

1 The Practice of Care

I was anxious meeting Pearl for the first time. I didn't want to say the wrong thing. Paul had already mentioned to me on a number of occasions that he finds it disconcerting when people ask Pearl questions she's not capable of answering. "What if she can understand the question," he said. "Don't you think it's cruel to ask her something when she has no way of communicating a response?" I had simply never thought about it before. For me, this style of communication is habit. Like Pearl, my son, Takoda, is nonverbal, and I suspect he has very limited receptive language—but there's no real way of telling. I often ask him questions as a matter of routine: "How was kindergarten, Takky? Did you have a good day?" My questioning is stitched into the rhythm of our interactions. I think my utterances, intonation, and pacing have meaning for him. But I absolutely understood Paul's point, which made me worry I was going to botch things up with Pearl. In the car on the way to his place I must have rehearsed in my mind at least a dozen times what I was going to say to her, making sure there were no questions.

With a polite smile I stepped into the cramped living room of their single-family home, where Pearl sat in her wheelchair. She was firmly striking the keys of a toy musical keyboard atop her wheelchair tray.

“Hi, Pearl. I’m Aaron,” I said, and knelt down beside her. “I’m going to stay here with you and your dad for a bit while I do some research. He’s told me so much about you.”

With her head lowered and bent to one side, she glanced at me sideways with a smile that raised her cheeks, exposing big white teeth, which had the immediate effect of making me feel more relaxed. Foolishly, I thought I’d compose a short tune on her keyboard as a kind of bonding exercise. She shot me a sharply critical glance. So, with resigned humility, I settled for spectator status.

Lying awake in bed that night, I recognized my life in Pearl’s fussing and yelling, which filled the house and filtered into my bedroom, breaking the dead silence, and in the sound of Paul’s pacing footsteps outside my bedroom door as he opened and closed cupboards and rattled drawers. Anxiety around Takoda’s disability cropped up in the furrows of my mind. I thought of how very little I had brought with me from my previous life to equip me for this one, as his caregiver. Although he was only four, sufficient uncertainty and distress had already been occasioned for me to know that I was living a life that felt deeply out of sync with the life I had lived and the lives of those around me. Pearl was twenty-two years old, eighteen years older than Takoda, and yet for Paul there seemed to be no end to the confusion, distress, and noise associated with his life as her caregiver. The truth is, I had been feeling badly about what I perceived to be my inadequacies as a father for some time. I was living with a gnawing uncertainty in what felt like a deeply ambiguous and ungrounded world. Finally, the house fell silent again.

Instead of going back to sleep, I sat in Paul’s kitchen in the dark and gazed out the window at the dark foliage fringing the back of the house. Forlorn trees with heavy, somber branches swayed gracefully in the wind, ghostly figures in the light of the half-moon. Disability has become a fact of life and routine for Paul. But far from being something he takes for granted, the everyday seems like something of an achievement, unfolding against a background of uncertainty and in relation to demands that clash with the imperatives of control and autonomy. Sitting there in the pre-dawn silence, I recalled a story he told me, not too long ago. It was about his visit with the school district superintendent right after the discovery that Pearl had been sexually assaulted. That had been six years ago. Paul

had found evidence clearly suggesting she'd been sexually abused sometime during school hours. A criminal investigation was launched, but it failed to find the person responsible. The incident powered a profound despair that still gripped him and posed a direct threat to his trust in others. In trying to win the sympathy of those in attendance at the school meeting to discuss the incident and evoke thoughtful consideration of his situation with Pearl, I believe Paul was trying to convey something about the uncertainties of their everyday life together and its precarious achievement. That is to say, while their life is beset by health crises and frightening seizures, they find some measure of control and security over the impersonal forces that lie beyond us through successful interactions of trust with others, an ongoing achievement that violence and prejudice can destroy at any moment.

He was sitting in the school district superintendent's office, along with the assistant superintendent for student services, the director of special education, and Pearl's mother. Despite the magnitude of the situation, there was a calm dignity softening the edges of his anger and despair.

He looked the superintendent straight in the eye and said, "Listen, I bet you and I start every day the same. Every morning I wake up, wiggle my toes, stretch, and get out of bed. Okay?"

The superintendent nodded in agreement.

"Then I put on a robe and slippers," Paul said.

More nodding.

