen-Collinson points out, these categories are not mutually exclusive (2016: 293). Engaging my lived bodily experiences of care was as much a part of the fieldwork process as it was

writing-up. At times fieldwork and writing were challenging and revealed at different times aspects of my past and ambivalent experience of care which forced me to confront contradictions and ambiguities within myself. By casting an analytical eye on personal habits and assumptions, repressed feelings and motives sometimes erupted to the surface, alongside other aspects of my historical situation which were brought vividly to consciousness, for instance, how my own actions are implicated in reproducing oppressive social relations.

These feelings emerged from my autophenomenographic material as the dramatic substance of my reality, the temporal and contingent features of my life as a carer. Throughout this thesis I have tried to be as open and honest as possible about these experiences. Because I view myself as a part of the community I describe, these self-disclosures raised important questions in relation to my participants' experiences also. In order to nurture these findings, there are times when I adopt a critical conception of culture and zoom out to pan the ideological constructions and power-laden institutions that exert influence over the ways the men in this study experience caregiving (Chapter Four & Five). Like Ellis, in my writing I attempt "to integrate physical bodies, feelings, talk, motives, actions, and face-to-face interactions" (2009: 15). I care deeply that this thesis has the potential to contribute to the ways we understand embodied difference and the role our interactions and bodies play in dilating our sense of selves and possibilities in relation to others.

A word on definitions

Disability

There is a lot of variation in the way disability¹² is defined and approached. In this thesis, I approach disability from a phenomenological perspective that considers the body-in-the-world. By drawing on my experiences and the

¹² See the Introduction of Stevens (2013) for a good overview of these definitions and approaches to disability theory.

experiences of my participants, this thesis illustrates a second-person phenomenology of disability. As we will see throughout this thesis, parents' caregiving experiences emerge in relation embodiment and the particularities of their children's embodied lives. The parents in this study are caring for children whose bodies and minds depart, quite radically, from what is considered socially and culturally normative. Therefore, I approach disability as an intrinsic condition of human existence which is irreducibly connected to both the way the world is disclosed through our embodied existence while, at the same time, being irreducibly conditioned by the world we are in (historical and social context, environment, relations of power, disabling barriers, cultural values, etc.). There is resonance here with what disability studies scholar Shakespeare has called a "relational approach" to understanding disability, one that shows the interrelatedness of both intrinsic and extrinsic factors that constitute disability (2006: 57).

Fathers, parents, and Caregivers/Carers

The approach to disability I have outlined above also informs the way I use the terms fathers, parents, and caregivers throughout this thesis. A methodological focus on bodiliness throws light on fathers' experiences of male embodiment. From an existential phenomenological perspective, "life both repeats history and departs from it" (Jackson 2017: 163). As Jackson tells us, we are always shaped by circumstances beyond our control—Our genetic and cultural inheritance, class, ethnicity, gender, etc. (ibid). In Heideggerian terms, this is the thrownness of human existence. In this regard, I consider dominant gender norms and practices as elements of culture and, therefore, factual conditions of existence. These gendered dimensions of existence, to borrow Barret's words, form the burdens and tasks of life, "and there is not a part of its warp and woof into which they have not entered" (1962: 109). So while it is arguable that fatherhood and manhood are separate constructs, I find at the level of lived

experience they are not so easily teased apart. Therefore, I have tried to be sensitive to the ways I use the terms fathers and parents/caregivers throughout this text. For instance, when I am considering phenomena where gender differences seem inconsequential, I refer to the experiences of parents and caregivers (or carers) to avoid the gender connotations associated with fatherhood – for example, the workings of memory, sympathetic perception, and affect are hardly the exclusive province of men. Primarily, then, I use the term ‘fathers’ when considering the gendered dimensions of existence or else when referring to the empirical realities of the men who are the subject of this research.

Conclusion

As mentioned above, this thesis represents my own experiences of caregiving alongside those of my participants. My description of the variety of experiences that carers live through in disruption and creating habitable worlds reflects my own movement through these layers of understanding (not in any linear order), therefore, there are parallels and correspondences between stories and experiences that reflect personal and shared worlds of disability. There were experiences that resonated with me strongly during fieldwork (for instance Chapter Four and Six), while other types of experience revealed themselves to me more slowly over time with relation to my own movements and changing perspective (see Chapters Three, Five and Seven). I begin this thesis in the next chapter by focusing on memory and the experiential quality of key moments in carers’ lives. I hope to set the tone from the outset by beginning with a chapter that illustrates how phenomenal worlds of care are given shape by our movements through time and relations with others, alongside our past experiences, feelings, and frameworks of reference. As I go on to show, these changes in self structure our memories and illustrate the process of movement

and becoming that characterises existence more broadly, and makes existential disruption liveable.

Interlude: BBQ

The unrelenting Sonoran sun beats through the windshield onto my bare legs. I'm sitting in the passenger's side next to Wayne. Wayne is in his late forties and is dressed in his usual attire: cargo shorts and a plaid short-sleeve shirt. His thick grey hair is combed to one side. His boys, Noah and Nick, sit in the back. They both have short dark hair and alabaster skin. Noah is fourteen and is all arms and legs. Nick is ten and has retained his boyish cherubic features despite being tall and solid for his age. Nick stares out the window silently, while Noah leans forward in his chair to ensure he is a part of our conversation. Wayne tells me that we are on our way to their favourite BBQ joint.

'How are you going?' Noah asks in his best imitation of an Australian accent.

'That's not bad', I lie.

'He's way better at it than I am', Wayne laughs, as we roll down streets lined with stucco houses and pebbled lawn scattered with succulents in a beat-up white mini-van. Wayne has a calm demeanour and speaks in a soft and careful way.

'We used to watch this comedian, Frank Caliendo, he does these impersonations', Wayne looks at Noah in the rear-view mirror, 'it's been at least a year since we've seen that, right?' Noah nods in agreement. 'Yeah', Wayne continues, 'we used to watch it all the time and it was just so funny. And Noah could do such a great job with these voices'.

'Impersonating the impersonator', Noah interjects dryly.

Nick says something but it's indistinct.

'What Nicky?' Wayne glances in the rear-view mirror but Nick is staring out the window, his eyes transfixed on the passing scenery. 'Oh, you're just talking to yourself? Alright'. Wayne returns his gaze to the road. 'He was doing all these voices of people he didn't even know. He could do, like, Al Pacino—'

A raspy Pacino phrase emanates from Noah. Wayne's lips stretch into a proud smile. He giggles quietly, humoured by the uncanny ability he thinks his son possesses.

'Oh yeah, all these huge famous Hollywood types to sports announcers, he would do such a great job'.

'You guys watch a lot of movies?' I ask.

'Oh man', Wayne responds, 'we are movie junkies. Ever since he was little'.

'I know that if Michael Bay did it, it's probably bad', Noah adds.

'That's not necessarily true', Wayne says.

'Ugh...I guess Armageddon wasn't bad'.

'They might be over the top but they aren't necessarily bad'. Wayne's face lights up, 'you better hope his next one is good because you know what his next one is, Noah?'

'Transformers Five', Noah answers, deadpan.

'Isn't he Star Wars?' Wayne looks confused.

'No, no', Noah gently corrects him, 'that's J.J. Abrams'.

'Oh yeah, yeah, yeah', Wayne concedes.

We roll into an empty parking spot outside a family-style BBQ restaurant. I climb out and the still and pitiless mid-afternoon heat engulfs me. Wayne takes Nick's hand as we make a beeline for the restaurant's entrance. It's an unfamiliar sight, to see a grown man holding hands with a child Nick's age—especially when the kid is as robust as Nick is. Moments later, I am greeted by the aroma of BBQ meats and 'blessed Billie', their favourite head waitress. Billie beams at us from behind the front counter. She is a woman in her sixties with shoulder length dirty blond hair. She's wearing a pair of light blue denim jeans and a black t-shirt bearing the BBQ joint's logo.

'How are my boys?' she asks, coming out from behind the counter to embrace Noah and Nick.

The joint is empty, which isn't surprising for 3pm in the afternoon—It's either too late or early for most to indulge their carnivorous appetites. Free-standing chairs and tables are scattered throughout the restaurant. Booths with soft upholstered seats line the walls. A large board above the counter displays menu items and to the side of that there are authentic pictures of the combo meals on offer.

Noah introduces me as 'Mr Australia'. Billie brings over a small plate with a selection of BBQ meats to help me decide what I feel like for lunch, and so I begin sampling the smoky-assortment. Wayne explains the significance of the BBQ joint: This is the place where he first attempted to diversify Noah's 'fussy' self-imposed diet by having him try a different menu item each week.

Billie tells me she has a teenage grandson who is sixteen and is 'on the spectrum'. He is just about to start school for the first time, she says, after a lifetime of home-schooling.

We all sit around a green vinyl booth. Noah sits by the window to my left. Wayne and Nick sit opposite us. Chicago paraphernalia adorns the wall in front of me: A gridiron helmet, a Chicago Bears flag, a framed picture of Chicago's cityscape from the bay. No time seems to have passed before Billie reappears with our lunch: pulled- pork buns with coleslaw, fries, and green pickles, served on checkered wax paper. Nick begins eating and mumbling to himself. Wayne leans in close to Nick and quietly whispers, 'are you OK?' Then Nick rests his forehead against Wayne's and they remain that way for a moment.

'Both my boys are growing like weeds', Billie beams.

Wayne repeats to me that Billie has a grandson on the spectrum. I ask if that's how they got to know each other, and Billie says, almost defensively: 'I loved them as soon as I met them'.

'Yep', Wayne says, 'she adopted 'em right away'.

Billie tells me that the second time she met Nick she got bruised. 'He pinched me hard', she explains, 'I was like whoa! Nearly dropped me to my knees because he's so strong'. As she says this, I trace my fingers over the patch of inflamed skin on my arm where Nick pinched me an hour ago.

Billie tells us that a regular customer, by the name of Chris, revealed to her the other day that he has a severely autistic son. Billie tells us she said, 'why didn't you say anything', to which he had said, 'I don't know. It's rough'.

Wayne starts to talk about autism rates— one in sixty-something—and Billie talks about cancer rates. I spill my soda everywhere and Billie tells me I'm French because I talk with my hands. Noah starts laughing and Nick stares at me with open curiosity.

‘Nick is just taking it all in’, Wayne responds.

‘Nick isn't fazed by anything’, Noah says.

Nick's indistinct noises grow audibly louder and Wayne gently puts his hand on Nick's leg. Billie asks Wayne about work and he tells her that he was recently laid off.

The place is still empty and we are receiving all of Billie's attention. She brings over some more brisket and gestures for me to eat. She watches my face closely as I sample it.

‘It's great’, I tell her, ‘but if I eat anymore I'm going to burst’.

‘Adam Richards from 'Man Versus Food' was in town recently’, she says, ‘boy, can he eat.’

Noah remarks on how much Nick can eat and Wayne tells us how much Nick loves to eat Raman noodles. Billie kindly rebukes Wayne for allowing the boys to ingest such high quantities of sodium. She tells us that she stopped her own grown-up kids from feeding Raman noodles to her grandbabies.

‘Did they listen?’ I ask.

‘You bet’, she says, raising a tightly-clenched fist.

Billie hugs all of us goodbye this time, and Nick gives her a kiss on the cheek.

On the way back to the van, I follow closely behind Wayne and the boys. Wayne and Nick hold hands and Noah does an impromptu impersonation of someone who is unidentifiable to me. The sun has lost some of its edge and has started its decent behind the mountains.

Chapter 3: The Depths of Time: Past Becomings and Habitable Worlds

Memory is the seamstress, and a capricious one at that. Memory runs her needle in and out, up and down, hither and thither. We know not what comes next, or what follows after.

– Virginia Woolf, *Orlando*.

I was no more than six years old when he hurled Ossie out the second-floor window of his house. Ossie lost both his eyes during the fall. Afterwards, someone filled them in with black permanent marker. I was upset because Ossie was special to me. You see, sometime before my third birthday my parents decided to have my 'wandering eye' surgically corrected, and Ossie had been there for me before and after the procedure. Mum tells me that I am mistaken, and that Ossie was a reward for having the surgery. Either way, that pink Ostrich was comforting. He reminded me of the lonely hospital room, the boy who cried in the bed next to me—whose face has been erased by time—and the nurse who comforted me on her lap. I can only remember her white shoes, that I'm told I threw up on, and how warm and safe I felt in her arms.

My cousin was six years older than me at the time of Ossie's accident. I couldn't fathom what I had done to provoke his actions. He was the same age as my older brother, who rescued Ossie from the shrubs below. Whenever my cousin's actions were questioned, his family invariably responded, "that's just Benji for you." I found Benji's behaviours confusing. He never joined me and his two brothers—they were all within six years of my age—when we played down the creek and around the storm drains. Instead, he would rat us out for playing where we shouldn't be. When I was eight we moved interstate and my friendships and ties with my cousins disintegrated under the distance that separated us. We returned four years later, but by then the passing of time had created a chasm large enough to keep us from ever re-connecting.

Sometime during my prepubescent years my father stayed with my aunt and uncle and cousins for a few days. He returned home with stories of Benji's "creepy" and amusing behaviour. He recounted the way Benji would peer out at him from behind the curtains in the lounge room while he stood outside smoking a cigarette. For effect, he exaggerated his frightened and uneasy reactions to Benji's unusual behaviour, callously mimicking his motor tics and slow and stalling speech. I found my father's uneasiness particularly humorous, I think, because he seemed so invulnerable and invoked such fear in me. Benji's motor tics became a source of material for my own comedic routines which I would perform in front of family members to get a laugh. Benji was different and his difference, at least to me, became something that was either funny or to be avoided. This was the least of my repulsive prejudices, however, and over time they morphed into new phobias: I refused to swim in public pools amongst those with visible disabilities or drink from the bubble tap at school if it had been used by the girl whose face was distorted with burn scars. Other neurotic behaviours emerged too: Lollipops soon lost their appeal because they reminded me of bald heads.

When I was fourteen my parents separated. It was an ugly separation. Weather-worn timber fences are embroiled in a dance of significances and call forth memories from around that time in my life. They remind me of my mother's white slip-on shoes and black leggings, although I can't be sure if she was wearing black leggings when she scaled the fence to escape my father's temper and the large kitchen paring knife he held, or if her love of black leggings has been imposed upon this earlier time. Other rays of the past peek through these timber fences too: I am sitting next to my father at a dining table in his newly furnished apartment shortly after my parents' separation, when he tells me that he *knows* my sister is "slow." This comes as a surprise. My sister is eight years younger than me and since she was a small kid I've known about her learning disability— which affects her ability to do math, according to my

mother. The word *slow* carries so much negative weight, especially with the way he says it. Slow reminds me of Jobe Smith, the simple-minded gardener from the early 90s film *The Lawnmower Man*. I shrug his remark off but I'm deeply unsettled because he says it like he's unearthed a shameful truth that should remain hidden. The truth is, I'm deeply protective of my sister, I've assumed a major role in her life ever since he walked out and distanced himself from us. After his departure, we were evicted. My mother, me and my two younger siblings moved into my Nanna's two-bedroom unit – by then my two older siblings had moved away. He doesn't know that I read to my sister at night or stop her from crying by pantomiming the story to make her laugh.

I would later learn that the stigma and secrecy that had shrouded Benji's disability was also the reason my sister's intellectual disability was never spoken about or understood in its full complexity. I'm not sure why my mother kept her intellectual differences shrouded in secrecy and ambiguity. But I know that there is a twenty-five-year-old cardboard box of paperwork tucked away somewhere containing the diagnostic details she was given by specialists when she was three. Was my father insinuating that there was secret collusion between my mother and me, as though we were Pandoras, determined to keep the lid closed on my sister's differences?

In my early twenties, my partner and I spent time at a children's orphanage in Blantyre, Malawi. Rooms were crammed with cribs filled with crying babies. The air was still and thick with the odour of saliva. A little girl peered up at me from inside a crib and smiled, her eyes sizzling with life. Her energy and warmth reached out and embraced me. Emma was her name and she had cerebral palsy. My time with Emma induced a deep feeling of shame for all of my past bigoted behaviour. Even though disability still felt strangely unfamiliar to me at the time, it wasn't. Through caring for my sister I had already developed a perspective that was sensitive to the embodied differences among us. What I couldn't have possibly known back then was how big a

part disability would play in my life– long after the last details of Emma's smiling face wandered from my mind.

When I was thirty, Takoda was borne. He was my first child and he had blond hair and a deep cleft in his chin that made my Nanna cry because he reminded her of her son– who died from encephalitis when he was a baby. At four months of age Takoda started having multiple seizures a day. There were moments when I thought I'd lose him. By two years of age it was apparent that he had multiple severe disabilities. I grieved what I felt like I'd lost. I experienced a stretch of bitterness over not getting the opportunity to fulfill my imagined fatherly role. But his smile reminded me of Emma's and from early on I could make him laugh the way I used to make my sister laugh. He smelled like the ocean's breeze and his tiny body felt warm in my arms. There was something else, harder to explain: There had always been a void, a deep ache inside of me. It had been a wellspring of discomfort, inducing feelings of homesickness in the most comfortable surroundings. Into this void rushed an understanding and love that was both resonantly familiar and unlike anything I'd known before.

In her study of autism parents, de Wolfe identifies key moments that signal an abrupt change in her participants lives, namely “the diagnosis moment”, “early intervention services”, and “telling family and friends” (2013: 76). Not only do these moments signal dramatic self-changes in parents' lives, according to de Wolfe, but they define the ways parents come to identify with autism through their multiple engagements with the autism label across various spaces and moments. The moments de Wolfe identifies also signalled abrupt changes in the lives of the fathers I spent time with. Although perhaps the word *change* isn't quite strong enough to do justice to the profound disruptive experience these moments speak to. I agree with de Wolfe that by attending to the ways parents experience and reflect upon these key moments we glean insight into how they

come to identify with their child's diagnosis and their roles as caregivers early on. However, parents' embodied emotional histories and incursions of memory lend form to the ways these moments and others are experienced over time.

Ellis (2009) cautions autoethnographers and memoirists to consider the ethical implications of including traumatic moments that involve intimate others in portraying their childhoods. Many of the past moments included in my account above are traumatic and involve intimate others. They are important to write about; however, because they form inseparable parts in the dance of significances that organise my experiences of disability and fathering, giving them their depth, texture, and open-endedness. In the preliminary account above, I've tried to capture both a sense of the significance of memory and its ongoing becoming. In this section, I treat memory, imagination and reflection as causally interdependent in the ongoing flux of perception and experience. This "fact of being constantly in touch with both the future and the past" (Wahl 1971: 18) makes possible a world that significant to the individual and in perpetual movement.

Notice, in writing about my memories I have structured them in a way that brings forth a sense of continuity. While it is possible for me to reflect on these past moments separately, here, they form parts of a narrativized whole. These memories and memories-within-memories have been woven together around certain significances concerning care, stigma, and disability in my life. However, it is not in the act of detached recollection, that is, within a reflective and analytic attitude that these memories have been regathered, reconfigured, assembled, and furnished with meaning – although in some instances this is the case. Rather, throughout the course of caring for my son it feels as though these past moments have gained their own identity. They articulate themselves as the most durable, memorable, and significant, furnishing my ongoing experiences of fathering and disability with meaning and an inexhaustible depth. This speaks to an implicit self-consciousness that underpins our subjective

experiences of selfhood across time, and the way modalities of experience are always already coloured by significances that are at once idiosyncratic and inherited by family, culture, and history – In a way that we can never quite get behind (Heidegger 2010). That is to say, we can never quite be free of these meanings or definitively tease apart their bearing on how perceptual experience is organised. In the following sections, I hope to tease out some of the ways fathers' experiences of disability are disclosed in accord with past meanings. Then, later on in this chapter, I will consider the ways memories are mediated by symbolic means and the stories we tell ourselves (Bruner 1990).

For my participants the past played a key role in shaping how they identified with their children's embodied differences, motivating their commitments, structuring their future possibilities, and, ultimately, getting an optimal grip on reality. Specifically, I find the work of Heidegger (2010) and Merleau-Ponty (1995, 1968) helpful in thinking through the role memory plays in fathers' experiences of disability and disruption. According to Heidegger (2010), we project ourselves into the future with relation to the past and the ways it discloses things as mattering to us. For Merleau-Ponty, former experiences and the anticipations they engender surround our perceptions as an atmosphere or horizon, structuring our perceptual experiences and what articulates itself as significant (1995: 22). To the extent that dramatic moments are felt as a disruption to fathers' taken-for-granted worlds, the past and its foreshadowed possibilities becomes all the more important.

In this chapter, I begin by presenting some biographical snapshots that depict fathers' arrival stories into their worlds of disability. While disability gains meaning within social and cultural contexts, here I focus on the ways it is lived for parents as a bodily experience of disruption and disorientation. Then, I shift my focus to how memories are newly articulated with relation to one's world of disability, before considering the limits they impose upon us in our ability to remake ourselves and create habitable worlds.

Wayne's arrival story

Wayne's father was a marine and so Wayne grew up on military bases, regularly attending air shows. He joined the military himself as a young man, but the stress he suffered from a shipboard fire cut his career in the navy short. Wayne was eager to share his love of air shows with his children and so when his first son, Noah, was borne, that is what he did. Noah was a precocious and spritely child with a love of reading and an express interest in rotating objects. The air shows provided Wayne an opportunity to continue this loved family tradition, while for Noah they afforded a chance to satisfy his idiosyncratic desire for spinning objects. They would spend whole days gazing at propeller blades and wheels in all their circular manifestations, amidst the people, the roar of fighter jets, and the smell of cotton candy.

But during an air show when Noah was two years old something unusual happened: A jet flew overhead and threw Noah into a horrendous panic attack. Wayne managed to calm him down, but another jet soon flew overhead inciting the same extreme reaction as before. Wayne carried his screaming son over a mile back to where their car was parked. In the months that followed, Noah began to exhibit a host of sensory sensitivities. He began wearing sunglasses inside the house and developed aversions to eating anything above room temperature. Wayne and his wife, Mary, consulted clinicians about Noah's unusual behaviours but they were assured that he would outgrow these peculiarities.

When Noah was four years old, Wayne and Mary had a second child, Nick. At this time, Noah showed no signs of outgrowing his sensory peculiarities, and his defiant behaviour was growing troublesome. Nick was slower than Noah to meet his developmental milestones, but otherwise seemed typical. But sometime after his first birthday he started experiencing fevers 40°C (104°F). The doctor's ran various tests, including blood and x-rays, and

discussed hospitalization with them, but, ultimately, they were unable to identify the cause of these febrile episodes. Gradually, Nick became more withdrawn and unresponsive. Slowly, he stopped responding to his name and making eye contact. Wayne and Mary consulted a specialist about their growing concerns and another spate of tests were organised. It was a speech pathologist who first suggested Noah had Asperger's, after witnessing his voracious appetite for books and his unusual competency with jigsaw puzzles. Within the coming months both boys were diagnosed with autism spectrum disorders.

Ray's arrival story

Ray was twenty-five in the fall of '85 when he decided to leave the coast guard, load up his Toyota truck, and head across the country for a fresh start. After arriving in Arizona, he soon secured a job at the local fire department as an engineer/paramedic and met his future wife, Suzanne, in the parking lot of a local church after service. Almost a year later they were married, and Suzanne became pregnant with Zachary. Two years and three days from the day they met, Zachary was born.

They had planned for a natural birth. But sometime during the labour the doctors decided to perform a C-section and Suzanne was rushed to the operating room. Ray recalls sitting in the waiting room, when Zachary was suddenly wheeled out of the OR in an incubator, and air lifted to the neurological institute. 'I'm standing there going, OK, now what?', Ray recalls, 'now what's going on? Life changed at that moment and I knew it changed. I didn't know how it changed or why it changed, but it was like, life is different now'.

Sitting in the doctor's office, Ray and Suzanne were told that their son had a rare neurological condition called Hemimegalencephaly: One half of

Zachary's brain was bigger than the other, which often caused seizures and cognitive and behavioural disabilities. The prognosis, they were told, was grim. They were cautioned he could have uncontrollable seizures and may have to undergo a hemispherectomy, where a hemisphere of the brain is removed or disconnected to control seizures. 'We were caught completely off guard', Ray told me, 'we were looking to fix our son because we didn't know what to do'.

Back in 1988, there was little as far as support and services were concerned for children like Zachary. The program of early intervention for infants and toddlers with disabilities was still in its infancy, signed into law on October 8, 1986. Like many parents, in the absence of any indication of disability in utero, Ray and Suzanne faced the unexpected. 'We were in survival mode', Ray said.

Ethan's arrival story

Ethan and Jennifer Strout married in their early thirties. Ethan was starting out his career in the toy industry at a company that manufactured and sold action figures. A couple of years into their marriage, Jen became pregnant with their first son, Carter. In 2007, their second son, Jack, was born prematurely, and spent three weeks in the neonatal care unit because of respiratory difficulties. But he made a full recovery and returned home, steadily reaching his developmental milestones as time wore on. It wasn't until 2009, Ethan recalls, that the trouble began. Jack experienced a mild fever after receiving his DTaP vaccination, and according to Ethan, began displaying peculiar movements: Jack was being seized by 'body hiccups'. This prompted the Strouts to investigate further.

Jack's body hiccups were recorded during an EEG at the children's hospital, enabling a quick assessment—so quick, in fact, that a neurologist from

the hospital called them shortly after their appointment and asked them to bring Jack back in immediately for admission. Jack was diagnosed with a form of childhood epilepsy called 'infantile spasms'. A follow-up MRI revealed that they were being caused by Cortical Dysplasia, an abnormality in the brains development where neurons fail to position themselves correctly. Over the next three months they would start treating Jack's epilepsy with medications, watching as he slowly regressed, losing some of his speech and becoming more physically uncoordinated.

Within the next six months the Strouts learned that a brain tumour was the focal point of Jack's seizures. At the end of 2009, Jack underwent temporal lobectomy to remove the seizure focus. 'Nothing really prepares you for seeing your 19-month old kid lying on a bed, pale-skinned and barely moving', Ethan recalled. In the coming months Jack received an autism spectrum diagnosis: Pervasive Developmental Delay - Not Otherwise Specified (PDD-NOS). This diagnostic label would later be folded into an autism spectrum diagnosis in the DSM-V. This string of events, Ethan said, were 'a symbol of when life changed for all of us, a point from which there has been no turning back'.

Existential disruption

Parents arrive at disability worlds that are both singular and shared. Despite how one arrives, however, the flow of experience is invariably disrupted: That is to say, what was self-evidently normal explodes. For many parents, this is felt as an experiential rupture, wherein one's taken-for-granted world of experience and understanding is exposed. As Schutz and Luckman explain, "familiar is usually graspable only in the negative, through 'effects of alienation', which occur when something hitherto familiar suddenly 'explode'" (1973: 159). Here, parents face a discordance between a past and what it was supposed to lead to and the reality they are thrown into. Landsman (2009) addresses this phenomenon in her work on mothers of children newly diagnosed with disabilities, documenting the ways mothers find equilibrium by reimagining motherhood and disability through their experiences of the non-normal over time.

Becker suggests that "cultural meanings of continuity frame the experience of disruption to daily life" (1999: 18). From a phenomenological perspective, we grow up on these cultural understandings around order and continuity, which arouse our expectations and permeate our conceptions of the life course, influencing the ways we perceive and are affected by certain events. Unexpected events, then, can disrupt cultural expectations about the structure of life (ibid: 19). For parents, normative familial expectations and broader socio-cultural values that emphasise the importance of independence and autonomy also operate implicitly in determining how disruption in the context of having a disabled child is experienced. The specific ways disruption is experienced is also connected to bodily existence and the subjective experience of self-continuity across time. In its being habitual, Fuchs tells us, "the lived body exhibits a specific form of memory that results from the continual embodiment

of existence” (2016: 291). Affinities, experiences, and capacities acquired throughout a lifetime, he tells us, provide a continuity of self that integrates the past in a person’s present being and potentiality (ibid). This self-familiarity gives us a view of the future. As Merleau-Ponty expresses it, “my world is carried forward by lines of intentionality which trace out in advance at least the style of what is to come” (1995: 416). So how to parents grapple with the disequilibrium arising from tensions between biographical meanings and future plans and the new worlds of disability and care they find themselves in? Throughout this chapter we will see the way parents achieve equilibrium through the continual project of knitting the past and future together.

Paul, who has been the sole caregiver for his daughter, Pearl, for twenty-two years, describes the arrival moment as a situation parents come to with ‘no basis of reality’. He explains, ‘both spouses are thrown into a monumental life-changing situation’. Similarly, Scot, who cared-for his daughter until her death at the age of twenty-seven, lamented:

‘It’s like a unique new agenda for families, situations that we’re in. They didn’t really exist before. It is so overwhelming. Your life is completely turned upside down and absolutely readjusted in a way that – it affects everything you do, all your ambitions’.

The new agenda that Scot describes refers to the cultural and social shift towards community care in the context of post-deinstitutionalization. Increasingly, informal and family carers have come to play a key role in the life of their disabled children (see Barrett et al. 2014; Kritsotaki et al. 2016; Bagenstos 2012). Thirty-odd years ago it was common for parents to relinquish their severely disabled children to institutions, often upon the advice of specialists (Solomon 2014). This is perhaps an unsettling thought and difficult to fathom for many parents today. Many of the children who are cared for by the fathers

in this study are not capable of normative reciprocity and will never achieve and experience the developmental and social milestones that parents typically anticipate for their children. Parents are left to contend with, simply, what is (Solomon 2014).

Kleinman (2009) writes about his personal experience caring for his wife after her diagnosis with dementia. For Kleinman, caregiving is a universal and central human activity; an existential and moral experience that defines our humanity. He emphasises the demands and tensions of caregiving, writing: "It can divide the self. It can bring out family conflicts. It can separate out those who care from those who can't or won't handle it. It is very difficult" (ibid: 292). The protracted and emotionally-consuming nature of caring for children with severe disabilities demands a strength and determination that is not easy. A recent study by Wolff et al. (2016) found that caregivers involved in providing complex care are more likely to experience emotional, physical, and financial difficulty than caregivers who provided no help with care, are 5.3 times as likely to experience participation restrictions in valued activities, and are 3 times as likely to experience work productivity loss. Of the fathers I spent time with, all but one of their children (who had died the year before) were still living at home under their care and vigilance.

I attend to the arrival moments I have depicted above as moments of experiential disruption; moments that move parents toward experiential disequilibrium. These moments throw into relief what was once thought to be familiar and determinable. Here, continuity and predictability are displaced by a perceived mismatch between the present and a past that was supposed to lead somewhere else. Of course, this resultant *de-worlding* includes more than just a breakdown in tacitly held assumptions, but also involves other structures of meaning that constitute our modes of presence and structure our familiar

worlds. Therefore, disruption is a highly subjective experience. Kelly argues that parents undergo a “conscious re-embodiment of the social category of parent” through myriad activities in a variety of settings: Which includes the private management of a child’s physical and emotional needs and the ways parents publicly present themselves as carers and with relation to their children in public settings (2005: 187). Meanings around disability and fatherhood also emerged for my participants within contexts of social interaction. However, there is also a tacit dimension to this process of re-embodiment that does not involve such deliberate and reflective modes of re-embodiment.

There is something to be said about past moments that are invisibly present in parents’ embodied experiences of disability and caregiving. Often, past moments haunt the edges of experience, that is to say, they are intuitively perceived even before they have been deliberately evoked or consciously reflected upon. In the case of the fathers in this study, the past gives their experiences of disability and upheaval their particular constitutive quality of being unique. In some instances, it is possible that the tension toward equilibrium may remain unresolved until explicit reflection and/or narrativization helps resolve the matter. But in others, these experiences have an experiential character from the outset, or tacitly assume one over time, that is contingent upon what actual past moments afford in their remaking. As Proust says, “each new character is merely a metamorphosis from something earlier” (2003: 70). It is to these past moments, told in both contemplative recollection and lodged within the circumambient world, that we now turn.

The presence of the past

Wayne remembers sitting with Mary in the Speech Pathologist's office, listening to her describe potential autistic behaviours. The boys hadn't been diagnosed yet but Wayne found every trait the speech pathologist identified as a potential symptom of autism resonating with him strongly. 'Everything she kept identifying', he said, 'I was just going, that's me. I'm like that. I was like that. I do that. I did that'. Wayne recalls Mary clarifying his assertions, nodding in agreement with him. Wayne has never been officially diagnosed with autism, but in the eight years since his boys were diagnosed he says that everything he has learned continually re-affirms his conviction that he is also on the spectrum. Wayne chuckles and nods his head in acknowledgement of how disorienting it must have been for Mary finding out within a matter of six weeks that the three men in her life had autism, but with jubilant elation he couldn't stop thinking, 'This is the greatest thing I have ever learned'.

We were sitting in Wayne's kitchen late one evening in July when Wayne leaned forward in his chair, staring at me, his eyes iridescent with a mixture of peace and sorrow, 'It explained my whole life, you know. I was almost thirty years old and I had lived in this deep dark void in space not understanding humans', he said. 'It was devastating for their mom but for me it was an opportunity to help my kids because I understood, directly, portions of what they were going through'. Wayne recalled becoming a valuable source of insight for Mary into the boy's atypical behaviour. 'Mary realised that I could relate so much to what she was reading, so she would ask me, do you think the boys think like that? Do you think like that?' Shortly after the boys' diagnoses, Wayne joined a group for adults with Asperger's. 'The more I learned about it the more I came to understand myself', he said. It suddenly made sense to him why he has been obsessed with numbers all his life. The more he thinks about

it, he admitted, the more he is convinced that his mother is also on the spectrum.

Months after our first meeting, I am sitting in his living room on a brown three-seated couch next to his eldest son, Noah. Noah looks a lot like his younger brother, Nick, but pubescence has thinned him out. Nick is sitting at the table in the small dining room eating a bowl of crisps, humming to himself loudly and making sounds that aren't quite words. It's Old Hallows Eve. In the kitchen, Wayne is on the telephone finalising sleepover plans for Noah. Eight photographs hang on the wall to my right—Nick and Noah are pictured in each one—above a small three-tiered bookshelf filled with self-help books with titles like: 'The Art of Connecting' and 'The Courage to be Rich'. The living room serves many purposes. There is a desk pressed up against the wall, papers scatter its surface and spill on to the floor. Next to it, there are rows of bulging manila folders arranged on top of a creamy-coloured lateral filing cabinet. The crowded space reminds me of Wayne and the balance he has achieved between chaos and order in his life.

My eyes fall on a large lithograph hanging on the wall above the filing cabinet: a dilapidated barn in the middle of an expanse of open grasslands, presumably somewhere in the Midwest. Wayne re-joins us in the living room and I tell him that I like the picture. He gives me a perky smile and tells me that with the right lighting the sky above the barn looks like watching the sun rise and sun set at the same time.

'I was in the navy, in Russian language school in Monterey California', he says, starrng at the picture, 'and my buddy and I were walking along downtown Monterey and, I don't even know why I went in there, we were just kids —'

"Damn kids", Noah interjects.

'We were like 21 years old', Wayne continues, undeterred, 'and I remember just walking down the street and there was this –'

'You're a spy', Noah shouts.

Wayne giggles, 'I was supposed to be', he says to Noah. 'Anyway, there was this gallery and we walked in and I stopped in my tracks and that [the picture] was like looking in the mirror. I was looking in the mirror. And that was back before I understood any of this [the boys] and like I said, I don't have a diagnosis but, you know, clearly, I'm like my kids'.

'What was it about the picture?' I ask.

'It was like, wow! There's this entity that's isolated. It's very solemn. It's very quiet. It's very meek. Like I said, I spent the first thirty-eight years in this deep dark void in space and I looked at that thing and it was like looking at a picture of me–'

Nick begins pacing back and forth, from the dining room to the living room. His splotchy green t-shirt clings to his rounded body. He claps his hands and makes indistinct noises as he passes us on his well-trodden circuit. There's a sing-song quality to his exclamations, like he's doing vocal warm-up exercises. Then, in a quiet and polite voice he asks Wayne, 'Go outside, please'.

Wayne peers at him over his spectacles, 'you want to go outside?'

'Outside', Nick confirms.

Wayne slides the backdoor open to the veranda where a mammoth green cocoon-swing hangs from a beam in the ceiling. Nick nestles into his cocoon and

begins slowly swinging around in circles. As we watch Nick's circles gain momentum, I ask Wayne if he feels the same when he looks at the picture now as he did twenty-odd years ago as a young man in Monterey, California.

‘Oh yeah’, he admits, ‘my perspective on a lot of things has changed with the understanding of autism—I moved around so much as a kid, so we never recognised that I always had really weird social patterns. I have very few friends that go past a couple of years. It's still a pattern that I have yet to break. But I don't have those deep roots around me and I think that has a lot to do with it’.

For Wayne, the confusion surrounding Noah and Nick's atypical behaviours quite suddenly lifted that day in the speech pathologist's office. Like a snap in recognition, his past experiences of estrangement and isolation re-join to his present situation as a father of two boys with autism. Casey describes recognition as the suffusion of past and present to the point of indistinguishability (2000: 126). He writes, "Whether it proceeds gradually or suddenly, implicitly or explicitly, all recognition aims at this moment as at a natural culmination" (ibid: 128).

The time of a child's diagnosis is often described by parents as a catalytic event demarcating space and time into before and after. Wayne's past experiences of isolation and loneliness invoke a sense of familiarity in the face of the boys' diagnoses, profoundly changing his self-understanding which facilitates a new understanding of and connection to his boys. In viewing Nick and Noah's autistic identities as inherited, Wayne has established a genealogical connection to his boys, a connection that has kept feelings of estrangement at bay.

Wayne's recognition of autism is not an act of intellectual synthesis whereby past moments are reflected upon and merged with the present for clarity and order. Rather, the past hangs in the background of his perceptual experience as a horizon, or in the words of Husserl, a "zone of indeterminacy that is infinite" (2014: 102), involved in articulating the present. In Wayne's case, the merging of past and present can be seen as a sudden movement. The mist of uncertainty around his boy's behaviour dissipates through recourse to past experience, and the amorphous subjective feeling of being alone and different. For other parents; however, this process is far more processual.

Historicity

I am sitting in the living room of Ray's beige suburban two-story home. He peers at the clock; he is waiting for Zachary, his twenty-seven-year-old son to arrive home from his day program. When Zach's bus arrives out front, Ray rushes outside to greet him. Moments later, Zach comes inside with Ray. He is dressed in a blue t-shirt and shorts. There's an awkward glide to his gait, a spring in his step that is encumbered by his inward turning toes. He opens a plastic bag and hands Ray a football fan-towel he purchased earlier, with the help of his care-aide, from his favourite sporting store. Then he makes a bee-line for the sofa and begins shedding his shirt and shoes—an evening ritual I have heard Ray describe before. He plonks himself down and points a lazy finger toward the television, 'Thomas', he mumbles.

'I don't want to watch Thomas', Ray says, feigning boredom.

Zachary flaps his hands, grinning, 'choo, choo'.

Moments later, Zachary leads me and his parents up a winding staircase to his bedroom on the second floor. The room is elegantly furnished with rich brown oak. A flat screen TV is mounted on the wall in front of his bed, and there are shelves and storage baskets along the walls filled with toys and children's television shows on DVD and VHS. There are posters scattered across the wall behind his bed: Bear and the Big Blue House, Barney, Kermit the Frog, The Muppets, Sponge Bob, a football poster. Every night, Ray tells me, Zachary sits on the floor and creates a collage with his favourite toys while watching TV. As foretold, Zachary kneels on the floor, his chest bare and his legs curled under him, and begins spreading his toys out before him—Ray helps him choose his favourite ones from a stack of storage cubes against the wall.

Earlier that day, Ray described his struggle early on dealing with his grief. He drifted away from his family and escaped into taking 'care of the things men do', he said; namely, breadwinning—while Suzanne provided the full-time hands-on personal care of Zachary. His feelings of estrangement were grounded in the disappointment and grief he felt over realising that his long-held dreams and expectations were irremediably lost. 'I'd never been down this road of having a child with a disability', he recalled. 'I was planning on having a boy, playing catch, and all of a sudden I found myself with a child that's non-verbal, he's always going to live with us, he's incontinent, and we're always going to be changing diapers'. At the time, I remember marvelling at the communicative bond he shared with Zachary and struggling imagine the chasm he described ever existing between them. Of course, Ray couldn't have known it at the time of our conversation, but in another two years Zachary would transition into a community residence, and he and his wife would take their first trip overseas together.

Disability would become the cynosure of Ray's life work. He described his emotional return to his family as an 'evolutionary process'. Fifteen years after Zachary's birth, he decided to create a men's support group in Arizona for fathers of children diagnosed with disabilities. He said that he wanted to create a space that fostered support, learning, mentorship, and a sense of community for men who were struggling with the same uncharted waters he had faced alone over a decade earlier. He was also acting as chairman of the Developmental Disabilities Planning Council when we met, in addition to his work with the Fire Department delivering emergency preparedness training for persons with developmental disabilities and their families. During the summer of 2015, Ray and I attended an Emergency Preparedness Summit together in Arizona where he was an invited guest speaker. During his address, he disclosed that his life as Zachary's carer and emergency preparedness work was founded on his earliest experiences caring-for his father as a child.

In 1969, Ray Snr. had just dropped a friend off at the hospital and was headed down the i-5 in Portland, Oregon, when an intoxicated driver, heading down the wrong side of the interstate, collided with him. At age twenty-nine, Ray Snr. became a quadriplegic. Ray recalled visiting his father in hospital and seeing him strapped to a circular bed with a tracheostomy tube for ventilation. 'You're the man of the household, now', his father said to him, 'take care of your mom and your sisters for me'. 'From that moment on', Ray said, 'my childhood was over'. He quickly assumed his place as 'man of the house' and all the manual tasks and responsibilities that came with it. 'I think that's why I love fixing things. It's always been a part of who I am', he said to me.

One afternoon, we were sitting in the courtyard at the rear of his favourite pizzeria, the sun slicing down on us, when he reiterated that his past has prepared him for his life today as a caregiver.

‘It's like you're a piece of clay and God's sculpting you’, he said gently.

I knew that Ray believed in some kind of divine order to life, but I was more interested in his past experiences that enabled him to reconfigure his world and transform his self-understanding.

‘How has He sculpted you?’ I asked.

He told me that for a long time he felt angry and bitter that he was robbed of a childhood. ‘He [his father] required a standard of care that stopped us from doing regular everyday things that families do’, he said, recalling how he used to help his father ambulate the city streets—in the days before electric wheelchairs—and the negative reactions his disability elicited from those within the community.

‘People would stare’, he said, ‘they'd be like, who's this twelve-year-old kid pushing this six-foot man around in a wheelchair? I remember he couldn't get into certain stores because the wheelchair wouldn't fit or there were stairs’. Despite these attitudinal and environmental barriers, though, his father maintained a positive attitude, he said, and started his own support group in a hospital outside of Portland for the mobility-impaired.

‘He taught me perspective and how to embrace life’, Ray recalled, with an easy self-confidence.

Then he segued into a story about his uncle who lost both his arms in a logging accident sometime during his childhood. He recalled voluntarily visiting to assist him with bathing and cleaning up. At the time, he said, home life was beset with problems. His mother struggled to come to terms with her husband's accident and so her drinking escalated. She had reached an advanced

stage of alcoholism by the time of Ray's adolescence, which fuelled his desire to leave home.

