

Envisioning a Different Journey

Negotiating Academe with a Chronically Ill Child

To combine the roles of mother, scholar, and professor means walking a precarious tight rope between our own hopes and expectations and larger constraints and options. These roles carry heavy social weight—with iconic images and high expectations of what is deemed suitable and satisfactory. The personal narrative that follows chronicles the author’s ten year journey of navigating these roles amid the daily reality of caring for a child with a degenerative life-threatening illness. The essay discusses examples of best practices that higher education faculty and administrators may execute to create a culture of care in academe.

Introduction

By the time my partner and I decided to pursue parenthood in our early forties, we were excited and felt psychologically prepared and emotionally mature enough to handle the challenge. In many ways, the ambivalence that I felt about being a parent mirrored the misgivings I had about pursuing my doctorate and transforming myself into an academic. Both roles of mother and scholar carry heavy social weight—with iconic images and high expectations of what is deemed suitable and satisfactory.

After three months of recommended “bed rest,” I gave birth to my twin daughters four months before defending my dissertation. I graduated with my doctorate when they were five months old, and I began teaching adjunct when they were eight months old. Six months into becoming parents, my partner and I had a well-orchestrated schedule where we both worked “part-time” (i.e., thirty to thirty-five hours a week) so that at least one of us could be with our girls most of the time. On a giant chalkboard, we had elaborate schedules of

the twins' eating, sleeping, and excreting activities; we were both exhausted and invigorated by this new co-parenting experience.

A year after my daughters were born, it became apparent that one of them was not hitting the typical milestones of development. Within months, all of my daughter's abilities to sit, feed or entertain herself had vanished. She became increasingly agitated and hypotonic, and endured mild seizures. It took almost another year for the doctors to figure out what was going on—after a battery of blood tests, a muscle biopsy, two MRIs, and a weekend in the intensive care unit. Our daughter's medical disorder impairs the growth or development of the myelin sheath, the fatty covering that acts as an insulator around nerve fibers and causes severe degeneration of mental and motor skills. When we got the news that our daughter has a disease that is one of a group of genetic disorders called leukodystrophies, we were shocked—not at the confirmation of her developmental delays but of the declaration that her life would be very short.

These were also my first two years out of graduate school. They were peppered with on-campus interviews while I hauled my breast pump around and prepared for classes at two different academic institutions. While knowingly participating in the “feminization of the contingent academic workforce” as Michele Gee and Sue Margaret Norton (165) call it, I was able to teach, to attend a couple of academic conferences, and even present papers during those first years of my children's lives. Undoubtedly the climate and economic realities on college campuses are dire in many regards, and the reliance of contingent faculty has become the norm in higher education (Castañeda and Isgro; Gee and Norton; Isgro and Castañeda).

In retrospect, those two years out of graduate school could have potentially been detrimental to my career had I actually been offered a full-time tenured job. The requirements of service, teaching, and scholarship as a junior faculty would have been paralyzing, as I stumbled around the grief that one of my daughters was so painfully ill. Given the massive amounts of medical testing my daughter was undertaking—sometimes two or three visits a week—no Medical and Family Leave Act would have adequately covered my days I missed work.

For me, being a contingent academic worker worked well for what we hoped would be a temporary situation. And *temporary* is the operative word here—my lack of permanent employment was tolerable because we had hoped it would be a short-term situation. As Gee and Norton note in their assessment of women's status in the academy, although more women are earning doctorates, their chances of landing a full-time tenure track job are increasingly dwindling. My situation definitely mirrored this national trend. As I continued to seriously apply for more permanent positions across the country, my daughter's condition worsened.

There was something metaphorical about my own seemingly futile academic job search and my daughter's diminishing myelin and white brain matter. If most of us really knew we would be unemployable after eight years in graduate school or that we would give birth to a child with a rare disease, we would stay in bed with the covers over our head immobilized with fear. All that I had presumed to be normal and fair—both in academe and in parenting—was proving to be yet another example of how we construct particular narratives that allow us to get up every morning. One mother of a child with a disability notes: “No one starts a family believing that a child will cause bankruptcy and illness. No one expects heartbreak; we are psychically protected against such fears, bound in a tight biological web to hope for the best with every child” (Tisdale 62). Yet without overstating the obvious, these post-doctoral/early parenting years were a major turning point for my family. At a historical moment when health, education, and custodial care are characterized as commodities and not rights, my experience as a mothering scholar of a child with a life-threatening illness illuminates the uneven and selective existence of a culture of care in higher education.