"Every morning, for twenty years, I walk down the hall and into my daughter's room to check that she's still alive and hasn't died in the middle of the night."

Silence.

THE VERTIGO OF EXISTENTIAL DISRUPTION

Existential disruption refers to an experience of profound disorientation that can make it hard to know how to go on or make sense of one's life. "To become disoriented," as the philosopher Ami Harbin writes, "is, roughly, to lose one's bearings in relation to others, environments, and life projects."¹ The site of disruption is one's world. Specifically, disruption is experienced

through profound disturbances to self- experience and understanding, lived time, and relatedness to others.² Upon entering their worlds of disability, many parents have no understanding of their new situations as caregivers. They are often at a loss, not knowing what to make of and with the world of which they are suddenly part. One father I met described his arrival moment as a “monumental life-changing situation that parents come to with no basis of reality.” Another said, “It is so overwhelming. Your life is completely turned upside down and absolutely readjusted in a way that affects everything you do, all your ambitions.”

Disruption tears people from their absorption in a familiar world and incites a confrontation with the unfamiliar. It is a mode of existence connected to the subjective experience of self-continuity across time. As psychiatrist and philosopher Thomas Fuchs tells us, because it is habitual, “the lived body exhibits a specific form of memory that results from the continual embodiment of existence.”³ Every new experience rests upon a background of affinities, expectations, attitudes, experiences, and capacities acquired in the course of a life.⁴ These aspects form a horizon that prefigures our current understanding and contextualizes experience, motivating the articulation of particular significances and concerns. Thus, the lived body conveys a “feeling of sameness,” as Fuchs puts it, or a “felt constancy of subjectivity,” by integrating the past in one’s present being and potentiality.⁵ Self-familiarity, then, gives us a view of the future. Or, as phenomenologist Maurice 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.”⁶ Disruption is an expression of a temporal disjunction between past (and its future) and present; a disjunction in the order of time. It gives rise to a feeling of disequilibrium, wherein the past with all the future anticipations it carries continues to bleed into the present unabated, often leading people to ask, “What shall I do now?” Regaining a sense of equilibrium, then, rests on the continual project of knitting the past and future together.

Disruption also takes cultural and structural root as it is shaped by age-related behavioral norms and shared social practices, as well as by societal values and behaviors that reflect and shape expressions of social prejudice against people with disabilities. Western culture tends to emphasize independence and autonomy as values, which then permeate our conceptions

of the good life and affect deeply how parents experience and respond to having a child who may require a high level of care for the rest of their lives. Furthermore, Western cultural ideas about biography, choice, progress, order, linearity, and temporal coherence reflect people's changing concerns, expectations, self-understanding, and priorities. Our grasp of the normative life course is shaped by these ideas and gives a powerful ordering to life so that disorienting events can prompt profoundly disruptive effects.

By deviating from the normative course of life, parents caring for children with severe disabilities find themselves out of step with the norms and practices of others in the community. This can lead to their feeling excluded from cultural lifecycle events, as well as to having fewer people to share their experiences with from social life more broadly. Indeed, for many such parents, unexpected hospital stays, watching their children fail to meet typical developmental and social milestones, fighting for services and for their child's rights, repeated surgeries, and participating in early intervention services can involve an ongoing conversation with an embittered form of social alienation. Creating a meaningful life thus involves reckoning with an experience of dwelling in incommensurate worlds.

Parents arrive to their worlds of disability by different routes, but invariably the taken-for-granted rhythm of life is broken. For philosopher Alfred Schutz and sociologist Thomas Luckman, the experience of a breakdown of the routines of daily life prompts a change of attitude toward reality, a break with one's familiar acceptance of the world. "Familiar," they write, "is usually graspable only in the negative, through 'effects of alienation,' which occur when something hitherto familiar suddenly 'explodes.'"⁷ What problems and potentials arise from this confrontation with the unfamiliar? For parents, moving from a sense of unfamiliar to the familiar requires careful cultivation.

In this book, I am especially interested in the experiences of men caring for children with major cognitive and physical disabilities, for both the literature on caregiving and cultural texts about disruption often elide these experiences. Fatherhood is often taken as simply a patriarchal backdrop against which other accounts of gender, kinship, and care are played out. Studies that explore fatherhood in its own right are still relatively uncommon; ones that deal with fathers as caregivers even less so. How do

they find some kind of normal with their children when the wider settings in which they exist render them as anything but? What possibilities, if any, does the moral experience of caregiving offer for one's life and ethical cultivation?