'She was a role model of what not to do', he said, smiling cynically. 'I remember coming home from high school and she would be passed out on the couch, you know, smoking cigarettes, and my dad would be in bed, whistling and hollering because he couldn't do anything for himself. It destroyed her life and the peripheral people around it.' Then, in a moment of consolidation, Ray said, 'Growing up in Oregon, my dad's accident, choosing to help care for my uncle who was a double amputee, these things helped prepare me for Zachary—all the fire service activity that has connected me to a diverse population of people. So, it's been compounding over the years with all the stuff that has happened, and then culminating with Zachary', he breathed a sigh of relief. 'It's like, there's a reason for all of this. God has a plan'.

Temporal shiftings

Brown and Reavey (2015) describe the functional approaches that have been taken toward understanding autobiographical memory. Citing the work of psychologist Martin Conway, they discuss the role episodic memories play in increasing our perceived orderliness of the world, wherein those memories most relevant to our current goals are more likely to be drawn upon, and thus offer the most value (2015: 26). "Autobiographical memory", they write, "is the reshuffling of past experience to create an orderly present and coherent life trajectory - or 'long-term-self' - where what we are doing now appears entirely congruent with what we have done before" (ibid: 26). This active element involved in remembering has been captured by earlier thinkers like Freud, who argued that the material present in the form of memory traces is "subjected

from time to time to a *rearrangement* in accordance with fresh circumstances – to a *retranscription*" (1896, cited in Rose 2007: 294). This perspective is quite different from those who posit memory in purely mentalistic terms, that is, detached from the surrounding world and occurring within the confines of the head—as engrams.

The way Ray consolidates his memories can certainly be seen to create a connection between past events and his life as Zachary's carer. However, it is the ways past moments are refurnished with meaning through our ongoing experiences that offers the greatest insights into the 'evolutionary process' that saw Ray re-connect with his family. Kohn (2010) invites us to consider the indeterminate ways meanings of the past are transformed through our ongoing relations with ourselves and others over time. She writes, "we think and feel through memories, and, as we travel through time around the world, the memories grow with us" (ibid: 197). Our pasts and futures, then, are in a perpetual state of becoming. They are refurnished with meaning and are newly articulated in relation to the interplay of shifting contexts and changing identities that accompany our experiences over time.

Merleau-Ponty (1968) uses the term *la chair* (the flesh) to describe the indissoluble link between body and world. According to Merleau-Ponty, the body and world are not ontologically separate but born in mutual relation. The body is made of the same flesh as the world. "They are in a relation of...overlapping", he writes (1968: 248). In the *Visible and Invisible* (1968), Merleau-Ponty introduces the related idea of 'reversibility' to describe the reciprocal and reversible exchanges between one's flesh and the flesh of the world in perception. Using the example of one hand touching the other, Merleau-Ponty illustrates the body as both perceiver and perceived, object and subject, sensed and sentient (ibid: 147). Weiss eloquently captures the essence of

his enigmatic notion, describing it as a "corporeal synthesis that is continually being played out in the daily experiences of touching and being touched" (2008: 35). Embodied acts of caregiving involve shifts between feeling and being felt, touching and being touched, perceiving and being perceived—I will discuss this further in the next chapter when I consider embodied care. What is relevant here, however, is the way Merleau-Ponty characterises time in the same way: "past and present are Ineinander, each enveloping-enveloped—and that itself is the flesh" (1968: 268).

The tensioned shifts that occur through caregiving, between feeling and being felt, seeing and being seen, invoke past moments and transform their meanings, and, in doing so, inform how parents understand present events, the stories they situate themselves in, and the futures they press into. As Foehl writes, "What we remember and anticipate shape the foreground meanings of the now, which transform memories and futures in turn" (2014: 489). Ray's childhood experiences with his father's disability and the neglect brought on by his mother's alcoholism contextualised my understanding of why he estranged himself from his family early on after Zachary's diagnosis. His capacity to make sense of his life as a carer is contingent upon the depths and potentiality of his past (Mazis 1992).

One morning, we were sitting in the late morning sun as it poured through the windows of his living room. He said, 'having a child with a disability really impacts how you respond because they're different. You have to find a new type of value because your life is never going to be like it was. It took years before I was able to really start identifying how I felt about Zachary. How did he feel about me? And I think that was the big thing, knowing that Zachary loved me, that Zachary wanted to be with me'. I recalled Ray's words from an earlier time, from that day we had lunch in the bright, leaf dappled shade in the pizzeria's courtyard, when he told me that his father taught him to

appreciate the simple things in life, 'a gentle look', he had said, 'a touch'. They're very important things'.

Many years passed between Ray's early experiences of bewilderment after Zachary's diagnosis, and the time it took him to acquire a 'new value system'. And yet, a part of his story attests to having acquired a perspective sensitive to the contingencies of life and differences among people early on through his childhood experiences of caring for his father and the lessons his father taught him. Here, his past combines with the present, illustrating the perpetual becoming of time and the constant movement of existence. As Usher writes, "our self-understanding is an unfolding into a future which is enfolded in a past, itself unfolding into a future" (2005: 25).

Ray stared at me, conviction washing over his face, 'when Suzanne was pregnant with Zachary, I put my hand on her stomach and said, Lord, fill our child with your wisdom, your way, not the worlds. That he may know you uniquely. That this child be blessed by you. Well, if I pray that prayer and then all of a sudden I'm given a child with hemimegalencephaly and the doctors are going, we've never really seen this before, I got to believe in God's answer to prayer'.

Here, the past returns to itself anew, "electrified with the charge of later connections" (Mazis 1992: 56). Ray understands himself and his life in accord with these temporal movements backwards and forwards. Importantly, these temporal shiftings hold possibilities for maintaining a sense of self-continuity across time and recreating an understanding of one's life in accord with the necessities of the present and the anticipations it foreshadows. As Leder states, "from the now we inhabit a meaningful past and a futural realm of projects and goals" (1990: 22). In the words of Merleau-Ponty, the past is found in an "openness upon general configurations or constellations, rays of the past and rays of the world at the end of which, through many "memory screens" dotted

with lacunae and with the imaginary, pulsate some almost sensible structures, some individual memories" (1968: 240).

Past hauntings

In this section, I focus on what both Fuchs (2011, 2012) and Casey (2000) describe as traumatic body memories. Traumatic body memories are past experiences that leave indelible marks on our subjectivity by anchoring themselves in our bodies. Casey writes, "body memory alludes to memory that is intrinsic to the body, to its own ways of remembering: how we remember in and by and through the body" (2000:147). More broadly, body memory refers to the ways well-practiced motion sequences and other repetitive patterns of perception and interaction become embodied as knowledge or skill in our daily practices (Fuchs 2011). Through repetition this sort of knowledge becomes reflexive, an implicit memory that enables skilful action. From this perspective, body memories take on an absent presence in our experience of the world by subtending conscious life as one of many habitual horizons that orient us in time and space. As Fuchs notes, implicit memories are "based on the habitual structure of the lived body which connects us to the surrounding world through its operative intentionality" (2012: 9).

In the preface to *Phenomenology of Perception* (1995), Merleau-Ponty describes the distinction Husserl makes between intentionality of act and operative intentionality. The intentionality of act is the level of intentionality associated with conscious acts, such as judgements and "occasions when we voluntarily take up a position" (1995: xviii). Operative intentionality, on the other hand, "produces the natural and ante-predicative unity of the world and of our life, being apparent in our desires, our evaluations and in the landscape

we see" (ibid: xviii). For Merleau-Ponty, operative intentionality is the condition of the former's possibility and the thread that ties us to a world where things have significance and solicit actions from us. Unlike the kind of habitual body memory that ensures spontaneous and reflexive skilful action needed for free movement and dealing with situations, Casey highlights how traumatic body memories have the potential to constrict such efficacy because the trauma disrupts spontaneous actions (2000: 155). In the course of this section I address the question: How might we think of parents' experiences of disability in light of traumatic body memories and to what extent, more specifically, can they frustrate efforts at creating habitable worlds.

I first met Ethan outside the doors of the Hilton Garden Inn on a warm summer's evening in Columbus, Ohio. We had arranged to have dinner upon my arrival. It was close to 7pm and I had worked up an appetite over the course of my eight-hour transit to the Midwest from Arizona. My first image of Ethan was a rear view: peering out across the empty parking lot and over the road at a steak house where a hundred or so biker enthusiasts had gathered for an expo. He was wearing a Baltimore Ravens baseball cap, shorts and a black polo with bold white letters sprawled across the back spelling, *Nintendo*. He sensed my presence as I exited the doors and turned to face me. His face was framed by a ginger/grey-coloured goatee and black framed glasses, behind which peered out a pair of blue inquisitive eyes. He looked different to how I imagined him. Indeed, this is a strange claim to make of a stranger but, at least for me, Ethan didn't feel like a stranger. I knew partial bits of his life already as a carer for his autistic son because I was a reader of his online blog. I guess he didn't match the image that accompanied my readings of him. He was a lot quieter than I had anticipated, soft-spoken and pensive, bordering on broody. His attire spoke to his previous job as Vice President of Creative Development at a toy company that had since gone defunct and his laid-back approach to

entrepreneurship: he spent twenty-minutes after dinner in the parking lot of a Japanese restaurant outlining his ideas for a carry-bag designed specifically for men—with all its masculine cosmetic trimmings—demonstrating its capabilities with a pseudo-prototype he brought to dinner.

Despite the simplicity of his attire, there was a melancholic depth that revealed itself, at least at first, in subtle ways: in a momentary pause mid-sentence or in the silences that bookended his eloquent verbal renderings of particular experiences. Over time, Ethan would reveal himself to be not only introspective but acutely self-critical. He seemed to be on a quest to re-imagine himself in the face of the challenges engendered through his lifestyle as a carer and the intensified moral responsibilities he felt.

‘I believe there's something about people who have suffered trauma where there's a connectivity between them’, Ethan said, staring at me astutely one afternoon as we sat in his living room of his house which overlooked a quiet suburban street lined with Elm trees. He was referring to our pasts of abuse and neglect, our shared experience of domestic violence, previously alluding to how these experiences become anchored at great depths within people, reverberating across time. When Ethan was five years old his biological father left home and severed ties with him and his sister and mother. Eventually, Ethan's mother remarried a cruel man, who Ethan refers to as his father, who began subjecting him to physical and emotional abuse. The cruelty stretched on for over a decade and culminated one afternoon in a violent confrontation between them when Ethan was just sixteen. The violent confrontation had come as a complete surprise to his mother, Ethan recalled, because she hadn't been aware of the abuse he had endured over the years. ‘He was always good at keeping her in the dark’, Ethan said. He recalled some of his father's more mundane terrorizing tactics like waiting for him to return at

night by hiding in a corner of the dark house and then leaping out unexpectedly to pin him against the wall by the throat. 'That is creepy dark shit to do to a kid', Ethan said, 'it does something to your brain'. Many years later, his father shot himself dead in a retirement home with a .357 Magnum.

He got up and moved in front of the window, his attention divided between the quiet street and talking to me. 'Any sharp or sudden veers or anything like that don't sit well with me', he confessed, 'physical punching and pinching makes me extremely upset', he continued. 'I get closed off and tight and reserved. It affects me. I take medication for it'. He paused, reflecting. 'It's a role reversal. Instead of father to son it's son to father. As a kid I was powerless against my father and then I regained my power when I left and started to find my own voice and life. And then Jack came and took that power away from me. He assumed my father's place, and there are times when he has complete power over me, just like my dad did. It's this creepy twist of life. I am not completely at peace with that yet'.

I told Ethan that my son cycles in his moods and behaviour, from being manic and irritable one week, to calm and pleasant the next. 'Jack cycles too', he said, 'he's in a good cycle at the moment but when he comes out of that cycle he will hit more and, like I said, when he does the pushing or pinching or emotional rejection, I struggle more. Those feelings, post-traumatic stress, I feel that more and start to say, did I ever get away from him?' He paused again, letting the thought linger in the air, 'but the difference is I want to be with Jack. It was easier with my dad, just leave and say I'm done, I'm finished. This is a whole different thing'.

The body can be seen here as a horizon that continues to mediate Ethan's experiences. The traumatic past moments remembered by Ethan's body pattern his visceral reactions to communications with others. They go on living in a

general style of existence (Fuchs 2007), manifest in the ways Jack's physical assaults and perceived emotional rejections are experienced by him. Perhaps the biggest challenge Ethan faces is remaking the present in light of the past's sedimented and unflagging bodily persistence and intercorporeal presence. Traumatic body memories can be deeply other-oriented. Fuchs describes the "implicit relational styles" we acquire through our earlier patterns of interaction as "intercorporeal memory" (2012: 15). In this way, our histories of embodied interaction continue to exert an influence over the way we relate to and interact with others. Jack's displays of aggressive behaviour pose serious challenges to the ways Ethan is able to remake himself. Thus, memories of domestic violence, written into the very way Ethan exists in the world, can be seen to bear down on his lived experience, impeding his rediscovery of the past and ability to make new connections with it.

Narrative horizons

Writing about the experiences of parents with children diagnosed with chronic medical conditions, Mattingly emphasises the importance of considering the narrative structure of experience and ethical practice: the ways stories inform our "commitments about what is possible and desirable, our...anticipations and judgements about how things should and will unfold, and an understanding of the motives and actions of our interlocutors" (2010: 43). Similarly, Frank stresses the importance of narration in people's experiences of illness as a means of "redrawing maps and finding new destinations" (2013: 53). "To think with a story", writes Frank, "is to experience it affecting one's own life and to find in that effect a certain truth in one's life" (ibid: 23). While lived experience is always more complicated than narratives can delineate, they are one of many cultural resources that assist individuals in creating both personal and shared

habitable worlds by imposing "the sequential and predictable order of *tick tock*" (Frank 2013: 46).

In *The Wounded Storyteller* (2013), Frank identifies three general narrative types—restitution, chaos and quest story-lines. Simply put, restitution narratives are premised in modernist expectations that there is a remedy for every illness. They focus on the restoration of health. According to Frank, this is the preferred narrative in our contemporary culture of restitution. Chaos narratives, on the other hand, are the antithesis to modernist restitution narratives. They imagine life never getting better. They are hard to bear witness to, Frank says, because they lack any discernible order or causality and therefore induce anxiety in the listener (2013: 97). As such, they are more of an "anti-narrative of time without sequence", he writes (ibid: 98). Typically, in telling our stories, "events are mediated by the telling", however, in lived chaos "there is no mediation, only immediacy" (ibid). Therefore, Frank maintains, that chaos stories cannot really be told but are only ever really lived (ibid). The third narrative type Frank identifies is the quest narrative, which is characterised by movement. The protagonist in these stories is active and undergoes some form of transformation through the illness experience, becoming a dyadic-body in their desire to reach others and make a difference in the unfolding of their stories (ibid: 127).

My participants also located themselves within unfolding stories. I find Frank's narrative typology useful in discerning thematic threads that run through fathers' stories, and the work they do for those telling and receiving them (Frank 2012). Some of the fathers I spent time with showed a great affinity for quest stories. Both Wayne and Ray, for example, invoked the notion of a transformative journey at times and spoke of their acquired insights that they wanted to share with others to help them. For some, however, the past makes

the hardships of the present uncomfortably visible. Stories provide a medium for patterning our memories into narrative order, keeping "the body out of chaos", as Franks says (2013: 108). Chaos narratives may only exist for a brief moment in one's life. Traumatic body memories, however, can be stubborn and may short-circuit our paths to "moral becoming" (Mattingly 2014), keeping the body in chaos.

Ethan frequently spoke of the pain in his body, 'Mental, physical and emotional. I just do what I can and accept being in agony every day', he said. Another time he lamented, 'a dense fog prevents me from seeing but a short distance ahead'. Ethan's experience describes a chaos narrative where he is ensnared in a what can be described as a web of immediacies and chaotic moments. According to Ethan, Jack's behavioural problems contribute to his anxiety and depression. In this sense, the hold of the past can stir up old trauma, stifling the potentiality of movement found in quest narratives. At times, however, Ethan fights against the insistence of his traumatic past, at times describing the pride he feels when he sees his oldest son displaying a patience beyond his years with Jack, despite their tumultuous relationship, or moments of revelation when he appreciates all the amazing things in his life. There are times I observed Ethan emplotting his story in a transformative journey: advising fathers to take into account 'the measurement of the wonders your child is to you, not who your child isn't'.

Later, Ethan wrote in one of his blogs¹³:

'that whole positive thing I tried? I wanted it. I could taste it. But I couldn't maintain it...my life just isn't that and has never been that. And from the look of things, it will never be that. I can't false project an air of

¹³ In order to ensure Ethan and Paul's privacy, I have decided not to reference their blog posts.

total positivity and feel that I am being honest. It feels like wearing someone else's skin. That doesn't mean I want to be negative either. I just can't lock myself in to any one thing'.

Conclusion

This chapter contributes to our understanding of the various routes taken by parents in coming to identify with their child's disability (see de Wolfe 2013 and Kelly 2005) by considering the role of the past and memory in mediating their experiences. The arrival stories portrayed in this chapter describe the existential disruption parents feel when their taken-for-granted world of everyday life is undermined. I have attended to the body's historical density to illustrate the experiential character of key moments and the differing responses parents have with relation to their new situations as carers. While Nick and Noah's atypical behaviours initially confused Wayne, the merging of his past and present at the time of their diagnosis was profoundly orienting, where autism became an embodied mode of being he was already deeply familiar with through his own past autistic experiences. The familiarity Wayne felt at the time of their diagnosis wards off unsettling questions, such as, what is autism? For example, is autism another way of experiencing the world or something to be cured? According to Wayne, 'they're just brilliant kids'. Thus, Wayne's identification with autism is quite different than, say, parents who feel like autism is a disorder requiring biomedical intervention.

While for Wayne the connection between past and present is given illumination in a moment of recognition, for others, like Ray, the past takes on its orienting significance over time. Through concrete acts of caregiving, Ray refurnishes his past and the future it enfolds with new meanings. The past's depth and potentiality afford creative developments and new forms of self-

understanding. For others, like Ethan, the deep bodily roots of the past disrupt his efforts at making new connections to the past. Traumatic memories, then, have the unwanted potential to inhibit the kinds of stories we can comfortably inhabit in our efforts to create habitable worlds. As we have seen throughout this chapter, memories are deeply personal and interpersonally significant. They provide one of many contextualising horizons for understanding parents' indeterminate and changing perspectives on and experiences of disability and caregiving.

Chapter 4: Between Bodies: The Fleshy Work of Caregiving and Attunement

And it's all okay, 'cause love will find a way to be what love is

–Julia Stone, *It's All Okay*

Every day around this time they navigate the early evening streets together. They appear a most unusual sight: big and small, old and young, hobbling through the urban landscape between townhouses and along uneven streets. For familiar others this sight must have bordered on the banal– after all, Paul has lived here with Pearl for over twenty years. He has been her sole caregiver since she was baby. He bends his tall body over Pearl's wheelchair, bearing his weight down through the handles, to propel her body forward. Every now and then she moves her head from side to side and flashes a wild and unbridled smile. His words from earlier linger with me, reanimated with new significance as I accompany them in their dyadic solitude: 'She is absolutely a part of me. We have a very strange connection. I can walk into her room because I know she is seizing without having heard anything. So, we have a connection on various levels'.

We arrive back at their place, one of the only single-story homes in the area, as the light lowers in the sky and casts long shadows that run away from us. Paul points to a large Japanese cherry blossom tree standing in the front yard. Its thick knotted trunk supports a network of gnarly branches that bend under the weightless clusters of fleecy pink blossoms.

'I planted that tree a year before Pearl was born', he tells me. He regards the overgrown and unkempt lawn that surrounds and stretches beyond the tree's elegance. Affecting an air of defeat, he says, 'I have pretty much ignored

my yard and let it overgrow like crazy because I just don't know what to do with it'.

He heads back inside with Pearl. I stay a bit longer before the tree which has stood strong and steadfast over the years, while love and beauty have grown, and youth and vigour have passed in their wake.

In the last chapter I considered memory as a significant and open-ended horizon that contextualises men's experiences of disability and caregiving. Memories were highlighted as an important resource that men draw upon in creating habitable lifeworlds. In this chapter, I continue with the theme of body memory but shift my focus to the reversibility of touch and fellow-feeling within the self and the body's potential for care. I argue that through the reversibility of touching/touched within the embodied subject carers access and establish intersubjective understanding between themselves and their children. In this way, parents acquire an embodied understanding of care that has the potential to enlarge their empathetic and moral imaginations.

Time and time again, I heard men recount caregiving routines that are the stuff of everyday life. What I found surprising was that, beyond affirming their sense of value as fathers, these accounts of their hands-on, tactile experiences of care – as told to me and in their various versions to familiar others – were often pervaded by an intense emotionality. The emotionality conveyed by these fathers speaks to the body's affective powers in awakening a deep resonance with otherness and facilitating intersubjective awareness. The fathers in this study often remarked that what seems insurmountable in the beginning is 'embraced' through time. My overarching argument in this chapter is that the relational space between bodies engenders tactile and affective experiences that are essential to understanding how parents access the

subjective lives of their children in the absence of verbal communication. I go on to argue that through embodied knowledge of care and feeling-with their children caregivers are able to assimilate an incomplete understanding of how their children experience the world. Thus, through everyday acts of care parents acquire knowledge that affords them a different way of resonating to the world and their children's needs.

It is worth noting that this chapter hinges on the ontological and epistemological premise that there is a lived analogy between beings that makes the experiences of others knowable to us (in this case, children rendered non-verbal) and that through, what I call the *fleshy work of caregiving*, the body's perceptual and feeling potential can enlarge caregivers embodied and moral grasp on the world. I pursue this exploration by drawing on the existential phenomenology of Merleau-Ponty and other contemporary theorists working within the phenomenological tradition. I find these traditional and current phenomenological writings particularly useful because they give us resources for understanding the relational possibilities of being and the body's deep potential for care (Hamington 2004; Daly 2016). The first part of this chapter discusses the care routines that parents take up and integrate in to their lives and the medical and social order they are embedded in. This is important for understanding the cultural orientations towards normalcy and alignment that prefigure the worlds of disability parents arrive at—and my later discussion of the body's epistemological potential in attuning caregivers to different aspects of their situation. Next, I draw on the work of Merleau-Ponty and Hamington to consider the body's potential for care which is grounded in the human capacity for empathy and our corporeal plasticity. These capacities foster sensitive and responsive caregiving by reorienting the way caregivers are directed towards the world and others.

Finally, I focus on the grounds of intersubjectivity between parents and their disabled children. My central claim here is that experiences of interpersonal touch, the reversibility between touching and being touched, offer parents the potential to develop a deep resonance with their children and habits of attention to the ways their children are influenced and affected by their surroundings. I go on to describe possibilities for embodied relating fostered through moments of inter-corporeal intimacy. I argue that new habits and knowledge alters the ways parents exist through a changed understanding they develop with regard to the world, which affects the ways they perform their moral identities as caregivers. Hence, what seems insurmountable at first is 'embraced', or grasped, over time.

Routines of care

When parents arrive into worlds of disability they are faced with the demands of acquiring unfamiliar knowledges and skills in order to meet the complex needs of their children: developmental, medical, and psychosocial. At the time of my study, the men I spent time with were fathers to children ranging in age from 13–26 years of age. Their diagnoses varied—sensory, intellectual, and physical—as did their needs. Despite the variation in their embodied differences, however, they all required a high level of attention and vigilance. Income, time available, and support are all crucial factors for caregivers. At one time, Wayne recalled both his boys receiving up to fifty hours a week of in-home therapies. Wayne and Mary, his then wife, both worked second shifts, with Wayne returning from his full-time job in the evenings to care for the boys, while Mary headed off to the university to work on her Ph.D. dissertation or teach classes. Availability and access to social services varies widely across the United States and accessing them can be time-consuming and bureaucratically cumbersome

(see de Wolfe 2013). Most of the parents in my study, however, resided in Arizona and had received, or were receiving, disability supports and services from the government, for instance, in-home and habilitation services and/or respite, etc., through the Arizona Department of Economic Security (DES) and the Division of Developmental Disabilities (DDD).

The worlds of disability caregivers enter can be coloured quite differently from the previous worlds they once knew, as they familiarise themselves with their child's treatment programs (Speech Therapy, Occupational Therapy, Physiotherapy, Applied Behavioural Analysis, nutrition services, etc.), and are thrust into medical spaces where suddenly partnerships with health care specialists take on new resonance (see Landsman 2009). For many carers, a child's medical health care needs may require they learn detailed knowledge on a range of medications and dietary related phenomena, and/or grow competent using various medical technologies, for instance, mechanical ventilators and/or gastrostomy tubes. Other parents relocate to areas that offer better supports and services or seek housing that can accommodate wheelchairs and/or hospital beds and other essential equipment.

Parents' experiences with the educational system may also look different to how they expected as they find themselves dealing more regularly with school districts and school professionals to make sure their children are receiving appropriate accommodations. In the United States, the primary law protecting the rights of students with disabilities is the Individuals with Disabilities Education Act (IDEA) which requires that a child have an Individualized Education Program (IEP) outlining their educational needs (sometimes referred to as an Individual Education Plan in United Kingdom, Canada, and Australia). These additional educational-related matters that parents of children with disabilities face often requires a higher degree of

parent-teacher interaction. Furthermore, it's in the best interest of one's child if parents familiarise themselves with the rules and regulations underpinning this educational contract to ensure that the primary tenets of the IDEA, that a child is accessing their right to a Free and Appropriate Public Education (FAPE) in the Least Restrictive Environment (LRE) possible, is being upheld (Crockett and Kauffman 2013).

At one time or another, these various activities and practices were constitutive of a socializing process for the parents in this study, as they learned how to navigate the new and diverse aspects of their everyday worlds. As with all practices and activities, they are embedded within time and tradition. Almost immediately, as a matter of course, parents of children diagnosed with disabilities in the Western world are swept up in dominant discourses and practices surrounding normalcy. As Yuen says, the parental perception of disability in the Western world is mainly based on "Western rationalized biomedical science", whereas in the Asian world, parents may hold the belief that children with disabilities can be cured through traditional or spiritual means (2013: 221). A significant proportion of the regimens caregivers take up in the West are structured not only around a child's health care needs, but around normalizing a child's identity and life through various medical and therapeutic interventions.

Early developmental habilitation programs, for instance, are based on neurodevelopmental and behavioural outcomes with respect to changing, correcting, and improving communication styles, movements, eating patterns, and behaviours. Western cultural standards of bodily normality, our cultural orientation toward restitution (Frank 2013), and modern Western medicine's desire to control and maintain bodies (Davis 1997) compel parents to feel, at least initially, as though they must work toward training their children to

achieve characteristics and behaviours that are as culturally normative as possible. As Wendell writes, “our proximity to the standards of normality is an important aspect of our identity and our sense of social acceptability” (1996: 88). Cultural idealisations of bodily normality and “disciplines of normality” (Wendell 1996: 88) are constitutive of the social and cultural worlds in which parents of disabled children are thrown. Their earliest experiences of disability and the caregiving activities they take up reflect this context. The various ways disability and normative standards of embodiment are naturalised and materialised through various disciplinary practices (Foucault 1977) speaks to relations of power and domination bodies are tied up in. These practices reflect culture-bound perceptions of autonomy as one of the most valued aspects of subjectivity, which supports the radical otherness of disabled bodies and their symbolic diminution. The cultural attribution of less than full personhood to those with disabilities, internalised standards of bodily and mental normality, and the disciplinary practices of normalcy that aim to produce bodies of a certain kind and function, are constitutive elements pre-structuring parents’ arrival experiences in to their worlds of disability. As Becker notes, “As a social institution...biomedicine reinforces and reshapes moral discourses about normalcy and makes judgements about what is normal” (1999: 98). For parents, these pre-existing cultural and social norms (restitution and autonomy) hold normative sway over their experiences of disruption and disability. The guiding influence of these norms can be seen in the way parents’ given situations appear as such a radical departure from what is normal in the first place. “The person who perceives”, writes Merleau-Ponty, “takes up a perceptual tradition and is faced with a present” (1995: 238).

On a current affairs program years ago (Noonan 2012) a father and his young son who was born with quadriplegic cerebral palsy were featured. The story was framed around the medical professions underestimations of a father's

love and determination. An intense weekly schedule consisting of a variety of intensive therapies, orchestrated by the boy's devoted father, assisted the boy in 'overcoming the odds' and standing for the first time. This milestone was followed by several more with the boy eventually learning to walk and talk. Two years after the birth of my own son, this story (and its follow-up) wielded significant affective influence on my own experiences as a father, as I received calls and advice from well-meaning family members who had watched the program, telling me of my son's potentialities and the possibilities born from some patience and tenacity.

While this moving story captures a compelling bond between father and son, what troubles me most is how this story genre perpetuates a moral imperative to "fix" one's child and supports the idea that an individual's worth is contingent upon their degree of autonomy and potential for conformity. But, in a more immediate sense, it was emotionally painful. It made me feel that by not adhering to this cultural script of "overcoming the odds" that I was a failure and had failed my son. Stories like these can be alienating, and not only presume a homogeneity of disability but of people's experiences surrounding it.

In the next section, I argue that through concrete acts of care and bodily plasticity we see the body's subversive potential. Through the understanding and skills parents acquire they develop meaning-rich perceptions of their children that often conflict with prevailing norms around 'normalcy', 'abnormality', 'alignment', and 'pathology'. Indeed, the advocacy work many parents embark upon to ensure their children's way of being-in-the-world is respected and accommodated for runs counter to the whole 'normalization' process—this will be discussed in chapter 6. Thus, parents are often pushed by events towards the limits of normal experience and may find themselves in situations that bear comparison with what Jaspers calls "border situations": summarised by Jackson and Piette as "situations in which we come up against the limits of our language, the limits of our strength, the limits of our

knowledge, yet are sometimes thrown open to new ways of understanding our being-in-the-world, new ways of connecting with others” (2015: 7-8). One online blogger and primary carer of his medically fragile and disabled son writes, “I believe it is only when you are surprised by yourself, when you are taken down a road that is unfamiliar to your psyche, that true change is happening” (Fischer 2016).

The body as a vehicle for care

For Merleau-Ponty (1995), the body’s active engagement with the world is the centre of all perceptual experience and consciousness. Central to Merleau-Ponty’s existential phenomenology is the concept of *motor intentionality*. Merleau-Ponty argues that motor intentionality subtends conscious life and embodied action. It connects the lived body to a world with meaning and potentiality through the body’s situational understanding of space and spatial features. He writes:

a movement is learned when the body has understood it, that is, when it has incorporated it into its ‘world’, and to move one’s body is to aim at things through it; it is to allow oneself to respond to their call, which is made upon it independently of any representation...in order that we may be able to move our body towards an object, the object must first exist for it (1995: 139).

Thus, the experiencing subject’s orientation in space and apprehension of the world are directed by what has become embodied knowledge or skill through the lived body’s daily engagement in physical situations. Merleau-Ponty argues:

A thing is, therefore, not actually *given* in perception, it is internally taken up by us, reconstituted and experienced by us in so far as it is bound up with a world, the basic structures of which we carry with us, and of which it is merely one of many possible concrete forms (1995: 326).

As Kelly notes, “grasping” is the canonical motor-intentional activity (2002: 377). Writing about motor intentionality, Kelly elucidates Merleau-Ponty’s claim that spatial understanding informs unreflective skilful action, such as typing on a keyboard or reaching for a doorknob. It cannot be explained in terms of the spatial understanding that informs reflective or intellectual acts, he argues, such as pointing at the doorknob to identify it (ibid: 377). As such, two vistas spread before us: those things we grasp or take hold of, things present to conscious thought and those things we apprehend via our motor intentionality—that, in many ways, constrain intentional consciousness. For Merleau-Ponty, in contrast to Cartesian thinking, consciousness, therefore, is “not a matter of ‘I think that’ but of ‘I can’” (1995: 137). According to this view, our primary relationship to the world is one of practical competence and mastery (Crossley 1995).

According to Merleau-Ponty, the acquisition of skill and knowledge changes our relationship to the world by determining the boundary conditions that specify what shows up as meaningful and the ways we respond to those meanings. In other words, the more we learn from our experiences the more our experience feeds back into the way the world looks (Dreyfus 2007). This pre-reflective grasp is captured by the phenomena of hearing “the creaking wagon”, as Heidegger says, and not “noises and complexes of sounds” (2010: 158). Merleau-Ponty calls this the *intentional arc* which “projects round about us our past, our future, our human setting, our physical, ideological and moral

situation, or rather which results in our being situated in all these respects” (1995: 136). Elaborating on this concept, Dreyfus writes, the agent “immediately sees things from some perspective and sees them as affording a certain action...skills are stored...as...refined dispositions to respond to the solicitations of more and more refined perceptions of the current situation” (2002: 8). So, what can the embodied habitual basis of care lend to our understanding of caring knowledge and parents’ moral identities as carers?

Perception and embodied skill are integrated at the level of the body-schema, according to Merleau-Ponty, which accounts for our pre-reflective grasp on the world and the ways we are set to deal with a situation (Merleau-Ponty 1995: 429). Gallagher and Meltzoff describe the body schema as a system of motor-sensory capacities that function without the necessity of perceptual monitoring (1996: 3). The body schema operates according to the latent knowledge the body has of the world which gives us an implicit understanding or grasp of the relation between our body and world. It is at the level of the body schema that the world opens and is organised. “The habitual body is the body of past experience understanding its way through the present conflicting and ambiguous, but inviting and invocative, elements of the perceptual field”, writes Mazis (1988: 236). “The acquisition of a habit”, argues Merleau-Ponty, “is indeed the grasping ...of a motor significance” (1995: 143).

For Merleau-Ponty, the acquisition of new skills or the appropriation of new instruments that are incorporated into “the bulk of our own body” changes our existence through refiguring the body schema (1995: 143). New skills, then, dilate our being-in-the-world. The most oft-cited example given by Merleau-Ponty is the blind man’s cane which, he argues, ceases to be an object open to synthesis in its use and instead extends the scope of the skilful user’s motility and bodily consciousness (ibid: 143). These body-schematic performances are

not explicitly owned because over time they disappear from conscious awareness. In fact, this relationship between the perceiver and perceived and what is thematized in perception is central to understanding the orientational structure of the phenomenal field that characterises embodied existence for Merleau-Ponty. The experienced world, for Merleau-Ponty, is arranged into meaningful gestalts that operate according to a figure-background or object-horizon structure.

The background against which a figure or object reveals itself, for instance, while indeterminate in the sense that it is not being explicitly attended to, plays an inseparable role in how the presentation of the object is experienced. For instance, the lighting in the room plays an indeterminate normative role in how the colour being attended to is experienced (Merleau-Ponty 1995: 305). Thus, attention is selective and is able to shift between focus and background. As Daly explains, there is also a second point to note in understanding the perceptual field that relates to a parallel mapping, from the perceptual to the intersubjective domain (2016: 214). She highlights the role affect plays in the body schema and argues that affect and emotion inform our attention, determining not only what subjects attend to in perception but also how the “intersubjective field becomes peopled with friends, enemies, and strangers” (ibid). The figure and ground are resolved through motor intentionality. As Bullington writes, “Foreground and background only exist between a subject who meets a view with certain interests and attention, and a world that shows itself *in terms of the* subject’s interests and attention” (2013: 24). Habits of care, then, effect intentional consciousness by changing the ways parents are oriented to the world, objects, and others. As Ahmed writes, “Orientations involve directions toward objects that affect what we do, and how we inhabit space” (2006: 28). One’s orientation is directed by the significance of things and what one is invited to see. That is to say,

intentionality arises from the non-linear and mutual causality of continuous sensorimotor interactions involving body and world (Totton 2015). The world isn't imprinted upon us like a photograph, explains Bullington, but is taken up "in an active moment of meaning constitution" (ibid: 24). As such, the perceived world is invested with meanings and values correlative to bodies and lives. In the following sections I interrogate the question, how do habits of care change the ways the fathers in this study see and feel about others and understand themselves as carers?

A midsummer heatwave rolled over the city, and the east valley broiled in daily temperatures above 43°C, matching records set back in 1896. It was 10am and we were seated around a table outside IHOP (International House of Pancakes). I poured myself a hot coffee and silently scolded myself for my stupidity. At this time of the year the bustling metropolis slowed to a lethargic crawl, a stark contrast to the cooler months when snowbirds, fleeing their bitter winters, seek solace in these same streets and strip malls. Apparently, all but IHOPS most loyal patronage had surrendered to the pitiless sun, and they were inside. I knew why we were outside. I employed the same strategies when dining with my son in public. Outside provides solace from the echo and incessant boisterous commotion unfolding between the restaurant walls—a sensory nightmare for some. When there is no outside seating available my son enjoys being squashed underneath the table, which breaks all types of cultural rules governing public behaviour and never fails to elicit righteous and confused looks from strangers, or misguided comments from family members. I don't care! Not anymore, at least. The darkened space beneath the table provides my son solace from the sensory spectacle that inspires him with such unease.

I was the youngest father at the table by at least ten years. Greg, a retired teacher in his forties sat next to me, his hands folded over his rotund belly. Ray sat across from us with his son, Zachary, who was thoroughly immersed in a Thomas the Tank Engine video playing from a portable iPad resting on the table. Charles, a man in his early sixties with a thick grey head of hair, sat a few chairs down from Zachary. Everyone at the table knew everybody else, except me. We ordered breakfast and Ray glanced around expectantly.

‘There’s supposed to be more guys coming’, he said.

Greg shoots him an answering look of confusion. It’s clear to me that Greg isn’t sure who else Ray is or could be expecting. I wondered if Ray was exhibiting a bit of anxiety over the size of the group given my explicit interest in fathers’ attendance at support meetings. True, it wasn’t much of a turn out, but I had anticipated this. Greg informed me, a week earlier, that the meetings often churn out the same faces—a group of men that have known each other for many years now, since Ray first started running meetings. It had been a while since they had recruited a fresh face, at least at this chapter, anyway—Ray organised several other meetings across the valley during the month, which I was yet to attend.

Over the next hour conversation ranged far and wide: beard oil, the financial crisis, travel, internet usage, the heatwave, race relations in America and the Charleston church shooting—Greg gives Ray a lesson on racism and the ‘white power structure’. To my surprise, no one talks about their children. No one talks about disability. Disability is mentioned only once and that is in relation to the church shootings and discriminated groups. Was this because the men were all so well known to each other? Was I yet to realise how mundane caregiving became over time? Or did the presence of someone new pose barriers to more intimate exchanges?

During these conversations, Ray feeds Zachary a plate of pancakes. There's a rhythm to the feeding. A joint awareness to the activity, even though neither Ray or Zachary are attending explicitly to it. Zachary chews and swallows the forkful of pancakes he has been given and then opens his mouth for more. Ray scoops the pancakes onto the fork and brings it back up to Zachary's mouth. Zachary doesn't have to wait with his mouth hanging open, signalling for more, because each anticipates the others movement. It's a dance of finely tuned readings. Sometimes, Ray brushes excess food off Zachary's lip before it falls or anticipates spillages before they occur. This is carried on as background activity to the main involvement, which is, for Ray, the conversation about discrimination; Ray is intensely engaged in a dialogue with Greg. I sit back and remain silent on the topic of conversation, despite my impassioned views regarding the structural and everyday injustices perpetrated by white supremacy and patriarchy. I am cautious about expressing my opinion before I have built a rapport with anyone. But I am enthralled in the feeding, the subordinate activity Ray is involved in. A smile bursts across Zachary's face as he watches Thomas and Ray stretches a hand behind his shoulders and gently caresses them.

The above scene at IHOPs typifies the ways the "body incorporates its own corporeal history" (Leder 1990: 32) of years spent in practice. For instance, Ray's movements while feeding Zachary are not calculable, rather intuition guides them. Also, this repertoire is thoroughly interactive, since its successful accomplishment is contingent upon Zachary's participation and reciprocal ability to read Ray's movements. Ray illustrates several habitual abilities that are backgrounded during the feeding, including a feel for the fork and finely tuned discriminations concerning how much food to put on the utensil and the

best angle to deliver it into Zachary's mouth. Ray's movements are responsive to a host of contingencies that include Zachary's postural changes and gradations in mouth movement. It is unlikely Ray remembers the feeding or that he has ever deliberately reflected upon its jointly achieved operation.

The above example offers one illustration of the ways certain things, like fine motor movements, recede into the background of our perceptual awareness in order to sustain our attention on the task at hand (Hamington 2004). As discussed earlier, this thematization is crucial to the ways Merleau-Ponty understands the orientational structure of the phenomenal field. In *The Absent Body* (1990), Leder focuses on the ecstatic/recessive qualities of embodiment in relation to the phenomenal field, examining the various ways bodies project into the world and the various modes by which they disappear from explicit perception.

Most notably, Hamington (2002, 2004) has taken up the theme of perceptual disappearance in his work on embodied care to argue the body is built and makes possible the care for others. In an eloquent passage, Hamington (2002) describes the tactile nature of washing his daughter's hair and the ways he consciously attends to her while the fine motor skills that accomplish the task and the sense-data that constitute his tactile perception are absent from perceptual focus. According to Hamington, the body's disappearance from perception not only highlights an important element of Merleau-Ponty's work, namely, that the body's disappearance instantiates subjectivity, "it is neither tangible nor visible in so far as it is that which sees and touches" (cited in Hamington 2004: 50; see also Merleau-Ponty 1995: 92), but the reversible structure of a figure-ground correlation also makes the body's potentiality for care possible by facilitating this other-directedness through these recessive

qualities (2004: 50). In other words, a primary condition of care is engrossment in the other which requires self-effacement.

Whether it be through routine feeding, scaffolding motor tasks and learning experiences, or holding and comforting a child through a seizure, the demands of caregiving call parents into different styles of being: that is, through the incorporation of these skills and competencies, parents' bodies are reorganised and refigured in ways that allow for new forms of agency. As Maclaren writes, "active touching brings about new bodily organisations because it demands...a reorganisation of the body guided by the imperatives of the things touched" (2014: 101). While corporeal plasticity is important for developing habits of care that enable parents in their roles as caregivers, these are not sufficient conditions alone to motivate parents to endure the difficulties they face as carers or account for the sacrifices they make in raising their children.

Up until now, I have emphasised the ways parents' active engagement with the world and the acquisition of caring skills helps them be responsive to their children's needs. But what of the conditions of passivity and being touched that denote an equally important aspect of our being-in-the-world, an aspect of experience that offers possibilities for parents' perceptual remaking and becoming? This brings me back to the significance of the emotionality conveyed by the fathers in this study regarding certain proximal and intimate experiences with their children. I believe the relational space between parents and their children within contexts of caregiving becomes a potent resource for parents in overcoming the unfamiliarity of disability through a "felt sense of the other" (Totton 2015). Through the experience of touching and being touched, both tactile and affective, parents acquire a form of habitual bodily knowledge

that deepens their understandings, commitments and investments in their children's needs, desires, and well-being.

Between bodies

Wayne had the air conditioner cranked up all the way, which blew frigid air around the kitchen. We were sitting at his table. The rest of the house was quiet and in darkness. Things were pervaded by a weighty melancholic atmosphere, which was in eerie contrast to the weekends when the boys infused the space with an energetic lightness. Wayne looked tired. Dark circles encased his eyes. He tells me that between working odd jobs and dealing with Nick's behavioural problems he feels 'pretty drained'. A couple of months back there was an incident at school where Nick bit one of the teachers six times, 'The bites were so bad it took eight weeks for the bruising to go away', Wayne recalls. The following day Nick also gave his mother her worst bite to date and uncharacteristically started physically lashing out at his two-year-old half-brother.