I. Navigating Academe as an Faculty Member

Even prior to our daughter's diagnosis, I was not keen on the idea of moving absolutely anywhere in the country for a job. As sparse as I knew full-time academic jobs are, I was not willing to relocate me and my family somewhere we otherwise would not have selected.

My priorities and resolve shifted dramatically once I became the mother of a chronically ill child; on my list of priorities was now the need to be within close proximity to a high-quality medical facility that could handle pediatric neurological disorders. We also did not want to be in an entirely new community, knowing few people, if and when our daughter died. Our family needed more support than that, especially given how fragile we were feeling as we came to terms with the gravity of our daughter's medical situation. We needed to have friends around who knew us prior to us becoming parents; we needed people who could hold us close and reflect both our pain and hope that is known through years of friendship. I became highly selective of the places I applied, with far more stock rejection letters than on-campus interviews or job offers. The process helped me crystallize how I was making decisions about my family and my late-onset academic career.

With some fortitude, ardent advocates on my behalf, a strong teaching record, and an active research agenda, I landed back in a geographical area and in a department I had previously worked prior to graduate school. Maintaining relationships with previous colleagues proved to be vital. On

and off over the last several years, my partner has been the fulltime stay-at-home papa, in part because I was the one who acquired a job with health benefits and some semblance of job security. I creatively design my courses, and with the onset of more technology, I find that I can be in contact with my students via email, instant messaging, and other social networking sites without having to be on campus constantly. This flexibility has been central as my family has acquired a new “normal” that includes multiple homecare workers. Such strategy for our family meant that for four years I supported our family of four on a visiting faculty salary, which is below the national average of household income.

Given the larger social, economic, and political factors that surround health care and education in the United States, parents of children with unremitting health problems experience chronic stress, depression, and fatigue; each is both gendered and unrelenting (Ryan and Runswick-Cole; Runswick-Cole; Scott; Tilsdale; Yantzi and Rosenberg). We also make accommodations in response to our children’s disabilities and needs as our children’s needs change. In their longitudinal study, Mailick Seltzer and her colleagues suggest that parents of children with disabilities may forego job changes involving geographic relocation and experience a higher rate of marital disruption. These issues are compounded, as disability studies scholar Katherine Runswick-Cole discusses, for those families with children who have life-limiting and life-threatening impairments. Physical and social isolation, economic hardship, and lack of social services, support, and respite are common for families such as mine.

II. A Culture of Care: Theory and Praxis

What has made my life as an academic not only tolerable but viable? There have been a number of meaningful moments and interactions that have supported and validated my work and my being. The bureaucracy of my life and the systems within which I function are burdensome and often overwhelming, yet there are little pockets of people and policies that have made a real difference professionally and personally. Being thrust into a maternal subjectivity is essentially interdependent and not aligned with the neoliberal notions of an autonomous, able-bodied, rational, and ideal worker. Life is messy, and this cannot be any more evident when parenting a chronically ill child.

Interpersonal Interactions

My commitment to engage deeply and mindfully with my undergraduates continues to be the lifeblood of how and why I get to work every day. My passion is to engage in critical topics with the goal of serving as agitator, midwife, and instructor for my students. There are merits in being transparent about our

personal lives as it affects our careers as parents, especially for those children who are medically intensive. At the beginning of each semester, as I prepare my syllabi, I know that at any point over the course of the next fifteen weeks, I may immediately be pulled away should my child end up in the Intensive Care Unit again.

This also means being a little more transparent with my colleagues and students about my personal life, more so than I have been in the past. The past and present deans and chairs of my department know the medical situation of my daughter. If I am more scattered than usual because my daughter's personal care assistant got sick or an in-home nurse recently quit, I sometimes let my students know. When my daughter was initially rushed to the ICU for a weekend, I confided in my students to be patient with me given the highly unusual circumstances I was going through. I wasn't seeking sympathy, merely reminding my students that professors are people too. My evaluations remained positive that semester, even when I barely remembered preparing for a single lesson with any coherency.

Likewise, my personal experiences with administrators in higher education have made a tremendous impact on my immediate life. At two different institutions, I have had three deans who were wholeheartedly supportive of me as I had to make some really difficult professional decisions. I never felt ridiculed by them as I told them candidly the personal challenges I was having while negotiating my schedule or family medical leave. The deans never asked me to choose my career over my family; instead, they helped me navigate through the bureaucratic systems that often define academe. One administrator organized a "meal train" for my family, providing food for us as we ran back and forth to the hospital for five months trying to figure out what was happening to our daughter when she first lost her mobility.