LIVING WITH DISRUPTION

When it comes to disability and serious illness, disruption is a familiar theme. Many anthropological and sociological studies have examined the cultural shape of disruption and emphasized people's attempts at finding meaning in the aftermath of change. In this book I examine worlds of care among fathers of children with major cognitive and developmental disabilities. I bring into focus the profound disjunction experienced by fathers upon the arrival of such a child and the ongoing impacts and adjustments that must be made or resisted as the child grows up. The demands both of caregiving and of achieving the level of responsibility that is needed in the non-self-interested labor that characterizes it can place tremendous burdens on caregivers. Many of the men in this book will never hear the words "thank you" or "I love you, dad." Caring for a child that is not capable of normative reciprocity, often expressed in language or reciprocal eye contact, and that will never achieve and experience the developmental and social milestones that parents typically anticipate, can amplify anguish and disorientation. Parents are left to contend, simply, with what is. It is the sheer level of complexity and responsibility at the heart of caregiving that makes it stand out in such a marked way.

My interest in addressing how caring for children with disabilities impacts families and individuals is grounded in my life as a caregiver for my son. My new life of practice as his caregiver started in the summer of 2011 when he began having frightening tonic-clonic (grand mal) seizures. He was only a baby then, four months old, in fact. At first, he was diagnosed with global developmental delay; sometime later, he was declared severely intellectually disabled. Flummoxed and disoriented, I found myself adrift in seas of strangeness. I no longer felt that I clearly understood my life. Whatever privilege my shell of comfort as a white

able-bodied male afforded me moving within and between people and settings without fear of exclusion or discrimination was violently cracked open. My son's body became a curious public spectacle in even the most prosaic spaces of daily life, and I felt this as palpably as though it were my own. Hearing the word "retard" muttered by a stranger made my bones quake with a feeling I had never experienced before. The truth is, my son's disabilities revealed a 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 accordance 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.

Within a few months of reading other accounts by parents, I came to realize that my experience of unexpected disruption reflected a common theme in the lives of caregivers. This became the springboard for my study and compelled me to carry out research into the embodied experiences of men—fathers like me—caring for children with major physical and intellectual disabilities. I desperately needed to know how they come to understand these unexpected changes to their lives and strive to make livable worlds with their children.

This book is a meditation on fathers' everyday lived experiences surrounding care and the moral personhood of their severely disabled children. Grounded in both my personal experience as a caregiver and ethnographic fieldwork carried out in the United States in 2015, this book is concerned with how fathers go about creating what I call "habitable worlds" after the existential disruption spurred by the major life shift of having a child that falls outside of what is considered species typical. I explore the concrete lives of men fathering disabled children, connecting the cultural experience of caregiving to the changing mediums of experience and existential conditions it is rooted in. In effect, I have written a book I wish I had been able to read back when Takoda was a baby.

What is perhaps new in my approach and thinking about care is my turn toward embodiment and personal experience.⁸ From the inception of my research, my presence pervades the details of this book. My familiarity with the lived world of caregiving gives me direct insight not only into the mundane activities that comprise giving care but also into the conflict,

uncertainty, quandaries, and intimacy it brings into play. Through caring for my son I am aware of the way the experience and practice of caregiving can call caregivers to be present in new ways and enhance life's meaning, while at the same time exposing "troubling truths about what it means to be human."⁹ Like others in this book, my story is one of embodied disruption. Thus, the inclusion of myself is another way that embodied experience makes an impact in this book. The ongoing discoveries and disclosures that lie at the heart of my experiences caring for Takoda provided important insights that have guided my observations, interpretations, and interactions with fathers, for example, my focus on how they gain certain kinds of access to the inner lives of their children or discover complementary ways of acting. My story is therefore inseparable from the picture that emerges in this book of how fathers create their worlds of care. By focusing on how fathers reorient their lives and find new meanings through different registers of experience and mediums of engagement with their children, my approach offers a bracing realism that qualifies heavily how we think of personhood, disability, and moral agency.