'Before we could get a response from the doctor we went ahead and reduced the medication back to the level it was a couple of weeks prior and immediately he started getting better', Wayne says, shaking his head, 'but that was months ago and he's still not back to where he was'. His lips tighten into a half smile as he tells me that they've been in 'crisis mode' the last few months, 'trying to get additional behaviour supports'.

After the divorce, Mary and Wayne's solidarity over the welfare of their children remained unbroken. They continue to work together to provide the most supportive and loving atmosphere for their boys, a fact that Wayne is proud to talk about. 'I think the divorce rate is in excess of eighty percent with

special needs kids...but we never lost sight of our kids'—a situation that is not lost on therapists and case managers, he says, who compliment them for their united effort ensuring the boys get the support and care they deserve. Wayne admits he was unaware there were so many couples who were driven apart by their child's differences and their own conflicting interests. In fact, many of the parents I spent time with reported the same statistic concerning divorce rates in families with disabled children. Some sources estimate that up to 85 and 90 percent of marriages disintegrate because of the stress disabled children bring to families (for instance see Price 2009: 1). Silberman (2015: 50) says this statistic is a "pernicious myth" perpetuated by the media and that families with children who are disabled are at no higher risk of divorce. 'I hear it is dads who leave because they can't deal with their kids', Wayne shrugs, 'I don't understand that'.

A few years ago, Wayne hurt his back which stopped him from being able to carry out many of his most cherished routines with the boys—like bathing Nick. Because Nick is hyposensitive he enjoys the sensory input from the water at bath time. Before injuring his back, Wayne described the quiet moment they would ritually share together at night as he pulled Nick from the bath, wrapped him in a towel, and nursed him in his arms. These days, Nick is too big to be nursed and has graduated from bathtubs to showers.

In the frigid coolness of his kitchen, Wayne says, 'my new thing is, I sit on the edge of the toilet and he just buries himself into my chest, puts his head on my shoulder and if his arms are on the outside of the towel he hugs me and...', tears cloud his eyes, 'that's my favourite moment with him because he is at his greatest peace of any time— he's smiling, he's laughing, he's playing in the mirror, he's engaged with me, face-to-face, eye-to- eye'. Wayne wipes the

stray tears that have escaped down his face and continues, 'His world is just so chaotic beyond that. It's probably the only time he hugs that hard'.

Merleau-Ponty's idea of 'reversibility' describes the reciprocal and reversible exchanges between one's flesh and the flesh of the world in perception. Using the example of one hand touching the other, he illustrates the body as both perceiver and perceived, object and subject, sensed and sentient (1968: 147). These mediums cross over and are intertwined in Merleau-Ponty's nondualist ontology of the flesh. Each experience makes the other possible. As Maclaren tells us, "the true living hand, when it is touched, feels to the touching hand as if it has a life within it, a nascent intentionality, such that it could turn itself back on the touching hand, the touching hand feels in itself its own latent intentionality" (2014: 99). It is not the case that the touching hand has the potential for being touched and vice versa, Maclaren argues, for this introduces too strong a separation between these two terms (ibid). Rather, there is a genuine ambiguity – "an activity that is also a passivity, and a passivity that is also an activity" (ibid: 100). Or, as Ratcliffe writes, "Touch is a matter of relatedness between body and world, rather than of experiencing one in isolation from the other. In touching something, a bodily feeling is also a perception of something other than the body" (2008: 77).

My feet are fastened to Koda's in a pair of joining sandals. I stand and adjust the tension in the straps so that our bodies are positioned correctly and are in alignment. I look down at our bodies coupled by a web of material, Velcro, and plastic. It is a strange sight for me to see him stand so tall. I wonder how tall he is in comparison to his peers? I take a step and his leg follows mine. I can feel his hesitation and the weight of his leg through my own, so I wait for him to initiate the next step. He does. My leg follows his through space. Slowly,

we find a rhythm and begin moving as one entity. I have to deliberately alter the length of my stride but otherwise we achieve synchronization. There are reversibilities at play. At times I lead, at others I trail. I am both passive and active, mover and moved. Sometimes we move in unison and it's hard to differentiate. We kick a soccer ball: I swing our leg and our feet make contact with the ball, which hurtles across the room. "Hey", I beam. He squeals and looks up at me. His face is awash with joy and his eyes are full.

Through the intertwining of our bodies and subjectivities a shared space is existed "of which neither of us is the creator" (Merleau-Ponty 1995: 354). Within this shared space a sense of emotional symmetry emerges where my radiance affects my son and his joy affects me, an emotional experience that is co-created and attributable to neither of us in isolation. In addition to the emotional intimacy engendered through embodied intersubjectivity, a sense of my son's agency is enriched through our negotiation of movement and space. During this dyadic state our lived bodies merge, "an experience shared by a plurality", where my movements affect my son and his mine (ibid: 355-56). In the beginning, I can feel his hesitation to follow my lead and so I wait until he initiates the next step. He does, and I can read my gesture in his movements as he begins moving toward the soccer ball. Similarly, my body grasps the significance of his volitional powers through his movements, as can be seen by my waiting for him to initiate the next step after his initial moment of resistance. I can feel myself oscillating between leading and following until we attune to each other's movements and synchronisation is achieved, our movements "woven into a single fabric" (ibid). An intimate space for communion is actualised through the lived body's capacity for symbolic communication and its affective dimension.

Merleau-Ponty writes:

The sense of the gestures is not given, but understood, that is, recaptured upon by an act on the spectator's part. The whole difficulty is to conceive this act clearly without confusing it with a cognitive operation. The communication or comprehension of gestures comes about through the reciprocity of my intentions and the gestures of others, of my gestures and intentions discernible in the conduct of other people. It is as if the other person's intention inhabited my body and mine his. The gesture which I witness outlines an intentional object. This object is genuinely present and fully comprehended when the powers of my body adjust themselves to it and overlap it (1995: 185).

Writing about the process of intertwining in cases of interpersonal touch, Maclaren writes:

When I am actively touching, I am also passively following, drawn, as it were, over into the other's bodily intentionality, responsive to it, not the pure agent of my movements. When I am passively being touched, I am also actively shadowing, drawn into a virtual inhabitation of the other's activity, never a pure object of touch. In each case I am coming to co-exist with the embodied other, to participate with that other body in its movements...Coexistence draws me into those touched areas of my body and out into the other's movements, while also...giving rise to the differentiation between us. This coexistence reveals my own boundaries, our difference. (2014: 100)

Maclaren is emphasising the inherent ambiguity in Merleau-Ponty's understanding of intersubjectivity and our relations with others, namely, our coexistence with embodied others is ambiguously encroachment and differentiation. By now it should be clear that Merleau-Ponty's reversibility thesis does not elide the alterity of the other. Rather, as Merleau-Ponty argues,

the chiasmatic relationship between self and other is always “imminent and never realized in fact” (1968: 147). “My left hand is always on the verge of touching my right hand touching the things”, he writes, “but I never reach coincidence; the coincidence eclipses at the moment of realization” (ibid).

While Merleau-Ponty recognises divergences in our embodied situation, for him, there is no absolute alterity because bodies extend into and encroach upon one another. As Reynolds writes in relation to Merleau-Ponty’s reversibility claims, we do not fail to perceive alterity by reintroducing an “imperialism of the same” because “the alterity of the other and our own alterity... are mutually encroaching, without ever being reduced to the other, and also without an ontological priority being accorded to either of them” (2002: 70). For Merleau-Ponty, our embodied situation is a story of correlation, we coexist through a common world, each of us a bodily perspective on a shared perceptual world. Thus, being-there-with-others is a necessary condition for my coming into consciousness as a subject. There is an “intersubjective significance” to our perceptions (1995: 352).

Merleau-Ponty captures the encroachment and differentiation inherent in our relations with others when he writes, “In short, just as the instant of my death is a future to which I have no access, so I am necessarily destined never to live through the presence of another to himself. And yet each other person does exist for me as an unchallengeable style or setting of co-existence, and my life has a social atmosphere just as it has a flavour of mortality” (1995: 364). In short, fathers’ embodied experiences of caregiving are located somewhere between “being in the world as touching” and “being in the world as touched” (Reynolds 2014: 117).

To interiors

“Engrossment” is described by Noddings as a “feeling with” the other “toward whom we move” (1986: 23). Engrossment is characterized by an open receptivity to the cared for and a genuine regard for their needs, desires, and well-being (ibid: 23). Noddings also emphasises the fundamental role of “motivational displacement” in ethical caring, where a transfer of “interest from my own reality to the reality of the other” occurs, motivating the one-caring to act on behalf of the other’s interest (ibid: 14). But how do parents involved in, what Kittay calls, “dependency work” achieve the level of engrossment and responsivity that I argue is necessary in the “other-directed and non-self-interested labour” that characterises caring for severely disabled children? (1999: 38) How do carers achieve the level of responsivity necessary for enhancing “the power and activity of another”? (ibid). Or expressed differently, how do parents access the life and mind of their children in the absence of language and cognitive-communication (gestures and sign language)? In this section, I argue that our relational selves and tactile affective experiences provide the grounds for understanding how parents achieve this.

Through caregiving for my son, I have become more aware of the ways the senses open us onto a world thick with meaning and comprise a bodily perspective from which the world articulates itself. For Merleau-Ponty, experience is irreducibly multisensory, “synaesthetic perception is the rule”, he writes (1995: 229). Within this sense of embodiment and perception, the body is a synergic system. The senses blend together and are united in my apprehension of the world: “I hear the hardness and unevenness of cobbles in the rattle of a carriage, and we speak appropriately of a ‘soft’, ‘dull’, or ‘sharp’ sound”, he writes (ibid: 230). The rise of scientific knowledge gave sight as a sense its special status in Western culture, denigrating the other senses as

inferior modes of knowing. Therefore, ocular-centrism is a historical and cultural trapping that “shifts the centre of gravity of experience, so that we have unlearned how to see, hear, and... feel” (ibid: 229). It casts our attention to the surface of things at the expense of interiors, it “traps us into superficial encounters with the world” (Brook 2014: 70), as though we were mere spectators.

Strangers often judge my son according to what they can see. He can’t handle crowded spaces. Public spaces with all their dynamic sounds and motion don’t extend the shape of his body, to borrow Ahmed’s (2006) phrase. They send him into a panic. Strangers passing by might see a boy writhing and wiggling, hands clasped tightly over his ears, screaming and grimacing as he attempts in vain to overcome his sensory surroundings and restore some equilibrium. Temple Grandin (2011) likens her sensitivity to loud noises to the pain one might feel when a dentist’s drill hits a nerve. She elaborates, “I still dislike places with confusing noise, such as shopping malls. High-pitched continuous noises such as bathroom vent fans or hair dryers are annoying...certain frequencies cannot be shut out” (1992: 106). One child said to me that listening to his mother sing produced the sensation of pins prickling his flesh from the inside.

In contrast, beach visits offer a vastly different sensory experience for my son. He will sit contentedly on the sandy shore as small waves break over his legs. I feel as though he would be quite happy to sit there the entire day, gently paddling the shallow surf with his hands and squeaking intermittently, in what is an expression of unbridled and immense joy. The wide-open space, the sun’s warmth, the cool water, and the gentle hum of the rolling surf provide him with solace and calm, a place to be. Here are some other things he likes: obtrusive sounds punctuated by long silences, water play, smooth and cold oral textures,

spinning objects with his fingers, gliding his hands through corn kernels and feeling them slip between his fingers. Through acting as a caregiver to my son, I have come to realise that ruptures in reciprocity and understanding between interactants are not only the result of neurological and social disjunctures, but also involves bodies and physical environs. Not all spaces are created equal and while there are many that he can project into easily, there are many more that restrict his modes of embodiment.

Brook argues that a shift to non-visual senses can help reconstitute the interiority of experience, presenting “interiors in a way...closer to them as given” (2014: 74). She uses three examples of interiors (a cathedral, the body, and diagram representing a ship) that pose problems for sight. She argues ocular-centric modes of understanding gloss over their *interiorness*, converting them into surfaces. Ocular-centric modes of understanding pervade parents’ disability worlds: from the detached stares of strangers that their children’s embodied differences invoke; to the diagnostic labels, definitions, and defining features that are deployed to describe the specificities of bodies; or the numerous charts and evaluative measures that professionals use to assess the capabilities of children so that parents can access supports and services. These are all examples of the ways surfaces underline the extent to which bodies are understood.

In the attachment theory literature, reciprocal patterns of interaction are said to aid in the development of infant-caregiver attachment formation (Hudson 2014). Among men in Ireland, Hanlon identifies reciprocal emotional benefits as motivation for providing care, for example, experiencing emotional intimacy and feeling loved (2012: 137). But as Solomon asks, “what becomes of the transaction with an MSD [multiple severe disability] child, who can often express only appetite or pain, then signal satisfaction when hunger and discomfort are assuaged?” (2014: 362). I believe attending to non-visual senses

and the affective-tactile-kinaesthetic body is a good beginning for understanding the embodied transactions between caregivers and their severely disabled children.

“The acclaimed visual is not the visual as we experience it”, Brook writes, “but a one-eyed, colour blind sense that is stripped of both depth and colour perception” (2014: 69). Being-with and feeling-with my son has helped me shed some of my cultural domestication by opening me to other ways of knowing the world, rooted in the reversibility of the flesh and our shared sensorimotor experiences; a world that is grasped by the body across the senses and through our visceral, proprioceptive, and kinaesthetic awareness. As Maclaren tells us, “Our bodies are not instruments that put us in contact with already existing determinate things, but rather that which enables things and a world, and which is equally constituted by those things and their world” (2014: 3-4).

There is sufficient evidence to suggest the body schema operates in attunement with others from the very beginning of our lives (see for instance Gallagher and Meltzoff 1996), allowing bodies to extend and connect to one another. In the presence of each other, and through our shared history together, my son and I fall into a space of attunement. Fuchs describes this in terms of dyadic body memory, which can be viewed as a space of two body schemas, he writes, which are attuned to each other through sensorimotor patterns generated by a shared interactive history (2017: 339). The body’s potential for coupling enables an incomplete grasp on the ways my son emotionally relates to the interiority of spaces and their atmospheric qualities. And this is no superfluous matter, beyond having a forceful impact on his emotions, these sensory spaces motivate certain behaviours and influence the ways he emotionally perceives and responds to future situations.

Attunement and interbodily resonance

Through being-with and feeling-with my son the resonance of my feeling body has been altered and refined to a workable degree of inter-bodily resonance. The atmospheric qualities of certain spaces and how my son relates to them are grasped instinctively. This atmospheric sensitivity is described by Pallasmaa as an “unconscious and unfocused peripheral perception”, which he describes as a biologically derived emotive capacity to instinctively capture the atmospheres and moods that are overarching qualities of our environments and spaces (2014: 243). Through acts of care and empathetic responsiveness, I have become aware of the way my son relates to interiors and the culturally conditioned ways we interpret our sensory surroundings, for instance, our culturally inflected reliance in Western societies on visual-centric modes of understanding others and our surroundings. These particular modes of grasping can cloud our ability to perceive the depths of our own embodiment and the different embodiments of others. Brook (2002) argues that if we chose as the focus of our experience the interiority of space then we must not be concerned with the appearance of things. “If instead we try attending to the non-visual senses the movement from outside to inside does reveal a very strong sense of interiority”, she writes (2002: 71). I suggest that this claim has ethical import in the lives of parents insofar as it articulates the shifts they make in coming to resonate with the inner worlds of their children.

We enter a restaurant, moving into the space our footsteps and the unanimous voice of its already seated patrons are muffled by the soft furnishings and fabric covered wall panels. There are no sounds coming from the kitchen. The ways the furniture is arranged and the various partitions break up sound paths. The audibility of the space feels welcoming; the sounds spread and resound throughout the space evenly. There is adequate spacing between the tables which lightens the density of the space. We walk towards a booth

situated at the back of the restaurant, the space is infused with the soft aromas of rosemary. The dim lighting, warm colour scheme, and the symmetrical and minimal arrangement of art work hanging on the walls create a restful and calming effect. All these elements pull together to create a pleasurable spatial experience for my son. I resonate with him. I can feel the consonance between our bodies, selves, and world. A buoyant feeling arises as my muscles relax, my breathing deepens, and I energetically dilate into space. It's a delicate balancing act.

Describing the phenomenology of touch, Ratcliffe explains the ways our bodies and the objects we confront often involve a "diminution or loss of certain other bodily boundaries" (2008: 91). For instance, he describes the diminution of feeling-felt distinctions in our tactile experiences as quite common place, for instance, when comfortably sitting in a chair the boundaries between one's skin and the cushions are phenomenologically inconspicuous (2008: 93). "Where boundaries are perceived", he writes, "they need not correspond to the physical boundaries of the body. The...inside-outside distinction is not an essential ingredient of tactile experience and the assumption that it is stems from the unwarranted a priori imposition of an internal-external contrast upon it" (ibid: 92). My focus here has been on the phenomenology of touch and feeling: certain tactile, kinesthetic, proprioceptive, and affective experiences where the boundaries between bodies become less defined, engendering profound moments of experiential connection and understanding. Moreover, these atmospheric effects (sounds, smells, colours, sights, illumination, layout, rhythm, motion) pervade our embodied experiences more generally, and my son quite intensely. The potential for pre-verbal communication is crucial in making sure my son is cared for properly and that his embodiedness is respected. It is crucial for "communion and interpersonal contact" (Erskine 2015: 45). Intercorporeal communication facilitates a shift from surfaces to

interiors, where attunement, communication, and the development of embodied relating is made possible.

In Merleau-Ponty's late conception of "the flesh", touch becomes his primary example of perception. As Totton explains, vision is reconceived within Merleau-Ponty's ontology of the flesh as an experience of contact, not distance: "When I touch—or see—an object, it is Flesh touching itself" (Totton 2015: 25). The flesh encompasses the space between carers and those being cared for and speaks to the co-existence and co-creation of self and other, "The coiling over of the visible upon the seeing body, of the tangible upon the touching body" (Merleau-Ponty 1968: 146) My argument here has been that this relational ontology provides the grounds for interpersonal communication and attunement, whereby "two people align emotionally and behaviourally to achieve understanding" (Griffiths and Smith 2016: 134). Erskine writes, "attunement is a kinaesthetic and emotional sensing of others knowing their rhythm, affect, and experience by metaphysically being in their skin, and going beyond empathy to create a two-person experience of unbroken feeling connectedness by providing a...resonating response" (2015: 45).

Back in Columbus, Ohio, Ethan is playing with Jack in the living room. Outside the sky is darkening. Jack, in his pyjamas, throws a large green plastic ball to Ethan. I am watching their game from an armchair. Jennifer is sitting on the floor cross-legged, a few feet away from me. She tells me about a new parent support group she has joined and how she expects its focus will be on sharing information with other parents about disability supports and services. When Jack catches the ball Jennifer quickly redirects her attention to him and

applauds. I follow suite. Jack beams with excitement and claps himself, shouting 'yeah'.

'Good job, buddy', Ethan says.

'Good job, butty', Jack repeats, still beaming.

'Did you just hit a home run?'

'Yeah', Jack smiles. 'Again. Catch', he demands.

'Yes, sir'. Ethan throws the ball back to Jack and he catches it again.

Everyone applauds. A clear intimacy shapes their interaction. There is a rhythm to their play, like a dance, just as Ethan had described to me earlier.

Earlier in the week, we were driving northward along the highway, heading back to Ethan's house. He had just finished giving me a tour of the neighbourhood where they all lived a couple of years ago prior to foreclosure. We sat across the road from their former two-story house which was nestled in an affluent area surrounded by other Colonial and Farmhouse-style homes with green manicured lawns. Ethan was deep inside himself, caught up somewhere beyond the bay windows flanking the front of his former home, captured by the memories embraced within, memories transfigured by time, always in motion. The experience left him in a reflective mode. As the scenery transitioned from houses to farm land, he told me that most of his interactions with Jack 'are like a dance'.

'It's a ritual type deal', he tells me in his characteristic careful and soft-spoken voice. 'I used to think Rain Man was a bunch of Hollywood shit', he confesses, 'but it's actually not. There's a lot of truth to that movie because if you start talking to Jack and he starts answering a couple of questions, you think he can talk to you, but he can't. If you say, Jack, did you have a good day today? Yes. He'll always say that. That's the answer he gives every time. No question. Whether he had a crap day or not. A lot of our conversations are just for the benefit of doing it. I don't know how to describe it. It's an emotional thing that I think he likes. He reacts well to it. There's a rhythm or cadence to it.

Like, the other day we were throwing the ball to each other and he was getting frustrated because I wasn't doing it right. He was looking at my face to react a certain way and then he sat down. I was doing it wrong, I think. So, I just sat down. It's weird'.

While this feeling toward the other with whom we move has the potential to enhance the quality of caregiving, attuning is a mutual process, "communicative power is shared" (Griffiths and Smith 2016: 136). As such, parents and their children move through varying degrees of convergence and distance according to the level of shared bodily resonance and understanding between them at any particular time. In their study on communication in carer-care receiver dyads, Griffiths and Smith (2016) examine the ways reciprocal feedback loops regulate how each person in the dyad engages with the world and with the other in the interaction process. They argue that dyadic attuning varies along two interfacing continua, one representing empathy (mutual understanding) and the other cooperation (in pursuit of a common purpose). Thus, attuning can be asymmetrical, for example, "one partner may be highly... 'attuned' to another, while the latter may demonstrate far less empathy, to the point of ignoring the partner or refusing to cooperate" (ibid: 133).

During moments of reciprocal and symmetrical attunement there is harmony between me and my son; a rhythmic attunement characterised by emotional, bodily, and cognitive synchronicity. In these moments, my son may smile or laugh in seemingly shared amusement. He may make momentary eye contact. He is receptive to being affectionately caressed and touched. Correspondingly, I feel a sense of expansion and openness. I feel lulled, confident, and happy. In this instance, the shape I find myself taking makes me feel competent and caring. Contrast this to moments of misattunement whereby he screams and withdraws from me, I find myself constricting in space. I feel challenged, tense, and uncomfortable. In these moments, I find myself taking the shape of someone imperfect and incompetent.

Fuchs (2013, 2014) refers to this phenomenon as ‘interaffectivity’, or ‘interbodily resonance’, where “our body is affected by the other’s expression, and we experience the kinetics and intensity of his emotions through our own bodily kinaesthesia and sensation” (2014: 5). According to Fuchs, this circular interplay of expressions and reactions modifies each partner’s bodily state, “they have become parts of a dynamic and sensorimotor and interaffective system that connects both bodies in *interbodily resonance*” (2014: 6, original emphasis). Through these shared affective states parents and their children converge emotionally. In cases where children lack verbal communication, interbodily resonance provides grounds for communication between bodies and the development of affective connections between parents and their disabled children that cognitivist theories fail to account for (for example, the ways autism is often characterised by theory of mind impairment, see Fuchs 2014; also Milton 2012). As with Merleau-Ponty’s conception of reversibility, there is no absolute fusion. As Reynolds writes, “the other retains its difference as well as its capacity to shock and break open the horizons of the same” (2002: 74).

Merleau-Ponty’s relational ontology accounts for bodies that are inexorably connected with objects and other beings through their co-inhabitation of space and time. As such, intercorporeality is a condition of existence (Diamond 2013). As Diamond explains, intercorporeality does not presuppose harmony or total attunement but can, on the contrary, be very unsettling because these intercorporeal states threaten to undermine the belief in the bodily I and body ownership (2013: 90). Importantly, touch can be transgressive and alienating (Maclaren 2014) –as illustrated in chapter 3 with Ethan’s experiences of physical abuse. As we saw, early intercorporeal experiences pattern the ways we relate to and interact with others. The resonance of the feeling-body, the emotional perceptions these resonances influence, and a person’s corresponding action readiness (Fuchs 2013), play a

foundational role in structuring our interpersonal relations and experiences. Within the context of caregiving, the body's existential orientation affects parents' capacity for responsiveness and attunement.

According to Fuchs, body memory can be seen, then, as extending beyond the physical body and constituting a "sensomotoric...and interactive field in which we, as embodied beings, constantly move and conduct ourselves" (2011: 92). Therefore, body memory plays a crucial role in mediating our affective participation and feelings of relatedness in the world (Fuchs 2013); contouring what is referred to as the *life space* (Lewin 1936). According to Brown and Reavey, Lewin's concept of the *life space* is defined by relations and not metric properties; the life space, they explain, connects the immediate scene to other spaces and actors which are necessary in order to understand a psychological event (2015: 49-50). Elaborating on this conception, Fuchs describes the *lived space* as the totality of the space "that a person pre-reflectively lives and experiences", he writes:

it is characterized by experienced characteristics such as closeness or distance, narrowness or breadth, connectedness or separateness, attainability or elusiveness, and it is structured by physical or symbolic boundaries which offer resistance to movement. This produces more or less clearly bounded sectors such as the peripersonal space around one's own body, claimed territories (property, home), the sphere of influence which emanates from someone, but also prohibited or taboo zones. The lived space is further permeated by tangible "field forces" or "vectors", in the first place those which attract and repel. Competing attracting or repelling forces in the life space lead to typical conflicts...They can be considered as conflicting directions of movement or possibilities which are offered to a person in a given situation (2011: 74).

The lived space, then, is dynamically connected to movement and development, social relations and meanings (Fuchs 2007: 426). As such, it is figured and refigured by a persons lived-through-world-experience. What is important here is to recognise that the context of touch and inter-bodily resonance matters deeply to how it is experienced. In light of this, I want to explore the conditions for the emergence of dyadic inter-relational spaces between parents and their children that foster the development of attunement and caregiving. I believe the intercorporeal intimacy between the fathers and their children in this study helps shed some light on the ways these intersubjective spaces are prepared and brought into existence.

Intercorporeal intimacy

It was the last day of my first stay with Paul in Massachusetts. We were sitting over lunch inside the Dumpling House in Harvard Square, Cambridge. Over a plate of steaming wontons, he tells me, 'it's very easy for me to see things through her eyes. I look at her and I get it. The environment, even physically, I can see things through her eyes'. When I ask what he attributes this sense of togetherness to, he responds, 'Just hanging out with her. We would both be watching the TV, or I'd tickle her, just sitting around physically, that's how we would relax in the evening. I can't do that anymore, she got bigger and is too heavy. The closeness happened, like, right away. Every night I would hold her before going to bed and talk to her and sing her songs that I can still sing and instantly get a reaction. Just made up songs. There was a mockingbird song', a smile breaks across his face, 'hush little Pearl don't you cry, Daddy's gonna buy you a pizza pie...'

Back at his place, Paul engages in his nightly routine of catching up on emails and other work-related issues. Pearl sits in her wheelchair to his side,

gently stroking the keys of a toy piano in front of her. To Paul's right, a flat screen TV peeps out from the same giant wall unit housing the computer he works from. The unit is a disorderly site, filled and stacked to capacity. Amidst the plenitude there seems little of value beyond the sentimental. A couch sits against the opposite wall. It is in a similar state of disorder, blanketed with objects. In the back corner of the cramped, multi-purpose space there is a large mobile changing bench. There's a small partition for privacy and photos hanging on the wall of Paul and Pearl and their life together. The muffled sounds of television and clicking keys unfold against a pregnant background of silence. Paul stares at the computer screen, and although his attention is anchored in the synthetic world before him, his hand caresses Pearl's. At times his hand shifts its contact to her leg. At other times, he perches her foot onto his knee.

Paul berates himself for not talking to Pearl more often. She has no means of effectively communicating her thoughts or feelings, he tells me. 'How long would you talk to your kid without any feedback whatsoever?' he asks. 'A week? Twenty-two years?' He laments feeling guilty over not talking to her more, 'I don't talk to her. I can't talk *with* her'. Paul feels this as a moral failing because 'parents are expected to talk to their children'. Despite the silence that enfolds them, Paul recognises that they share an experiential connection. Throughout my time with them, I noticed that they were frequently in physical contact with one another. Below the threshold of these conceptual understandings of how parents are supposed to interact with their children there is a more primordial form of communication at play between their bodies. Intimate, personal knowledge of one's child and their lived social experience emerges from these intercorporeal and affective experiences. And these experiences are crucial for the development of corporeal connectivity that parents and children often share.

During fathers support meetings and other public engagements, Ray often espoused the importance of ‘rebuilding your life’ and finding ‘new hope’ and ‘new dreams’ and a ‘new type of value system’. On many occasions he repeated, ‘your life can be richer and deeper because of your child’s disability if you allow it to’. When I asked him for a concrete example or an explanation that demonstrated how one actually achieves such an existential reorientation, Ray invariably defaulted to particular interactions with his son:

My son, he is twenty-six. Cognitively, he is like a two-year-old. This morning I came home from the fire station, I went to his bedroom, he wasn’t awake yet, and he sits up and looks at me with a huge smile on his face and he goes, “aaieeee”. And I lay at the end of his bed and he turns and drops his head into my left shoulder and rolls back and forth, going “aaieeee”. And, I’m like, if that’s not love, what is?

Ray didn’t elaborate beyond the specificities of these moments of shared intimacy. It was as though he assumed that everyone he told these stories to would grasp their significance—or, maybe these moments simply spoke to a layer of meaning he could not truly avow. These intimate moments and caregiving routines are more than just expressions of love or care. They are potential sites of emergence. They are places of imaginative and transformational potential, as the following section suggests.

Moral identities and imaginative horizons

Merleau-Ponty provides a corporeal epistemology that recasts the mind as inextricably integrated with the body. As Leder writes, “If the body as lived structure is a locus of experience, then one need not ascribe this capability to a decorporealized mind. The self is viewed as an integrated being” (1990: 5).

Hamington's theory of embodied care offers itself here, particularly the ways he sees caring habits and knowledge as inexorably connected to identity formation, caring imagination, and ethical and political action. "Care cannot be disentangled from its relational ontological, and epistemological elements as well as its moral responsiveness", he writes (2015: 1). Similarly, Monroe writes, "our moral choices reflect our basic sense of who we are in relation to others...identity constrains moral choice through setting the range of options we perceive as available" (2012: 258).

According to Hamington, the subtext of care that is tacitly grasped by the body during interpersonal touch has the potential to contribute to our "caring imagination", which draws upon this stock of affective knowledge in our caring about and responsiveness to others across physical, social and temporal distances, "we cannot care for that for which we do not know" (2004: 60). For Hamington, proximate knowledge does not narrow our empathetic focus but rather breeds clearer imaginative possibilities, it expands our imaginative horizons (ibid: 69). "Caring is corporeal potential realized through habits", he writes (ibid: 5). Hamington views caring habits as moral resources that when integrated with our caring imagination can be adapted and applied to new situations that enhance our caring efforts. Embodiment and tactility are thus given a unique epistemic privilege within Hamington's embodied theory of care. The body is a repository of knowledge that contributes to both pre-reflective and deliberate performances of care. Here, I treat the knowledge that parents inhabit through caregiving as having the potential to broaden their imaginative and empathetic horizons also.

Not only do parents enhance their bodily powers for action through the incorporation of caring skills, then, but enhance their imaginative powers for care also. This can often be witnessed, for example, when parents shift from

advocating for their children (case advocacy) to expanding their focus to others with disabilities (cause advocacy) (Wright and Taylor 2014). For example, Paul's style of being-in-the-world has changed throughout his twenty-odd years of caregiving. He shows an explicit concern for the ways certain spaces don't always extend, protect, and accommodate those with disabilities. This concern is reflected in his commitments to push back against the boundaries of material and social spaces in which disabled bodies stand out through his work as a special education advocate. As Hamington argues, acts of care not only create the potential for developing the skills that make care possible, but in their performance serve as a feedback loop that shapes moral identity (2015: 83) –this will be discussed further in Chapter Five.

There is a social and performative side to embodied care that Hamington emphasises in his later work. He writes, “[care] performances are public, they leave physical and perceptual imprints on others and ourselves”, they inform both self-identity and socially inscribed identity (2015: 19). Whether I view myself as a caring person and what kind is “instantiated through iterations of actions within the context of my relationships” (ibid). Hamington argues that these identities are inherently political because they are negotiated within spaces informed or constrained by political norms and social expectations. Similarly, in her work on the relationship between fathering and care, Doucet (2006a) emphasises the ways moral obligations are tied to social and moral spaces. Doucet underscores the ways fathers' moral identities are informed by how they feel they should act and how they think others will view their actions. In the next chapter, I consider how socially and culturally regulated gender norms and values affect the ways men feel and act as carers in relation to the worlds of meaning they are situated in.

Conclusion

In this chapter, a particular emphasis has been placed on the dyadic dimensions of caregiving and the transformative potential of caring habits and moments of intercorporeal intertwining that corporeal plasticity and sympathetic perception enable. As Diprose writes, “It is because bodies are opened onto others, rather than being distinct that we can act, be affected, have an identity, and remain open to change without conscious direction” (2012: 69). From these examples, we can see that parents move toward equilibrium in their role as caregivers through their experiences of touching and being touched as caregivers. These structures and modalities, for instance, the plasticity of the body and its affectability, enable parents to grasp the intentional signification of their children’s responses and actions and thus enhance their ability to respond to their needs. To return to Merleau-Ponty’s reversibility thesis, these shared embodied activities have the potential to expand and enrich the worlds of both parents and children. Through a phenomenological framework we gain an appreciation for the body as a crucial medium for connectivity, throwing light on the ways the fathers in this study access the subjective lives of their children. Furthermore, I have discussed the potential iterative acts of care have in tacitly refiguring habits of consciousness and the boundary conditions of perception and action; which benefits moral agency by heightening one’s sensitivity to others and the ways we respond to and care for their needs.

Interlude: Greg's Arrival Story

It was Good Friday, April, 2003 and Greg had the week off from teaching. He'd just finished visiting his wife at work and was on his way to the mall with their seven-and-a-half-month-old daughter, Mia. Greg took the off-ramp and came to an abrupt stop behind a line of cars, red lights flashed ahead, signalling that structure work was underway. Behind them, the driver of a flatbed truck was distracted because he had dropped a road map under his seat. He was still fishing about for the misplaced map when he turned onto the off-ramp. Greg recalls seeing the flatbed truck barreling down on him and Mia. By the time the driver realised the traffic had come to a stop closer to the freeway than he anticipated it was already too late. The onrushing flatbed truck slammed Greg's stationary car from behind at 60 miles an hour, spinning them forward two hundred feet. Greg's seat collapsed into the back seat and the windows burst, showering glass everywhere.

When Greg gained awareness, he realised Mia was unresponsive and covered in glass. The screams welled up from somewhere deep and primordial inside. Passers-by attempted to calm him, but it was no use. He feared the worst: that Mia was dead. Then, Mia let out a few small grunts.

There were no fatalities that day. Greg's scapula was broken and the passenger in the tow truck sustained a broken leg. But Mia spent the next five weeks in hospital. During that time, she underwent surgery for a subdural hematoma (bleeding between the brain and skull). Greg and his wife, Cherry, were cautioned that Mia might not survive. But she did. After ten days in the ICU, Mia was transferred to the Children's Hospital where she was treated for more internal swelling. Family flew in from Pennsylvania but there was nothing that anybody could do. Greg and Cherry were preoccupied with Mia's

recovery and the ordeal had consumed their thoughts and spirits. By the end of May, Mia returned home and started her new life of therapies.

Over the last twelve years Mia has made developmental strides, but her acquired brain injury caused multiple physical and cognitive impairments that will require care for the rest of her life.

Chapter 5: Conditions of Possibility: Patriarchy, Masculinity, and Moral (Re)Orientations

To be born is to be born of the world and to be born into the world. The world is already constituted, but also never completely constituted; in the first case we are acted upon, in the second we are open to an infinite number of possibilities

–Maurice Merleau-Ponty

Thus far, I have focused on the possibilities of self-transformation that arise with new habits of care, sensory attunements, and the wide range of interpretive tendencies that narrative and the past lend themselves to. It must be said, however, that as dimensions of embodied existence they are as relevant to the lives of mothers as they are to fathers. So, while this research is empirically driven by the lives of the men who participated in this study, the embodied phenomena I have discussed so far has applicability beyond father-child dyads. In this chapter, however, I shift my focus to the gendered dimensions of caregiving.

Doucet (2006a) and Ranson (2015) both explore the relationship between hegemonic masculinity and care in their ethnographic research on fathers' experiences of caregiving. In *Do Men Mother* (2006a), Doucet examines the ways Canadian men experience care in relation to gendered social situations and the ethical expectations that structure them. In Ranson's research, she considers the practical and moral transformations inaugurated through acts of intimate caregiving. In addition to these, there are numerous studies that examine the external contextual factors that affect the ways men construct and enact their roles as fathers, for example, Hoffman (2011) identifies the factors that are most likely to have a negative impact on the fathering role, for instance, workplace policies (parental and personal leave) and other social supports. However,

while these studies help identify the best ways to support and enhance the quality and intimacy of men's fathering practices, they don't account for the commitments, motives, sentiments, emotions, and capacities that I take to define their moral modes of being as carers, for these cannot be explained solely in relation to the conditions that favour them.

It is my aim in this chapter to fill the gap in this research by considering the sedimented histories and pre-reflective moral dispositions that structure men's experiences of and reflections on fathering, masculinity, and caregiving in the context of disability. The significance of these inarticulate moral attunements in configuring and disclosing worlds of thought and action, much like fathering in the context of disability, has received little anthropological attention. Fathers' caregiving experiences cannot be fragmented away from their personal emotional worlds and the existential feelings that disclose them. I believe examining these personal histories opens the possibility to capture their transformations and becomings over the course of their lives. Within this framework several questions emerge: How do their social identities as men affect their embodied experiences as carers and the ways certain events resonate with them? How do gender norms and values, intrinsic to our self-understanding, bear on personal moments of moral significance and complexity? How do their histories of living through and being oriented towards prevailing gender norms shape the ways fathers perceive, interpret, and interact with the world and others around them? And is it possible to break free from habitual patterns of thinking and acting, and, if so, what is involved in the process of projecting new possibilities?

In asking these questions I take a zig-zagging course, weaving together portraits of fathers' lives and my own to capture the ways we inhabit worlds relative to our perceptual habits of attention, concerns, feelings, and needs. In doing so, I also consider the role broader interlocking systems of oppression and privilege (patriarchy, capitalism, heteronormativity, sexism, ableism) play

in constituting the familiar, informing intersubjective moral relations, and influencing how men affectively find themselves oriented in the world. I end the chapter by considering differential moments of moral dissonance and disruption and the potential these moments have for engendering critical self-reflection and moral development.

Patriarchy and modes of attunement.

From the time we are born, we inhabit a world with others; a world in which we learn with and through others the requisite skills, knowledge, and customs to successfully get along in the world. This is what Heidegger refers to as 'being-in-the-world', the way I am always already involved in the world which is disclosed in our understanding of the world (2010: 55/145). Or, as Merleau-Ponty puts it, "I am a psychological and historical structure and have received, with existence, a manner of existing, a style". (1995: 455). To be situated in the world is thus to find oneself already inhabiting and involved in a world of cultural and intersubjective norms and practices with others. Thus, in Heidegger's words, we grow into a customary interpretation of ourselves and grow up on that interpretation (Heidegger 2010: 19). This gives the world its felt sense of familiarity. But the shared dimensions of our being-in-the-world are also deeply personal. Thus, it is my life, my responsibility, my concern, my care-for, and so on.

We can break this down further and say we are involved in a world that privileges and is patterned by and for certain *kinds* of bodies, according to their needs and interests. Heidegger says our being-in-the-world is "thrown-projecting" (2010: 175). We project or press ourselves into possibilities that accord with how we understand ourselves against a socio-historical situation we did not choose (ibid: 141). This is Dasein's thrownness, according to

Heidegger. Blattner points out that for Heidegger the ways we press ahead is not a “free-floating liberty of indifference” but contingent on how we find ourselves affectively oriented (2005: 82). Examining Heidegger’s thoughts on thrownness, Blattner says that if our comportment (pre-reflective, non-intentional ways of thinking and acting) is “taken over from a pre-existing community—taken over through socialization into that community; paradigmatically in being raised in it—and if that comportment is normalized, then it has built into it a subjection to local norms” (2005: 63).

In this chapter, I consider how fathers’ moral sentiments and dispositions around giving care are connected to norms of masculinity and patriarchal culture. These are the constituting conditions against which parents are acted upon, and upon which they act throughout their lives as subjects (Jackson 1998). As Ahmed underscores in *Queer Phenomenology* (2006), the boundaries of bodies that demarcate the limits of what it can and cannot do are an outcome of our histories of feeling and acting towards value-laden objects, both tangible and intangible (thoughts, feelings, etc.). What is disclosed in our understanding of self, other, and world is permeated with possibilities for existing and acting. For Merleau-Ponty (1995), these lived-through sedimentations lie at the core of consciousness. Alcoff writes, “the concept of horizon helps capture the background framing assumptions we bring with us to perception and understanding, the congealed experiences that become premises by which we strive to make sense of the world” (2006: 95).

In *Visible Identities*, Alcoff draws on the tradition of phenomenology, particularly Merleau-Ponty, to emphasise the embodied and situated features of subjective experience, writing: “consciousness is richly indexed by its time, place, and corporeal foundation” (2006: 108). Alcoff focuses on the ways racial and gendered identities operate as horizons which are constituted “by and through historically specific cultural practices and institutions” (ibid: 110). According to Alcoff, racial and gendered identities derive their reality from “the

fact that they are visibly marked on the body itself, guiding if not determining the way we perceive and judge others and are perceived and judged by them” (ibid: 5). Alcoff maintains that the ways bodies are situated and culturally located by structures of race and gender affects the kinds of experiences we have access to, as well as differences in “perceptual orientations and conceptual assumptions” which are shared among members of a social identity (ibid: 114). As horizons of significance, then, identities make an epistemic difference, in Alcoff’s view, orienting us to perceive and interpret information in certain ways (ibid: 43). She recognises, however, that while others play a major role in the constitution of the self, our perspectival locations are dynamic and open because “lived experience is open-ended, multilayered, fragmented, and shifting” (ibid: 110).

While it’s certainly not possible to capture all the presuppositions and historical sediments that are relevant to the ways the men in this study experience caregiving– or signify their masculine identities–it is my intention to provide partial sketches of these sedimentary histories in order to illustrate their relevance to the ways men comport and understand themselves as caregivers. I find Alcoff’s horizontal approach to identities important for considering the position of men within the social gender order and their situatedness within a horizon of shared meanings infected by patriarchy. While simultaneous locations within social categories (education, race, gender, class, ability, sexual orientation, religion, etc.) differentially pattern our subjective experiences and access to power and privilege, these will be touched on mostly implicitly throughout the chapter: That is to say, while these intersections produce important variations in the way men experience masculinity and caregiving, my primary focus will be on how ideals of manhood and habits of thought and behaviour engendered through a patriarchal value system–indeed, the very things it relies on for its maintenance and reproduction–are lived

through by fathers as “an obsessive presence, as possibility, enigma and myth” (Merleau-Ponty 1995: 446)

For instance, men’s feelings, thoughts, and actions often cohere around gender role expectations with respect to expressions of fatherhood and masculinity. This can be seen, for example, in the perduring legacy of post-war masculine ideals of the nuclear family patriarch which, I argue, significantly influence the way men understand themselves as carers and their attempts to gain purchase on their caregiving experiences. As Heidegger tells us, these self-interpretations are often so pervasive and near to us that they are often the hardest of all to see (2010: 15-20). In this chapter, I argue that the ways the fathers in this study understand themselves and are motivated to act as caregivers is coherent with their personal pasts which are collectively imbricated in contemporary patriarchal culture. As Heidegger writes, things are always already understood in terms of their relevance:

interpretation does not...throw a significance over what is nakedly objectively present and does not stick values on it, but what is encountered in the world is always already in a relevance which is disclosed in understanding of world, a relevance which is made explicit by interpretation (2010: 145).