These administrators were flexible as they still upheld a certain standard to assure that my students were getting the best classroom experience they deserved. The scary piece of this story is that my feelings of validation and support could have been blocked merely by one or two less than friendly or supportive administrators—a chilly academic climate can begin on the dyadic level in profound ways for better or worse.

Institutional Supports

Thus, having institutional supports and policies in place and being used is another way a culture of care can be created in higher education. Unless we learn and demand what is legally available to us as workers, these policies and best practices remain hollow. I've been privileged to work at a number of institutions that have strong teacher unions, informed and helpful human resource staff, and solid institutional policies. I realize that not all higher

educations have such infrastructures. Nevertheless, it is my responsibility to be well versed in my rights as a worker and a parent, and to be sure to know these going into any negotiation.

These institutional supports also include having the academic freedom to pursue research that is personally significant. As a feminist scholar, I know that public obligations of emotional labour and care (including the service and committee work required of me on my campus) tend to be undervalued and underproduced in a market economy. But I have also come to the realization, as feminist motherhood studies scholar Andrea O'Reilly asserts and confirms, that motherhood does not have to be a liability in women's lives. Being primed as a feminist social scientist, I also know that no research is truly objective. As such, I have taken my lead from a number of other academic parents of children with disabilities who have interwoven their personal lives into their academic pursuits (Adams; Bérubé; Mills; Rapp and Ginsburg; Ryan and Runswick-Cole). We have something to offer our colleagues, students, and the larger community as a result of our many years of experience as parents and caregivers of children with disabilities and medically complex needs.

On a theoretical level, what my daughter's neurodiversity has allowed me is a better understanding of how disability and difference are constructed in our lives. In her essay "Seeing the Disabled," Rosemarie Garland Thomson notes that the very broad term *disability* encompasses the various categories of disadvantaged people "by devaluing bodies that do not conform to cultural standards" (348). She, like other disability studies scholars, argues that through a complicated set of practices, the systematic comparison of able and disabled bodies is constituted. The very corporeal experience of incubating, breastfeeding, and raising two children who have disparately different cognitive and physical abilities has informed my teaching and research. In my interests of the politics of representation and identity, my daughters' genetic compositions and the ways in which we respond to their social and physical needs have very real effects. I have begun researching the ways that disabilities are discussed and portrayed in the media, and I focus specifically on public mothers, such as Sarah Palin, who have children with disabilities. I have interviewed mothers of children with Down's syndrome to ask them about their experiences with health care providers (Isgro). I have also designed a course in health communication that examines the different perspectives and systems of health and health care. For a while, I blogged for an online resource for parents of children with special needs, and I am currently on advisory boards for the state of Vermont's pediatric palliative program and the children's hospital. My lived experiences have redirected my advocacy in directions I had not expected prior to becoming a parent.

Gendered Labour

Part of this advocacy has not only been for myself in academe but also for the services needed for my daughter and the providers of these services. Because of my daughter's disability, she requires constant care in all aspects of her life. Rather than our lives as parents becoming a little easier as our children grow, we have found that parenting and caregiving has intensified as our daughters have grown. The work-family strain that many families in the US experience is compounded for parents of children with disabilities by the extra child care demands and the need to arrange and supervise a variety of services (DeRigne and Porterfield; Mailick Seltzer et. al.; Ryan and Runswick; Runswick-Cole). Since the onset of my daughter's illness, our family life feels far more chaotic and free form. As Sallie Tisdale states, "the element of surprise is part of the struggle" of parenting a child with a disability (62). In addition to serving as physical and emotional caregivers for our children, we have been brutally thrust into the unknown world of care management. Our days are cluttered with filling out forms, negotiating with social services we didn't even know existed, making various medical and therapist appointments for our daughter, adjusting her medications and equipment, and monitoring her seizure activities and reporting such events to medical staff. Quite bluntly, caring for ourselves as caregivers is difficult; we have little respite, no paid leave or access to services that may sweep in and give us a break.

The other piece of my new "normal" life with a chronically ill child is that my personal life is riddled with the very issues around emotional and caring labour that many feminist theorists and activists have taken to task. Tending for the young, sick, and elderly disproportionately falls on women, and my daughter's care providers, aside from her father, are female. My partner's caretaking role is not to be underplayed, but it has been noticeable how unusual his active home role is when there are few other male care providers coming through our doors. When the staffing is available, our daughter's care is distributed among practitioners such as therapists, case managers, teachers, social workers, and personal care assistants. Their remunerated work has a relatively high turnover and burnout rate; as a case in point, our family has had over thirty personal care assistants and nurses since our daughter's diagnosis. We have gone for months at a time with no coordinated care manager or an in-home nurse available to provide respite. Working mainly with women as formal care providers, we are excruciatingly aware of the limited wage offered to these caregiving workers by the state, their agencies, and by private families. Most of these women have been incredibly generous in their attention and emotional labour they exert towards my daughters. Given the traffic of people in and out of our house caring for my daughter, our physical home space, and the activities that occur within it, is quite public to a number of acquaintances.