CAREGIVING, FATHERING, AND MASCULINITY

This is a book about men and caregiving—specifically the work of fathers caring for children with major physical and cognitive disabilities in America. Several aspects make this form of caregiving distinctive: the complexity, protracted and morally demanding nature, and intimacy of care provided. As sociologist Gillian Ranson notes in relation to caregiving more generally, it is usually mothers, not fathers, who are recognized as doing most of this informal labor.¹⁰ The reasons for this are embedded in societal and cultural understandings about how men and women, as fathers and mothers, should think and behave. Therefore, the link between masculinities and caring is an important one. Given that most prevailing dominant cultural forms of masculinity are "largely associated with a devaluation of the feminine while caring is often equated with feminine practice,"¹¹ men's caregiving experiences need to be partially contextualized by a consideration of how they think and feel about themselves as fathers in relation to dominant conceptions of masculinity, or what gender theorist R. W. Con-

nell describes as the most celebrated or “honoured way of being a man” in a particular social setting.¹² Dominant masculine ideals provide cultural reference points for the ways men ought to relate to themselves and think and behave toward others.

A focus on fathers’ embodied experiences of caregiving requires an exploration of how their experiences are mediated by their already existing relation to the world and ongoing embodied interactions with others. In a nutshell, this exploration involves what it is that fathers are actually doing in the care of their children and a focus on the inner resonance of particular moments and events, which can serve as a window into their deepest feelings. A focus of this kind necessarily throws into relief moments of being that expose norms of gendered embodiment, their practice, and implications.

This book extends the boundaries of care to make visible the embodied experiences of men involved in what is sometimes referred to as “extreme caregiving”¹³ and explores how their histories of gendered embodiment bear on their experiences of caregiving. Rather than reducing men to exemplars of different types of masculinities, I am interested in the relationship between their sexed and gendered bodies and embodied emotional histories. I describe everyday experiences in order to reveal some of the unquestioned presuppositions and values about everyday life that mediate fathers’ expectations and understandings about particular events and situations, which help constitute a context that articulates the significance of an event or situation.

My starting point for a consideration of the link between the embodied character of fathers’ caregiving experiences and dominant gender norms is grounded in my own life and the ways my childhood and relationships prepared or failed to prepare me for the eventualities I go on to describe. The experience of caregiving and fathering cannot be disaggregated from the changing personal and emotional worlds that provide the grounds for a powerful sense of who we are and what we should be doing and that guide the ways parents find themselves morally oriented in the world as caregivers. We “grow into a customary interpretation of ourselves and grow up on that interpretation,” to invoke existential philosopher Martin Heidegger’s famous dictum.¹⁴ Instead of continuing to focus on the structural conditions that support and nurture greater fatherhood involvement

as so much of the literature on fatherhood has done, I emphasize the way everyday feelings, actions, and words embody an interpretation of who we are, albeit one that is often covered up by its habitual character, and how this opens certain possibilities for fathering projected in the ways men understand their lives. In this regard, I see dominant and persisting gender norms and ideologies as part of the factual conditions of ethical life. “There is not a part of its warp and woof into which they have not entered,” to borrow philosopher William Barret’s words.¹⁵ So while it is arguable that fatherhood and manhood are separate constructs, at the level of lived experience I find they are not so easily teased apart.

MAKING CONTACT WITH THE PEOPLE IN THE STUDY

My wife, Kim, Takoda, and our daughter India joined me on the fieldwork I undertook for this book. I began the research in Phoenix, Arizona, after contacting Earl, the founder of a support group for men caring for disabled children, and who ran monthly meetings across metropolitan Phoenix (locally referred to as the Valley). At the time, Earl was on the cusp of retirement—a married white male in his late fifties who worked as an engineer/paramedic with the fire department. Earl established the support group some fourteen years earlier, when his disabled son, Zachary, was fourteen. My family and I arrived and settled in Scottsdale, an affluent suburb northeast of downtown Phoenix, at the beginning of a record-setting heatwave that lingered over the sprawling desert metropolis for three weeks. During those first weeks, I recruited several men from Earl’s support meetings into the study.

Early on, support meetings seemed like a sensible way to access fathers. From the preliminary research I had conducted back home in Australia, support groups for men caring for children with severe developmental disabilities were scarce to nonexistent in that country. But my early impression of his thriving support group proved erroneous, as Earl’s meetings also suffered severely from a lack of attendance. During my first meeting, for example, only one other person attended. During the second, at a different location, there were four of us: me, Earl, and two other guys he has known for over a decade. There was no set agenda. We sat around a long