Moods (*stimmung*) plays a special role in Heidegger’s philosophy, influencing the ways things are disclosed in their mattering (2010: 132). Gallagher and Zahavi write. “Moods such as curiosity, nervousness, happiness disclose our embeddedness in the world and articulate or modify our existential possibilities” (2012: 133). Or as Fuchs explains, moods render the subject prone to perceiving things in a certain way, for instance, anxiety, boredom or depression may disclose uncanniness, emptiness, or the burden of existence (2013: 618). Moods can be understood as modes of attunement that pervade the

ways we comport ourselves toward others and the options we perceive for acting. They are the “conditions of possibility for specifically focused emotions”, Fuchs tells us (2013: 619). I examine the relationship between patriarchy and how men experience themselves in the world as gendered, historical beings. As Beauvoir captures in *The Second Sex* (2011), restrictive gender patterns build up over a lifetime and can limit our freedom and prove hard to break free from. As a basic structure of being embedded in the world, then, I think the concept of attunement is useful for considering a phenomenology of gendered experience. In an effort to extend Heidegger’s insights, alongside Beauvoir’s (2011) feminist phenomenology concerning the lived body, I consider the ways cultural patriarchal norms and ideas influence the ways men are affectively attuned to things as already mattering in their worlds of caregiving. I ask: how are fathers’ local moral worlds influenced by personal histories imbricated in prevailing cultural notions of masculinity that emphasise the subordination of empathy, the risk of vulnerability, and the value of control and recognition?

Furthermore, I consider moments of, what Zigon (2007) calls, intersubjective moral breakdown: that is, moments that shake us out of our everyday modes of moral attunement and give rise to ethical moments of reflection and deliberation. Zigon draws on Heidegger’s existential phenomenological insights to propose that morality should be thought of as “bodily dispositions enacted in the world non-intentionally and unreflectively” (ibid: 135). He goes on to say that to be moral is to inhabit a bodily disposition that is familiar to oneself and others (ibid). It is in this sense of “familiar sharedness”, he says, the we can speak of “being good” (ibid). Ethical dilemmas, then, according to Zigon, are analogous to Heidegger’s insight that it is only when our concerned dealings with things breaks down, for instance, when the hammer becomes too heavy, that we are drawn out of our familiar

and pre-reflective ways of dealing with things. For Zigon, ethical dilemmas constitute moments of moral breakdown, when our everyday, unreflected upon moral dispositions rise to reflective consciousness to which we must respond. Near the end of this chapter, I consider what these intersubjective moral moments of breakdown contribute to fathers' moral experiences of caregiving and the ways they refigure their understandings of manhood.

We are standing in the kitchen of Ethan's single-story weatherboard home. He is making coffee and telling me how much he likes his mother's partner, George: 'He's a *really* nice guy. I remember being at their place once and they were installing a washer and dryer and he wanted to know if I wanted to help him. So, I did', he pauses a moment and makes eye contact with me, his mouth hanging open in thoughtful appraisal, 'during the process of doing that I broke down in tears and he asked me what was wrong and it was because the whole experience of helping him do that was so different than when my father would ask me to help him. When my father asked me to help him it was give me this. Grab this tool. Put that away. Shut the fuck up. Get out of my way. It was just a horrible experience, 'till eventually he might just clog me with one of the tools. I mean, that's why I have such an aversion to tools'.

His story brings me back to myself and awakens my past; the past is *remembered*. I'm twenty years old. I'm sitting at a small table in the kitchen of a two-bedroom farmhouse that my father purchased and remodelled a couple years after the divorce. It's a small structure – white clapboard siding and a metal roof–set amidst 14 sprawling acres (5 hectares) in a rural town outside of Ballarat in Victoria. It's miles from anywhere. My father is standing by the stove cooking a recipe he recently learned from his mother, eyes fixed on Gus

through the window—a black Rottweiler he claims he bought to protect the property (not to assuage his isolation and loneliness) –who is cautiously exploring the edges of a large dam. I listen to him boast about his nephews (my cousins), who he recently caught up with and who both work in trades. He’s brimming with unsurprising satisfaction at their transition from boys to ‘men’s men’ who work with their hands.

‘I’m going to have to show you how to do a few things’, my father tells me, ‘so you don’t end up a useless male. You don’t want to be a useless male?’ But it’s not really a question and there’s no sense of irony in the way he says it. He doesn’t look at me either and I’m relieved because I can feel the affect of his words in my breathing. One glance in my direction would surely undermine my uneasy attempt at nonchalance. I keep quiet. It’s late and I’m not in the mood to be driving home. The last time I confronted him—over a vitriolic heterosexual tirade, many years before my brother would reveal that he liked the bodies of men—fury exploded through him causing his whole body to tremble. ‘Sparks are going to fly’, he warned me. His uncontrollable rage had resonated so strongly with our dark history of family violence that I slept the night at the train station in the freezing cold.

Back in Ethan’s kitchen, he continues, ‘but with George it was, here’s how this works. Here, check this out. Let me show you what this does. And it was such a moving thing for me’. Ethan slides my freshly brewed coffee towards me. I ask for some sugar. He motions with his eyes to a small bowl nearby. I feel self-conscious as one...two...three...spoonfuls make their way into my cup, as though he is silently judging my sugar vice, silently keeping tabs on how many spoonfuls I sink into the cup’s steaming murky depths—an impression that reflected the many years of living under the weight of my father’s controlling and judgemental gaze. But when I look up, I see that Ethan

is watching Jennifer through the kitchen window as she mows the back lawn. 'I get embarrassed', he says, quietly, shifting his gaze back to me. 'It's really something I should do'.

'That's not what I was thinking', I reply.

There's a brief silence during which neither of us says anything. And then he returns his gaze to Jennifer, 'It's just one of those things. That kind of resentment does build because she does feel that way', the corner of his mouth turns up into a sardonic smirk, 'even though she will deny it. But she thinks it: that I don't do what I'm supposed to do'.

These days, Ethan sells toy collectables on eBay. His basement comprises three adjoining rooms: One has been converted into an office while the other two house his meticulously stored inventory. He admits that sometimes he feels like a 'junk dealer', something like Fred Sanford from the 70s sitcom Sanford and Son, especially when he considers his once lucrative career in the toy industry. He spends the next ten minutes explaining that since 'losing the house' and starting work from home a few years ago he has still managed to keep a steady stream of income flowing into the house through his eBay business. The problem isn't that they're not making enough money, he tells me, but that they don't manage their money well; 'that's the core of our problem'.

A discordant melody

My mother always said that if my father allowed her to manage the finances then his businesses wouldn't have been liquidated. I remember waiting with my older sister after school under our regular pick up spot (a cherry plum tree). It was 1989 and I was eight years old. She was almost twelve and at the age

when most kids start to care a little more about their peer's perceptions. Eventually, my father arrived in a rusty old station wagon. I didn't pay much attention but my sister asked where 'our' car was, a blue 1988 Ford Fairlane. He grew irritated and defensively brushed her off. Little did we know that his business and assets had been liquidated, along with the family car.

At that time, we lived a short drive away from where my paternal grandparents lived. I remember spending a lot of time there. They were heavy smokers and their house smelled of stale cigarette smoke and other unidentified bits and pieces—a smell committed to memory and as alluring as ever. My grandfather was a short and quiet man with a big cleft at the end of his nose. Most of my memories involve him sitting at the kitchen table underneath a large oil portrait of a lion with a dark mane, smoking one cigarette after another. He had come over from Scotland at fifteen and retained strong traces of his brogue. He worked as a nurse educator most of his life and I'm told he was a charismatic and charming teacher; popular among the female nursing staff. But his popularity didn't extend past the hospital walls.

According to my mother, when my grandparents decided to marry, my grandmother's father, John, pinned my grandfather against the wall by the throat and forbade him to marry his daughter, threatening to sever ties with them if he did. Idle were these threats beside the uniting force of love. They got married and true to his word, my great-grandfather John didn't speak to them again until after their three boys were born. He died of an aneurism when my father was five years old. Despite their short time together, however, my father bonded strongly with his grandfather and idolised him. One of the only other tales I heard about John was told to me by my father. It was a tale of retributive justice: John pulled up at a petrol pump to refuel when he saw a man at an adjacent bowser kicking the shit out of his dog. When he was done, he threw

the dog into the back of his truck like a threadbare tyre. Before the sadist could settle in behind the steering wheel, John pulled him from the vehicle and delivered a series of solid kicks into the man's backside, driving him onto the pavement on all fours.

Whatever unity my grandparents possessed early on evaporated by the time stomach cancer ravaged my grandfather. After a series of admissions to the hospital and forty-odd years of catering to his needs, my grandmother decided that some other community living situation would be more appropriate. After all the years of subservience, it was as if she were finally claiming her right to speak for herself. She called a family meeting at the hospital, where my father and his brothers agreed to support her decision. My father remembers his dad sitting in a wheelchair by himself in the hospital corridor, hands over his face, sobbing 'like a child'. He said seeing his dad like that was challenging. After all, this was a man who never cried. My grandfather was adamant that he didn't want to leave the house he had lived in for more than half his life. In the end, he didn't have to. He died weeks later in hospital.

Growing up, my father often recounted living under his father's exclusive control and his forbidding and mocking demeanour. My father entered a trade by the time he was sixteen and worked at steel mills and in metal construction for most of his life. When he was a young man, he would get into heated arguments with his father over who worked the hardest. For my grandfather, intellectual labour was the province of hard work. For my father, manual labour was the definition of man's work. I wondered if my grandfather ever felt judged by his father, who had worked manually all his life. In a cyclical turn of events, my father would demean my career choice whenever he could.

'What are you up to?'

‘Just working’.

‘Working? I wouldn’t call that work!’

Despite these additional fragmentary sketches of my grandfather, it was hard for me to imagine him as anything outside of the quiet and solitary figure I had known through childhood.

My grandmother, on the other hand, was animated, warm, and funny. We had a meaningful connection based on our mutual love of ‘red dicks’ (mini Frankfurters) and George Burns movies. But these times were short lived. Not long after our Ford Fairlane mysteriously disappeared, my father did too. But not before my four siblings and I were shipped off to live with my maternal grandmother. My father had a falling out with his parents over borrowed money he couldn’t return, and his debts owed to townspeople had led him to experience the social discomfort sometimes reserved for outsiders. He resurfaced six months later once he had secured a job across the country, in the suburbs south of Fremantle in Western Australia. Soon, I was studying at a new school on the other side of the country. I wasn’t afforded the chance to say goodbye to my grandma and grandpa and I never saw them again.

My father always had an explosive temper but there were stretches of time where things were ostensibly peaceful and there was no drama at home. But even then, I was constantly on guard. Physical and emotional violence were meted out for the slightest acts of transgression. He didn’t handle dissent well. This was never clearer to me than the night I ignited his temper by disagreeing with him, I can’t remember what it was over. And even though the usual physical assault was absent from this encounter (not its threat), it left an indelible impression. On that night, I was told that I was no longer his son. I was nine at the time and in a provocative move I reacted by threatening to leave

the house. He cautioned that I would be leaving as naked as the day I arrived in this world since he had provided everything I owned. So, in the suit nature endowed me with, I made a break for it and hid outside behind a neighbour's car for ten minutes to see if he cared that I was gone. But it was my mother who appeared backlit in the open doorway, and my heart felt heavy.

An ethic of domination

Patriarchal culture wields immense influence over the ways men and women negotiate their gender identities, which are lived and enacted within and across fields of social difference and power. Like me, domestic violence robbed Ethan of a nurturing, teaching, respectful, and protective space to grow up in. Despite our social differences in class and environment—Ethan was from a middle-class background and from the American Midwest and I was from a working-class background in Australia—both our fathers embodied, what hooks (2004) calls, “dominator models of masculinity”. These dominator models, hooks states, collude with patriarchy as a political-social system by expressing male power and a relation of domination (2004: 18). Through these patriarchal gender relations and gendered performances, the ruling social structure plays out within our most intimate spaces. In phenomenological terms, these histories and lived experiences inform part of the horizon that structures the possibilities of gendered bodily experience and identity.

Ethan often lapsed into morose periods of introspection, descending into obstinate silence as he grappled with his complex and tormented inner life. Ethan confessed to having both struck and abandoned his children, ‘I’ve been *both* fathers to him [Jack]’, he admitted. Two of the worse incarnations of disorderly fathering, in his view. Careful attention to Ethan’s vocabulary

reveals connections to an earlier past where he was subjected to both failings by different men: abandoned by his biological father and abused by his stepfather. After a brief interregnum last year, where he and Jennifer lived apart for a short period, Ethan realised that he ‘crushed Jack’ and was ‘being selfish’. ‘I hated not being around’, he recalls. ‘It was such an alien life for me. It was like losing myself. The stress was so enormous but I couldn’t live without it. It’s been a totally different approach for me since I came back’.

I am standing in Ethan’s bedroom upstairs. He reaches for a stack of drawings piled on top of the desk and hands them to me. I sift through the illustrations, renderings of iconic super-heroes and some new incarnations. Each illustration is pencilled with expert precision and detail. To the uninitiated, like myself, they are indistinguishable from the comics I collected as a small boy. With pensive contemplation Ethan tells the stories and events behind the illustrations, weaving them together, creating a temporal flow that highlights the evolution of his artistry and life; detailing his failure as a promising artist, his rise as the chief toy designer at a respected toy and collectables manufacturing and distributing company, and his ultimate shift to selling toy collectables on eBay from home and caring for Jack. He remarks that Jennifer would prefer him to make the move back to full time employment; an expectation that sits uneasily with what he feels are Jack’s best interests.

‘The whole idea of working has affected my experience as a person and fills me with self-doubt and makes me question my value. Then, on the other hand, I feel like the path I took with some of the things I have done over the last eight years were good for Jack. So, the expectations, I try and measure them, you know, are they mine or are they societal? Or are they my partner’s? And then I put it into perspective when I – my 30th high school reunion is this year, okay? And one of the first thoughts I have is: I want to go but there’s a part of

me that is embarrassed to go because what do I say when someone says, what do you do? Which is a question people ask all the time. What do you do? I don't really know what I do. And the question has a complicated answer and I don't know if people really want to hear it'. Ethan laughs. 'You know what I mean?'

'Have you rehearsed what the answer would look like?' I ask.

'No. Maybe I should. I guess you could say, I own my own business but then there's the follow up question to that: what's your business? Well, I can't just say I sell junk on eBay, even though that's kind of what I do because it's more complicated than that and more interesting than that. If you have a job that's defined, there's usually only one way to paint it, which is: I'm the Chief Operations Officer of Think Way. Oh, how is that going for you? Good, the pay is good and I have two weeks that they send me here and here and I'm up for promotion in two months and then you move on. I don't want to get involved in this complicated discussion about why the last eight years of my life I veered off from a career that was really good. Unless you want to. Because some people might be interested in the story. But some people might just want to hear that everything is fine'.

Ethan and I are nearing the centre of town, driving quickly to make Ethan's routine appointment with a chiropractor for his chronic back pain—the reason he can't do the 'male defined' chores around the house, like mowing the grass. He seems more at ease this morning. Maybe the chiropractor's ability to close the pain gates, even momentarily, brought him some peace of mind. He tells me that he attributes his failures in fatherhood to the lack of positive fatherly influences in his life. 'How do I be a better person, husband, father? I guess what I'm trying to do at forty-seven years old is find all the things my dad never gave me. Really, that's the truth. Before it's too late not to give those things to my kids'.

This creates a segue into a description of a documentary on fatherhood that he watched recently on the effects of father absence on boys. 'This guy, John Eldredge, appears in this part of the documentary and I found him fascinating and so I started reading some of his stuff. He is of the mindset that the maleness of men is slowly being stripped away. It's an amazing book about how men have lost something, particularly our generation. I guess we're still in the same generation. Anyway, because of our upbringings and our dads were dumb, we didn't get some of these things that should have been put into us and what will happen, or the fear of what will happen is, we'll retract, and the tendency will be to withdraw and not deal with things'.

Ethan is talking about Christian masculinist writer John Eldredge, the author of New York Times best-selling *Wild at Heart: Discovering the Secret of a Man's Soul* (2011). The title alone is enough to clue us into Eldredge's narrow characterisation of men and his universalistic framing. Like Christian masculinist movements, Eldredge's gender politics are about men reclaiming their natural power over women (Kimmel 2010: 21). Thus, Eldredge emphasises the importance of discovering the "masculine soul". "Every man wants to play the hero", he proclaims, "Every man needs to know that he is powerful" (2011: 12). Above, Ethan positions us both in accordance with Eldredge's notion of the undeveloped man. That is, boys deprived of the love and affirmation of fathers who consequently become spiritually and psychologically broken, their masculine souls damaged; men adrift from their natural and primal qualities, their potential to come alive as men left unrealised. It is worth exploring Eldredge's view a little further because I believe it provides a good example of the way our relationship of being-with others manifests in our everyday sense of relatedness to the world: the ways we are affected by others, the choices we see for acting, and the expectations we hold about what constitutes normal

behaviour. As we will see further on, these provide the conditions for moments of moral breakdown and ethical deliberation.

Eldredge states elsewhere, “identity—especially gender identity—is bestowed by the father. A boy learns if he is a man, if he has what it takes, from his dad. A girl learns if she is worth perusing, if she is lovely, from her dad. That’s just the way God set this whole thing up” (2004: 15). Eldredge’s evangelical ideology is premised in a well-worn gender essentialism and biological reductionism that justifies male dominance by positing that male and female identity are based in biological difference. As Alcoff points out, bodily differences in which subjectivity purportedly originates from are “key to the ideological claims that they are natural” (2006: 103) Thus, Eldredge makes the universal claim that men act and derive significance from their roles of leadership and productivity, and women from their relationships. Accordingly, the biggest fear men harbour is failure in work and career, while women fear abandonment (Eldredge 2017). Essentially, the “fearful” and “weary” men that Eldredge identifies as being wounded through emasculation have been robbed of an entitled superiority and influence (although not a sense of it), for “in the heart of every man is a desperate desire for a battle to fight, an adventure to live, and a beauty to rescue” (2011: 9). Eldredge says that the veracity of his claims are affirmed by the number of men around the globe who find resonance with his personal theology (Eldredge 2017). I would argue, however, that this purported global resonance of Eldredge’s authentic masculinity speaks to the naturalisation of patriarchal power and not nature’s truth.

“Passivity and masculinity are...fundamentally at odds with one another”, Eldredge writes (2011: 248). Masculinity is thus defined as essentially distinct from femininity, and so are our roles as mothers and fathers. The informing patriarchal ideal of his unapologetic authentic masculinity is that

men need to take charge. In his view, journeying toward authentic masculinity requires men to fulfil their benevolent responsibilities of leading, protecting, and providing for their families. Despite the glaring heteronormative bias—built into the masculinist Christian worldview—a move towards masculine integrity and achieving a more emotionally fulfilling masculinity may seem laudatory. In reality, however, it keeps intact the social grounds of male identity rooted in an ethic of domination (hooks 2004). Counter to his call for a more emotionally fulfilling, meaningful, and responsible masculinity, he enables the threat of emasculation and an ethic of violence to remain principles that guide the ways men construct their masculine selves. There is little doubt in my mind that Eldredge’s message finds such diverse resonance among men because of the male privilege it speaks to. It is standard fare, he claims, to hear women ask in books and talk shows, “where are all the real men?” (2011: 7). By co-opting the question to further his agenda, this question becomes consonant with his Christian muscular ethos. I would suggest that the women he speaks of are hardly in short supply of self-entitled men.

I wonder how Eldredge would make sense of men who are inevitably dependent on others to have their needs met—through illness, disability, or old age, for instance. Do they fail to attain the status of manhood according to his ethical perspective because of their inability to live up to these masculine ideals? Furthermore, does lacking the strength or ability to fulfill these traditional patriarchal obligations relegate them to a ‘feminine’ condition of enfeebled passivity? I think the claim that activity and passivity are mutually exclusive reveals a paucity of imagination. There is no place in Eldredge’s view for the kind of relational or moral equality that underpins social and political equality. Also, it neglects to see vulnerability as a core condition of humanhood, which can draw us closer to others and reveal our responsibility for them.

The significance and enactments of gender and manhood in the lives of the men in this study disclose patriarchal culture as an indispensable background against which they pattern their perceptions and co-existence with others: “a zone of generalised existence and of projects already formed, significances which trail between ourselves and things and which confer upon us the quality of man”, in the words of Merleau-Ponty (1995: 450). Ethan’s experiences as a father and man are beset by tensions and contradictions. Ethan is caught between the competing expectations enfolding post-war ideals of masculinity and fatherhood: between serving as the breadwinner for his family, on the one hand, and the expectation that fathers participate in the psycho-social development of their children, on the other (Diehl 2016). At times, Ethan feels like he is fulfilling the cultural expectation to provide for his family through his eBay business, at other times, however, he feels this achievement is negated by his failure to climb a career ladder. Furthermore, Ethan’s perceived failures to protect his children through his own past punitive actions and mistakes are at odds with the notion of patriarch as a guiding and protective familial force (arguably, this has been exacerbated by a sense of vulnerability evoked by Jack’s disability).

McDowell writes:

patriarchs are supposed to protect, provide for, and solve the problems of others. Competence in these areas is highly valued and evaluated as individual accomplishment. There is an inherent contradiction, however, as none of these expectations are singularly within an individual’s control. Protecting and providing are contextually situated and depend on access to resources, *degree and type of family need*, political climate, and so on” (2015: 29, emphasis added).

Ethan's family situation and lived experience underscore McDowell's point. Ethan is drawn to the myth of Eldredge's authentic masculinity, which appears to enhance and give retrospective form to his experiences. But the ethical demands of his family and its composition (and other debilitating physical ailments), continue to undermine its grasp. The uninhabitability of this post-war model of fatherhood and the ever-increasing tension between fulfilling these ideals (i.e. healing the wounds of emasculation through the restoration of domestic patriarchy) and meeting the demands of his situation, which include being responsive to Jack's needs, has induced an internal schism.

The felt weight of these moral gender expectations presses in on Ethan's everyday experiences of fatherhood and caregiving, squeezing out their potentiality for an analytic reworking of his thoughts and emotions, or alternatives for thinking himself out of difficulty—rendering problematic his relationships with his wife and children in the process. Ethan's experience speaks to a moment of moral breakdown, an ethical moment where his once pre-reflective moral dispositions (to provide, to harness recognition, to lead his family) stand in tension with his particular situation and Jack's care needs. As Zigon notes, "the primary goal of ethics...is to move back into the world; to once again dwell in the unreflective comfort of the familiar" (2007: 138). Herein lies Ethan's ethical challenge as he engages in ethical questions like what kinds of actions and ends are worth pursuing?

According to Ethan's ethical perspective, by virtue of being men, fathers contribute something irreplaceable to boys. Ethan confessed to feeling castrated because of his choice to work from home and play a larger part in caring for Jack, 'I can't really fight that [feeling castrated] because I ended my career to care for Jack. To resurrect my career means to leave him. To take an alternate career means to diminish his care to whatever degree. I need to figure a lot of

stuff out, instead I spend most of my time in avoidance'. His renewed commitment to his family and responsive, attentive, and caring qualities did not easily figure in to his self-perception as a man or father.

These mediative gender norms were prevalent in other fathers' intentions and experiences of moral disequilibrium too, like Wayne, for instance, a father in his late forties who shared custody of his two autistic boys, Noah and Nick. The first time I met Wayne was at a fathers' support meeting in Chandler, Phoenix. Wayne shuffled into the small conference room where Ray and I were sitting at a rectangular table that could have easily accommodated ten. He exuded a nervous and unpredictable energy that belied his solid frame, a look of someone who had pushed himself too far and was on the verge of collapse. In a weak economic climate with few job openings, Wayne seemed to be staying afloat by doing odd jobs through his church and from the support he received from family. He admitted to feeling 'emotionally drained'. The culmination of living alone, working, caring for the boys, stress eating, and the pressure of being behind in child support payments had led to a recent spate of cardiac palpitations, according to Wayne. He feared these palpitations were an ominous sign of something worse to come, something like God sounding the final eviction notice. But they turned out to be nothing.

Wayne revealed that when his children were first diagnosed he thought, 'I gotta live to be a hundred and twenty years old so I can outlive my kids. I gotta take care of my kids. That was the mindset from day one'. Later, he adds 'it pains me in some respect that as a man I can't provide [private therapy] that for my kids and I hate being dependent on the government. But we are. That's where we are. I don't know how many people I have thanked over the years for paying their taxes'. Months later, a scan of the titles on the spines of the books

in his bookshelf affirm this felt moral expectation: *Lead the Field, Learn to Earn, The Courage to Be Rich, Acres of Diamonds*.

Wayne and Ethan's experiences and reflections speak to the ways their constructions of fatherhood and experiences of caregiving are given value and disclosed in relation to ideals of breadwinning and success in the marketplace. Their inability to access the power, privilege, and status conferred through participation in the formal economy has left them feeling discredited as both men and fathers. Schwalbe (2014) makes the more radical claim that the very notion of manhood is ontologically tied to exploitative relations of power. Because of Schwalbe's clarity, I quote his argument at length:

The impulse to exploit acted upon by males and enabled by male physiology, is what gave rise to men...This is why signifying not only the capacity to exert control but also to resist being controlled is an essential part of a manhood act. In part, this is about signifying that one should not be identified as a member of the category of exploitable Others called "women" ...Just as men are not optional within exploitative relations of production, being a man is not optional for an individual male under these conditions. To refuse being a man is to invite identification as a target for exploitation. It is to forgo the benefits that come from membership in the exploiting group. Once exploitative relations of production have been established, the ability to signify a masculine self—a self-capable of exerting control and resisting control—acquires enormous survival value. Within exploitative relations of production, the benefits and rewards of manhood status compel all males to claim it, even against conscience (2014: 104).

During the meeting, mid-conversation, Wayne reveals that he's recently joined a men's group. Before he can drift too far from his remark, I interject:

‘What men’s group?’

‘It’s a twelve week – it’s kind of hardcore. Most bible studies are like eighty percent bible and twenty percent, you know, relationship touchy-feely stuff. This is like biblically-based, twenty percent focus on the bible and the other eighty percent is like hardcore’.

‘Like Fight Club?’ I ask, but inside I am eager to excavate the deeper layers of what he is saying.

Ray and Wayne laugh together.

‘Yeah, it’s really intense. You have to sign a thing saying you won’t talk about anything you hear –’

‘What kind of things do you do?’ I ask.

Ray interjects, laughing, ‘Not talk about it’.

Wayne bursts into laughter and continues, ‘We just get into the meat of things, you know’.

‘Where is this?’ Ray asks.

‘Men of Valor’.

Ray nods, ‘Oh, ok. Yeah’.

‘You’ve heard of it?’ Wayne asks.

‘Yes. Yep’, Ray nods, encouragingly.

‘Is it a similar kind of group to the one you attend?’ I ask Ray.

‘Rebel? No. Well, it’s a lot of the same concepts but its – Men of Valor is more structured. Rebel is more free flowing. Its men getting up to share their testimony, their story, *getting in your face with stuff* they’ve dealt with in life. We sit around and *get in each other’s faces* in regard to what was talked’.

Wayne says, ‘And typically you have about enough people in it that every week someone really takes time to spill their guts and really open up and just – I mean, I’ve seen some *really really tough men* just bawling, you know, through these meetings. The first time I went through, man, I was crying a lot’.

‘What do you hope to get out of the experience?’ I ask.

‘Honestly, I’m not sure why I even went’, Wayne emits a constrained laugh, like he’s afraid he might burst a pair of sutures. ‘I was just in need of communication and relationship because I had been out of work for months and um just really starting to lose – just turning into jelly and, you know, really needed some guys to rally around and in turn rally around them, not just me but, you know, to be a part of that and in it...’

The hyper-masculine language employed by Ray and Wayne is revealing. Firstly, it’s illustrative of the ways men shift in and out of their masculine identities, just like their caregiving ones, according to the situations that they inhabit with others. But more importantly, the material and symbolic rewards conferred through participation and success in the work place are not the only things at stake here. Wayne’s own self-perceived credibility as a man and a sense of how he measures up to other males also seems to figure prominently in the ways he defines himself as man. Wayne’s dependency on state support and benefits and an inability to prove himself in the work place has engendered feelings of failure and shame. Arguably, his participation and acceptance in a group of ‘tough’ men enable him to maintain feeling like a man;

satisfying his self-perceptions and his relational value vis-à-vis other men. Furthermore, through his participation in Men of Valor, Wayne is able to maintain membership in the dominant gender group.

Ray's description of group participation at Rebel and 'getting in each other's faces' defines a particular style of interaction, charged with masculine aggression. Whilst Ray has experienced a successful career as a firefighter paramedic and is a productive and recognised member of the Maricopa County community, these expressions of hyper-masculinity may have served to distance himself from feminine elements and ward off any affronts to his sense of manhood that the preceding emotionally-intimate conversations about caregiving gave rise to.

A discordant melody (cont'd)

I learned early on that my father's identity as a man and father was anchored in his instrumentality as the breadwinner of the family. But my father's excessive investment in the symbolic capital that breadwinning provided came before other expressions of care (physical, emotional, or intellectual). Of course, breadwinning does not negate one's ability to express care. Indeed, the role of economic provider can be framed as a form of care, supportive of another's care labour (Hanlon 2009: 174). But even so, this rarely involves hands-on care activities, because, as Hanlon writes, according to the ideology of the male breadwinner family, other expressions of care are subordinate to caregiving in economic terms (2012: 187). In the case of my father, the male-breadwinner/female-caregiver logic lent itself too easily to the emotional distance that accommodated his abuse.

By the time I was six years old I learned that dissent in the ranks would not be tolerated and that my father's position of dominance within the household would be maintained through physical and emotional violence. When business liquidation and debt threatened his masculine identity, particularly his economic power, authority, and sense of hard work, he sought to restore his masculine self-worth and position as head of the household at whatever cost necessary; even if it meant disappearing for lengthy periods of time or estranging his children from loved ones who threatened him with emasculation through economic dependency. Very early on in my life, I understood that my father's displays and use of violence were negatively affecting the ways I felt towards him. These early experiences would affectively load many of my future relationships and survive in my body's permanent readiness for conflict.

For a short while, before their divorce, we had lived as a family—my father, my mother, my two sisters, my two brothers, and I. A man of habit, my father would leave early for work in the morning, and then, return in the evening, tired, disgruntled, and entitled. He would demand solitude, peace and quiet—spending the next hour or so talking with my mother or playing a video game, until our family dinner. And even during this moment of family togetherness, we would sit in a clenched atmosphere, for whoever committed a transgression that day would surely fall into his crosshairs. He worked hard as the sole breadwinner, sometimes two jobs, and I imagine this wore down his patience. But what could have been an interlude for my father from the pressure and grind of the everyday was instead spent fulfilling his self-imposed duties as the disciplinarian. His energies spent away from home working were concomitant with rising standards of living and the flourishing pleasures of materialism. He once remarked with resentment that we never went on holidays as a family growing up because his earnings were spent on our needs

and providing the kind of Christmas that my mother demanded, year after year. Like many men throughout the twentieth century in capitalist societies, my father's status and position of privilege within the home was tied to his participation within these wider systems of domination. As Schwalbe puts it, most males will fail at claiming manhood status based on success and power in the workplace being what economic and political realities are in a capitalist society: "capitalism constantly thwarts these ambitions and expectations. Be a man, males are told. Be strong, ambitious, potent, competitive, achieve wealth, status, and power; get ahead of others, and do not let yourself be dominated" (2014: 115). My father no doubt compensated for this sense of powerlessness within the work place by tightening his authoritarian control within the home.

There were other political and economic changes afoot that also threatened my father's sense of control and unspoken privilege: rises in women's employment, expansion of publicly supported childcare, and increasing divorce rates, fostered the emergence of new family compositions. These shifts undermined the cultural ideal of the modern nuclear family engendered by the two-parent, gender differentiated household –itself a product of specific historical and social conditions (Gerson and Torres 2015). And by the time my childhood arrived in the 1980s, the economic and social terrain had been shifting for some time. Australia witnessed increased changes in patterns of work which signalled a new economic order: from an industrial to a post-industrial era (Macintyre 1999). The economic future would no longer be based on the labour-intensive factory production that my father perceived as a 'real mans' work, but on high-technology information industries.

Looking back on it now, our family structure was organised around three principles: breadwinning, heterosexuality, and hierarchical authority—and to varying degrees, I recognised these same expressions of patriarchy within the

homes of my friends growing up. These principles, in action, functioned to uphold my father's position of superiority, privilege, and authority within and outside the home (to varying degrees), maintain his need for respect and fear within the home, and ward off displacements that threatened to disturb his credibility as a man. My father did not hesitate to feminise or express disdain toward things that threatened to undermine his sense of manliness and level of comfort: from white-collar 'pencil pushers' who signified his subjugation to his father and acted as a screen against which he defined his brand of masculinity, on the one hand, to me and my older brother who preferred movies and acting over football and fishing, on the other. As White underscores, patriarchy creates hierarchies across different groups and subgroups of men wherein manhood is defined in ways "that conform to the economic and social possibilities of that group" (2008: xv).

My father drew on the symbolic resources available to him in substantiating his masculinity. With little formal education, he put great stock in his strength and virility. His definition of manliness was incarnated by all his favourite action heroes of the time (Stallone, Seagal, Schwarzenegger, Van Damme—the glory years of action cinema!) But it was also implicitly articulated in the various stories he told us growing up, like the story of great-grandfather John's retributive violence, or in other heroic tales that bolstered his virtues of manliness: Once, a freak tidal wave threatened to absorb me and my father. He clung, with one hand, to the jagged cliff face soaring above the sea, and to my infant-body with the other. According to my parents, left in the literal hands of certain *kinds* of men who had not cultivated my father's mettle and physical strength through hard manual labour, I would have met certain death.

But my father's enactments of manhood were an exercise in contradiction and ambiguity. Despite his perceived independence and self-

sufficiency, my father relied—or, rather, took for granted—the care work of my maternal grandmother and her unquestionable willingness to have us live with her. Tronto has termed this “privileged irresponsibility” (1993: 121; 2006: 12). It is one of many patriarchal privileges. In this instance, it speaks to my father’s structurally privileged position as a man to pursue his economic goals (and whatever others he had) by disappearing for protracted lengths of time while excusing himself from the responsibilities of care labour at home. In these instances, he was the beneficiary of my maternal grandmother’s good will. He never thanked her for the times she took us in over the years and I doubt he ever felt like he should. This is how privileged irresponsibility works; it is invisible and like other hegemonic mechanisms it relies on its invisibility to sustain and naturalise hierarchical gender systems and power relations both within the home and socio-cultural institutions (Tronto 2006: 12).

In fact, my father’s enactments of fatherhood were in accord with post-war models of fatherhood based on breadwinning. Zoja identifies the breadwinner, consolidated by the twentieth century, as the preeminent model of fatherhood in the west (2003: 273). He writes, “It is encouraged by market economies and leaves little space for the demands of psychology and feminism. Such a father spends very little time with his children, but generally feels no guilt about it; he is much more likely to experience feelings of guilt if he loses an opportunity for economic gain, even if the loss results from no fault or lack of initiative of his own” (ibid: 273).

Other behaviours, though, contrasted uneasily with the archetypal emotional stoicism and self-control my father aspired to. Once, when I was fifteen, my brother and I stood outside his apartment in the dark waiting for our mother. They had only been separated for several months at the time. She was inside with my father and it was clear by their gestures that they were

involved in a pretty serious conversation. We could see her through the window. My father was visibly embodying some powerful emotion, and my mother started edging back toward the door. Then, he fell to his knees, winded by emotional pain. A man of formidable proportions felled by the same human vulnerability that unites us all. My brother and I exchanged a silent look of shared surprise and discomfort. And then we began to mock him for ‘crying like a bitch’.

Tokens of privilege

Many of the families I spent time with illustrated the variability in caring arrangements that are negotiated according to practical demands and constraints, economic resources, marital and family status, relationships, access to supports and services, and patterned according to attitudes and obligations along race/ethnicity, class, religion, disability, and gender lines. Despite the degree of flexibility in family caring arrangements, patterned as they are by differences in intersectional identities, the moral responsibilities of caring and earning that are culturally assigned to mothering and fathering figured prominently in the lives of the women and men I spent time with, holding significant sway over their moral identities as mothers and fathers – highlighting the deep entrenchment of cultural myths about the nature of male/female relations in popular culture and how deeply they affect the ways we think and feel about caring arrangements. As Kohn and McKechnie write, traditionally caring has been viewed as natural to women, “intrinsic to their femininity” and has, “therefore...been defined by conceptual dichotomies which have ordered a division of labour, naturalized moral responsibilities, maintained the low status of caring” (1993: 3-4).

The conflation of motherhood and female normalcy, wrought by patriarchy, works to naturalise the unpaid care work women engage in. Ethan commented, 'the guy mind-set is a bit fragile as far as being able to process complex emotions. This is what I think, women are just better equipped to handle very difficult circumstances in the family and men tend to run from it'. Inherent in his remark is an essentialising assumption about the maternal capacities and inclinations of women. According to this particular gendered worldview, women are naturally endowed with the feminine (emotional) qualities necessary to care for a disabled child. Failing to live up to one's natural feminine vocation, then, is socially judged as moral incompetence. Essentialist assumptions of this variety serve a patriarchal agenda by wedding women to domesticity and care labour.

In his research on men and care work in Ireland, Hanlon found that such essentializing rhetoric provides men with a rationale to avoid care work (2012: 98). According to Hanlon, from this perspective, those who choose to involve themselves in care work do so because they feel emotionally equipped to cope (*ibid*). However, as Hanlon points out, these "narratives of choice" are myopic because they locate "the source of action upon free acting individuals unencumbered by structural constraints" (*ibid*). Hanlon writes, "Care choices are facilitated by a gender regime that legitimates what is desirable cultural and emotional capital of men and women" (*ibid*). The fathers in this study are engaged in a higher amount of hands-on caregiving than is typical of fathers across North America. Despite their non-conformance to traditional gender practices and normative expectations, however, the privilege conferred upon them for being men is discernible in many areas– in processes of exchange and accommodation.

In the last chapter, Wayne stated, 'I hear its dads who leave because they can't deal with their kids'. In fact, many of the fathers I spent time with quoted the same dubious statistic: there is an 80% divorce rate in marriages where the parents are raising a disabled child. There is no question that women have traditionally borne the responsibility of caregiving—which Kittay attributes to “a legacy of tradition, of sexism, and of a sexual taboo against men being involved in the intimate care of women's bodies” (1999: x)—and continue to bear the major responsibility for providing care for disabled children in North America (Landsman 2009). As mentioned earlier, I can find no evidence, however, to suggest that parents separate at the rate according to these figures based on their circumstances as parents of disabled children¹⁴. That said, the legacy of tradition and the myth of high divorce rates in families raising disabled children influence the ways the fathers in this study viewed themselves and were viewed by others as anomalies. As exceptions to the rule, then, they were often commended by their spouses and others for their efforts and commitments to their families. These commendations were unidirectional, unmasking social expectations concerning female morality and the moral obligation socially assigned to women to assume caregiving responsibilities. What does this say about the perceived state of manhood when one's commitment to family and one's emotional intimacy with one's children are heralded as exceptions, rather than the rule?

Sometimes, both spouses were involved in constructing or telling masculinist narratives that explained a father's committed presence and ability to deal with the tribulations of caring for a disabled child. The kinds of fortitude cultivated, for instance, as one couple told me, from ranching in Alaska's Aleutian Islands. These narratives worked to uphold fathers' masculine identities as caregivers; practices often linked to a feminine gender identity. In

¹⁴ As indicated by Silberman (2015) and my own research.

these instances, fathers' caregiving identities were organised around biographical snapshots that signified adherence to prevailing images of masculinity transmitted by the media, churches, schools, families, etc. that dominate the US cultural landscape: self-reliance, strength, and resilience. In these ways and many others, fathers receive recognition and praise for doing what women are socially expected to do to fulfill proper motherhood.

Another advantage conferred to men systematically relates to the ways they are lauded when they bring their personal stories into public spaces. Often these stories detail their journeys as caregivers and foreground the commitments and sacrifices involved in caring for disabled children. I witnessed this a couple of times in cases where the men in question had already established a public presence for themselves through their participation in the paid labour force. In these instances, men were publicly acknowledged for their efforts and often praised, passively taking credit for the emotional and physical caregiving work their spouses had tirelessly performed over the years. I wondered if their spouses, who sometimes shouldered more domestic responsibility, would ever realise the same opportunities to share their personal caregiving stories. These examples unmask a pervasive patriarchal mindset that promulgates male privilege and the unequal distribution of power and privilege between men and women.

A discordant melody (Cont'd)

Over time, my father was pulled further adrift through the expression of rigid gendered meanings. In the end, his commitment to breadwinning and relentless pursuit of control contributed to his inability to fulfill another expectation of post-war fatherhood: to be a role model (Diehl 2016), and consequently to the

ruination of our family unit. It seemed to me that neither my father, nor his, understood the personal costs beset by the demands of patriarchal masculinity and living up to its illusory ideals; a point well expressed by hooks when she writes, “patriarchy demands of men that they become and remain emotional cripples” (2004: 27).

True to the impermanence and flux of life, domination, control, and power conferred through traditional patriarchal relations are most seriously undermined by illness and/or age: the patriarch falls or sits sobbing in a hospital corridor alone, bereft of intimate connections. In his older years my father has revealed a gentler side. It is hard for me to tell whether time has cultivated this or if it was always there underneath his veneer of stoicism. Perhaps. But most likely its seedlings were suffocated under the anaerobic conditions of patriarchal manhood. There is no doubt in my mind that my father’s tumultuous relationship with his own father provided the earliest experiences for the constitution of his masculine identity and gendered orientation in the world: his hopes and fears, prejudices and aversions. In fact, everything he aspired to was in contradistinction to his father, except the very thing that made them the most alike: their will to power.

As hooks (2004) reminds us, both women and men teach this dominator model of relating to children, and patriarchal ideology gripped my mother’s consciousness too. According to her patriarchal logic, my father was acting in the ways socially expected of him as the patriarch and breadwinner of the family: he provided us with a home, kept food on the table, and never “denied her” more children (they had five). This breadwinner/homemaker ideal is powerful in aligning manhood with the public realm (Howson 2006), and as Demos writes, conformance with this ideal increase the father’s recognition and supremacy within the home because of the sacrifices he makes (1986: 52). For

over twenty-three years my mother submitted to her perceived 'biological destiny' and tailored her feelings and desires to his. According to her, she had taken her rightful place in the natural social order and had fulfilled the feminine and 'natural' vocation assigned to her as mother and wife; devoting over thirty years of her life in service to the practical and emotional needs of her husband and children.

My mother renounced her sovereignty when she married my father at the age of seventeen. I don't think she had time to experience the "agonizing dilemma" that Beauvoir suggests the "woman-to-be" must struggle with until much later: that is, the conflicts that arise between a woman's "originary claim to be subject, activity, and freedom, on the one hand and, on the other...the social pressure to assume herself as a passive object" (2010: 403). But, in the end, my mother yearned for more outside her marriage and the lot assigned to her in patriarchy. I got the sense that a great ambivalence grew from the chasm she felt open between her "properly human condition and her feminine vocation" (Beauvoir 2010: 403). Years after their divorce, she would reflect despairingly on the stifling conditions of her marriage and would celebrate her freedom, activity, and desire.