Concluding Thoughts on a Culture of Care

Coming into one's identity as an academic is a process and is much like *becoming* a mother, an advocate, or a whole human being. Similarly, a culture of care is also a process; it is cultivated and made a priority to be successful. It may or may not be deliberate, but there must be intention and attention placed on it if we are to have a working environment where people of all identities and abilities and caretaking responsibilities are able to fully participate in higher education. I rue the day that I will have to face my colleagues and students when my daughter finally dies. I don't deal well with people's sympathies, and yet it is only through talking about my daughter's illness and my own struggles as an academic with a medically complicated offspring that perhaps the isolation of such an experience may be shared. This experience has also made the theoretical deeply personal in terms of thinking about best practices that organizations can implement to create a "culture of care" for employees. Practising a "culture of care" within academic environments opens opportunities to acknowledge the multiple identities and responsibilities of campus citizens while also fostering a campus culture that is compassionate and productive. Although creating a "culture of care" is often uneven and messy, it is possible in higher education.

Works Cited

- Adams, Rachel. *Raising Henry: A Memoir of Motherhood, Disability, and Discovery*. Yale University Press, 2013. Print.
- Bérubé, Michael. *Life As We Know It: A Father, a Family, and an Exceptional Child*. New York: Pantheon Books, 1996. Print.
- Castañeda, Mari, and Kirsten Isgro. *Mothers in Academia*. New York: Columbia University Press, 2013. Print.
- DeRigne, LeaAnne, and Shirley L. Porterfield. "Employment Change Among Married Parents of Children With Special Health Care Needs." *Journal of Family Issues* 37 (2015): n.pag. *Sage Journals*. Web. 14 Nov. 2015.
- Garland Thomson, Rosemarie. "Seeing the Disabled: Visual Rhetorics of Disability in Popular Photography." *The New Disability History: American Perspectives*. Eds. Paul Longmore and Lauri Umansky. New York University Press, 2001. 335-374. Print.
- Gee, Michele and Sue Margaret Norton. "Improving the Status of Women in the Academy." *Thought and Action* 25 (Fall 2009): 163-170. Print.
- Isgro, Kirsten. "From A Caretaker's Perspective: Mothers Of Children With Down Syndrome As Advocates." *Women & Language* 38.1 (2015): 63-82. Print.
- Isgro, Kirsten, and Mari Castañeda. "Mothers in U.S. Academia: Insights from Lived Experiences." *Women's Studies International Forum* 53 (2015): n. pag.

- ScienceDirect*. Web. 14 Nov. 2015.
- Mailick Seltzer, Marsha, Jan Greenberg, Frank Floyd, Yvette Pettee and Jinkuk Hong. "Life Course Impacts of Parenting a Child with a Disability." *American Journal on Mental Retardation* 106.3 (2001): 265-286. Print.
- Rapp, Rayna, and Faye Ginsburg. "Reverberations: Disability and the New Kinship Imaginary." *Anthropological Quarterly* 84.2 (2011): 379-410. Print.
- Ryan, Sara, and Katherine Runswick-Cole. "Repositioning Mothers: Mothers, Disabled Children and Disability Studies." *Disability & Society* 23.3 (2008): 199-210. Print.
- Runswick-Cole, Katherine. "Living with Dying and Disabilism: Death and Disabled Children." *Disability & Society* 25.7 (2010): 813-26. Print.
- Scott, Ellen K. "'I Feel as if I Am the One Who Is Disabled.'" The Emotional Impact of Changed Employment Trajectories of Mothers Caring for Children with Disabilities." *Gender & Society* 24.5 (2010): 672-696.
- Tisdale, Sallie. "On Spectrum: My Daughter, Her Autism, Our Life." *Harper's Magazine* April 2010: 59-64. Print.
- Yantzi, Nicole and Mark Rosenberg. "The Contested Meaning of Home for Women Caring for Children with Long-term Care Needs in Ontario, Canada." *Gender, Place and Culture* 15.3 (June 2008): 301-315. Print.