Of course, family life is only one of many avenues through which we are exposed to dominant cultural beliefs and practices that govern how we should think and feel about our gender identities—the media, pornography, religion, and schooling, among others. Gender policing is a persistent experience in the lives of men and starts as early as school, where male identities are under surveillance and policed by peers who set the standards against which one's actions are measured and judged (Kimmel 2010). Often, transgressing these gender boundaries or failing to suppress expressions that do not conform to domineering forms of masculinity result in violence and ridicule. According to

Noriega, this “masculinizing violence” creates fear and adherence to “the project of becoming a man” (2014: 143).

I remember being bullied in fourth grade for taking pride in my hair. My slicked back Elvis quiff invited verbal homophobic taunts and random episodes of physical assault by older boys. Teachers advised my parents that the torments would most probably stop if they discouraged my stylistic rockabilly inclinations. At home, I was taught to fight back and that retaliatory violence was a legitimate expression of my maleness. This advice proved useful as my acceptance at every new school I attended hinged upon my ability to prove myself to my fellow Brethren through my capacity to do violence when antagonised—and it never failed to get me in my father’s good graces. Like other mediums of masculine socialization, violence operates under a cloak of invisibility, and it appeared quite natural to me early on.

Existential and moral orientations

I was fifteen minutes late getting to the Mediterranean Grill in Mesa where I was meeting Greg for lunch—the 101 was congested and a trip to the pharmacy, to inquire about a weeping rash my son had developed across his face, delayed my departure. Greg was sitting at a booth by the window in front of a cup of soda when I arrived. Except for a couple of other patrons, we had the place to ourselves. I enjoyed Greg’s company and his unique blend of humour and insight. In a past life Greg was a teacher—he had an MA in history—and had taken some classes back in his twenties at the University I attended back home in Melbourne. ‘Melbourne reminds me a lot of Portland, Oregon’, he tells me. He reminisces about his time spent in Melbourne, drinking beer and playing pool at a hotel I’m familiar with, just around the corner from my University. I

ask if he gets the chance to travel these days and he replies gently, 'with Mia it's too difficult'. I didn't understand then, the way I do now, how difficult travelling with a severely disabled child becomes over time: the logistical nightmare of manoeuvring bodies and wheelchairs, transporting a breadth of supplies (nappies, food, etc.), securing a vehicle with enough space to accommodate said wheelchair and supplies, and trying to secure accommodation with the appropriate bedding (with railings etc.).

Greg had moved to Arizona fourteen years ago with his wife to take up a teaching position in a charter school. He tells me he's acclimated to the hot desert weather but misses the restaurants back in Portland. After Mia's injury, though, Greg made the transition to being her primary carer. Kris stayed on working full-time because she was earning more than Greg; a decision that, he admits, sometimes weighs heavily on her moral conscience. Greg doesn't seem burdened in the same way as Kris by the prescribed social meanings that index our social identities as fathers and mothers. He reveals in a cavalier manner that Kris sometimes picks up on subtle deprecations from others when they learn he is Mia's primary carer: a disapproving look or gesture, to which he admits to being oblivious. Like other fathers in this study (including myself), the meanings of fatherhood for Greg, the values and motives stitched into his thoughts and actions, cohere around his experiences growing up:

'I didn't want to be anything like my dad. I wanted to be as financially successful as my dad, but he's not a very demonstrative person. He doesn't hug a lot, you know. He doesn't even smile a lot or laugh a lot or anything like that. And I think he learned that from his dad, who grew up in the forties; he was an old Polish guy that came from the old country. You know, so he wasn't demonstrative. And I never understood how you could live your life like that'.

The waiter brings over two chicken kabob pitas. Greg takes a mouthful and launches straight back in:

‘He’s not a bad dad, at all. It’s just his attitude is to provide financially and everything else is mum’s job. I was kind of like, why doesn’t he seem to care that my sister and I are doing well. Like, he’s complimented me once in my life and I remember it ‘cause it was only once and I was stunned: I got a really good grade point average in my first year of college and I got my transcript and he was like, good job! I was like, who are you?’ He breaks into a rolling chuckle. ‘And so, when I was growing up, I was like, I am not going to be like him. I don’t want to be that kind of person with my kids. And I’m not that kind of person. We did a lot of good things growing up and he was never appreciative of it. It was like he didn’t care. How do you live your life like that? I would play soccer—I wasn’t very good at soccer—and maybe win, maybe we’d lose, but if we won like 2-1, that was golden. He’d talk about the one I gave up and why I didn’t do a better job and I’m like, we won the game!’ He laughs again defensively.

‘It’s true’, I respond.

‘So, it was mostly my father. I have consciously tried to be more accessible. I think you have to be empathetic. I don’t mean to sound like an arrogant jerk but I don’t know why I am that way because, like I said, dad was not really there. He wasn’t an emotional part of the equation. He’s a good guy. He’s not like, you know, touchy-feely. I don’t know if it was my mum, she’s very, you know, I would call her a good Christian—as opposed to an evil Christian’, he says self-mockingly. ‘But she’s a very nice person. She wants to help other people, that sort of thing. I don’t know if it’s that. I have no idea. But I’ve always been empathetic. I really have’.

In asking fathers to reflect on some of the experiences they think may have contributed to their caring orientations, they often responded through recourse to their fathers. During these conversations background gender assumptions often came to the fore, a taken-for-granted sense of how men felt themselves belonging to the world. The conflation of male sexed bodies with attributions of masculinity often wedded men to the significance of their fathers to the ways they are directed in their lives as caregivers. This sense of reality constrained their thinking, curtailing the possibility of other alternatives: the great variety of possible influences one may be exposed to and the variety of contexts in which caregiving is carried out. Greg alludes to the possibility of his mother's influence, but it is the significance of his father around which his thoughts circle. Consequently, men often enact fathering in conformance or dissent to their own fathers and normative models of fatherhood. Paul offered an exception.

His father had been a college football star ('fleet footed' according to a local newspaper); earned a degree in physical education; and was a fighter-bomber pilot and captain in the Strategic Air Command during the Korean War. He worked in the pharmaceutical industry (early on as a pharmaceutical sales rep selling Mylanta) until his retirement in the 1990s. 'He was a great man', Paul recalls, 'emotionally available if we needed him to be'. He succumbed to dementia in his final years of life and his increasing dependency and helplessness had been a difficult blow for someone who had always been so independent, and for his wife who had always known him to be so, according to Paul. She cared for him until his death in 2010, by that time they had been married for 62 years.

'She's a very special person', he says, as we drive to the local farmer's market. 'Her father died when she was six and her mother had to work; so as a

child she used to come home to an empty house. So, my mother insisted on being home every day when I got home from school. Then, in eleventh grade, with tears in her eyes, she asked me if it was okay if she went to work—to pay for my college. I said, Ma, I don't need you at home when I get home from school. I tell you that because for sixteen years I was home every day for when Pearl got off the bus. My mother influenced me greatly'.

Greg and Paul's existential and moral orientations and choices illustrate the influence of past experience and acquired knowledge, as well as background assumptions that are shaped by larger cultural and societal gender constructs. "Normality is reflected in a set of norms that is set by tradition", as Gallagher and Zahavi note (2012: 95). Or, as Husserl writes, "I am a member of a we-community...I am what I am as an heir" (1973: 223, cited in Gallagher and Zahavi 2012: 95). As such, worlds of disability are disclosed as mattering in particular ways, as bearing imports. And these imports motivate commitments, choices, and actions.

It took Ray some years before he noticed his restrictive ideas of manhood had permeated his emotional encounters with the world (see Chapter 3). He set himself adrift from his family by plunging himself into work and taking 'care of the things that men do'. By seeking refuge in masculine ideals of earning and providing for his family, Ray attempted to distance himself from the care labour Zachary depended on and the abiding imprint grief had impressed upon him. As time would have it though, he eventually lost a sense of fulfillment that came with the habitual expectation of breadwinning, and the influence of the appointed gender order with which he was at grips with became a little clearer and more comprehensible. Ray realised that if he wanted to be the kind of father that Zachary *needed* him to be, rather than the kind of father he felt he *ought* to be, then he would have to shift his priorities and commit himself to

being more present and involved with his family; foregoing the restrictive notions of manhood from which he had arrived at an understanding of himself and his relationship to others. The strength of Ray's repudiation of old patterns may seem surprising given his convictions that caring for his disabled father robbed him of a childhood. But the growing disconnect between his everyday moral expectations and disposition and the needs of his son constituted an ethical dilemma that Ray had to work through and attempt to reconcile. It provided an opportunity for Ray to step out of his habitual attunement to things and reflect on his moral comportment in a new light. In the next section, I turn to different moments of intersubjective moral breakdown that engender ethical moments where fathers' various moral modes of being-in-the-world are challenged and reflected upon.

Moral breakdown and awakenings

Wayne was barely inside the door and removing his coat when he heard his father's voice in the adjoining room charged with frustration.

'You're not listening to me!'

From the doorway, Wayne could see his father, Bill, sitting at the oval kitchen table with Noah. They were working on a jigsaw puzzle together. But Noah wasn't quite as locked-in as Bill, instead his eyes were fixed to the television in the lounge room.

'Noah?' Bill let out a gusty sigh and leaned back in his chair.

Wayne is what is often referred to as a *military brat*: his father, Bill, served in the military (two tours in Vietnam) and so Wayne experienced the kind of nomadic upbringing that befalls most military children, relocating homes every

year or so. This nomadism walled him off from the outside world. He never settled in any one place long enough to make friends and he never inhabited a place long enough to forge the kind of connections that create a sense of home. His only enduring point of reference was a lithograph depicting a dilapidated barn in a vast expanse of nothingness, caught somewhere between sunrise and sunset. During a support meeting, Wayne once confessed to me and Ray that his biggest fear before having children was that they would be born autistic. Ray had suggested that God was making Wayne face his own autism, elaborating that God had specifically chosen him as a father for the knowledge he possessed as an autistic person. Wayne had passively accepted this. But I wondered if the propounded emotional elusivity of autistic children invoked a fear of further alienation for Wayne: A fear of disconnect from those most firmly within his orbit.

Wayne has immense respect for his father (an eighty-year-old ex-Marine who could still do one-armed push-ups) and, unlike his other siblings, still depends on his parents for financial support. 'I've probably wiped whatever inheritance they [his siblings] had', Wayne joked one night as we stood in the parking lot of Mi Amigo's Mexican Restaurant in Mesa. According to Wayne, although Bill was rarely outwardly angry, he had grown up under his obsessive idiosyncrasies: Bill exhibited an authoritarian style and prized composure and efficacy above all else. To Wayne, his manner of fathering was at odds with Noah's best interests and needs.

'Noah?' Bill repeated.

Wayne focused his quiet desperation on Bill. He was impelled to say something, anything. Surely words would help clear the path of revelation cutting its way through his body. Finally, he said, 'Dad, can we speak outside for a minute?'

Bill followed him outside, where he stood opposite him, exhibiting a steady, blank gaze.

‘I know you don’t mean any harm, okay. But you can’t talk to him like that’, Wayne said.

Bill shifted his weight slightly, guarded but attentive.

Wayne continued, ‘Everything I thought I knew about parenting went out the window when these boys were born. The ways that worked for you, when we were growing up, won’t work for them. You can’t talk to him like that’.

I was thirty when my son was born. It was evident by the time he was four months old that he was disabled. There is nothing more gut-wrenching and disorienting, I learned, than watching your infant in the throes of neuronal chaos, seized by electrical impulses gone awry. His tiny body, multiple times day, would stiffen and turn red; his altered state of consciousness holding me (and him) in interstitial suspension, between the known and unknown, between stability and chaos. Afterwards, I would hold his limp body in my hands, havoc roiling inside, the contradictory muddle of self-pity and loss combined with the profoundest fellow-feeling imaginable. As my son grew older and his disabilities more profound, I grieved losing the opportunity to raise a son the way I had envisioned. I grieved the lost opportunity to raise a boy who would be emotionally perceptive, attentive, and responsive to the needs of others. This was partly reactive to the rigid gender definitions that shaped my experiences of being male growing up. I wanted to provide the kind of home environment that was free of the gendered expectations and perceptual practices that beset me during childhood and through the sinuous passages of adolescence and

then into early adulthood. I hoped to create the kind of safe and loving space that would encourage him to explore his selfhood and settle into his own skin as a man. But this was not to be. My familiar everyday world was shattered by this utterly dependent and afflicted body, and the promises parenthood had failed to deliver on.

When my son was two years old, my eldest brother posted a meme on his Facebook page that contained obvious ableist undertones. I hastily confronted his complicity in spreading bigotry. Giving him the benefit of ignorance, I asked him to remove it from his Facebook page. He responded quickly with defensive aggression, as though his very manhood were being attacked. At first, he cut off all communication. Then days later, on a Saturday night, he responded with a text: *what are you going to fucking do about it? You can't do shit. And neither can your son!* The statement hit its intended mark. It induced a readiness for conflict and violence that was familiar to me, strongly sedimented through traumatic childhood experiences. With my blood thumping in my ears and my body tensing to the point where it was hard to breathe, my indignation grew, robbing me of the latitude to think. I was angry that my son had been unjustifiably attacked and devalued. And my manhood had been challenged through his insinuation of cowardice. I was clenched in a trembling state of rage. Broiling with anger and hurt, endowed with my expertise in Thai boxing, I planned to drive to his house and prove to him *what* I could do.

I still don't know what it was that stopped me. At the time, my son was aimlessly rummaging among his toys, happily stimming¹⁵ them. By then, we had a daughter too. She was lying on her back, intently watching her brother. I believe it had something to do with caring for them, something of the intimacy

¹⁵ Self-stimulatory behaviour.

involved which had expanded my outer world; my children had existentially increased my range of motion. Years of caregiving had pressed upon my identity as a man, which gave rise to an existential tension between my newfound self-esteem and respect and the way I still resonated in affect to the patriarchal demands of resisting control and recognition—which I think illustrates a particular way of being morally attuned to things.

By the time I was fourteen I clearly recognised that I didn't want to be anything like my father, and my mother often assuaged these unarticulated anxieties by emphasising our physical and dispositional differences. But even as she renounced my father's oppressive grip of domination and control over her, plunging herself into economic uncertainty, she continued desiring and dating men who expressed in belief and action the same patriarchal ethos he did. And the same contradictions shrouded my moral experiences. Through my lifelong exposure to various twisted forms of domestic violence, I was repulsed by patriarchal dominance and my father's restrictive brand of masculinity. And yet, I had incorporated bits of this same signifying behaviour into my own performance of masculinity. I was defending what I thought was a credible masculine self: resisting control and expressing masculine dominance.

Months passed and the anger sat quietly in the margins of my awareness, a dysphoria coloured my experience of the world and kept me awake at night. I experienced an emotional bi-polarity, where I oscillated between feeling compelled to do what I ought to do as a man and retaliate, or honour the feelings of dignity and strength I had discovered through caregiving and being-with my son (and daughter). I was pulled between the demands of participation in a violent and controlling male culture—that diminishes the power and worth of embodied others who do not conform to oppressive patriarchal golden standards—or honouring alternate expressions of manhood

that would nurture the kinds of values I wanted to inhabit (accountability, integrity, trustworthiness and a high regard for love); expressions that would create the kind of emotionally-safe and protective space I desired for my children from the outset. This event forcibly ushered me to sit in silent communion with my consciousness. I realised that I was different in degree from my father, but not in kind. As a man, I had enjoyed the same sense of strength steeped in my capacity to exert control over others. That emotional event elicited a profound sense of indignation—steeped in paternalism? – that I was going to use to justify my violent ends. My vulnerability had been exploited and I was responding through masculine dominance. And what could be more masculine than the retributive violence I envisioned? I didn't want to live in my father's shadow or perpetuate the patriarchal behaviours and practices that nurtured its growth. Furthermore, I came to realise that by inhabiting the world in this way, I was tied up in maintaining the same exploitative social hierarchies that undermine my son's value and that are antithetical to expressions of care and the spirit of communal mutuality that would nurture his wellbeing (and others like him).

Several years after the first event, while on fieldwork in Norfolk County, Massachusetts, I was unknowingly infected with the spirochaete bacterium, *Borrelia burgdorferi* (Bb): the etiological agent of Lyme disease. These cork-screw shaped spirochetes enter the bloodstream and disseminate to multiple organs, colonising the heart, brain, nervous systems, and joints. I experienced full-body joint pain, muscle twitching, cardiac abnormalities, depression, fatigue, and other neurological disturbances. Early on, the confluence of symptoms confounded medical professionals. It took almost twelve months before I was diagnosed with Lyme disease. My illness, much like the arrival of a child who deviates from neuro-psychological and physiological norms, punctured my familiar world and cast my life into uncertainty. As Carel writes,

“bodily changes bring about a change to other fundamental aspects of selfhood: beliefs, judgements, trust, hope, and desire are all torn up and then either replaced or given up on...Loss of control causes immense anxiety” (2016: 117).

I was no longer able to participate in the activities and fulfill the responsibilities that defined me as a carer. Instead, I became dependent on my spouse for care. Being a caregiver was an important part of my identity. I was living a life of equality and intimacy which, in my mind, separated me from the likes of my father. I was in a relationship based on equality and respect, which separated it from the strange, and at times perverse, union that characterised my mother and father’s marriage. Chronic illness amounted to a loss of living the way I desired. I began to feel like I was contributing to my partner’s burden as a carer. This feeling conspired with the psychiatric symptoms of my disease and experiences of medical marginalisation to push me further into the depths of despair. Eventually, hyperthermia treatment in Germany would help ease some of my symptoms, but that didn’t happen until midway through Autumn in 2017, and the preceding two years had been especially trying. So, on a quiet morning at the end of summer, I tried to kill myself.

Change is slow. But as Zigon notes, “the goal of ethics is to move back into the world; to once again dwell in the unreflective comfort of the familiar. Ethics is the process of once again returning to the unreflective mode of everyday moral dispositions” (2007: 138). Every now and then I recognise the way my moral orientation towards the world has changed through these events and acts of giving and receiving care. My chronic illness altered the relationship between my body, self, and world. I have come to understand the vulnerability at the core of human life and how inevitably dependent we are on each other. I believe this has existentially deepened me in some ways; increasing both my

appreciation for those around me and my compassion towards others. Moments of breakdown have the potential to make the familiar feel strange and give form to what is vague and indeterminate, making thematic the implicit interpretations and attitudes that structure our moral modes of being with others. A clarifying light has been thrown on the cultural idealizations of masculinity and the healthy body, forcing me to confront my demand for control and mastery, alongside my complicity in perpetuating unjust social arrangements through comporting with patriarchal ideas and behaviours. By working on these things, I hope to be a better father and partner.

As I described at the beginning of this chapter, moments of moral breakdown are engendered when we are no longer able to interact with objects, people, and occasions in the ways that once characterised our habitual tendencies. On these occasions, we may find ourselves out of step with the habitual practices of others in the community, as previously unrecognised moral sentiments are thematised, reflected upon, and altered through our attunement to new moral concerns. Moments of moral breakdown can enable a shift from a governing causality to a first-person causality; forcing one to step outside their everyday moral mode of attunement and reflect on mediative norms and values that are ordinarily backgrounded and lived through as orienting features of our phenomenal worlds. Conflict arises: Someone responds to your child in a way that no longer feels compatible with your sense of fairness; or a situation arises that calls attention to a disposition that no longer feels liveable, or one must reconcile themselves with unexpected circumstances that threatens one's identity.

Throughout this chapter, I have given examples to show the potential these moments have in making thematic troubling sentiments and norms that no longer seem liveable or compatible with one's circumstances. As Harbin

writes, “disorientations are most promising when they not only jostle, but also propel” (2012: 277). She argues that experiences of disorientation can be morally productive in heightening our sensitivity to vulnerability, strengthening our relationality and spurring political prioritising (ibid: 271). Harbin stresses that while disorientations can highlight norms that govern our lives, they are not easy to change in social worlds textured by them, especially among others who maintain them by being oriented within them (ibid: 276). But through awareness, she argues, we can sustain subversive identities (ibid).

The ethical moments of reflection I have described throughout this chapter underscore the subversive potential of the body and care habits, while recognising the normative sway personal histories of contact with patriarchal objects of thought and action have on constraining our experiences. As Merleau-Ponty writes, “Our body is inseparably both freedom and servitude” (1995: 85). These disruptions¹⁶ offer men the opportunity to reflect upon what is lived through in experience and take an objectifying stance on their behaviour and thoughts in relation to the words they share with their children. Experiences of moral breakdown offer fathers possibilities for rethinking one’s identity as a man and relationships with others, and thus become more responsible for their actions and identities as men.

Importantly, I am not suggesting fathers’ lives are free from contradiction or ambiguity. Rather, through wanting to be better partners and fathers, men take steps to more equitable relations. As should be clear by now, it isn’t that fathers adopt an explicit moral stance, declaring themselves pro-feminists and supporters of women’s equality. Indeed, many men seemed oblivious to the gender power relationships that mark patriarchy. Instead, they

¹⁶ It is important to note that disruption in this context does not always equate to negatively charged experiences, there may be many that are felt as pleasurable, for instance, moments of communion and connection—some of these moments were discussed in the previous chapter.

typify more discrete stances, engendered and inhabited over time through experiential connections made between masculine dominance and power (authority and control) and the social debasement and neglect of their children. These insights and connections are made over time through experiences that lay bare their complicity in perpetuating oppressive norms involved in the diminution of others. Slowly, their practical relatedness to the world shifts. I would be remiss to neglect the perilous dimensions of moral breakdown. The above examples allude to only some kinds of experiences that are part of a much larger continuum, ranging from mild perturbations to radical existential breakdowns. The ways men respond to these moral breakdowns, reflect upon gender norms, and alter their moral dispositions is contingent upon the personal and spiritual resources they bring to bear in creating their lives as carers.

Conclusion

A phenomenology of gendered embodiment is important for understanding men's heterogeneous experiences of masculinity and fathering in the context of caregiving and disability. These experiences are structured by the ways we find ourselves attuned to a world of concernful mattering. In my analysis, I presented fragments of memoir to investigate masculine socialization, embodiment, action, responsibility, and freedom. Examining the micropolitics of domestic gender relations that I grew up in throws light on implicit and explicit articulations of masculinity that influenced my self-understanding as a father and moral orientation to the world and others. These gendered patterns of socialisation are constitutive of the ways we find ourselves situationally attuned. My personal history set the "conditions of my emergence" (Ahmed 2006: 38) into fatherhood and world of disability.

In the above accounts we see how worlds of caregiving are individually inhabited within the generalities of tradition that wield influence over our moral ways of being, for instance, the ways fathers express and construct their caregiving and masculine identities in response to the perduring legacy of mid-century gender role expectations. I have argued that it is not possible to understand men's experiences of fathering and masculinity in the context of disability in isolation from the sedimented histories that condition their individual possibilities for existing and acting, or from the cultural and social conditions in which these experiences accumulate. Most importantly, I have focused on moments of moral breakdown that speak to a dialectical causality between sedimentation and world-experience; where what was once taken-for-granted is made transparent and new ways of thinking and acting are fed back into the way the world is patterned and felt. As Alcoff reminds us, we are "interpellated into existing categories as well as making them our own" (2006: 111). Ethical dilemmas have moral value in their potential to engender existential and moral reorientations by explicitly attuning fathers to new aspects of their situations. Finally, through wanting to be better fathers and partners, men make steps toward fostering more equitable relations with others.

Chapter 6–Part One: Asylum

This cultural history of disabled bodies is important for understanding the cultural and social context in which families caring for disabled children attempt to carve out lives for themselves in the era of post-deinstitutionalisation in North America. In this section, I discuss the historical exclusion of disabled bodies from able-bodied spaces and culturally inherited ways of apprehending Otherness. I argue that dehumanising practices maintain the social and spatial order of these spaces and block our capacity for perspective-taking and relating to others empathetically. These historical and cultural horizons of disability are important to understand because they both situate parents' experiences of care and disability in 21st century North America, and also circumscribe their possibilities for acting and interpreting their lives.

Throughout this section I refer to the label developmental disability. Developmental disability is defined in the *Developmental Disabilities Assistance and Bill of Rights Act Amendments of 1994* as a severe, chronic disability of an individual five years of age or older that is attributable to a mental or physical impairment that results in substantial functional limitation and is likely to continue indefinitely (cited in Bryan 2002: 162). As Bryan tells us, the majority of those designated to this category have been those classified as intellectually disabled¹⁷ and “have received the most inhumane treatment of any disabling condition” (2002: 163). “They have been abused and even killed”, he writes, “for no other reason than they acted and/or appeared to be different” (ibid).

¹⁷ Formally classified mental retardation, intellectual disability reflects changes in U.S. federal law: Rosa's Law of 2010 P.L. 111-256.

Anomalous bodies

Uncanny sensations can grip us in an instant. Sometimes as terse and fleeting encounters; other times they linger in their passing, growing in virulence until their conspicuous features are given form.

Grim green lighting infuses the shadowy darkness of the room. Rusty wheelchairs adorn the ceiling. Broken beds and straightjackets are scattered with abandon. There's a man sitting on the floor, clad only in striped pyjamas, holding his knees. He looks at me with a strange, grim expression. He wears a mask of neglect and abandon. Then, a figure appears draped in a white nightgown, inky long black hair covering its face, something like Adako Yamamura from Koji Suzuki's *Ring* novel series. The figure lunges toward me and I narrowly circumvent its grasp. And then I am back in the warm and windless night.

Below the surface of confusion there's a leadened recognition: Some counted as more. Some counted as less.

Asylum Haunted Houses (like the one above) speak to very specific ideas in the Western social imaginary¹⁸ concerning representations of the physically and mentally disabled and their institutional treatment: They present ideas and typifications of 'maniacs', 'sadistic surgeons', 'malicious matrons', and the pitiful and/or frightening 'feeble-minded', embedded in the not-too-distant-past when those with psychiatric and developmental disabilities were routinely locked away in mental hospitals and state facilities—the latter often treated as subjects for medical experimentation (Guerrini 2016). The public

¹⁸ This refers to the grounds on which we imagine our social existence and how we fit together with others (Taylor 2004: 23)

exposure¹⁹ of institutional life in some of North America's most well-known deplorable facilities for those with developmental disabilities, such as Willowbrook State School on Staten Island, captured and fed the public imagination.

The exposure of these institutions revealed the underbelly of institutional life in these state facilities and hospitals as inherently antitherapeutic, oppressive, and parasitic to health and life. Images of discarded bodies housed within these cavernous walls were signs of institutions profoundly ill equipped to care for their residents. This is pointedly captured in a series of photographs taken by Jack Dykinga during the 1970 exposé of the Lincoln and Dixon state schools in Illinois—for which he won a Pulitzer Prize in 1971 (see Trent 2016: xv). At the time, he was working as a photographer for the Chicago Sun-Times. “For the first hour and a half, I didn’t take any pictures at all”, he is reported saying, “I just watched and was overcome by horror”. (Leekley and Leekley 1982: 80). After the series of photographs appeared, the scheduled funding cut for the Department of Mental Health was reversed by the State of Illinois (Trent 2016: xv). Similarly, the inhumane conditions at Willowbrook were exacerbated by a series of budgetary cutbacks and a hiring freeze instituted by New York state between 1969-1972, which led to a radical reduction in employees—the staff-to-resident ratio declined to 30-40:2-3 respectively (Fisher 1996).

Besides eliciting a mix of righteousness, condemnation, pity, and outrage from the public, the exposure of institutional life in America's most notable and notorious facilities furnished images of individuals entrapped in surrealistic symptoms and maladies, discarded and broken: “Residents were seen naked and idle, others were screaming, rocking and bound, most were filthy, and

¹⁹ For instance, investigative journalist, Geraldo Rivera, drew wide attention from the public when he exposed the conditions of Willowbrook State School in his 1972 exposé: *Willowbrook: The Last Disgrace*.

some were naked and covered in excrement” (Bursztyn 2011: 10). During his unauthorised visit to Willowbrook, Geraldo Rivera described the smell of “filth, disease, and death” (Fisher 1996; Rivera 1972: 22). Tourist attractions based on the asylum, or rather its representation in American culture, exemplify the ways images and testimonies captured during this dark chapter have worked their way into public perceptions and sensibilities of physical disability and mental illness.

The fear evoked by the perceived deviance of corporeal Others is drawn on in the creation of asylum attractions, which reinforce collective cultural ideals surrounding corporeal normalcy. These spectacles also speak to implicit configurations of meaning surrounding disability and, specifically for my purposes here, those with developmental disabilities—who often occupy the most socially degraded status. To put it another way, these attractions derive their entertainment value from the ways those with developmental and cognitive disabilities are posited as certain kinds of objects, both deviant and lacking, in our collective cultural consciousness. And these frames of reference are grounded in the ways non-disabled persons feel and experience themselves as particular kinds of bodies. The phenomenal quality of these haunted experiences rests on the ways non-disabled persons are already acquainted with disabled others as particular kinds of objects—evinced by the ways they are judged, seen and feared. This human practice is often explained in terms of our psychological impulse to establish identity and shore up self-worth by negating others, that is, by qualifying ourselves by what we are not.

Kristeva explores the fear the disabled figure provokes:

Disabilities...confront us with incomparable exclusion, different from the others: the disabled person opens a *narcissistic identity wound* in the person who is not disabled; he inflicts a threat of *physical or psychological*

death, fear of collapse, and, beyond that, the anxiety of seeing the very borders of the human species explode. And so the disabled person is inevitably exposed to a discrimination that cannot be shared (2010: 251, original emphasis).

In a similar vein, Garland-Thomson describes the disabled figure as representing the “incomplete, unbounded, compromised, and subjected body susceptible to external forces” (1997: 45). Those perceived in the cultural imagination as anomalous are positioned via what she calls the “normate”: “the corporeal incarnation of culture’s collective, unmarked, normative characteristics” (2002: 10). Thus, they support the privileged norm: “the cultural other and the cultural self operate together as opposing twin figures that legitimate a system of social, economic, and political empowerment justified by physiological differences” (1997: 8). Grosz also points out that those with severe physical disorders have historically been constructed as objects of horror and fascination because they imperil “the very definitions we rely on to classify humans, identities, and sexes—our most fundamental categories of self-definition and boundaries dividing self from otherness” (1996: 57). In each of these analyses, disability is considered to violate physical norms and the ritualised behaviour that social relations depend on (Garland-Thomson 1997). In summary, anomalous bodies confound “the classification systems that organize collective cultural perceptions” (ibid: 69).

Like Douglas’s assertion that “when something is firmly classed as anomalous, the outline of the set in which it is not a member is clarified” (2002: 47), Garland-Thomson suggests, “marked bodies shore up the normate’s boundaries (1997: 8). In *Purity and Danger* (2002), Douglas identifies five common cultural responses to anomalous forms that arise within and threaten the coherence of classification systems: anomalies may be reduced through

categorisation, physically controlled, avoided, labelled dangerous, or incorporated into ritual, “to enrich meaning or call attention to other levels of existence” (1997: 49). Garland-Thomson draws on Douglas’s “cultural solutions” to describe the cultural and historical treatment of anomalous bodies in North America.

In the first solution, Garland-Thomson identifies the disabled/able-bodied dichotomy as a system set up to reduce anomaly by classifying bodies according to particular identifying traits, even in cases where the rest of the body is functioning ‘normally’ (1997: 34). In her assessment, the eugenics movement and forced sterilization laws²⁰ in the U.S from the early twentieth century reflect the second of Douglas’s cultural solutions, which aimed at physically controlling those deemed unproductive and eugenically unfit. The third cultural response can be witnessed, according to Garland-Thomson, through institutionalisation, segregated education, or segregation legislation like the ‘ugly laws’ of the nineteenth and twentieth-century that “banned visibly disabled people from appearing in public places” (ibid: 35). As she tells us, stigmatic situations like those ghettoized by poverty and lack of education “frequently coincide with and reinforce marginalization based on physical traits” (ibid: 35). Fourth, anomalous bodies are labelled dangerous through social and political practices of segregation and elimination, according to Garland-Thomson (ibid: 36). I would argue that asylum attractions also present disabled others as dangerous.

The final treatment of anomaly in the Douglas/Garland-Thomson scheme can be witnessed in the ways those with “extraordinary” bodies are reconstituted through radical representations, like the carnivalesque figure, as “bearers of a fresh view of reality”, rather than as discomfiting abnormalities

²⁰ In 1907, Indiana enacted the first involuntary sterilization law in the U.S. (Pfeiffer 1999: 14).

(1997: 38). Garland-Thomson reframes “particularity as a mark of empowering distinction” (ibid:17), positing the potential the extraordinary power of human variation has in unsettling the modern social order that excludes and marginalises various forms of difference from political, social, and civil life. While I think this appraisal is laudable, it’s highly unlikely that those with severe developmental or cognitive disabilities will be conferred the same mark of distinction as other kinds of anomalous embodiments. Garland-Thomson’s vision, I think, fits the skin of some more than it does others.

The potential embodied others have in challenging the status quo and refiguring the social order by offering a ‘fresh view of reality’ does not mark the threshold of humanity, as Grosz similarly remarks, “but of acceptable, tolerable, knowable humanity” (1996: 55). My aim in this chapter and throughout this thesis is to open up a space that shines a light on parents’ experiences and views of their children’s embodied difference so that we may consider more thoughtfully the cultural tradition and taken-for-granted assumptions that influence our interpretations of corporeal difference as Other—so that we may place ourselves “imaginatively and sensitively in the world of the other” (Benner 1994: 30).

De-institutionalisation and community-based care

The historical treatment of disabled children was never far from the minds of the parents I spent time with during fieldwork. They sometimes spoke of individuals generationally-near-family relatives they had heard about during their childhoods—that had lived and died in institutions. One father, Scot, whose daughter was born in 1988, described modern community-based care as “a unique new agenda for families”. Scot spoke about the financial, emotional, and

physical costs of caring for children permanently dependent; the importance of social supports in providing assistance and buffering the stressful concomitants of disability; and the challenges involved for parents in grasping this new life of difference: ‘these kids aren’t going to magically heal and they are totally dependent on you, and that life, you’re there, for real. That’s it. You’re joined at the hip’.

While, at best, the historic rationale behind asylum expansion throughout the nineteenth century—and their earlier colonial incarnations as almshouses in the eighteenth century—focused on the welfare and education of ‘idiots’, that is, protecting disabled persons from neglect and/or harm or providing them with specialised treatment, other instances clearly reveal that the motivational relevancy²¹ behind setting up state facilities was mixed (Burnham 2016: 57). Even under the best circumstances, these motivations reveal stigmatizing attitudes towards disabled Others. For instance, Governor Francis Fauquier delivered a message in the 1766 session of the Virginia House of Burgesses that occasioned the establishment of the first mental hospital in the British North American Colonies (Burnham 2016). Referring to those with mental and physical disabilities, he suggested: “a poor unhappy set of People who are deprived of their Senses and wander about the Country, terrifying the rest of their Fellow Creatures ... A legal Confinement and proper Provision, ought to be appointed for these miserable Objects, who cannot help themselves” (Burnham 2016: 57).

Similarly, in a report made to the Massachusetts legislature on the condition of “Idiots of the Commonwealth”, the nineteenth century abolitionist and advocate of educating children with disabilities, Samuel Howe (1848),

²¹ The rise of custodial formalism and the framing of those with disabilities as a social problem reflected broader changes in the U.S. economic and social structure, alongside changing ideas in medicine (see for instance Bryan 2002).

reported “a...class who...contribute nothing to the common stock...and who are dead weights upon the material prosperity of the state”. Howe appealed to the “humanity and justice of the legislature” to take immediate measures for the formation of educational facilities for instructing and training ‘idiots’ and transforming these persons “back into *human shape*” (Howe 1848; also cited in Noll and Trent Jr. 2004: 25, my emphasis). Bérubé writes:

Before long, the institutions had developed a self-perpetuating logic of their own, complete with a permanent crust of administrators and new technologies of personal management. By the twentieth-century, the “feeble minded” had become constructed as a class of civic menaces who were routinely sterilized, and by mid-century they were officially classed as “mental deficient” and packed by thousands into vast, hellish state-run caverns” (1998: 108).

By the 1960s and 1970s state facilities and hospitals were increasingly being viewed by civil libertarians and other advocates of deinstitutionalisation—fuelled by the ideas of Foucault, social constructionists, and the anti-psychiatry movement—as institutions of social and medical control (Bagenstos 2012). Goffman referred to these as “total institutions”: places “of residence and work where a large number of like-situated individuals, cut off from wider society...lead an enclosed, formally administered round of life” (1991: 11). Goffman (1971) was concerned about the systematic denial of freedom to those involuntarily institutionalised, which often led, in his view, to patients exhibiting offensive and irrational behaviour in an attempt to express themselves and maintain a meaningful existence. During this time, the risk of erroneous diagnosis and the consequent entailed loss of freedom wrought by institutionalisation gave rise to civil libertarian concerns over the carceral power of the ‘therapeutic state’, attached as it was to psychiatric diagnosis,

calling into question not only the legitimacy of psychiatry but the very existence of mental illness (Donnelly 2003: vii). For those with developmental disabilities, however, the facticity of their embodiment was never questioned with any prominence in the same way (Bagenstos 2012).

In the case of those with developmental disabilities, it was the shocking exposure of dehumanising conditions at institutions like Willowbrook on Staten Island and Lincoln and Dixon state schools in Illinois that mobilised individual parents and parent-led organisations like the Association of Retarded Children (ARC) in favour of reform or deinstitutionalisation²² (Rothman and Rothman 2004). Parents previously immobilised by political and personal constraints sought to establish standards of care and treatment by law (ibid). A major emphasis of advocates and families in favour of deinstitutionalisation was the development of community supports and services that would enhance the lives of persons with disabilities by fostering their autonomy to whatever degree possible and providing opportunities for social participation.

Between the 1960s and 1990s many of these institutions were closed or downsized²³, and in 2009 it was reported that of the 354 largest state facilities operating between 1960 and 2008 in the United States, only 162 facilities

²² Individual's supporting reform, in its broadest sense, were divided. Some families supported the movement for deinstitutionalisation, while others set out to challenge the conditions of institutions, not the idea of institutionalisation itself (Bagenstos 2012: 16).

²³ Deinstitutionalisation is not without its critics, some argue that it is responsible for the epidemic of homelessness and poverty in North America among those with psychiatric disabilities who were supposed to be released into supervised community settings, while opponents of this view suggest it has more to do with cuts to social welfare programs in the 1980s. Deinstitutionalisation of those with developmental disabilities, on the other hand, has been less controversial (Bagenstos elaborates on both these points: 2012: 2).

remained open (Bagenstos 2012: 6). “Willowbrook cast a long shadow”, Bursztyn writes, “Advocates and parents gained a foothold on policy forums and their efforts facilitated the passage of sweeping educational reform” (2011: 10) –further advancing the rights and opportunities of those with disabilities²⁴. These changes coincided with, and played a part in ushering in, what Bryan terms the period of “advocacy, consumerism, and cultural competency” (1976 to present) (2002: 164).

The passing of the *Americans with Disabilities Act* (ADA) of 1990 marks a crowning moment in the legislative history of disability rights, and it marked an important shift away from restitution for those with disabilities towards accommodation. In the ADA, Congress required that all public entities refrain from discrimination and identified “unjustified segregation” as a form of discrimination” (Olmstead 1999: 600). Furthermore, the integration mandate of title II of the ADA provided the foundation for the landmark 1999 *Olmstead* ruling: The United States Supreme Court declared institutionalisation in cases where community care is appropriate to be in violation of the state’s obligation to provide services to those with disabilities in the most integrative and least restrictive environment possible (ibid). This highlights the kind of activism and cultural labour that Rapp and Ginsburg identify as having been crucial to reconfiguring the disability imaginary in America and elsewhere (2016: 525). Transitioning care and support from residential facilities to community-based care constituted a “significant philosophical sea change”, according to

²⁴ Legislation included the Developmental Disability Assistance and Bill of Rights Act of 1975 (originally authorised in 1963) which promotes independence, productivity and inclusion in the community by providing federal financial assistance to agencies (state, public and non-profit) to support the delivery of community-based services to those with developmental disabilities, and the Education of All Handicapped Children Act of 1975, which was later renamed Individuals with Disabilities Education Act (Bryan 2002: 166).

Kritsotaki et al. (2016: 4). They write: "It represented what was supposed to be a momentous transformation in the relationship between society and the mentally ill, in how mental illness was conceptualised and in how it was treated" (ibid).

Dark tourism

While many of these obsolete institutions have been demolished or repurposed, there are others which lay abandoned across the country, congealing the history of institutionalisation and its legacy of alienation and suffering. Some institutional structures have been reopened as tourist attractions; attracting droves of visitors evincing a mix of obscure interest and melancholic fascination. These frequently visited locales of "death, disaster, and atrocity" illustrate a growing trend in what is described as "dark tourism" (Wilson 2008: 9). In its broadest conceptualisation, these attractions of mourning and death include battlefields, assassination and crash sites, former prisons and hospitals, Holocaust memorials, natural disaster remnants, and museums of torture and death. The nature and appeal of dark tourism is widely debated: the range of expectations tourists bring with them to these sites are explained in terms of education (Lennon and Foley 2000), edification (Skinner 2012), a quest for heritage (Korstanje 2015), and/or entertainment and "ghoulish titillation" (Wilson 2008: 169). For Korstanje (2015), these spaces of death and suffering are "employed to reinforce the pillars of capitalism". Korstanje and George argue that dark tourism reflects the arrival of a new stage of production where the consumption of the other's death is the main commodity to be exchanged (2017: 151).

In the case of the haunted attraction industry, embodied difference appears interchangeable with the likes of zombies and other demonic apparitions. Here, embodied Others are routinely viewed and represented as cultural objects of deviance, constructed on the grounds of abstraction, objectification, and negation. In these instances, the painful lived experiences of those that were once housed in dehumanising settings are anonymized and annihilated, their behaviours and expressions abstracted from their cultural and meaning context, denuded into a form of entertainment. Notably, this resonates strongly with Victorian America's obsession with freakshows where those with various bodily anomalies were exhibited and commodified. Garland-Thomson argues that freakshows testified to America's need to "ratify a dominant, normative identity by ritually displaying in public those perceived as the embodiment of what collective America took itself not to be" (1997: 59). In our demand-driven consumer culture, these various asylum expose's (see Johnson 2014) and haunted house attractions—itsself a \$300 million per year industry (Alton 2016)—illustrate a perverse habitual orientation toward corporeal and embodied differences and reify typifications long held in our collective cultural consciousness.

There is a clear tension that exists between the social, legal, and political progress that has been made by and on behalf of those with disabilities and the historical discrimination and objectification of those with disabilities that shadows the present²⁵. Lifeworld relations can lag behind systemic relations, notes Crossley: "To change our laws is relatively easy compared with the often hidden and always deeply embedded structures of communication and intersubjective relations" (1996: 171). Presently, the latter is witnessed in its

²⁵ Ginsburg and Rapp underscore a similar tension which they refer to as the "double telos of modernity": our "democratizing impulse toward the inclusion of disability" and its opposite, "the drive toward perfectibility that fuels much recent culturally seductive neoeugenic medical innovation and intervention (2016: 526).

various reproductions: from public tourist attractions and exhibitions like asylum haunted houses and hospital tours, to the ways disability is represented in film and media, to the various prenatal mediototechnical innovations and interventions that Landsman (2009) identifies as reflecting our cultural impulse toward perfectibility. These tensions also speak clearly to the historical and cultural worlds in which we are thrown and also have a hand in making (Jackson 2016: 94). They speak to the realities that parents of disabled children live between, and inherited cultural and historical meaning-structures that act as the boundary conditions on the worlds of asylum parents try and create for their disabled children in the era of post-deinstitutionalisation in North America.

Interlude: Connectivities²⁶

It is uncanny, the way we secrete and encounter negativities, the ways they can slip out of reach and then reappear later, the feelings these encounters disclose or conceal. It's mystifying, the circularities we insert ourselves into and the connectivities we get caught up in; the fragmentary moments that we inhabit, that slip through our existential fingers, only to be reinhabited anew. What of our adherence to things caught between what they are no longer and what they are yet to become?

The boy and his grandfather, Francis, are tooling down remote backroads on their way to Nancy Martin's place. She's a recent widow and Francis likes to buy groceries and deliver them gratis. He does this for all the widows he mingles with on Friday nights at the Arthur Murray Dance Studio. The boy is licking a vanilla ice cream cone that his grandfather brought him moments ago from a nearby drug store that will, decades later, become a Whole Foods Market. The boy watches the countryside passing by in a blur. He thinks of how someday he would like to be a famous ballroom dancer, someone like Arthur Murray himself. He doesn't know it now, but his dancing dreams will be crushed when he realises that he can't memorize the dance steps. By comparison, he makes the heavy-footed cop and burly Irish guy taking the same class look like Anna Pavlova. His inability to memorize sequences will cause him to struggle with chemistry, also. Instead, the boy will grow up and become a paramedic. When the boy is nineteen years old he will opt out of attending the family's weekly dinner at Francis's home. On the same night of his absence, death will surge up to meet Francis and it will be a heart attack that removes him from the world.

²⁶ This vignette is a piece of creative non-fiction.

Frequently, Francis told the boy to marry a nice Jewish girl. To buy a house. To have kids. It's as if Francis accomplished the impossible, he ripped open the fabric of time and peered into the unfolding of things. But the future's contours would be different. The boy would marry a nice Jewish girl, who would later become an eminent professor in Romantic Literature, but when their two children are diagnosed with the same rare genetic disorder, an unbridgeable chasm would claim the space between them, propelling them along different paths.

Francis stops at a red light and the boy licks the ice cream residue off his young, chubby fingers. A man crosses the road in front of them. His body is bent and his stride is laboured and unnatural. The stranger looks up long enough for the boy to see his face is twisted to one side. Francis grips the boy's thigh, 'And that's why we get our shots at the doctors'.

Chapter 6–Part Two: The Between: Metastable Situations and Horizons of Unsettlement

And though our awareness continually oscillates between self-interestedness and commitment to the common weal—being on stage and off stage, seeing things from without and seeing things from within, associating with others and dissociating ourselves from them—we remain, paradoxically and inescapably, *both* islands *and* parts of the main.

–Michael Jackson

By an internal negation we understand such a relation between two beings that the one which is denied to the other qualifies the other at the heart of its essence—by absence

–Jean-Paul Sartre

The day had arrived for Randall and Kathy Stuart to meet their future daughter-in-law's parents²⁷. They didn't know too much about the Haddon's, except that they were a country-club set from Colorado. Glen had been dating Sally for four years and so Randall and Kathy had gotten to know her quite well during that time. To them, she was down-to-earth, easy to get along with, and possessed none of her parent's reported pretentious elitism. Ordinarily, Glen spent Christmas with his in-laws in Colorado. But this year, because of their

²⁷ This is a piece of creative non-fiction, a fictionalised account of a story I was told.

engagement, the Haddon's had travelled over eight hundred miles south to spend Christmas with the Stuart's in their blue-collared neighbourhood on the fringes of the Sonoran Desert. There was no other option anyway. Travelling with their daughter, Sam, required too much preparation and effort. And lately, with her kidney issues, Sam found travel especially tiring. Last year's trip upstate for her twenty-fifth birthday had left them all exhausted, culminating with Sam's frantic meltdown in the congested commuter traffic on the way home, where she directed her abject energy toward Kathy by mounting a physical attack.

This time of year the weather was temperate and the desert evenings cool. Kathy and Randall set up the outside patio for dinner which opened onto views of jagged mountain ranges and boundless azure skies. Randall was happy that Sam was in a mild mood and seemed excited to have company. She was always more relaxed in her own dwelling which made things easier to manage if anything unforeseen happened, which was unforeseeably predictable. The evening had started like Randall anticipated: stiff and formal. But as the night wore on everyone increasingly eased into comfortable conversation. Randall glanced across the table and was both relieved and joyed to observe Glen engaged and unguarded. He knew how anxious Glen had been about his future in-laws meeting his family. After all, growing up with Sam hadn't always been easy. The past was loaded with as many laments as triumphs. But tonight, he seemed happy, almost buoyant. Tonight was one of those nights that offered a momentary reprieve, a balancing of the scales between the grind of care work and the joys of parenting. Randall watched Sam, she glowed beatifically. When there was synergy between her interior world and the surrounding one, her teasing and playful self, usually reserved for intimate others, could be glimpsed by everyone.

But halfway through an earnest conversation with Mr Haddon, Randall felt a shift in the atmosphere. Then, Mr Haddon's face turned pale and his

mouth opened. Randall turned his head toward the disruption. It was Sam. She was standing before them, completely naked, gripping her wet diaper in her right hand. The Haddons shifted uneasily in their chairs, averting eye-contact. Randall felt the lived-space between them thicken with an impalpable incomprehensibility. Sally stifled a grin and Glen collapsed back inside himself. For Kathy and Randall this was a common occurrence. Under normal circumstances they would gently rebuke Sam and usher her inside to be cleaned up and re-dressed. But tonight was different. Tonight there was an audience. Kathy and Randall exchanged a look that captured thirty years of shared experience, a mutual recognition that had the power to assuage each other's anxieties. Then, Randall relaxed back in to himself and thought, 'You can dance around it for so long but here it is in living colour. Welcome to our world'.

Since the 1960s a marked reorientation has taken place in the ways care is provided for the developmentally disabled: from institutional treatment to community-based care, as discussed in the previous section. In that time, social attitudes in North America and Australia (the respective sites of this study) toward those with disabilities (more broadly defined) has improved in many ways. Laws have been passed to increase and protect the rights of those with disabilities, and community support and health centres are common. Yet, despite these changes, those with disabilities are, in many instances, still isolated from their communities in state and group homes, sheltered workshops, and special education facilities. Litvak and Enders observe that "isolated support systems for disabled people may produce defacto discrimination", overlooking the bigger generic supports that are needed to exist in the community (2001: 723).

Community marginalisation also extends to the ways those with disabilities are excluded from visual and narrative representation in film and television. Notably, when such representations of disability do exist, the disability community has frequently expressed that their experiences are misrepresented through ableist narratives, as witnessed in the controversy and backlash against the film 'Me Before You' (see for instance Pask 2016) and more recently, the Netflix docuseries 'Afflicted'. When those with developmental or cognitive disabilities are represented, however, it is often in the guise of a monstrous apparition, like 'Twisty' in *American Horror Story*, or as props to create an eerie atmosphere, like at the end of the documentary film *Catfish*. In my experience, the families of those caring for individuals with developmental, cognitive, or severe multiple disabilities are absent altogether from representation.

Parents of severely disabled children, then, can be conceptualised as living in a state between: Between a world of language and a world of silence. Between personal, interpersonal, and transpersonal perceptions of their children. Between meanings that are multiply constructed and sometimes at odds. Between the world they once took for granted and the world they grasp through their second-person perspective of disability. Between different, and often incommensurate, apprehensions of reality.

In this section I identify and attend to parents' modes of care and expressions of resistance as they traverse social spaces and structures in their daily lives as parents. In these spaces, the cultural devaluation of disabled bodies is manifested and reproduced in socio-spatial ways. I refer to moments when parents encounter norms and practices that degrade their children as *metastable situations*: Experiences of parental unsettlement inaugurated in social and institutional spaces around competing notions of care, concern and duty.

Here, I pay attention to the ways relationality is annulled through the objectifying gaze of non-disabled persons upon disabled persons. In this chapter, I address the ways fathers respond to symbolic associations and moral evaluations of their children, alongside attitudes of acceptance or resistance expressed by others towards them. Here, I draw on Sartre's (1992) notion of 'the look' in describing fathers' empirical experiences of unsettlement. Rather than viewing conflict as an essential structure of our relation to other consciousnesses, however, as Sartre does, I situate these experiences of unsettlement and conflict within particular social spaces. These experiences consist of moments when one's hold on the world is threatened, to borrow Sartre's words, when "everything is traversed by an invisible flight and fixed in the direction of a new object" (ibid: 343).

The Other's look, Sartre says, alienates us from our own possibilities (1992: 352). I consider the alienation caregivers experience when their meaning-rich perceptions of their children are decentred by the ways other persons understand and organise the world. I understand these moments as playing an important role in motivating parents in their individual and collective attempts to challenge and transform the shared ideas and practices, institutions, and social relations that construct disabled persons as marginalised and invisible. Importantly, these moments throw light on another dimension of parents second-person phenomenological experiences of disability²⁸: how they are affected by their children's first-person experiences of oppression. By socially and politically contesting the unjust treatment of their children, caregivers attempt to refigure these spaces of social activity; envisioning worlds that are imaginatively and empathetically sensitive to the needs of embodied others. In this way, parents attempt to reinhabit historical and cultural horizons of

²⁸ In her book *The Phenomenology of Illness*, Carel refers to "second-person phenomenology of illness" where a significant other may experience significant changes in their lives also (2016: 47)

disability inherited from the past in their own unique ways. This chapter explores three orders of unsettlement: experiences that arise through navigating bureaucratic institutions, those that occur through the mortifying treatment of one's child, and, finally, by having one's child incarnated by another. In each of these instances parents encounter realities that diverge from their own.

As we saw in chapter four, there is an interplay between symmetry and asymmetry in our embodied dialogue with others. This chapter focuses on moments when mutual understanding is an accomplishment rather than a given, such as when empathy breaks down between persons and diverging apprehensions of disability and bodies collide. The gulf existed through a breakdown in the intersubjective constitution of meaning may appear, at times, unbridgeable, showcasing the ways our relation to others can be blocked by ideology and conditioning (Daly 2016: 233). But the between can also be a productive juncture, engendering important knowledge and connecting us with others who have been on a similar journey and have arrived at similar level of understanding despite the different routes taken—I will explore this more in the next chapter. Finally, this chapter is also about what I have learned about myself through those I have shared time with. This chapter focuses tightly on Paul's life and my time spent with him. In doing so, I look at the public meanings and roles delineated by our shared world that circumscribe my possibilities for acting as my son's carer, but also the ways our experiences together brought to light for me different commitments and perspectives on these very possibilities.

Fears of incest.

I had been reading Paul's online blog for a couple of years before I contacted him to be a part of my research. His virtual self was articulate, assertive, cognitively agile, and even downright intimidating. Within the digital realm he projected himself as a voracious advocate for his daughter, Pearl, and he documented, with detail and caustic humour, his charged encounters with medical and educational professionals and his troubles and successes navigating the web of bureaucratic processes caregivers' find themselves caught up in as they attempt to secure supports and resources for their children—and that permeate civil life more broadly. He was unsurpassed in temerity, candidly documenting his perceived shortcomings, alongside his strengths and, I think, by not pretending to be more than he was, he drew a strong online following. But within a couple of days of meeting Paul for the first time I realised that the online world I had grown familiar with over the years through his writing was a simulacrum of the flesh-and-blood realities we body forth.

It was noon on a Tuesday in August and the rain and fog were beginning to clear. The warm air was thick with a sticky humidity which abetted the fatigue-induced nausea sitting defiantly in my stomach. I had arrived in Boston only six hours earlier on the red-eye from Arizona and though I managed a couple of hours sleep it wasn't enough for me to feel rested. I was also engrossed in the anticipation of meeting Paul for the first time which enhanced the contact boundary between my skin and the opacity of the fog and humidity hanging in the air. After several minutes of waiting, Paul arrived. I climbed into the car and was immediately struck by Paul's long and slender frame. He was a lot taller than I imagined: around 6'4. He was wearing pants and a dark polo

shirt which featured the logo of his now defunct high-tech computer engineering business.

We shook hands and he pulled back onto the road, heading toward Brookline Village.

‘How are things? How was the flight?’, he asked in a curious, articulate and melodious drawl that would, over time, insinuatingly worm its way into my memory.

‘Yeah, good. Hey, thanks for picking me up. I appreciate it’.

‘You want to get something to eat or a coffee?’

‘Coffee would be great’, I replied.

‘Then we can head back to my place and you can meet Alice. The girls will be home later, so you can meet them then’.

Paul’s life had changed significantly over the last year. His online identity cohered around his status as a single father and his experiences involved in intense caregiving for his profoundly disabled daughter. Cultural incest taboos weighed heavily in his documented experiences as a male tending to a vulnerable female body. There were a host of trying experiences that he revealed and articulated as part of his everyday. His online narrative had quite a lot of grab because he was shining a light on a situation that is often unrecognised, subverting this taboo system through happenstance. He would recall many encounters during our time together that spoke to the heavy burden of being vulnerable to the distortions of others; refracted, as these distortions often are, through cultural codes.

‘I’ve had it in changing rooms’, he tells me, ‘when Pearl was smaller and I wanted to change her or try clothes on and they [sales assistant] would ask, who’s going to help her? My own sister, a very intelligent and loving lady, said to me, shouldn’t you get someone to bathe and dress her in the morning?’ He feigns dismay. ‘She’s never had a kid of her own’, he concludes, seemingly switching her ignorance for naivete. ‘I said, if I’m with mom and she’s having real trouble getting in and out of the bathtub, is it okay if I help her? She said, yeah, of course. So, it’s an ingrained thing’.

He recounted unsettling interactions with medical professionals and mandated reporters also. There was an event when Pearl was much younger when a school nurse called Paul to notify him that she had put up an ad for someone to help him with bathing and dressing Pearl in the morning. During their phone conversation, the catalyst for the whole affair came to light: earlier that week she had checked Pearl’s diaper and discovered that she was not as clean as she thought she should have been. Paul recalls how livid he had been by her accusation of neglect. He wasted no time explaining to the school nurse that Pearl lives in a diaper 24/7 and always experiences discharge before menstruation. ‘Do you have any clue what her care at home is?’ It was unclear whether the nurse was acting in response to state surveillance and legislative requirements to report suspected cases of child neglect– failure to do so is often punishable by a fine or court action–or some other whim. Regardless, Paul had the matter resolved by lodging a complaint with the school district superintendent’s office. ‘I also passed on a fact that no-one else in the school district knew’, he tells me, ‘that my girlfriend at the time was living with us and was Nurse Manager at a paediatric rehabilitation hospital’. Two days later he recalled getting a phone call with an explanation, ‘not an apology’: ‘the nurse had a problem with a single father taking care of teenage girl’.

Aside from these experiences, Paul unapologetically documented the ambivalences and ambiguities surrounding caregiving that are often wrought through experiences of social marginalisation and the everyday reality of providing care. Blogging served as an accommodating platform. Through writing Paul could articulate issues that would be discredited or misunderstood within everyday spaces contained by the status quo. But the blog wasn't intended for everyone. Over a hot breakfast in a diner with hardwood floors, light mahogany accents, and 80s rock music, I asked Paul if his sister or mother ever read his blog.

'I don't need to have my mother, Pearl's loving grandmother, reading some of those things', he said. "I don't know if you understand this *yet* but very few people understand'.

This kind of understanding speaks to a mutual recognition between caregivers premised in their embodied and engaged coping with the world, a taken-for-granted alignment that was also expressed by Ethan when he told me that he may not have been as willing to share his life with me if I wasn't a caregiver myself. However, as I will discuss in the next chapter, these alignments are always tenuous and shifting.

Within the blogosphere, Paul's views were accepted and encouraged and he generously omitted anything outside the purview of his dyadic experiences with Pearl. It wasn't surprising, then, when I found out that he stopped blogging once his situation changed. The blog's entire premise no longer worked. Twelve months before I met Paul his household population expanded from two to four. Alice was in her mid-fifties. She was small in stature but big in intellect. She met Paul within the blogosphere where she also documented her experiences mothering a severely disabled daughter, Ava, who was roughly the same age as Pearl. After a whirlwind courtship, they were married and

Alice and Ava emigrated from Canada to live with Paul and Pearl in Massachusetts. Paul remembered the night he knew that he wanted to marry Alice. The event that precipitated this was alluded to in Chapter Four, when I discussed Paul's meeting with the school district Superintendent to illustrate the everyday as, what Das (2010) calls, a site of danger and achievement.

The day had started off like any other with Paul sending Pearl off on the school bus, 'with full trust and total fear as usual', he tells me. It's a fear that any parent can relate to and one that is deepened when a child is incomparably dependent on the good will of others—especially when this good will has historically been in short supply. When she returned home her eye was partially swollen shut, her bra was on backwards, and, later, Paul discovered a cut on her vulva. Paul questioned the teachers but nobody could explain why her bra had been repositioned or why her eye was swollen. A full investigation would ensue. Perhaps the most frustrating and damning thing is that Pearl, like my own son, inhabited a pre-verbal and pre-symbolic world. Without the expressive capacity of language, children like ours can't bear witness to the failures and inhuman misdeeds of others— and even when they can, institutionalised and systemic practices often discredit their testimony, for these are anomalous bodies that are socially tainted with a damaged subjectivity.

Three months after Paul recognised Pearl had been sexually assaulted they were attending a doctor's appointment together. Paul raised Pearl's assault in conversation with the doctor and Pearl burst into tears, affirming what Paul had known all along. Back home, Paul locked himself in the bathroom and cried, his mind travelling toward all the things that had transpired and all that he was helpless to remedy. 'You're supposed to protect your daughter', he told me, 'you're supposed to fight for her and make sure she has every tool needed

to become the best she can. You teach her love by example. I failed my daughter’.

I suspect he said the same things to Alice over the phone in the bathroom that afternoon. He tells me that Alice yelled at him, ‘go and talk to your daughter. I don’t care if she understands you or not, go and talk to her and apologise’. That night, Paul would lift Pearl, now a grown woman, from her wheelchair and would lie down on the bed next to her like they used to when Pearl’s body was much smaller. He spoke to her for a couple of hours, made her promises and told her he would visit school every single day, and, then, they abandoned themselves to a quiescent state of sleep. Paul knew, then, that he wanted to marry Alice.

Enforcing normality

A couple of days later, I accompanied Paul to a satellite immigration centre in Boston. Recently, Ava’s citizenship application had stalled because Ava has been unable to complete the biometrics exam: obtaining her fingerprints has proven challenging given her muscle spasticity and hand position. Or rather, the functionaries during her appointments had displayed a lack of imagination in the methods they employed to obtain her information. After three unsuccessful attempts to obtain Ava’s fingerprints, including a manual one, Paul tells me that they applied for a waiver. But weeks had passed and the stress was mounting up. Paul and Alice hadn’t heard anything back from their case manager and now he was seemingly unreachable.

We arrive at midday in hopes of getting hold of the case manager and, if possible, some answers about the status of the waiver. It is a big empty room suffused with the smell of toasted sandwiches, magic markers and paper. Rows

of plastic seats face a wall-mounted television set. I follow Paul as he saunters down to the back of the room to the administration tables where we are met by a short, dark, thickly-muscled bureaucrat who introduces himself as George. He is dressed in tight-fitted shirt and pants, his black hair is heavily slicked back, gold chains hug his thick neck; he has rolled his shirt sleeves up below the elbow exposing a pair of heavily tattooed forearms. Paul opens a manila folder filled with paperwork and says something that is inaudible to me, but before he's finished George extends his hands out over the folder. At first it looks like he is going to take the forms, but instead he closes the folder in Paul's hands, 'I can't discuss it with you', he spits out.

Paul starts out, 'All I want to know—'

'I cannot help. You have to wait until your case manager is in. Do you understand?'

'The whole reason I'm here is because he won't return my calls'.

'I don't know what you want me to say?'

The interaction stirs up an uneasiness inside me, there's something unsettling about Paul's placid conviviality and bemused expression, in contrast to the bureaucrat's confidence and unwillingness to cooperate. They continue down the same fruitless path of conversation, George unbudging and Paul trying to reckon with the senseless. They're in a motionless standoff and their conversation lapses into silence. I'm caught off guard by the discordance I feel between Paul's online public persona and 'don't fuck with me' attitude and the amiable and powerless person of flesh-and-blood before me. George shrugs but Paul remains undeterred by his show of passive-aggressive nonchalance. Paul's voice slips into inaudibility but I can tell that he is persisting in his request for George's assistance, his countenance has an expression of good humour.

Finally, Paul seems to have done the impossible and broken through George's seemingly impenetrable knee-jerk defensiveness.

Many of Paul's online projections, his humility and rigour, for instance, were given in the flesh during our time together. But by accompanying him on his errands and observing some of his atomized interactions with the state, I learned that Paul possessed a patience and an unwavering malleability that were absent in his blog and that I suspect were more attributable to the occasional advocacy achievements he exulted in. Paul showed me that these ventures were also a spiritual exercise: one's efforts had to be carried out in the spirit of what one was fighting for (accommodation and respect for our equal value), for the two could not be separated without doing great damage to the truth.

Over lunch, Paul laments: 'Everything is a hassle. Everything is impeded by bureaucracy. Everything is black and white'. He looked tired. He didn't need to explain himself further. I already understood from our previous conversations that he was referring to how exhausting it can be resisting the various conventions (architectural, attitudinal, educational, occupational, and legal) based on assumptions that bodies appear and perform in certain ways (Garland-Thomson 1997: 46). Not every day is a trial for parents. But it is within the changing and complex landscape of engaged caregiving that complex structures are navigated and significations relevant to their pursuits as caregivers are drawn out. As the saying goes, the devil is in the details, and Paul came to realise the devil emerging from the totality of his atomized interactions with the state and other bureaucratic procedures affected by cultural orientations towards normalcy. Of this phenomenon, Garland-Thomson remarks on the ways these daily material practices enforce a "narrow range of corporeal variation" (ibid: 24).

Pearl was twenty-two when we met. Seven years earlier, Paul had entered into a battle with the state of Massachusetts in an effort to exempt her from participating in federally mandated annual state standardized testing, or the alternative assessment offered to those with disabilities. The No Child Left Behind Act (NCLB) was signed into law in 2002 and was a reauthorization²⁹ of the previous Elementary and Secondary Education Act (ESEA). NCLB supported standards-based education reform which was intended to raise academic achievement for all students in the K–12 population and “close the achievement gap between poor, inner-city schools and schools in middle-class suburban areas” (Bryant et al. 2015: 22). Aligned with the goal of annual progress, the law mandated that students, including those with disabilities, take annual assessments in reading/language, arts and arithmetic. As such, schools and school districts dependent on federal funding were held accountable for eliminating the achievement gap and raising academic achievement. For Paul, the testing signified and threatened an annihilation and transcendence of Pearl’s subjectivity.

In his fight against the state, Paul contacted local and state authorities, alerted the media, and petitioned the state Commissioner of Education, writing: ‘Pearl will experience heightened stress and anxiety at the time of the exam by not being physically able to respond to any part of the exam. She will experience loss of self-esteem and self- image by completely and totally failing an exam that is not designed to test or assess her knowledge but the mastery of the Massachusetts curriculum frameworks’.

In her ethnography of parents caring for children diagnosed with autism, de Wolfe identifies bureaucratic procedures as mechanism of symbolic violence

²⁹ It has since been replaced by Every Student Succeeds Act (ESSA), which was passed in 2015.

employed by those in positions of institutional authority to force parents into positions of subjugation, either through their use as mechanisms of deterrence (in the case of costly social services, for instance), and/or by requiring parents fill out paperwork that “describes their situation or that of children in a way that they do not agree with” (2013: 168). Stevens (2010) draws on Althusser’s concept of interpellation to describe the disruption parents of disabled children experience when their expectations or self-interpretations no longer fit culture-specific modes of parenting. Althusser (1971: 174) writes:

ideology ‘acts’ or ‘functions’ in such a way that it ‘recruits’ subjects among the individuals (it recruits them all), or ‘transforms’ the individuals into subjects (it transforms them all) by that very precise operation which I have called *interpellation* or hailing, and which can be imagined along the lines of the most commonplace everyday police (or other) hailing: ‘Hey, you there!’

Stevens suggests that Hage’s notion of “misinterpellation” is a useful frame for understanding the experiences of exclusion that arise for parents when they attempt to heed the call of this new identity as parents of disabled children only to be blocked from fulfilling it (2010: 786). Through such attention to these exclusionary social practices and experiences of marginalisation, we see the ways parents are positioned between incompatible worlds, often times “eclipsed rather than fulfilled” (Jackson 1998: 54). As we will go on to see, these moments can also energise resistance which can be observed when parents subvert the scene of interpellation.

Stevens notes, due to the medicalisation of most disabilities, the medical system is a place of primary interaction for the family with the state, “and it is therefore frequently a baseline context for interpellation and misinterpellation” (2010: 787). In order to access social welfare services and disability-specific programs and funding (e.g. early intervention and support for aids and equipment) children must be medically certified as disabled. Early on, my

partner and I were not eligible for certain social services because Takoda had been diagnosed with Global Developmental Delay which was not included on the list of eligible diagnoses that qualify families: CHARGE syndrome, Angelman syndrome, Down Syndrome, Fragile X Syndrome, Rett Syndrome, Foetal Alcohol Spectrum Disorders, Deaf-Blindness, etc.

As de Wolfe notes, documents outlining a child's diagnosis have the double effect of delimiting the kinds of services and supports parents are eligible for—in the US this includes educational services and insurance deductions—and stigmatizing “the child as “disabled” and the parent as “the parent of a disabled child”” (2013: 150). This experience for parents entails having one's child hailed as a medical subject. And it's not always comfortable accepting these medical interpellations of one's child, even provisionally. “Diagnosis does the work of interpellation”, writes Frank, “the disease becomes not only what one has, but more significantly what one is” (2014: 34).

Applying for Supplemental Security Income³⁰ (SSI), Paul was astounded by the volume of information and paperwork that was needed to meet eligibility requirements. Beyond the scheduled phone calls, documents, and state certificates certifying Pearl's disabilities, it was the *function report* that really got to him. He felt it diminished Pearl's existence. It served as a tangible representation of the totality of her deficits, which not only set him adrift in a world organised and defined by others, but momentarily threatened to decompose his perceptions of her.

In bold and all caps, he recalls, the document stated: **DO NOT LEAVE ANSWERS BLANK**. They already knew Pearl's diagnosis, doctors' names, medications, etc., Paul recalled, but here was another eight-page document centralised around her physical and cognitive limitations. There was no space,

³⁰ Federal income supplement administered by the Social Security Administration (SSA) for individuals with disabilities with limited income.

Paul thought, for preserving the things that make Pearl the being she is. There was no option for skipping the series of repetitious questions that had been answered elsewhere, and that didn't apply to Pearl's existence anyway. It was her pure reference to Otherness that upset him the most. 'She has a major effect on people, but you see none of that [in the report]', he said. It was the little things, according to Paul, that muted and suppressed the hard realization that Pearl was profoundly disabled: her contagious smile, her bursts of laughter that were unexpected but well-timed, and snarky expressions.

For Paul, this event is connected to a web of other moments that have threatened Pearl with erasure. 'We have a great team of doctors, teachers and therapists', he said, 'but there have been—there was a doctor and he wanted me to lift up her shirt so he could see her development and he never even got off his chair. He never spoke directly to her. And he wanted *me* to just lift up *her* shirt, so he could see her development. I said, I have a better idea. And I opened the door and just walked out. Show some respect on some level. That was really awful'.

The identification of those with disabilities as medical objects has its roots in the nineteenth century with the rise of industrialisation and medical science, where approaches toward disabled radically shifted: illness and impairment were medicalised, medical experts rose to dominance, and institutionalisation for the disabled became widely accepted (Galis 2010). This doesn't extend across all medical spaces, as Paul attests by acknowledging the 'great team' of professionals that are part of his care network. Indeed, over the last sixty years the disability community has challenged the problematic biomedical view of corporeal difference as pathology, attempting to divest modern medicine of its hegemony over discourse and influence over the ways disability is socially understood. Notwithstanding, the supremacy of the

biomedical paradigm is well-entrenched in western societies and continues to cast a long shadow over medical care and the ways medicine is practiced.

The way Pearl is unjustly claimed by the doctor speaks to the ways embodied subjects are transformed into objects of ideology within the doctor/patient encounter. Within medical contexts, disabled children are interpellated into a whole subset of medical discourses. From the above example we see Pearl stripped of subjectivity and situated as a broken body, assigned, as it were, to a moral order that subordinates her. “At the moment of interpellation”, notes Erevelles, “the actual act of “naming” the impairment immediately triggers off an entire semiotic chain of meaning that draws on an already historically situated discourse that links impairment with the “defective body”” (2008: 371). From Paul’s perspective, the doctor’s call to lift up Pearl’s shirt affronted his conception of her and how he sees himself as her carer. By refusing to cooperate, Paul momentarily resists medical interpellation, divesting medicine of its extensive power and traditional authority over patients like Pearl. It’s not only within medical spaces that parents are summoned to enter another’s world and pulled from their normal frame of reference, however.

‘People are not empathetic’, Paul tells me months later as we drive to Natick, Massachusetts. We are on our way to a Durable Medical Equipment (DME) Supplier to drop off Pearl’s wheel chair for repairs. ‘They don’t put themselves in other people’s positions’, he continues. ‘Pearl loves swimming. That’s something we know she really loves. There was a school swimming day and the regular PT was absent. They [teachers] found out a little late and so they still changed Pearl into her bathing suit and had her sit by the pool, *not go in*, and at the end of the hour changed her back into her clothes and put her back in the classroom. I said, OK, and did someone *explain* to Pearl why she had

to watch everyone else do exactly what she loves and wasn't allowed? Did someone ever think that maybe that wouldn't be so nice to her? Could you have called me, so I could have come down to the pool and gone in with her myself? Could you have kept her in the classroom? Could you have done anything else? Did anyone look at it from her point of view? No. Empathy: thinking of things from other people's point of view. It's a big deal'.

How can this grasp on the other's experience be as elusive as these encounters seem to suggest? These attenuated understandings of disability come into play against a background of spatial isolation and erasure in the crafting of difference in selfhood. It could be described as a situation where intelligibility and recognition are denied those with severe cognitive and physical disabilities because of destructive ideologies and conditioning, alongside the ongoing disabling social scripts and processes that mediate our imaginative associations and affective empathetic responses to others. Empathy can break down, Daly argues, or be actively annulled (2016: 233). "It is clear that empathic responsiveness is not guaranteed and is never an all-or-nothing relation", she writes, "it requires constant feeling attention, care, refinements and recalibrations so as to attain a workable degree of empathic resonance, in which both one feels one understands and the other feels understood" (ibid).

In the moments above Pearl is stripped of empathetic significance. Dehumanising actions and language are connected to the ways disabled persons have been historically excluded from society and culturally and socially designated as anomalous Others. The systemic expulsion of disabled bodies from everyday spaces works to contract our recognition of sameness and maintain the 'skin' (Ahmed 2006) of the able-bodied community by keeping at a distance those who are conferred a phobic and/or denigrated status. These moments of mortification and negative interpellation provide a window into

shared public ableist norms that serve to reconstitute the skin of the normative community. In a broader sense, these histories and practices of ableism pose existential obstacles to achieving communion with disabled persons. When we fail to grasp the intentions of another or become empathetically unavailable, the mutual confirmation necessary for becoming selves is lost.

Carel attributes this gulf between the experiencer and observer to our limited imagination: an inability to imagine what a counterfactual situation would be like (2016: 137). “We have little capacity to imagine a complex situation remote from our own life”, she says, “because crucially, we do not have the required detail. Without having first or at least *second-hand knowledge*” (ibid: 138, my emphasis). This raises the existential issue of how, in the words of Jackson, “the claims of any individual can be adjusted to the claims that others make on him or that he makes on himself on their behalf, such that everyone finds validation and dignity in the many” (1998: 54). Or in the case of parents, how their perceptions of their children can be adjusted to the claims that others make of them.

These moments of mortification, however, can be ameliorated through inclusive practices and corporeal proximity between non-disabled and disabled individuals. As Ahmed writes: “the stranger reappears as the one who is always lurking in the shadows” (2014: 212). Spaces of proximity offer sites of possibility to engage intersectional differences. Proximity can help foster empathetic attunement and responsiveness, and the perceptual support necessary to bridge the differences we inhabit and more authentically enter into another’s world. I believe that proximity between bodies is key in eroding socially agreed upon views of embodied difference as abjection and instituting the kinds of perceptual realignments that would foster the kind of attitudes, behaviours, and acceptance that grants embodied difference. If the repetition of

exclusionary gestures and actions towards embodied others constitute spaces and influence the ways we inhabit them and comport ourselves in relation to others, as Ahmed (2006) lucidly points out, then gestures and actions can also give support to refiguring those same spaces through new layers of signification. At first glance, much of Paul's resistance to these alternative moral spaces and discourses may seem mundane or even reactionary. But on closer inspection, they speak to the struggles and powers of daily life that Mattingly (2014) looks at in her ethnography on the moral ordinary.

Mattingly (2014) takes inspiration in Neo-Aristotelian action-oriented virtue ethics, investigating the problem of action and judgement in the shifting and unknowable world for African American families caring for children with disabilities. In Mattingly's view, moral selves frequently find themselves "befuddled about the "good" or about who they should become...and continue over time to revise and critique their past selves or revise and critique their future in light of the things that have happened to them" (2014: 309). Everyday spaces are looked at by Mattingly as moral spaces of reflection, deliberation, practice, and possibility (ibid: 311). She considers the experiences that are created within these spaces as "experiments in how life might or should be lived" (ibid): singular events and scenes of action where the "new" is inaugurated and the "possible is pitted against the predictable" (ibid: 309). Despite being marked by radical uncertainty, Mattingly tells us that these singular acts have the potential to transform the social and material spaces that are attached to our projects of moral self-making.

These ordinary moral spaces are also sites where the personhood of those with disabilities is made and unmade in everyday life. In these singular events above, we see Paul striving to create a good life for himself and Pearl within the routine of everyday life. His subversive actions within these situational encounters function in the experimental way that Mattingly

identifies, as he presses forward into his possibilities as a carer and out of a concern for Pearl's feelings and in the best interest of their life together. In doing so he expresses new meanings to Others that contribute a new sense to Pearl through his treatment of her. By decentring the other's perspective through these actions and inviting them to enter his situation, he attempts disrupt the given social order and invite others into their sphere of experience.

Things have not gone well! We have just picked up Pearl's wheelchair from the DME supplier and the laterals have been re-positioned incorrectly. Earlier that morning, Paul was emphatic that they not be messed around with because Pearl's physical therapist had especially modified them to give her optimal stability and balance. The technician denied having touched the laterals, and a flush of anger had turned him scarlet at Paul's insistence.

'I can't believe they fucked up', Paul says, as we drive back to Brookline with Pearl's broken chair in the back.

'You knew they would'.

'Welcome to the world of assholes'.

There's a long silence. We merge on to the empty freeway. It's late and the sun is starting to lose some of its force.

'If this was some other piece of equipment would you care as much?' I ask, finally breaking the silence.

'No. How dare you do this to Pearl. I mean, this is what they do to all of us as parents. This is all she has. This is her only *anything*. She could love the chair more than she loves me. Okay. You don't do this. You *don't* do this to her'.

'Why do you think they're so unhelpful?'

'That's a good question. I guess because no one holds them accountable. I don't know. I don't understand it. It is an attitude that's just for cripples? Now we get into empathy. People have very low empathy. That's how you find

people who matter in the world—I'm very convinced of that in my life. The difference between schmucks and everybody else is empathy. They can't empathize with Pearl. Okay. You give them a kid in a chair and say go live for a week, then they'll learn a lot. They just don't empathize. They don't understand, you know. What's the big deal? They don't understand that life is tough enough, why are you adding to it? And again, would a car dealership give you a brand-new car with scratches on it? And would you take it? No. But I'm supposed to take a seven-thousand-dollar wheelchair with scratches on it? It just boggles my mind. It's just so infuriating and it's just that much worse because it's Pearl'.

Later that night Paul sends me a copy of his email to the Director of Branch Services and the Rehab Technology Specialist. He opens the email by identifying the problem with the laterals and the obstinacy of the technicians. Then he writes:

I cannot get Pearl in and out of the chair without opening both laterals, cannot get her sling on and off, cannot change her blouse nor bra and *I cannot open both laterals now... They were carefully set and positioned by a PT while looking at x-rays showing Pearl's scoliosis.* I have no idea how to properly place the laterals. The arm rests have a proper height for her best access for daily activities.

Now before you suggest that I change the height of the arm rest over a dozen times a day to allow the lateral to open let me ask you this ... is it ok if your car is in for repairs and when it comes back you are told that you must open the glove box and slide the seat forward before opening the driver's door? Every time? Of course not. The chair is different, negatively, and it is causing us problems, throughout the day.

So, in brief (!) the laterals need to be fixed, the seat cover needs to be replaced, the abductor wedge needs to be replaced and *Pearl deserves an apology*.

Incarnating the other.

The experiences of unsettlement and alienation that texture parents' social and cultural lives are emergent in spaces where they experience their children's bodies as it is for the Other (Sartre 1992), assuming the Other's point of view on their children. But not all of these between spaces involve apprehending one's child as they are for others in their abject Otherness. Sometimes, for instance, experiences of unsettlement arise for parents when conflicting interpretations, free from the spectre of violence and paternalism, are brought to bear on each other. Such is the case during encounters with professionals in school settings. During these encounters parents experience their children as they are according to another's reading of their gestures, and, what's more, by professional staff that come to know one's child quite intimately. In this section, I refer to this process as *incarnating the other*. Parents may experience this phenomenon in the subtlest of ways, such as when someone attributes a thought to one's child in an offhand manner, which is more often a reflection of their own thinking than anything more considered. At other times, however, these conflicting readings of a child can be at a distance from the ways parents understand their children. In these between spaces, subjective claims to knowing another are open and provisional, negotiated and contested through iterative processes and diverging epistemic claims. Like all claims to knowledge, these arise within specific contexts.

The emergence of these misalignments between parents and school professionals can be thought of in terms of the different virtues professionals and parents bring to their encounters (Kittay 1999). Darling writes, “While professional responses to disabled children are generally characterized by affective neutrality, universalism, and functional specificity, parental responses are affective, particularistic, and functionally diffuse” (1983: 148). I also think these experiences of unsettlement are revealing of caregivers’ moral hopes and dilemmas. For caregivers, there is a lot at stake when they encounter others’ competing definitions of reality. The competing claims of others can threaten to divest carers of their hard-won, precarious subjective realities and what matters between them and their children.

Paul collapses to the floor in attempt to escape the pain that has seized his feet and back. He doesn’t look comfortable: He is half sitting half lying on the kitchen floor, his long legs sprawled out before him, his back to the cabinets below the kitchen sink. It’s Friday night and he has spent the day in advocacy meetings. Ever since Pearl aged out of the school system a couple of years ago he has directed his efforts to building a career as a Special Education Advocate³¹ and Special Education Surrogate Parent³²— re-purposing his acquired know-how from the years he spent navigating the special education system for Pearl.

‘I used to wrestle with this one’, he says. ‘If they gave me a pill and said give this to Pearl and she will be normal, here’s the cure, would I give it to her?’ He reflects for a moment: ‘I’d lose Pearl. But how do you define Pearl? If I gave Pearl a pill and she wakes up in the morning and says, fuck you, daddy. I’m getting my nipples pierced, would I give her the pill? The conclusion I come to

³¹ Special Education Advocates help parents navigate the special education system, attain special education services, and achieve their child’s educational rights.

³² A special education surrogate parent is a person appointed to act in the interest of someone who is without a parent or guardian to oversee their educational rights, usually someone in a residential setting.

is—’ he pauses, his face assumes an undefinable expression that evokes in me a mix of melancholy and an ineffable knowing that reaches down deep —‘probably’. Then, in a flat voice: ‘I would lose my Pearl’. He pauses. ‘But I always look at quality of life from her point of view. So, can I give her half a pill and then she’ll be able to tell me if she wants it? I don’t know. Pearl is all I know. Pearl is what I have’.

I was anxious meeting Pearl for the first time. Paul frequently expressed throughout his blog and in-person how concerned he is when people ask Pearl questions she is not capable of answering. What if she could understand the question but just had no means of communicating her response? For me, though, this style of communication was habit. Koda is also non-verbal and I often ask him questions as a matter of routine: how was school today, buddy? I don’t think he has significant receptive language, but my questioning is stitched into the rhythm of our interactions. I believe my utterances, pacing, and intonation have meaning for him. I was worried that I was going to botch Paul’s cardinal ethical concern, and so in the car back on the way over I silently rehearsed in mind what I would say to her.

She was sitting in her wheelchair in the centre of the loungeroom when we arrived—Paul disappeared into the kitchen somewhere with Alice. Pearl was firmly striking the keys of a musical toy keyboard atop her wheelchair tray.

‘Hi, Pearl. I’m Aaron’, I said, kneeling down beside her. ‘I’m going to stay with you while I do some research on you and your dad. He’s told me so much about you’.

With her head lowered and bent to one side, she glanced up at me sideways with a smile that puffed her cheeks and exposed her teeth. With that reception, I decided to sit down beside her. As a bonding exercise, I thought I’d

compose a short tune on the keyboard, but Pearl shot me a sharply critical glance and so I resigned to spectator status.

Back when Pearl was attending elementary school, Paul had difficulty reading notes from teachers and therapists.

‘It was really infuriating’, he tells me, as the warm afternoon sunshine pours through the windshield in the car. We are sitting in the car outside a compounding pharmacy that prepares Pearl’s medications.

‘It was just very upsetting’, he says. There was one note that reported Pearl did math.

‘I went into the school’, he recalls, ‘and Barbara saw me, she was the principal—and she saw the look on my face. ‘What’s the matter?’ she said. I just handed her the note and said, read this. She looked at me and said, ‘yeah, that’s a problem’. I told her, I just want to know if during the day something is different, if there is a problem or something. I don’t want pie in the sky— I mean, this is crazy. Pearl doesn’t know math!’

We enter, Paul in the lead, and walk up an empty aisle toward the back of the store. We wait at the prescription counter as the pharmacist fills Paul’s order.

‘The school has this thing about choices’, Paul says, ‘Pearl has to make a choice. All disabled kids have to make a choice’. At the time, I am naïve to what Paul tells me. But in the coming years Koda’s Individualised Education Plan (IEP) will include similar activities that are oriented around making choices. The teachers and therapists believe they will help him develop communication skills. ‘Koda is working on making choices between two objects’, various reports will read.

‘So, they gave her a choice’, Paul recalls. ‘Do you want Pediasure or juice? And they gave her what they *think* she chooses. And they tell me, and I say, unless the choice is Pediasure or battery acid and five days later she starts

always choosing the Pediasure, then it's bullshit. And they look at me like I'm crazy. Ok, 'cause obviously it's crazy, they're not giving her battery acid. But you could give her lemon juice. You could give her vinegar if you want to know if she's choosing'.

The pharmacist bags two bottles of medication. At the counter, Paul takes out one of the bottles from the white paper bag, gently opens the lid and smells the contents. Then he does the same thing with the second bottle. The pharmacist rings up the bill, eyeing him out of the corner of her eye. There's a middle-aged man in a sharp suite next to me. He talks into the phone with a loud confidence that makes me feel uneasy. His voice fills the space the way the fluorescent lights do. I hear him let somebody go because they live too far away to attend regular meetings. When Paul has finally finished inspecting the contents of the bottles he pays the bill and we walk back down the empty aisle toward the exit. He tells me that in one of Pearl's last IEP meetings, before going on to adult services, the teachers and therapists tried to tell him that if she is given a switch to hit to keep the music playing, she gets it right 75% of the time.

'I said to them, what you're telling me is 75% of the time she wants the music to continue? Yes. I said, so she would get it right 100% of the time if she always hits the switch? Yes. What if she hates the music? And they look at me. I said, let's do an experiment right now –and I imitated putting a switch on the table. So, I turned to the PT in the room– who was the only person in the room that I liked–and I said I'll name colours and you hit the switch on every colour you like. So when we are done, let's say I've named 100 colours and you have hit the switch 54 times, what does my report say? I could say you got it right 54 percent of the time. What if you had no clue what I said and you randomly hit that switch 54 times? What if you misunderstood the question and you hit the switch 54 percent of the time for colours you didn't like? You got it right zero percent of the time. What if you were just fucking with me and you know you

got it right 32 percent of the time? So how are you giving me an official report telling me how many times Pearl wanted the music to continue or wanted her Pediasure when you have *absolutely* no clue what Pearl was doing? And they look at me like I have three heads! And my reputation goes to shit’.

‘Do you think they’re trying to create hope?’ I ask.

‘I don’t think they’re lying to me. I don’t think they’re thinking it through. There’s no empathy. They don’t put themselves in Pearl’s position. And every meeting they think they know more than I do’.

Although Koda hadn’t started school yet, I could relate to Paul’s lament. I had similar disputes with family members over the ways Koda’s expressions and actions were interpreted. Someone would suggest, for instance, that he had a love of classical music, or that his indiscriminate hand flapping was an attempt to mimic the dancing on television. Alice once referred to this as the Christy Brown/Ann McDonald syndrome³³: the spurious view sometimes held by caregivers and intimate others that the severely disabled child possesses an exceptional intelligence or gift. I recognised how important it was for people build their own personal relationships with Koda. And I had no intention of policing these relationships. But I grappled with an unrelenting feeling that the creation and attribution of these meanings were often carried out in service to their own needs and desires. I worried about their normative and ableist content: That existence is rendered lesser in the absence of a remarkable intelligence or the possibility of achieving typical developmental milestones. In many ways, Paul embodied Kittay’s (1999) regulatory ideal of transparency. Unlike the fully autonomous and self-interested person in traditional liberal theory, Kittay proposes the “transparent self” as the paradigmatic dependency worker: “this self does not allow its own needs to obscure its perception of

³³ Christy Brown was an Irish writer and painter with cerebral palsy. Ann McDonald was an Australian author and activist with cerebral palsy.

another's needs nor to have its own needs offer a resistance to its response to another" (ibid: 52).

The discursive and social authority of professionals within school settings has the power to affirm or divest parents of their perceptions of their children. By social and discursive authority I mean the social legitimacy the education sector has as a specialised sphere of knowledge, and the power and control a cadre of professionals within the school setting exercise in initiating and directing conversations around a child's education, behaviour, prescribing therapy and treatment, and making assessments about progress. Valle posits that special education practice within public schools is premised in the "medical model": discourse, for instance, is dominated by medical and legal language which can confound parents and/or prevent them from collaborating as legal advocates for their children (2009: xiii). Valle also observes that medicine's social and cognitive authority institutionally legitimises a range of special education practices. A child's educational problems (symptoms), for example, are assessed by school psychologists (experts) in order to diagnose problems which then inform the IEP (prescription) and educational goals (course of treatment) (ibid: xiii-xiv).

Many years later, Kim and I would have our first IEP meeting. I still remember sitting around the crowded table, outnumbered 12 to 2, teachers, classroom aids, therapists and nurses probing us with special severity. We learned first-hand, then, and would hear more stories later, about professional dominance in school settings and the paternalistic attitudes that are sometimes directed at parents during meetings like ours. We listened quietly as various teachers, class aids, and therapists told us about Koda's class participation and progress. Joint experiences were recalled and many of them resounded deeply and joyfully with us. These were accounts that spoke fully to Koda's bodily intelligence, intentionality, and the love and affection that are his primary ways of communicating and reciprocating. In contrast to these stories, there were

others wherein professionals, insofar as we felt, incarnated him with their own meanings. These meaning attributions cohered around, what Garland-Thomson calls, the “normate self”: a self that is founded on principles of liberal individualism. In these instances, Koda was made to inhabit projections that were uncritically rooted in cognitive intelligence, linguistic understanding, rationality, and progress.

I didn’t challenge any one that day on my view that their readings of Koda were grounded in norm-governed assumptions, nor did I articulate my problems with the representational functionalism they heralded. But during the meeting Paul’s laments weighed heavily on my thoughts. It was then that I realised that my empathetic stance had been shaped and, in my view, enriched through knowing him. Paul’s notion of empathy can be understood as fellow-feeling, a sense of shared identity or “identity-in-difference” (Daly 2016: 298). I came to realise that I didn’t want Koda to exist according to the normate channels through which meanings typically flow. I wanted him to be seen for who he was, for *his* possibilities and capacities. Anything else, I thought, would be a failure to recognise his humanity. Projected feelings of narcissistic self-identification could never enable the shift from typification to a deeper relation of empathy that makes authentic joint experiences possible.

But I think there is more to be said about the moral distance between school professionals and caregivers’ in these negatively charged encounters. Mattingly shows that within these social and institutional worlds parents come into conflict with moral normativities and authorities that can clash with their sense of a good life (2014: 8). I believe the guiding norms of individualism—understood here as self-reliance and independence— in medicine and special education clash with the deep experiences of caregivers. Many IEPs are premised in the presupposition that educational goals toward self-sufficiency and separation are worth pursuing. As Candib sees it, “declaring patients to be

autonomous...recasts them as fictitiously independent actors rather than as the emotional and social beings we all are" (1995: 128).

Within the practice of special education, professional staff may not consider parents' meaning-rich perceptions of their children as anything more than self-interested feelings. But caregiving is a deeply interpersonal and relational practice. What is at stake for parents here can go to the heart of who they are and what they have learned to endure. For instance, the well-intentioned but over-inflated interpretations that school professionals voice can poke at sore spots. In my case, these reading of Koda's behaviour threatened to undermine my hard-won precarious acceptance of the reality that he was not likely to ever acquire the skill to walk or ability to communicate.

As Kleinman (2013) illuminates, through the everyday practices of caregiving meanings, emotional and moral, are created and sustained. The meaning attributions of school professionals (and others) can trivialise parents' experiential knowledge or undermine the ways they engage with and care for their children, reaching deep into what matters most to them (their lives with their children, aspirations, fears, etc.). I was most uneasy with the implicit valorisation of normality expressed by the teaching staff in their meaning attributions of Koda's behaviour. It took me a long time to measure my expectations around what our lives together would look like and what he would be capable of achieving and what he wouldn't. After this meeting, my partner and I were fleetingly haunted by guilt and a sense of inadequacy for failing to notice Koda's purported abilities.

Teaching staff need to be more attuned and responsive to the particularities of the relationships between caregivers and children, which would foster parent-professional collaboration and the moral support that carers need over the long haul. Paul's searing criticisms reveal the constraints of professional impartiality which can be seen during IEP meetings which are supposed to address a child's concrete needs and yet overlook the

interdependence between the caregiver and care receiver. The moral task of school professionals, then, I would suggest, is to be committed to particularity and mindful that disabled children and their parents are not inherently independent but deeply interdependent. School professionals need to be sensitive to the particularities of parent/child relationships which may appear to be similar to others on the surface.

Conclusion

In the first section of this chapter, I considered the historical exclusion of disabled bodies from able-bodied culture, and culturally inherited ways of apprehending Otherness. In the vein of existential philosophy, these are the conditions in which carers are acted upon or thrown and must carve out lives for themselves with their children. In the second section, I focused on parents' empirical experiences of unsettlement and moments when empathy breaks down between subjects. The attenuated understandings of disability that parents encounter in spaces where their children are degraded and marginalised unfold against a background of cultural and societal erasure that influences our imaginative associations and empathic responsiveness to others. Spaces of proximity were depicted as sites of possibility for engaging intersectional differences and fostering our sense of relatedness to others. I attended to Paul's second-person experiences of Pearl's social treatment and oppression to throw light on the divided social worlds in which parents encounter conflicts and the role they play in motivating particular forms of social and political resistance. Furthermore, through spending time with Paul, I discovered new possibilities for acting as a carer and advocating on my son's behalf.

Interlude: an unpolished radio guest

I ride alongside Donald Hoffman in an old and dusty blue Ford Bronco. His attention is split between giving me a run-down on the structure of tonight's radio show and the map on his iPhone that plots our trajectory. Donald is somewhere in his late fifties; his blue jeans and a plaid short-sleeve shirt hang loosely on his thin frame. His voice has a resonant, baritone quality to it which I find enjoyable to listen to. He is the talk show host of a weekly regional family-oriented radio program that deals with topics about health, relationships and family. Tonight's theme is fatherhood and I have been asked to contribute as a guest speaker.

He stops talking and runs a hand through his short receding ashy-coloured hair. He squints out ahead at the street signs through a pair of heavy-lensed Buddy Holly hornrims that dominate his face. He nods, 'OK, now I know where I am'. He flashes me a smile; his straight white teeth contrast uneasily with his weathered face. Donald's appearance doesn't match his smooth and authoritative radio persona (or voice), and my nerves are grateful for his unassuming demeanour. As he pilots us down wide streets lined with palm trees, he tells me about his experience fathering. With an air of regret, he reveals that he's never sired children of his own. But he speaks fondly of his relationship with a troubled teenage girl he met many years ago and of the paternal role he plays in her life. I get the occasional whiff of an ocean breeze fragrance emanating from an air freshener clipped to the air vent and it causes my mind to wander: I can see my son kneeling in the sand, giggling as a current of air from the sea catches his breath, stretching his body upwards as he flaps his hands.

We are moments away from being on air. I sit behind an almond-coloured horseshoe-shaped desk, between Jay and Mary. Jay, a columnist and author, is a regular on the program and serves as Donald's bantering partner.

Mary, a life coach and Gulf War Veteran, is a returning guest. Donald sits opposite the three of us in front of two computers that surround a small soundboard. Behind me, a large window gives Donald a clear line of sight into the audio engineer's control room. Four microphones await appropriation. Mary smiles at me and gently swivels a dome shaped microphone my way. Donald passes me a black headset, which I slip on. The padding pushes in around me, silencing my surroundings. The temporary deafness draws my attention to the pumping of my heart, which feels like it's shifted out from behind my sternum and settled into my throat. The room smells like peanuts and stale air. Donald shuffles anxiously with a stack of papers, his brow creased with unspoken thoughts. Then, it softens and he smiles:

‘And now’, he announces into the microphone, weighing his words,
‘here's what's coming up on tonight's show...’

During the program, Donald frequently gazes up at a digital neon clock on the wall. I can feel time closing in around me. The neon numbers roll forward in triple-time. I would like to respond more thoughtfully to his questions, but my anxiety and his detached time-keeping suffocate my thoughts. And then Donald cuts to a musical interlude, which affords me a temporary reprieve. Frank Sinatra's *That's Life* plays over my headset. No one exchanges words during the interlude, only head nods and tight-lipped smiles. Mary sways her head and shoulders in time to Ol' Blue Eyes.

Then, we're back on air. Donald asks what I would like ‘parents of children with special needs to know’? I meander through a response, suggesting, in less articulate terms, that I would like parents to know that they are not alone in the challenges they face, or the experiences of despair that may arise in light of those challenges.

‘What are some of those challenges?’ Donald asks.

I begin to delve into the demands of caregiving when a small note is slipped across the desk to me. It reads: How are you a better man?

Seamlessly, I switch direction in my narrative:

‘–But I’m definitely a better person than I was before I had him. And I’m a much more patient man –’

‘Because you do get a lot of joy with your son?’ Donald asks, but it’s more of statement than a question.

‘Yeah. Absolutely’, I respond. A cowardly sensation gnaws at me and I feel myself awkwardly turn inward.

Chapter Seven: The Axiom of Equality: Moral Lives and Communities of Care

The world is teeming: anything can happen

–John Cage

I am you and you are me. Why's that such a mystery?

–Lenny Kravitz

“Welcome to Holland” is a widely distributed story, frequently given to and shared amongst parents of disabled children. It was first given to us by a key worker from Vision Australia who provided the earliest of early intervention services for Koda before we were properly integrated into social services. Emily Perl Kingsley is a social activist and mother of a son with Down Syndrome and she wrote the parable in 1987. The narrative depicts the initial disappointment of arriving to an unfamiliar destination (one's world of disability) through the metaphor of an unexpected journey to Holland, instead of one's eagerly anticipated vacation to Italy. The story invites those who identify with it to enjoy the lovely things Holland has to offer (like its windmills and tulips) by discarding their expectations and recognizing Holland's possibilities, instead of mourning the loss of Italy's. While directed primarily at parents who may recognise themselves as having a shared experience, it works as an allegory for anyone grappling with the uncertainties of a new situation.

Shuman writes, it provides a “counternarrative to other culturally available narratives about having a child with disabilities as tragic or to medical and social narratives about the child as an unwelcome problem” (2011: 155). Likewise, Rapp and Ginsburg view the employment of this counternarrative as an example of family activism against “the categories imposed by medical and

bureaucratic regimes" (2001: 546). They recognise "public storytelling" and "kinship narratives around the fact of disability", as authored by those with disabilities and/or their family members, as an important part of disability rights struggles. Over the last fifty years, they point out, re-scriptings of disability and normalcy have disseminated intimate insights about life with disability among broader publics, fostering networks of support and catalysing new forms of activism (2011: 381, 2001: 537). These *re-presentations* of nonnormative family life, they continue, have reverberated throughout the public domain with the remarkable effect, engendering important transformations to the law and our social fund of knowledge around the difference disability makes (2011: 398, 2001: 537). This "growing sense of public intimacy", they argue, presents alternative worlds of kinship based on shared experiences of difference and a sense of kinship that extends beyond the realm of the biological family (2001: 534).

Admittedly, I was moved the first time I read Kingsley's essay. I found comfort in thinking I was a part of a new kinship network comprised of families who had undergone similar experiences. Early on, it was an allegory that I felt represented and authenticated my experience entering this unfamiliar world. But Shuman makes a good point, I find, when she suggests the parable erases "the difference that makes a difference in understanding others" (2011: 155). "Welcome to Holland", she argues, aligns parents of disabled children by encouraging them to recognise Holland as "slower paced" than Italy. Additionally, the narrative positions the disabled child as a "lost dream", she says, in which the "desired child exchanges places with the child with disability" (ibid: 167). Slower paced isn't just different, she pointedly remarks, but "grounds for exclusion in many social worlds" (ibid: 167). She offers this important insight in relation to her own experiences mothering a disabled child:

“[W]hat is destabilizing...is not the loss of a dream but the loss of what I knew, what I took for granted” (ibid: 170).

Living between anthropology and caregiving shapes my moral experiences around caregiving and the ways I apprehend my world of disability. This complex intermediate space I inhabit is not always easy to negotiate and is filled with an uncompromising ambiguity. At times this between space is the source of emotional struggle and ongoing disruption. But it has also been an important juncture and source of epistemic insight, shining light on the multiple converging and conflicting interpretations of life with disability that, ultimately, affect the ways parents feel positioned and repositioned within kinship networks of caregivers and in relation to each other. I reckoned with diverging worldviews and interpretations of disability during fieldwork. At times, this made it difficult to relate to and understand my participants as a researcher and at other times as a father. At this juncture, moral pluralism revealed itself as characteristic of everyday life. Despite such pluralism, however, connections are forged and subsisted across difference through the shared tremors of uncertainty surrounding caregiving and a positive ethos on diversity.

Spending time with my participants and listening to them talk about their experiences and feelings alerted me, not only to the dynamic and active nature of care and subjectivity, but the ways the dialectic between bodies, difference, and social worlds stirs consciousness towards its various ethical possibilities and new ways of ethically-being-in-the-world (Hatab 2000). This compound expression indicates that as situated and socialised beings, we are already shaped by ethics before we reflect on it (2000: 57). I feel comfortable using Hatab’s (2000) Heideggerian-inspired notion that we are ethically thrown. It speaks to the ways our deeply held moral intuitions move and alter

themselves as they are drawn into the “dynamic integration of past, present, and self” (Rosenfield 1992: 141), and announce themselves in our commitments and the ways we evaluate our lives according to what we feel is fair or unfair.

This chapter serves as a meditation on fathers’ everyday moral experiences surrounding care and of the moral personhood of their severely disabled children. This chapter is divided into three main sections: 1) I portray the ways we are ethically thrown as situated, socialised beings. Specifically, in the following vignette I embed discussions around race, class, and income and consider the role faith plays in articulating what is given in experience. As an affective and constitutive aspect of subjectivity, faith provides a powerful moral source some parents draw on in making sense of their lives. In these instances, faith directs one’s ethical comportment toward the world and others and underwrites higher order ethical commitments and judgements. 2) I discuss the tensions existing between epistemic communities and how parents’ ethical commitments are motivated by their everyday concerns and what is at stake in their local moral worlds. 3) I describe existential hope as the background that makes possible these endeavours and pursuits by providing a sense of worldly possibilities (Ratcliffe 2008). Moreover, throughout this chapter I tacitly consider the moral personhood of disabled children which requires focusing on modes of agency that are sometimes overlooked in our language-centred culture. This involves a focus on embodied interaction and the emotional dimensions of disabled children’s social lives. This invites us to consider personhood and forms of ethical life grounded in capacities beyond rationality and autonomy.

In the next section, I use a creative nonfiction vignette as evidence for the ways carer subjectivities and commitments take shape around the moral sentiments and intuitions that are formative for their identities: That is to say, I

use the vignette to illuminate the ways carer subjectivities hang together with the referential context of one's life, animating the ethical and political projects one takes up. Furthermore, I consider the relational lifeworlds of disabled children and their moral interactions in the context of disability by being attentive to the bodily and emotional dimensions of moral life. This slice-of-life vignette has several advantages. Firstly, it allows me to address and compress an array of research findings and theoretical points into a single portrait (Smith et al. 2015). Secondly, this medium leads to more interpretive openness and allows the reader to momentarily inhabit another's lifeworld (ibid).

Bigsby Street³⁴

He enjoyed spending his downtime watching others, usually from the corner table inside his favourite Subway restaurant. Sometimes he would visit the shopping mall and wander around watching other people talk and laugh, striking up a basic conversation with strangers, momentarily re-joining the outside world. Today was especially hot though, even for Laveen, and so Raul took refuge in his favourite sandwich shop, absorbing the air-conditioned surroundings and filling himself with a tuna melt and cold soda. It had been over twelve years since Abigail was born and even though he had grown familiar with his new world, which was both temporally and geographically distant from his former one, every once in a while, he missed the ease and indifference with which he participated in his former social activities and that self-evidently satisfied his gregarious instincts.

In the past, he had been ambitious and avidly sociable. He had grown up in a large Hispanic family in a mining town in Southern Arizona where

³⁴ This vignette is a creative piece of nonfiction, a composite narrative that draws on fieldnotes and interview transcriptions to depict experiences that have happened.

socialising at family fiestas, weddings and quinceañeras played an important role in family life. He had once served in the military. He had worked three part-time jobs while putting himself through college. He worked for twenty-five years in parks and recreation organising community programs for 'at-risk' youth. And he had been good at delivering services and programs that they could relate to. After all, he knew first-hand what it was like to grow up in a community pervaded by an atmosphere of hopelessness. Drug use, prostitution, violence and gang-related activity were aspects of daily life back then. Many of those he went to school with were either dead or in prison now. Much later, when he thought about how well he and his brother and sister turned out, he concluded that it was the sacrifices his mother and father made (and the grace of God) by which he escaped the chaos and personal distress that so often grips those living at the social and economic margins of society.

That evening, Raul and Abigail went through their usual routine, Raul cooked dinner while Abigail's care worker, Mary, showered her and got her ready. They usually tried to eat dinner together, which wasn't always possible on the nights Ruth returned home late from work. But tonight, there they were, together as a family.

At the dining table, Abigail poked a finger into the pile of whipped potatoes on her plate and scooped a finger-full into her mouth.

'That won't work', Raul laughed, 'pizza and hotdogs are okay but for potatoes we use a spoon'.

He gently placed a spoon in her hand and guided it to her mouth. Then, very very slowly, by herself, Abigail lifted a heaped spoonful to her mouth, her eyes fixed ahead in full concentration. Their eyes locked and Abigail smiled with a sense of pride and accomplishment. Raul relished these moments, for the

very skills that we commonly take for granted Abigail had to acquire through practice; and though feeding her was still a time-consuming process, she was slowly learning to do it by herself. He was both proud of her achievements and in awe of the remarkable progress that she had made throughout the last six years.

Raul attributed much of Abigail's progress to the cessation of her seizures. Early on, their lives had been engulfed in human drama and complications. Abigail's life hung in the balance from the cataclysmic moment of Ruth's amniotic fluid leak at fifteen weeks. They decided they were going to fight for her existence regardless of the consequences. Despite the fearful apprehension that pathed their journey into parenthood, however, nothing prepared them for the love and trepidation, familiar to most parents, that gripped them the moment she opened her lungs for the first time.

But Abigail's tumultuous journey had just begun. She experienced a haemorrhage at birth and developed hydrocephalus as a result, which would later become the basis of her cerebral palsy diagnosis. By the time she was six she had already undergone over twenty neurosurgical operations because of shunt complications. Early on, it had been Abigail's fragile health status and seizures that prompted Raul to retire. Back then, Ruth was earning more money in her career and he was near retirement age anyway. They had decided that they could no longer in good conscience leave her in the hands of paid carers—relative strangers—given her complex needs and their deep convictions that they would do a better job caring for her.

They had several paid carers over the years provided by the Department of Economic Security which they were extremely grateful for. They knew, as did most families caring for dependents, that paid carers can be an essential piece of one's care network, enabling parents to meet expectations of

parenthood, like maintaining one's leisure time, work life, or financial security. But Raul and Ruth had struggled over the years to find someone that could carry out the intensive labour Abigail required with the kind of responsivity and emotional investment that they believed was integral to meeting her care needs.

There had been one carer a year or so ago that they had been fond of. She displayed the degree of emotional engagement with Abigail that they yearned for in a caregiver. Raul loved watching them together: the way the carer would dance with Abigail and sing to her. Then, late one afternoon, he returned home a little earlier from his chores than expected. Through the side window of the house he could see the carer asleep on the couch, barely visible underneath a blanket. Abigail was left alone sitting on her bed. He was horrified. He couldn't shake the thought of Abigail falling off her bed and hurting herself. In the end, they decided to let Abigail's carer go. It hadn't been an easy decision. And there had been no one since then who displayed the same level of affection or emotional responsiveness toward Abigail.

That night, Raul was woken by squealing. Abigail had started this routine a year ago. He would inevitably give in to the command it summoned. But for now, he would resist, hoping that she would stop so that he could stay comfortably sprawled out in bed next to Ruth. By the fifth scream, though, he had climbed out of bed, and was walking calmly down the wide hallway to Abigail's bedroom. Through the open door he could see Abigail sitting in bed, her arms stretched out toward the cross hanging on the wall. He remembered a priest once telling him that children with disabilities sometimes have a special connection with the Divine. Most people that knew Abigail knew that she was deeply religious, he had passed his religiosity on to her. Despite her limited communicative capacities, she loved listening to prayer over her augmentative

communication system while holding her rosary beads. But he found himself reticent to initiate others who didn't share their faith into Abigail's late-night communions with the supramundane. He loathed the thought of reliving these moments through the perceptions of others who may appropriate them through their own sense-making and presumptive secular reasoning. Better to keep what he witnessed close where it could endure unscathed.

The next morning, Raul woke up earlier than usual. He drank a coffee, ate a piece of dry toast, and finished the weekly spreadsheet detailing the family's budget. He returned to his bedroom, finished getting dressed, before waking Abigail up and getting her off to school. Usually, she would catch the bus to school, which was only a few blocks away, because she enjoyed the ride with the other school kids. But today was the beginning of Fall semester and so Raul decided to take her in himself. The weather was cooling, fall was lending its hues to the landscape, and snowbirds were frustrating residents across roads throughout the Valley of the Sun.

As part of the School Breakfast Program at Abigail's Elementary School, it had been arranged that students attending special education classes would join the general population in the cafeteria for breakfast, instead of eating breakfast within the confines of their classroom. In fact, Raul and Ruth had been at the forefront of this initiative. That morning, he was unimpressed to find Abigail's classmates eating breakfast alone in the classroom, isolated from the rest of the school kids. He questioned the classroom aid about it and she insisted the cafeteria staff were at fault: 'They said the kids take too long to eat'. He felt angry as well as sorry for the kids. His indignation carried him off to principal Todd's office. And when he was told that Todd was busy (the most overused phrase ever) he found himself crossing paths with Naomi, the school's speech pathologist. She was in her late twenties and Raul found her

deft, responsive, and pleasant to deal with. She invited him back to her office and he was grateful for the chance to vent.

‘What?’, she responded when he told her.

‘Is that insensitive or what?’

‘What?’ she repeated, her face seized in confusion.

He felt a momentary gust of comfort from her vindication of his outrage. ‘So just be aware that that’s going on over there. If you can talk to the cafeteria staff and see what you can do—’

‘Yeah. I’ll do that today, for sure’.

He stands there a minute feeling deflated but hopeful, and is about to leave when she says, ‘By the way, I just heard about the resource fair when I came back to work this year—which was kind of a bummer—’ She says this with a sort of admiration that he finds thrilling.

‘Well my wife did this—’

‘Which is totally awesome’, she says.

Like most parents, Raul and Ruth knew very little about their world of disability in the beginning. And like many others, they lacked the practical skills that enable parents to find their way around the medical bureaucracies and social spaces in which they become immersed. They were both college educated and yet learning the language of doctors and insurance companies had proven demanding. During this time, they became acutely aware of the inequities affecting Hispanic families caring for disabled children within their community. Many of these children were living in low-income Spanish

language-only households. Raul often wondered just how pervasive this language barrier was in affecting the services they accessed, or were even aware of.

The more Raul acclimated to his world of disability the more he found his thoughts turning towards issues of diversity and inclusion; toward the circumstances of parents and families deprived of the opportunity to stay home and care for their disabled dependents because of financial constraints. And through these concerns he discovered a renewed appreciation for the time he had been given with Abigail. Over the coming years he and Ruth drew on their shared propensity for community involvement (which had been such a big part of their former lives) and began to focus their time and energies on local projects that fostered inclusion and integration in the school and community. The Latino Disability Resource Fair was their latest venture. It had been Ruth's brainchild, but Raul climbed aboard proudly. It went some way, they believed, in helping families access timely and appropriate resources that make life as a caregiver easier and that, ultimately, shape the potential life of the child.

'Ok. Ok. Well, she got money for it, the whole works, all the sponsors', he says, his enthusiasm makes the words fall out of his mouth at a frenetic pace, 'Ok. She went to Todd—I was incensed—she says, Ok Todd, I've done everything I can do, can you mail the flyers out to parents? And he says no. How can you have a parent take all this time and energy and resources and not mail—I mean, what's the thing with mailing?'

'I'm not sure'.

'So, if I have to, I will find out where the special needs classrooms are in every school and I'll give them out myself'.

They talk a little longer. She asks him to keep her informed and he promises he will. And then he finds himself walking out the door, leaving the school, and heading to Subway for lunch.

Raul took Abigail to the movies that evening. Afterwards, they strolled around Walmart and watched the world around them. Abigail had always shared his natural sociability. If she spotted someone heading in her direction she stretched her arm out of her wheelchair to greet them in their passing. Early on, Raul had been devastated to find people both unintentionally and deliberately ignoring her, averting their gaze or brushing past her indifferently. Once, she was so very deliberately ignored that she burst into tears. That episode had really worn away at him inside. He felt it was his duty to protect her self-esteem. It was then that he decided to anticipate her social overtures and inform Abigail's potential interlocutors of her intentions. 'She wants to say hi to you', was his refrain. He found that people, once he had exposed them in this manner, often responded favourably to her openness, either shaking her hand or sitting beside her and initiating a more intimate interaction. But there were always those who employed ruses to evade an encounter (a faux cell-phone call was a classic), and others who remained standoffish and awkward, they couldn't seem to transcend whatever implicit behavioural contract Abigail undermined with her embodied difference. Their painful tentativeness made it clear they were afraid of saying the wrong thing. And once the awkwardness was in play there was no escaping it. It was like a vortex that pulled everyone in proximity down into its logically fallacious depths.

That night, as he tucked a sheet around Abigail, his body remembered what it had been like to hold her as a baby. It had been over twelve years since her birth and he rarely thought about the obstacle course of dangers that characterised those early years anymore. But he had never, not once, resented

the exigencies of his situation. From the time he held Abigail in the palm of his hand when she was just 25 weeks old and weighed one pound he could feel something ineffable and gracious through her. She was tiny and fragile but stretched from the earth to the heavens. And it was his job, he told himself, to keep watch over her, to guard this earthly messenger and the secrets she carried.

Epistemic communities, parental ambivalence, and the existential demands of ethical life.

In this section I look at the ethical implications of parents' efforts to make the strange familiar and the deep divides that can exist between epistemic communities. The complexities of representation, visibility, voice, and silence in this section point to the varied nature of parents' committed actions—breaking a silence, advocating for social change, providing care and treatment for their children—widening our understanding of the tensions that exist in activism. Finally, I describe how parents endure through the hardships of caregiving and the ways they come together in diverse communities through their shared experiences of care, as they speak on behalf of their children who cannot bear witness themselves and testify to living life with a difference.

Alignments between parents of disabled children can't be taken for granted because of an abstract notion concerning the loss of a shared dream or idealised child. Beyond an appreciation for the ways parents reinhabit the space of possibilities in which they contingently reside, the experiential category of 'special needs parent' (or any other compound term that designates parents to a particular class of disability) may not be that informative in terms of shared

experience and footing. For many parents the shared oppression of exclusion matters more than their child's diagnosis.

The stress and coping literature often privileges the negative ways parents are impacted by their child's disability as a means to better inform and reorient health and education practices and service delivery (see Carpenter and Towers 2008; Rendall 1997). In these conceptualisations, caregiving burden is treated as a pathological condition that needs to be overcome or rehabilitated. These approaches, however, come at the expense of capturing the ways care is embodied by parents' in relation to the particularities of their given existential situations and the particular bodies they care for. By contrast, I view carer burden and the modes of being that arise from it as foundational to subjectivity and an ethical life.

While the labour involved in caring for disabled children comes with its own continuing personal, physical, and emotional challenges, "familiarity and routine", as Featherstone puts it, has the potential to "blunt our awareness of disability after a while" (1980: 41). But even hard-won changes in familiarity can be precarious and quickly undermined through experiences of cultural marginalisation, social isolation, and stigma. Koda's continued social alienation and misrecognition by others, that is, his frequent relegation to the outskirts of human belonging, are inseparable from the emotional pain, exhaustion, and existential vulnerability to suffering that, has, at times, marked my experiences as his caregiver. I consider these modes of being central to the ways care is embodied.

Before Koda started school, a well-intentioned nurse remarked on the great strides we as a society have made in accepting and recognising disability. She lent this notion support through a personal anecdote concerning a disabled child her children attend school with. She affirmed, 'They pay no attention to

his disability'. She was kind in attempting to assuage whatever anxieties I had about Koda starting school for the first time. But I found her allusion to societies *corporeal blindness* misguided. Her words resounded distinctly in my mind one morning at kindergarten as I watched Koda attempt to ingratiate himself with two classmates. Two boys chased each other, he followed, crawling to catch up, smiling excitedly. When they finally came to a standstill they barely acknowledged that he was sitting happily at their feet, his eyes fixed on them. Her words have lived in my mind ever since, rushing out of the shadows on other occasions too. How to do justice to the dizzying spell of emotions that arise when your fellow café patrons move tables after sighting your physically disabled child. That was when I realised how comfortable these misguided fallacies are to wear.

The idea of *corporeal blindness* is as specious to me as those who think we live in a post-racial society where the colour of one's skin has no relevance or political meaning. As critical race theorist and legal scholar Williams writes, while colour-blindness can be held as a legitimate hope for the future, "the very notion of blindness about color constitutes an ideological confusion at best, and denial at its very worst" (1997: 2). She goes on to say that these claims to blindness can leave people of colour "pulled between the clarity of their own experience and the often alienating terms in which they must seek social acceptance" (ibid). Like race, the othering of disabled bodies through social practices that position and produce them as inferior or abnormal can take on subtle forms. As I discussed in chapter six, these Othering processes can be witnessed across a range of material and social practices and on an interactional level between interactants. It is certainly more comfortable to escape the stigma of ableism or avoid the discomfort of diversity work that we are all responsible for by maintaining that accurate social recognition and comprehensibility of embodied others has been won. But I find this claim stands in stark opposition

to the experiences I share with so many others of having our children's bodies dominate our consciousness in public settings³⁵.

Ethan put it this way:

It's that look on their [distant friends/strangers] face, that deer in the headlights look: "Oh my God, you've confronted me with something that makes me horribly uncomfortable. I don't want to have to face this, it's too horrifying. I have kids of my own. I can't fathom what it would be like. Let me go back to my normal life, please". And I get it. I do. It's human nature. It probably happens to everyone who has something that is vastly different. So often we isolate ourselves, so we don't have to see that look on their face. I'm not shocked as to why special needs parents get so angry and feel so slighted by society. If we feel that way, so marginalised, I know somewhere deep down inside Jack feels it. He's gotta. He's a human being. He has feelings. So if I'm feeling it, he's feeling it. It sucks. So it makes me mad. It makes me sad.

It is not only through these vicarious experiences of a child's stigmatisation and derogation that parents face exclusion, but also from the ways disability and family life are culturally marginalised in media, literature, and film. While I was in the U.S. for my fieldwork in 2015 an online initiative called *Sesame Street and Autism: See Amazing in All Children* was launched. The program was viewed by Sesame Workshop³⁶ (SW) as a promising web-based platform offering educational videos about autism and resources for individuals on the spectrum and their families. Julia, a muppet with autism,

³⁵ In the last chapter I spoke about the ways *corporealization* structures the visual field and historically inherited perceptual practices of identification and classification.

³⁶ Sesame Workshop is an American non-profit educational organisation responsible for educational and social impact programs.

was introduced as part of the initiative to help spread awareness and reduce stigma around autism. Among the parents I spent time with, this initiative was met with mixed feelings. While some thought it would jump-start a cultural conversation around autism, others met this initiative with apprehension and concern. Ethan found it disquieting that Julia was relegated to the online program, rather than being a part of the mainstream show—Once again, it appeared as though disability was being confined to the cultural peripheries.

Other parents expressed concern over the ways autism would be represented. Would this social platform, for instance, represent those embodying more complex and challenging behaviours and what it takes for their families to survive, or would they be overshadowed by an agenda for inclusion based on autonomy and independence? –a disability-rights agenda that is often reluctant to admit to vulnerability and the divisions born of profound difference within its own cause. Jeanette Betancourt, Sesame Workshop’s Vice President of outreach and educational practices, certainly seemed to suggest as much when she proposed that in order to breakdown misconceptions around autism they “wanted to demonstrate some of the characteristics of autism in a positive way” (Dell’Antonia 2015).

While it’s hard to imagine that anyone would disagree that sensitivity is a good thing, too much caution can potentially miss an important segment of the population affected by autism. That is to say, the tendency among autistic self-advocates and those within the neurodiversity movement to create cohesion within the category of autism by representing only a portion of the spectrum, that is, those who self-identify as being autistic, can alienate other members from the community whose experiences and needs are vastly different.

One mother responded to the unnecessary cultural marginalisation and social isolation of those raising severely disabled children by writing:

NOW, show me a picture of a kid in an involved wheelchair, with a vent, a g-tube pump and a suction device. Show me a kid with combined severe cognitive and physical disabilities. Talk about dystonia, spasm, tone, seizures, scoliosis, drop foot, silent aspiration. Show me the parent(s). Show me how they are living. In short...show me something that I can identify with. Show me something that acknowledges the existence of this type of disability and everything it entails. Openly discuss struggles as well as joys. Tell me, tell my kid that what is important is just getting on with our day to day lives as best we can, even without a specific contribution or goal or happy-ending-in-sight. We can be "happy" and "successful" if you broaden the definition of those words.

Emphasising the effects these representational choices have on carers, Salon³⁷ writer, Scot Sea, laments:

New Age pests, overdosed on media mythology, overhear you are the parent of an autistic child and, eyes aglow, pronounce, "Oh! And isn't that just a blessing?" In Wisconsin, storefront fundamentalists suffocate an 8-year-old autistic boy [to death](#) while attempting to "exorcise" his strange behaviors...Clueless neighbors, whose own children run wild, devoid of discipline, remark, "Yeah, our kids are just like her -- 'cept we got three of them (2003).

Affirming difference and the burden of caregiving is not without its ethical quandaries. Scot was vilified by some readers for the Salon piece. Those

³⁷ Salon is a news and opinion website.

who have read the essay might determine that Scot is an activist who speaks to, what Ian Hacking refers to as, “the family-shattering impact of severe autism” (2009). I recite Scot to some length because his narrative captures the anaerobic conditions of fatigue and endurance that permeate parents’ experiences of caregiving. He writes:

Celestial metaphors do little to temper the exhaustion you struggle with as your daughter, still going strong at 3:30 a.m., cranks out her version of the diagnostic handbook for developmental disorders' Greatest Hits...The deeper into brutal night she marathons the more wired, delirious, hypermanic she becomes. You have isolated yourself in her room. The same home-taped "Sesame Street" plays the same two and a half hours over and over. This, an integral part of the same preservative tic impelling her to clutch to her chest all manner of unrelated objects: a door stop, a bean bag, a ball of foil, a coaster, a hairbrush, a subscription card, a winter scarf. When she bends to pick up yet another item -- a shoe -- invariably the lot of it gets away from her and you watch as the bundle spills to her feet. Dutifully, robotically, she gathers everything up again, dropping some, retrieving, dropping again like a bumbling vaudeville comic. You watch this fascinated, then impassioned, then with alarm (what ... the hell ... is she doing?) then with dull acceptance. It is just the same scene from the same interminable clip on the Late Show from hell.

Daylight seems to click her down a few amps. She seems alert and ready for the day. A full circle has transpired and now, a familiar morning ritual. Calming, predictable. Breakfast. More pills. Hair. Teeth. Dressed. (Help your 15-year-old daughter on with her bra every morning and the female breast loses most of its mystery.) Get her on the bus. Now you must leave for work. Can't take any more sick days. So sleepwalk

through the motions. Hope your reserves kick in. Take an early lunch. Doze in the car for an hour. Throw down three cups of mud stewing since morning. Limp 'til 5:30. Collapse at home. Sleep through midnight. Again, your wife wakes you. Yeah, she's still up, she informs you -- napped two hours at school, cruising ever since. Your wife has clients tomorrow. She must crash. Time for your shift.

I met Scot and his wife, Patty, in 2015 after reading his autobiographical essay on autism. The Salon piece had been published twelve years earlier when their daughter, Jessie, was sixteen. At that time of our meeting she had been dead for a little over a year. Her early exit from the world at the age of twenty-seven from kidney disease had left an irrevocable absence in their lives which was very much present during our time together (glimpsed in all manner of gestures and looks between them). The space they would have to remake for themselves was still under construction during our time together. Scot said, 'She could just never catch a break. It was this and that. She couldn't communicate, she was thoroughly intellectually delayed, she had seizures, as well as GI issues, and she gets polycystic kidneys from me'.

That afternoon, on the back patio of their home, in the warm shade, I asked Scot why he wrote the piece. Unflinchingly, he said, 'I can tell you exactly my reason. I'd finally had it with seeing these--you'd see them in like Lifestyle magazines or Sunday paper supplements and they always had the same title: how my diabetic cousin inspires me or how my niece with cerebral palsy taught me bravery. Or they're authored by some television celebrity or some athlete's wife, you know? And the photo is always of --they're all well clothed, in a big grassy backyard with a golden retriever, a twenty-four-hour nanny, and a six-figure salary, and everything is fine. Things don't look that bad'. There was something haunting the edges of his surface composure, an experience perhaps

that pointed to the ambiguity of inhabiting both sides of the divide: the indeterminate future that was once past potentiality. ‘And I remember reading these things and saying to myself, you want to know what it’s like?’ There was silence. And then he added drily, ‘So that’s why I wrote the piece’.

As Ian Hacking notes, autism narratives do not only describe one’s reality but help forge the concepts in which to think about this unstable category (2009). As such, there is often heated exchanges between parental groups and charities and members of the disability and modern neurodiversity movements that link with broader socio-political themes concerning representation, identity, and the ultimate position of those with autism in society (see for instance Belek 2017). But these heated public exchanges, often carried out over social media platforms, are not limited to autism. They extend beyond particular diagnostic categories and pertain to the epistemic tensions that exist within singular diagnostic categories and uncomfortable contradictions that exist between different knowledges and articulations of clinical diagnoses. In Scot’s particular case, there was a bipolarity in the feedback he received between those commending his bravery in giving a voice to the visceral daily lives of families caring for autistic individuals and those condemning his account as offensive and fear-mongering.

In his book, *NeuroTribes*, Steve Silberman mentions how terrifying Scot’s piece is for families grappling with a child’s diagnosis and seeking information on the internet (2015: 59). Arguably, the most contentious aspect of Scot’s essay, and the part that Silberman takes to task, is the ways Scot extends his sympathy to Delfin Bartolome, a fifty-five-year-old father of three, who murdered his 27-year-old autistic son in 2002 before turning the gun on himself. By all accounts, Delfin was a devoted husband and father (Tran and Anton 2002). His nephew is reported saying that he never had the impression that Delfin saw his son as an

immense burden nor that he felt unduly weighed down caring for his family (Parsons 2002). Speculating about Delfin's motives for the murder/suicide, Silberman writes, he "had been laid off just before retirement, shunting him into a series of temporary jobs and putting his son's future care at risk (2015: 59).

It would seem that many self-advocates within the disability community feel that parents' embodied situation illegitimizes their representational authority of their children's disability, claiming that their own situation as a disabled person puts them in a closer position to those who are non-verbal and interminably dependent. Some parents/caregivers, on the other hand, while valuing the insights of disabled individuals, see a distance too immutable between the children they care for and the existential and embodied situation of self-advocates for their insights to be of any practical import. Ethan said, 'I'm a human. He's a human. Humanity is a large spectrum. Doesn't mean one end knows jack dick about the other'.

These uncomfortable contradictions and tensions often play out on social media platforms, like Twitter. For example, in an exchange oriented around the politics of representation, a fellow user, responding to a post written by disability rights activist, Gregg Beratan, conveyed her dismay over parents' refusal to 'accept/love their kids' and a presumption that 'their experience trumps all'. Gregg responded, 'And that's my big issue with awareness campaigns never moves onto acceptance they don't even shed the idea that we are broken' [GreggBeratan]. (2017, February 23). But for those parents caught in the monotony, stress, and exhaustion of intimate caregiving and dealing with the potential violent or maladaptive behaviours of their children, pathologizing their children might not seem like a stretch, nor a question of love.

I understand the fervour with which disability activists and self-advocates argue that efforts like Scot's promote a discourse that undermines the strides the disability community has made in breaking with demeaning stereotypes and creating a sense of identity and individuality around disability. And the matter also concerns political representation regarding who is morally qualified to speak on behalf of whom—an issue that has troubled my own academic discipline of anthropology (Clifford and Marcus 1986). Some parents find accounts like Scot's offensive on the premise that his representation rhetorically dehumanizes those with autism or disabilities by publicly representing those individuals as sources of misery and hardship. Others may suggest that it reeks of self-pity. But with such large swathes of public ignorance on display, just what kind of disclosures should be made? For example, a sibling of an autistic man responded to Scot's essay by suggesting that his brother is gainfully employed and has an active social life thanks to his loving family's support and the strong educational background they provided him with. 'I don't "feel" for the man who killed his child and himself', he writes, 'Did he exhaust every opportunity for his child's development?'

In 2015, an article in *The New York Times* (Harris 2015) reported a story about a United Airlines flight that was redirected from Portland to Salt Lake City for an emergency landing after the crew decided an autistic child's disruptive behaviour warranted removing the family from the aircraft. The incident began, according to the article, after Ms Beegle requested to purchase a hot meal for her daughter, Juliette, in order to keep her settled. The flight attendant refused, offering her a sandwich instead. Juliette was overcome by an outburst of frustration and was eventually accommodated with a hot meal to settle her down. But by then, an emergency landing was already underway. The comments section to the article reveals a multitude of responses that can be easily divided into two camps (the most hostile comments aside): those

sympathetic toward the plight of Ms Beegle and her daughter, expressing their admonishment of the airline for its insensitivity, and those displaying the kind of ignorance and misunderstanding that lends itself to families' experiences of social estrangement and the cultural disavowal of their children:

'If...her daughter required a hot meal, why didn't she book first class tickets'.

'Rules still apply to them'.

'Other people have their own problems'.

'If you know your autistic child will...act out...stay home or drive places'.

'Stay home and lock your kid in a closet seems to be what you're recommending', one parent responded, 'That was fashionable in the 19th century and early 20th centuries. Sorry, I'm just not down with that solution. Thankfully things have changed a little. But obviously not enough'.

Testifying to the rigours of caregiving can be done in the spirit of making the strange familiar. But by acting on this side of ambivalence, parents risk representing their children in ways that resonate with views that have been deployed throughout history towards those with physical and intellectual disabilities in justifying their social debasement and neglect. In the past, the scientific criteria and diagnoses used to identify people with autism and other disabilities has been crucial for families wanting to access important social supports and services. Scot feels that delineating the negative impacts of caregiving and the suffering and vulnerability of caregivers is necessary in appealing to legislators in hopes of changing public policy; in order to better

help guard families against the inexplicable vulnerabilities that arise in desperate situations.

‘There are legislators here whose grandchildren were autistic, had no idea what that was during their careers in politics’, Scot said. ‘They probably didn’t have much patience from constituents who were telling them about these obscure lifestyle wars they were waging until it happened to them’. In the interest of emphasizing the importance of respite assistance for families and other social services, Scot wanted to forcibly demonstrate what it takes to endure the exhaustion and monotony of caring for one’s remarkable and impossible child, and what it looks like to make a life on a different planet, “where the gravity is strong, and the climate rarely changes” (Sea 2003).

I disagree with some people’s claims that Scot’s discourse amounts to hateful rhetoric. My conversations with Scot and Patty made it clear that Scot loved his daughter deeply. From the perspective of parents, the moral calculus is complicated. Caregiving entails the irreducible confluence of exhaustion and love. To sympathise with the situation in which these murder-suicides arise is not to endorse them. Paul admits to hoping for the ‘mother ship’ to come for Pearl or for a tear in the fabric of space-time to swallow them both up. ‘I’m into this twenty-three years’, he said. ‘I’m fifty-six and I have to worry about whether Pearl will outlive me’. The numbing monotony of caregiving and the isolation and exhaustion that permeate carers’ experiences can lead, then, to problematical ethical feelings and, at times, like Delfin’s story illustrates, moral tragedy. The more important question, perhaps, is how to create a space for different stories to breathe within different epistemic communities without stigmatising difference in the process?

The path between balancing one’s own interest and the interests of one’s charge, between empathetic responsiveness and self-interest, is riddled with

complex moral choices; sometimes they harmonize, at other times they conflict. Our ethical commitments take shape in a world of losses and constraints that can frustrate our best attempts at achieving equanimity. The encumbrances and contingencies parents face are important for understanding how they exist ethically. I share Hatab's view that most parents do not base the care for their children on inferential reasoning but are rather thrown "in and amidst a situation that *calls* for care" (2000: 83, original emphasis). "The ethical force is simply *there* in the child's...fragile need, and parents dwell *in* that need", he writes (ibid). Parents are always free to act otherwise through neglect or abuse, he says, "but such freedom can easily be deemed unethical...as the disowning of a thrown responsibility" (ibid). Ethical responsibility, therefore, cannot always be explained by rational choice models. Our ethical imperatives arise within and are existentially responsive to concrete persons and situations (ibid: 85). In many respects, dwelling in the circumscribed situations into which they are *thrown* can be the most difficult for parents of children with disabilities, as they attempt to accept and embrace their ethically thrown responsibilities and envision a freer and more just world.

An uncertain inheritance

In the last two sections I have addressed lived morality and how ethics function in parents' experiences. I have argued that to understand how carers feel positioned within caregiver networks we need to consider the existential conditions that constitute, reconstitute, and motivate their ethical feelings and actions, and the demands and difficulties that arise with relation to caring for their children. In this section I will focus on the ways parents endure through care, lived meanings and uncomfortable contradictions, and the ways they

come together around their shared understandings of what it means to be human.

We drive down the grey ribbon of highway which stretches across the desert, then falls away into the distance. We're heading back to Arizona after a weekend in Las Vegas with family. It's a four-and-a-half-hour trip back to Scottsdale, Arizona, but we are taking our time, enjoying the vastness of the desert's magnificent solitude. Two hours in, we stop at an In-N-Out to get lunch and refuel. From the register I can see him in the back seat of our car, staring out the window, his mouth hanging open a little.

A door in my mind is opened. 'Suzie calls them window lickers when she sees them on a bus', my father said, sometime not too long ago. 'Me though, I just feel sorry for them', he had added in his typical self-aggrandizing manner.

I thought that I had grown immune to his calculating barbs over our previous years of estrangement, but I had been wrong. His vernacular onslaught left me feeling hurt and indignant. At that time, he hadn't met my son yet. And the more I thought about it, the more I loathed the thought of them meeting. I simply didn't have the emotional agility or wherewithal to vicariously experience whatever discomfiting feelings my son would awaken in him. Why? Because I have spent a great deal of energy on trying to release my white-knuckled grip from the familial projections and social attitudes around disability that began to claw at the walls of my consciousness a long time ago. Which, of course, is not a simple task, as they can keep even the most well-meaning of us ensconced in ignorance, limiting our selfhood in indefinable ways. It's not only a child's disability and the social experience it brings that add to parental ambivalence. I suspect many parents reckon with the tyranny of internalised prejudices and the deep aching of sorrow that can become such a standard state.

This is my life.

Admittedly, at times I feel like I'm living someone else's.

Hopeless.

'I hope you don't feel like you have this bleak future', Ethan said to me before I left the Midwest.

Unmet expectations had been a deep source of disappointment and confusion. I confessed I was trying to surrender to the present, expectation-free, which was becoming harder to do.

'You have to have some level of hopeful, positive energy', he added, 'Not that he'll get up and walk and talk and dance and do those things, but the answers will open up'.

After a long pause, he continued, 'It's not for me to say. I'm in a totally different situation. So, I don't know'.

And then: 'I feel bad for you'.

'Don't feel bad for me', I snapped back, irritated.

'It's not pity'.

'I know'.

'It's not that'.

His exhortation felt empty, like a mask he was putting on for my benefit. From what I had seen, Ethan was dwelling in contradiction, trapped in the dark recesses of his body memories, locked in a corrosive grief. If love and care can mould an identity, so can exhaustion and despair.

We plunge back onto highway 93, fringed by low mountains. Sun on my face. Soothed by the flow of cold air from the air con.

"No expectations without experience", Koselleck writes, "no experience without expectation" (2004: 257). I felt like there was something fundamental missing from my life, absent from my experience. The radical contingency that governs human life had stolen the power of expectation from me, and the intelligible world it fosters. What form could any substantial hope take in the

face of such an uncompanionable world? If hope is the confluence of desire and confidence, or an investment in an assumption, as Pettit (2004) suggests, that galvanises thought and action, it felt out of my reach. Desire and confidence seemed worlds apart.

I was following a road unknown to myself. I had wandered from the designated path, and all the types of idiosyncratic and cultural meanings that defined its contours (individual and shared experiences: That is, all the individual and collective activities, predictions, anticipations, aspirations, and potential future life events that comprise our meaningful possibilities. This might be thought of as a “loss of the practical meanings upon which hopes rest” (Ratcliffe 2015: 105). Suspended in the presence of the unknown, Meyer says, “we anxiously await the breaking of the storm, the discovery of what unrelenting fate has decreed” (1956: 29). This general state of suspense, he says, involves a set of non-specific expectations which make us sensitive to a range of possibilities grounded in past experience, beliefs and attitudes (1956: 29). What kind of hope could I hope to inhabit in this state of suspension when the horizon of expectation that gives a sense of familiarity to our indefinite possibilities had abandoned me?

Ethan seemed so sensitive to every tremor and evidence of failure, that I wasn't sure how useful his brand of hope was. Ray had started a support group for fathers in Arizona, and although I had initially been interested in how such participation could help men reframe their experiences of disability (including my own) and facilitate meaningful social connections, I found his Leibniz-esque doctrine of divine providence stultifying: that God is perfect and so, then, are all existing things in the universe. ‘Every child is uniquely designed’, he repeatedly proclaimed, and ‘each parent is distinctly right for their child’. In fact, competing definitions over the purpose of the support group seemed to be a common source of dissonance among attendees, and probably explained its premature plateau in numbers. In the beginning, my attendance seemed to

heighten participants' awareness of and interactions with each other, which was cause for all kinds of emotionally charged discussions during these sparsely populated meets.

At one meeting, Brent, a father of a prepubescent autistic boy, remarked that his friend has kids with serious drug problems who have been incarcerated, 'he has a hard time believing your philosophy that we are the right fathers for our kids and that they're the right kids for us', he ventured. 'He feels like there's no way he could be the right father to his kids with the lives they've had'.

Ray's face visibly fell in on itself as he lowered it from Brent's gaze, nodding tolerantly, 'But the alternative that we're not is pretty bleak', he said, 'what quality of life would that bring?'

At least to me, rational instrumentality seems beyond the province of belief. As sensible as Pascal's Wager may be, it seems outside the realm of discretionary control.

For others, hope seemed too compatible with self-deception. At least that's the way it appeared to me then. Wayne retold the same story over and over again with an inseparable mix of anguish and joy. Noah, his eldest, was graduating from grammar school. Wayne took him suit shopping, so he would have something nice to wear for the ceremony.

'It was a solid looking Johnny Cash outfit', he said, 'and we found this burgundy fedora-style hat and bow tie to match. He came to the full-length mirror outside the changerooms and just stopped and stood real tall and said, *you know, I'm starting to feel like a young man*. It just blew my mind', Wayne recalled, tears sitting stagnant in the bottom of his eyes. 'He is so far ahead of what we expected', he continued, 'not that we didn't hope that he would be here, but just from where he was six years ago, even two years ago, that's not the young man that I would have expected to see at this point. But he's killing

it, socially and academically. He's really smart, they're *both* really smart, you know'.

In light of Nick's severe behavioural problems, I felt like Wayne's coming of age tale about Noah circled around *Nick's* potentiality. That is, the hope that he would one day reach a similar point in his development and being, despite all evidence pointing to the contrary.

And how was I supposed to make sense of the profound contradictions that created a gap between Paul's experiences of caregiving and disability and the ways he narratively communicated them at various times. This discernible gap seemed to speak to a hope shot through and through with the beclouding effects of self-deception. Paul often talked about inhabiting a hope for a future that would be easier going. Paul seemed to recognize beyond all doubt the oppressive interactional and institutional practices, cultural beliefs, and social attitudes that make caregiving and life for those with disabilities difficult –after all, most of his blogs were geared towards explicating his experiences with these –and yet, at times, he managed to hide these perturbations from himself.

Anthropologist and prolific blogger, William Peace, made a point of criticising the continued use of school segregation and school transportation industry in perpetuating negative perceptions around disability. He writes, “Are we unable to incorporate and educate those that think differently and not at the typical, perhaps demanded, pace? The answer to all these questions is yes. By itself this is damning to our educational system and the culture that created and perpetuates it” (2014).

Peace's blog seemed to elicit a particularly defensive reaction from Paul, who responded to the piece with a blog of his own, denouncing Peace's claims that the accessible bus is sometimes referred to by other kids as the “retard bus”, suggesting that these were words of projection from Peace—who has been paralysed since he was eighteen years old. Paul emphatically stated that Pearl has not experienced any social alienation, discrimination, or battle for

accommodation, and that any discrimination they have faced has come from the intrinsic socio-cultural supposition that men shouldn't be involved in the intimate care of young women. Did Paul's subjective grasp on the world, I wondered, and embrace of hope for an easier future, somehow require an illusion to the way things were?

That night, after parting ways with Ethan, in the frigid darkness of my hotel room on the outskirts of Columbus, I cried; despondent, hot tears running down my face, my body seismic. I remembered Paul's words from sometime earlier, from a blog post that curled its way into a corner of my memory long ago. 'It hits you out of nowhere', he writes, 'You think everything will be okay, at this point you can handle anything. Bullshit. Like an unexpected left hook, life just crashes...I will never die having seen my child get a diploma. Lots of people die in that situation. It was not my plan. Not my hope. Not my dream. I will never walk my daughter down the aisle. Never be proud of her accomplishments. And no, it's not about not loving what I have, what they are, and if you think that's what it is about, well fuck you too'. Facing the uncertainties of Koda's life and health and what caring for him would look like had opened a chasm I would have to live with, but I didn't yet know how to. Regardless of the progression of time and no matter how much I learned over the coming years, there would always be this colossal hole. A deep abyssal unfamiliarity.

I usually feel at home in the desert. I love the buzz of my body under the burning desert sky and the intensely pleasurable aliveness the breathless hot air awakens in me. Succulents grow abundantly out here, bold and distinct against the inhospitable landscape. But driving back to Scottsdale— my son, as quiet as a ghost, in the back seat—I feel a great distance between myself and the uncompromising life and beauty of the desert. Anxieties surrounding fatherhood and my research engulf me. Thoughts of inadequacy, on both fronts, wake me during the night's deepest hours. Fieldwork, the hallmark of

anthropology, has been more confronting than I anticipated. Often, it's carried out in places that aren't familiar to the anthropologist. Often, this is the point. For me, however, this couldn't have been further from the case, both geographically and in subject matter. My life as a father to a son with profound disabilities and my research into the lives of parents affected by disability in North America are intimately connected. They are irreducible. There is no respite from my research topic. My intimate world of disability is always awaiting me. Often, it's front and centre stage and all my thoughts circle around it. Other times, it holds together and overlaps with other conscious formations. Rarely, it haunts the edges, quietly, like a ghost.

Fieldwork had been full of carbon copy and contrast, contradiction and inconsistency. I needed time to sort out the alienation and discontent that had become integral to my craggy emotional landscape.

We're approaching Phoenix city limits. The megalopolis begins to surround us, stretching across the desert landscape, lapping at saguaro peppered mountains. One desert slowly bleeds into another, the suburban sprawl. For now, I am more at home in the nature-defying sunbelt city, amid the noise, neon signs, and franchise restaurants.

Communities of care and corporeal diversity

Eighteen months later, we pull off motorway 93 into a gas station in the foothills of the Alps. We need a motorway vignette to cross over into Austria.

We have planned some recovery time in Lake Garda in northeast Italy before flying back to Melbourne. We have spent the last two weeks in the spa town of Bad Aibling in Germany. Despite its suspiciously ostentatious sound, I have been cooped up in a hospital room with my wife and two daughters for the last two weeks. Having spent the better half of the year bedridden,

conventional regimens failing, symptoms raging unabated, we decided to fly to St. George Hospital for whole-body hyperthermia treatment. By then, I had been in a progressive state of decline, my physical and mental health, and my identities attached to them, steadily deteriorating. If there was a chance that the borrelia spirochetes colonising me would be rendered defenceless under the extreme heat of hyperthermia (41.7°C/ 107.2 °F), then I was happy to be basted and cooked.

The rugged, snow-dusted, Kaiser mountains bear down on me from around the gas station. The treatment has taken a toll on my body and I still feel weak with nausea and fatigue. The cold air runs its icy fingers along my skin and I gently close my eyes.

This is my life. Life is happening.

I have lost time. I have lost the first twelve months of my youngest daughter's life.

When I open them, I'm looking at the dense white clouds hanging above the mountains, descending down their far side. Everything up there is calm and still.

Inside the gas station restaurant, there is a young man sitting next to a young boy in a wheelchair. The young boy's mouth is open and his eyes are fixed skyward. The man is eating, one hand resting on the boy's arm. At first, I think they are father and son, but on closer inspection they look like brothers. Kim is standing next to me. She gently places a hand on the small of my back, and I can tell she is feeling the same way as I do.

I miss Koda.

I remember Paul saying, 'that is the dichotomy, given the chance to put Pearl in a residential facility and spend the last third of my life doing the things I desire, I choose not to'. We hemmed and hawed about taking Koda on fieldwork. In the end, we decided it was important for him to be with us, united

as a family, despite the logistical burdens of travelling with him. But this time it was too difficult a task to bring him along, logistically and emotionally.

We buy terrible tasting coffee and then head back to the car. I close my eyes and strain to occupy that same space as before, the chill on my skin, to feel that same cosmic whisper, but now there is nothing.

Illness stripped me of an enticing future, compounding the loss of significances and personal meanings Koda's disability confronted me with and that I had been grappling with for some time. There was a point in my illness when time flattened out before me and I lost the capacity to hope for anything at all. Slowly, with the love of my family and Kim's enduring care, I managed to pull myself from those anarchic depths of woe, forever touched by the humility of being cared for. I realised, on the fringes of that existential dead zone, that the capacity to hope is different from not having any hope at all.

Koda's disability had catalysed the decay of my "meanings and associated system of hopes" (Ratcliffe 2015: 107), which exacerbated my feelings of estrangement from others. In the face of such uncertainties, I was curious about how parents find things significant again in their lives: How they forge a meaningful life and future in the face of life's uncompromising blend of finitude and infinitude. Specifically, I wondered how my participants retained hope, as they claimed they did, when they testified to having all their hopes vanquished.

I had been wrong. It wasn't that their hopes were shot through and through with illusion and/or self-deception. It was simpler than that. It was a choice to invest in more encouraging prospects and not get swept up in the unstable tides of experience and evidence. Caregiving can entail lost possibilities, limitations to what the future may look like or hold. But the parents I spent time with hadn't lost the space of possibilities that make new possibilities seem imaginable (Ratcliffe 2015). Rather, caregiving had induced, what Ratcliffe describes as "a modification of the 'style' in which one hopes"

(ibid: 123). The grounds of their taken-for-granted intentional hopes may have eroded, that is, the propositional content of their hopes, but they still had hope. They inhabited an *existential hope*: A hope that the answers might open up, or that things would get easier in time.

There was a Camusian logic or spirit to achieving a sense of familiarity or control for parents that, paradoxically, involved acknowledging the world's ephemeral and elusive character, its "unreasonable silence" (Camus 2005: 26). Assuming one's fate freely involves an appreciation for immediacy, spontaneity, and pleasure, and the tempestuous adherence to finding meaning in what one has, for what other choice is there? Pondering his future, Ray said thoughtfully, 'I don't think we'll ever retire because of our life, who we are and what we've been through. We'll continue to move forward, and I want to support and encourage people to accept what life has given them and enjoy it'. And Paul admitted to investing his confidence in the small and tangible things that make life worthwhile in the face of life's painful vicissitudes, 'I stopped asking God why a long time ago. I'm more or less a day-to-day kind of guy', he said. At another time: 'I could put Pearl in residential living logistically. *Not* emotionally. There's thoughts towards maybe buying the house next door and turning it into a group home'.

Ratcliffe refers to existential hope as a kind of "pre-intentional hope" that plays a distinctive phenomenological role (2015: 103). It may be devoid of specific contents, but what remains is the possibility of new possibilities, "an orientation that is presupposed by the possibility of hoping" (ibid: 109). Gradually, against the threats to my existence and my retaking a stand on it, I experienced a return of hope or possibility in my life, and came to understand this distinction. By embracing one's life and unalterably changed circumstances, parents inhabit a hopefulness that Garcia says, "presents a picture of the moral that embraces its own vulnerability and unpredictability" (2014: 59).

If the relationships we form are the essence of human meaning, then having a disabled child adds another dimension to that meaning. Changes in one's circumstances produces changes in one's subjective grasp on the world. The demands of care knocks one out of their familiar world and impels a reconfiguration of one's habitual way of being in the world. The everyday inconspicuousness that Heidegger identifies as characteristic of our average being-with-one-another or mattering-to-one-another can thrust caregivers into mindful being-with-others (2010: 120). Of course, parents are not equal to the demands of care, for each must remake a self in accordance with the new paths instituted by care and in relation to the referential contexts of their lives. Throughout this thesis I have been exploring the ways parents reinhabit these horizons—temporal, cultural, social, spatial, intersubjective, gendered, imaginative, ethical.

But by associating with their own contingency and recognising dependency as an intrinsic human trait, parents often show a concern for the well-being of other caregivers and the selfhood of disabled children, speaking to what Frank calls a “communicative body”, one that “sees reflections of its own suffering in the bodies of others”, turning outward in “dyadic relatedness” (2013: 49). Ray was committed to others through the support groups he ran in Arizona. And many other men had established online blogs to commune with others—those who hadn't often expressed a desire to do so. ‘In the beginning it [testifying] was very satisfying’, Scot recalled, ‘it was like a thirst or having a good meal. You're trading your stories and you're talking to families who have the same thing in common and enough of that goes by and it's like tools in your belt’.

I regard these online communities³⁸ that parents participate in as a salient medium for socially engaging and connecting with one's horizontal community. These emergent spaces of storytelling and cultural convergence can be seen as cosmopolitan spaces, where individuals, sometimes from substantially different socio-cultural backgrounds, come together through their shared experiences of caregiving, forming deep bonds of mutual comprehension in the process. Through these online collaborative engagements, parents are afforded the opportunity to tell their stories, share grievances that those in one's local world may not understand, exchange information, negotiate meanings, discuss experiences of alienation and exclusion and other problems (both theoretical and pragmatic), and share their struggles, strategies and wins as they advocate for inclusion and equality. These shared online spaces are characterised by mutual collaboration, respect, and a concern for social justice. The particularities around caregiving that arise within local worlds intersect here, then, with a global community of parents and bring forth caregiving practices that are rooted in an ethic of universal inclusion and moral respect for all persons. These online spaces of cultural convergence can be thought of as moral cosmopolitan communities (Komito 2010).

These caregiving communities are strengthened through parents' emotional and ideological commitments to countering the hegemony of ableism and creating more accessible communities; and a reality that validates and advances the rights and well-being of all kinds of embodiments. These communities facilitate storytelling where parents are afforded the opportunity to share narratives with the public that throw light on their child's capacity to ethically affect others. Paul said, 'My kids taught me love unconditionally, how

³⁸ A portion of the material in this section on cosmopolitan communities will appear in my forthcoming article (2018) 'Embodied Spaces, Cosmopolitanism and Corporeal Diversity', *Sites*, 15(2).

to appreciate the little and big things, that without perspective we have nothing'. Similarly, now waxing pensively, Ethan wrote about seeing his son for who he is, a boy that loves to sing the ABC song by rote; not understanding it as an alphabet, Ethan writes, but as a game that ended with daddy clapping and him jumping up and down, saturated with joy. As Delante notes, cosmopolitanism "resides in social mechanisms and dynamics that can exist in any society at any time in history where world openness has resonance" (2009: 88).

Parents' efforts speak to the humanitarian aspects of cosmopolitan activism which are grounded in a shared recognition of our ineluctable but different forms of dependency, the value of caregiving to society, that suffering is not necessarily inimical to life, and that there are other ways of inhabiting the world and affecting others that depart from the mental qualities we usually associate with moral agency: In short, a recognition of human unity by virtue of our differences. One could argue that it is the act and experience of caregiving itself that turns caregivers into moral cosmopolitans. This resonance with difference is the basis upon which caregivers come together and support one another. Caregiving narratives can offer radical hope to other caregivers and demand of others in their telling an interest and concern to the life, existential vulnerability, and possibilities of others.

Concluding thoughts

As I have shown, having a child with a disability is experienced as an existential disorientation for parents that disrupts their identities, futures, and sense of relatedness to the world. I have demonstrated the varied ways parents live their disruptions over time, and how much their temporal and historical situation as individuals affects the kinds of experiences they have and how they respond to their changing circumstances (Chapter Three). I analysed the role the body and iterative acts of care play in changing habits of consciousness, opening up new possibilities for acting and relating to others and potentially refiguring parents' moral identities as carers (Chapter Four). This focus on embodied actions and practices of relating throws light on the body's deep potential for care and ability to help reorient parents by opening up a new space of possibilities. As I have also shown, these disruptions are felt and experienced differently for parents according to the existential contexts of their lives, but they invariably reflect personal histories that are interwoven with others and embedded in historical and communal meaning-giving structures.

I have also illustrated that over time as parents struggle to inhabit the worlds of disability they are thrown into they encounter other contexts of disruption, precipitated by this larger event, that have potential to explicitly manifest what was once taken for granted and pervaded existence as natural. I have attended to these experiences throughout as moments of intersubjective breakdown (Chapter Five) and moral unsettlement (Chapter Six). During these experiences I have shown that parents are directed to specific contexts of injustice through their inability to interact with objects, people, and occasions in the ways that once characterised their habitual tendencies. I have shown how these moments arise when parents feel a dissonance between taken-for-granted understandings and their situations as caregivers and the social conditions they want to foster for their children. By sparking critiques of the normative and

suspending parents' everyday modes of being and relating to others, these moments of intersubjective breakdown and moral unsettlement have the potential to contribute to parents' moral agency and sense of relatedness to others. That is, these moments not only unveil taken-for-granted oppressive norms, ideologies and relations of power that construct and position disabled persons as Other, but one's own complicity in reproducing and sustaining them. As such, these moments of consciousness-raising have the potential to make caregivers more aware of relations of privilege and oppression that structure the local social landscape they are embedded in.

Importantly, though, as I have mentioned, such disorientations do not necessarily lead parents to adopt an explicit moral stance on disability and gender equality, for instance. Rather, acts of care can shake loose deeply rooted taken-for-granted assumptions and understandings about oneself and the world. As Ahmed writes, "disorientation as a bodily feeling can be unsettling, and it can shatter one's sense of confidence in the ground or one's belief that the ground on which we reside can support the actions that make a life feel liveable" (2006: 157). Through wanting to be better carers and partners, the men in this study can be seen reinhabiting their local social landscapes over time, through their moral grasp on expressions of oppression and privilege and by changing the ways they act, think, communicate with and relate to others and themselves. These experiences have the potential to renovate their thinking and acting, but not in a predictable or stable kind of fashion, for as I have indicated, parents' experiences of care are beset by contradictions and ambiguities and can't be detached from their moral and existential concerns and the needs of their children (Chapter Seven); nor are they applicable, then, across all contexts of their lives. Instead, these moments have the moral potential to tacitly inaugurate changes to their style of relating to others and the world. This shines through strongly in parents' daily lives in the ways they respond to others and

confront individuals and institutions that conduct themselves in unfavourable ways (Chapter Six).

In other instances, however, caregiving experiences can generate decisive moral orientations and judgements, for instance, when parents become more aware of ableist norms and are consequently moved to engage in advocacy work or switch career paths (Chapter Three, Six and Seven). Throughout this thesis we have seen the kind of advocacy work parents get involved in and the community commitments they make on the basis of wanting to help foster the kinds of social conditions that are supportive for people with similar embodiments to their children. This thesis can also be seen as a form of personal care on my end with potential political consequences, as I attempt to highlight the moral personhood of my son and others like him and secure just treatment for him.

As I have noted throughout, parents aren't equal to the demands of care or the ways they are able to live with disruption. Facticity, thrownness, and historicity provide important concepts for understanding the existential and moral grounds upon which parents must create habitable worlds of disability. I have drawn on many of my own experiences of disability and care to help illustrate the ways our creative agency, caring imaginations, and existential freedom are circumscribed by our embodiment (Chapters Five and Seven). The ways the carers in this study make habitable worlds is contingent upon the temporal, affective, spiritual, moral, and bodily resources they bring to bear in creating their lives.

Again, experiences of disruption are not always morally productive and can slowly erode one's world, or threaten it with a terminal kind of collapse— as I considered through my experience of having a misunderstood chronic illness and the medical and social alienation it effects. This highlights the importance of social context and the role others play in helping parents live with disruption

through empathetic understanding and an appreciation for a world that is comprised of “multiple perspectives residing in different kinds of bodies” (Pederson 2011: 62). In the lives of parents, online communities and support groups were shown to function as important social supports that make living with disruption more bearable. In this thesis, online communities afforded parents the opportunity to socially engage with their horizontal community and find validation and acceptance of their caregiving experiences. These spaces are most supportive when members display an accepting and supportive attitude toward all forms of self-disclosure. In some cases, these spaces may be supportive for some and much less so for others. For instance, in the fathers support meetings I focused on there was an expectation to be oriented in a particular way (toward religious beliefs) to begin with, which can further alienate those in the throes of disorientation who do not share the same religious convictions or faith (Chapter Seven).

Having acknowledged the various mediums of experience interwoven with the complex nature of existential disruption, I found that parents do not overcome disorientation so much as inhabit it more easily over time. I have also demonstrated the important role of researcher reflexivity in knowledge production. As a carer myself, many of the caregiving experiences I have documented here would not be possible if not for my own experiences and the disclosures they yielded. This goes beyond the experiences of caregiving I share with my participants’ and the mediums of experience that I have identified in how worlds of care are felt and made liveable. Contra to criticisms that view researcher subjectivity as an impediment to the production of knowledge, seemingly unrelated personal experiences delivered important insights into my participants’ lives as carers. I don’t think I would have grasped the important roles ambivalence and existential hope play in making carers’ lives liveable without drawing on my own ambivalent experiences of care and personal loss

of hope through illness. I started out to contribute to understanding carers' lives and ended up understanding my own life more clearly through their struggles.

This brings me to reflect on one of my main aims of this thesis: to clarify the morally beneficial effects of caregiving and the role our corporeality plays in its development and practice. As I have noted throughout, embodiment influences how parents experience, are affected by, and respond to the demands of caregiving and the disruption it generates. Who they are and the historical communities they are a part of are key factors in how they experience caregiving and the variety of ways they create habitable worlds. By drawing out the way the fathers in this study find humanity with their disabled children through embodied care, this thesis contributes to the field of social ethics by highlighting the body's potentiality to cross existential boundaries. In this way, my research joins a long line of others within the realm of care theory that sees our intrinsic relationality and caring relationships as sources of personal and social morality.

The account of care that I have provided is compatible with Hamington's (2004) notion of embodied care, where embodied knowledge and habit are seen to contribute to morality and social caring. I have proposed that ruptures in reciprocity and understanding between interactants are not only the result of neurological and social disjunctures, but involve bodies and physical environs also. Through the practice of giving and receiving care, I have shown the ways parents come to acquire care knowledge and develop habits with and through their children and others. It is through the body's resonance with otherness, then, that we find the moral potential of caregiving in this thesis. While the limits of our empathetic imagination and understanding of others are circumscribed by our embodiment, I have argued that the intrinsic experiential connection between self and other is strengthened through proximity and

intercorporeality. Bodied encounters, then, provide opportunities to develop and exercise caring knowledge and habits that dilate our sense of relatedness to others.

Inter-embodiment and affective connections provide the grounds for cultivating our empathic availability and rethinking the way we perceive and interpret difference. In developing and exercising care for others, our affective inter-involvement can play an important role. Intersubjective connectedness can deepen our resonance with embodied others and underwrite our moral actions and the responsibilities we feel with relation to fighting injustices and political and social conditions that attenuate empathy. By critically examining my own experiences of caring for a child who inhabits the world in a radically different way and those of the fathers who participated in this study, this thesis shows us that it is possible to enter the feelings of another through our shared corporeal existence. Parents' worlds are made more liveable through the proximity and comfort of being with others and a capacity for care which exists in potential. The moral and existential practice of giving care offers an opportunity to foster our caring potential. And that potential is nurtured and comes through the body and the acquisition of caring habits and skills that dilate our sense of relation to other embodied beings to whom we are answerable.

Epilogue

I was expecting a click moment, where all my uncertainty around caregiving and the lives of my participants would transmogrify into insight, where everything would come together in one clarifying instant. No such moment occurred. My participants didn't speak of any epiphanic moments either. It's the slow dripping of time that changes one's embodied perspective. With the gift of time, I found myself more easily inhabiting my ambivalence towards caregiving.

The men and women I spent time with during fieldwork provided my entrée into the subaltern world of caregiving. Before then, I had felt especially isolated. I read blog posts written by Ethan, Alice, and Paul when Koda was a baby. And I had taken personal comfort in their brazen testimonies of struggle and love and living life with a difference. As Scot once said, reflecting on his controversial Salon piece, 'I'll take that splash of cold water now'. But I had never participated in these online communities, nor had I experienced any real moments of experiential convergence with them beyond the point of having a child diagnosed with a disability.

Back then, I wasn't sure what to make of their unformulated future projects or the ways they seemed to cling to past significances and attachments. Often, it seemed that living with these perplexities trapped parents in a cyclical revolt, not unlike the kind of complicated grieving that Bowker describes, where the "lost object is resuscitated in fantasy, repudiated for departing, destroyed by scorn, revived, and revolted against again and again" (2011: 173). The disruptions occasioned by caregiving and the refusal to let them go seemed to anchor parents in ambivalence, keeping them, I thought, from settling things once and for all.

Their lives, however, testified in excess of the contents contained in their online stories. Hope, commitment, love, vulnerability, ambivalence, and

endurance permeated their narratives and occupied the vibrating silences that passed between us during our time together. Furthermore, their narratives and experiences resonated differently, more strongly, with me once I acquired more personal experiences caring for my son and being cared for myself. After all, during fieldwork Koda was only four and chronic illness had not yet robbed me of a “capacity for everyday anonymity” (Salamon 2012: 246). Retroactively, my experiences made the silences between things more articulable. There were meanings I couldn’t or wasn’t ready to hear at the time.

Through these merging perspectives and experiences, I came to realise that we live lives of interdependence and that two people can create something far greater than either can achieve alone. Structural and interpersonal stigma and the abstract cultural meanings attached to disability give form and direction to parents’ lives. But, as Angrosino says, if we want to grasp firmly the essential character of not only the various cultures but the various sorts of individuals within each culture, we must descend into detail, past empty similarities (1998: 271). At the level of lived experience, we see the ways intimacy, bodily ties, love, and relationships act as a buffer against these prevailing relations of power and corporeal norms. To be sure, with all the moral and practical complexity of caregiving, the parents in this study seemed to share the sentiment that we are answerable to our responsibilities for others and that our own care and freedom have no meaning without reference to the care and freedom of others.

While affective experiences born out of the demands of care constitute a horizon of commonality, the complexity of caregiving can profoundly affect the perceived ‘aliveness’ between parents. That’s because moral experience in the context of caregiving reflects the concrete conditions from which parents’ experiences within the socio-cultural spaces they move through as caregivers are made intelligible. Moral experience is situated at the intersections of justice, care, agency, bodily difference, and the complex interplay between disclosure

and finitude that structures our ethical-being-in-the-world. Shifts in footing between parents within care networks speaks clearly to the differences that make a difference in the continual project of “making sense of one’s life as an embodied human being in an intersubjective world of mutual concern” (Weiss, 2008: 202).

Ambivalence is a component of care that can keep caregivers open to the interminable paths they are set on. Solomon says, “asking the parents of severely disabled children to feel less negative emotion than the parents of healthy children is ludicrous...You cannot decide whether to be ambivalent”, and concludes, “all you can decide is what to do with your ambivalence” (2014: 402). These findings on endurance and existential hope offer a way to consider morality as the blurring of vulnerability, care, commitment, exhaustion, pain, love, and loss.

We are nearing Lake Garda. The early evening sun is melting into the hills. For now, those dark months of the soul have passed, along with the numbing silence that had entrapped me in such depressive despair. Thoughts stir in my mind, some clearer than others, but I’m too tired to inhabit any of them and so there they must stay, in the ether somewhere, as formless potential. The sun slices golds across my face and I close my eyes and for the first time in a while there is an aching hope.

Life is happening.

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Appendix A.

Anthropology of Disability Review

Anthropologist Robert Edgerton's (1967) pioneering study, *The Cloak of Competence* (1967), helped lay the groundwork for future anthropological studies of disability by offering a look into the place of disability in American life during the paradigm shift of the 1960s, when many institutionalised individuals were repatriated to their home communities. Using Goffman's theory of stigma as a theoretical framework, Edgerton presents a series of biographical case studies to illuminate the social consequences of being ascribed a spoiled identity (Goffman 1968), and the extent to which the social restricts the lives of the intellectually disabled. Edgerton argues that by developing a cloak of competence (a set of strategies to mask their disabilities), those with intellectual disabilities negotiate normalcy.

As McKearney and Zoanni write it, Edgerton and others were raising a question that remains with us today, perhaps best captured by Ruth Benedict long ago when she asked: "In how far can we regard inability to function socially as diagnostic of abnormality, or in how far is it necessary to regard this as a function of the culture?" (2018: 5; see also Benedict 1934: 60). Benedict's question was prescient in foregrounding disability as a culturally defined identity and foreshadowed the growing emergence of social constructionism in the 1980s (McKearney and Zoanni 2018).

During this time scholars and activists began articulating what is now known as the Social Model of Disability (Finkelstein 1980; Oliver 1990). In contradistinction to individual and medical models of disability which situate the problem of disability in the individual's own body—arising from functional limitations—a social model situates disablement in society. According to this line

of thinking, social and material conditions experienced by disabled people restrict their participation in mainstream economic and social activities (Oliver and Barnes 2012).

McKearney and Zoanni note that Robert Edgerton cautioned against armchair speculation though, finding no clear correlation between the actual treatment of people with cognitive impairments and socioeconomic circumstances (2018: 6; see also Edgerton 1970: 540). "Instead", they write, "he tentatively concluded that what mattered most was a grab-bag of social factors, including culturally variable expectations about marriage, social competence, religion and stigma" (2018: 6). They clarify that Edgerton's cautious conclusions do not mean that we should ignore the "ways in which the globalization of Western economic, political and educational practices can make people with cognitive disabilities more dependent and constrained than they might have been in previous generations", but instead, "avoid jumping to general conclusions on the basis of romantic speculation about idyllic societies where people with cognitive impairments are not truly disabled'" (ibid)

Anthropological studies have yielded important empirical data and critical insights into the disabling dimensions of society and cross-cultural interpretations and responses to embodied difference (see Ingstad and Whyte 1995; Benedict 1934). Anthropological interest in disability burgeoned in the 1980s, in part due to Louise Duval's (1986-88) newsletter named *Disability and Culture*, which welcomed many contributions from medical anthropologists (Reid Cunningham 2009; Kasnitz and Shuttleworth 2004). Much of this research has focused on cultural dimensions of social marginalisation and the extent to which people are conferred personhood across cultural and economic settings (Scheer and Gross 1988; Ingstad and Whyte 1995). This body of research elucidates the sociocultural mechanisms by which impairment is made meaningful according to societal standards for normative bodies, behaviours,

and role fulfilment. As well as with regard to radically different epistemologies (Fadiman 1998).

There are strong points of focus in the literature on the social consequences of stigmatised health conditions (Albon 1984, 1988, 2010; Becker & Arnold 1986; Gussow and Tracy 1968, 1970; Predaswat 1994), the creation of communities, whether they be inclusive or exclusionary of difference (see Ablon 1981; Becker 1980), and the political and socio-cultural histories of particular embodied differences that affect the social lives of those who inhabit them (see Deshen 1992; Groce 1985; Gwaltney 1970; Rao 2006; Stevens 2013). In the latter case, for instance, Groce (1985) examines the relationship between social norms and inclusion in her anthropological study of deafness on Martha's Vineyard. Deafness did not pose an obstacle to communication or inclusion within the community, she finds, because of the high incidence of hereditary deafness on the island and standard use of spoken sign language (ibid).

Some anthropologists when confronted with their own disabling conditions have drawn on an autoethnographic approach in their theorising about disability and illness (see Greenhalgh 2001; Martin 2007). Murphy offers a classic case. In his book *The Body Silent* (1990) he documents his struggles with a spinal tumour and his progressive loss of bodily control. Murphy sheds light on the cultural and social dynamics of marginalisation by drawing attention to the ways disability transgresses North American cultural values of independence and self-reliance. He argues that the marginal status of disability echoes the states of liminality that van Gennep (1960/2004) identifies as the transitional stage that individuals pass through in ritual initiations (see also Murphy et al. 1988). For Murphy et al., it is this social state of liminality that characterises anomalous bodies, "disability is not a thing, it is a juncture within a process—an arrestment in life history that is dramatized in a rite of passage frozen in its liminal stage" (1988: 241).

However, as Kasnitz and Shuttleworth point out, extrapolating too exclusively on the experiences of those who acquire disability later in life and in terms of what is lost through disability, as Murphy does, risks over-generalizing (1999: 10). They argue that Murphy's use of liminality when applied to disability is too restrictive to account for those with early-onset disabilities who do not experience the separation from normal bodies (ibid)—nor, I would add, can it accommodate the experiences of those with congenital disabilities. In calling for anthropologists to engage more with disability studies, Kasnitz and Shuttleworth³⁹ argue that a richer understanding of disability research issues can be gained from paying closer attention to the interpersonal experiences of individuals with different disabilities in diverse societies and the ways they contend intersubjectively with stigmatization and other barriers to full social participation (ibid).

Recent scholarship by anthropologists interested in disability speaks to an ever-growing and eclectic field of research spanning diverse fields of interest. Some anthropologists have focused on understanding the diversity of human perception and experience (see Grinker 2007; Prince 2010), alternative socialities and sociocultural ecologies that impede or foster their development: autism (Solomon 2010; Ochs & Solomon 2010) and deafness (Friedner and Helmreich 2012). Other scholars have considered the enabling significance of media worlds (Coleman 2010; Ginsburg 2012; Ellis & Kent 2010), the politics of recognition (Shuman 2011), and the ways human rights and citizenship are conceived (Rapp and Ginsburg 2001, 2011). For instance, Rapp and Ginsburg's work focuses on the ways families take their insights beyond the home to connect with broader publics through disability narratives (see also Bérubé 1998). My research joins the vast body of anthropology of disability scholarship in two ways: First, I contribute to the anthropology of cognitive disability

³⁹ See Shuttleworth 2000 for a critical-interpretive anthropology of disability.

research by considering the particular ways persons inhabit and meaningfully exist in the world. As McKearney and Zoanni write, “subjects might have not just different locations within social life, but also different kinds of relationships to the social altogether” (2018: 6). Second, I throw light on the intersubjective dimensions of disability by focusing on parents’ second-hand phenomenological experiences.