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## Finding Resilience Through Research: Completing a Ph.D. While Parenting an Intellectually Disabled Adult “Child”

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## Finding Resilience Through Research: Completing a Ph.D. While Parenting an Intellectually Disabled Adult “Child”

### Abstract

Unlike the progression of most traditional-aged, college or university students, my non-traditional, academic trajectory as a parent-caregiver to an intellectually disabled (ID) adult has been fraught with barriers, disruption, and discouragement. Motivation to complete my doctorate rests on a commitment to disability issues, caregiver activism, and intellectual capacity-building of my self. Guided by the “evocative” autoethnographic methodology of Bochner and Ellis (2016), this “insider’s” narrative retrospective autoethnography will attempt to shed light on and evoke an understanding of a doctoral student caregiver’s context and experience in the academy. It encompasses embodiment, a geographically constrained sense of place, marginalization, and neoliberal abandonment—elements that have contributed to my sense of burden, inferiority, and non-competitiveness in the academy. An analysis of my autobiographical experience would suggest that increased institutional awareness of a caregiving student’s complex obligations, recognition of their non-traditional contributions to society, and offerings of flexible modes of participation could improve equity and inclusion for caregivers who are challenged in extraordinary ways.

### Keywords

autoethnography, ID adult “child,” non-traditional doctoral student, parent caregiver, resilience

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# Finding Resilience Through Research: Completing a Ph.D. While Parenting an Intellectually Disabled Adult “Child”

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Unlike the progression of most traditional-aged, college or university students, my non-traditional, academic trajectory as a parent-caregiver to an intellectually disabled (ID) adult has been fraught with barriers, disruption, and discouragement. Motivation to complete my doctorate rests on a commitment to disability issues, caregiver activism, and intellectual capacity-building of my self. Guided by the “evocative” autoethnographic methodology of Bochner and Ellis (2016), this “insider’s” narrative retrospective autoethnography will attempt to shed light on and evoke an understanding of a doctoral student caregiver’s context and experience in the academy. It encompasses embodiment, a geographically constrained sense of place, marginalization, and neoliberal abandonment—elements that have contributed to my sense of burden, inferiority, and non-competitiveness in the academy. An analysis of my autobiographical experience would suggest that increased institutional awareness of a caregiving student’s complex obligations, recognition of their non-traditional contributions to society, and offerings of flexible modes of participation could improve equity and inclusion for caregivers who are challenged in extraordinary ways.

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## Introduction

We autoethnographers want our audiences to see that there was meaning and value in our suffering and that we are affirming life, ours, and that of the other people who are characters in our stories. When you read autoethnography, you become a *witness* to the narrative context of another person’s suffering. (Bochner & Ellis, 2016, p. 70)

Most of us would argue, “we’re out of sight and therefore out of mind,” and the unseen struggle is multi-faceted and real. While academic literature tallies up such things as societal “costs” and logistics of providing end-of-life care to aging populations, little attention is given to parents of intellectually disabled (ID) adults who provide life-long, unpaid, and often, unsupported care. Isolation, poverty, and poorer than average mental and physical health is commonplace “suffering” for this population. Challenges aside, the parent-caregiver’s tenacity is testament to the power of the innate “parental bent,” the expression of love and nurture towards an offspring, despite the demands (Veblen, 1914, as cited in McCormick, 2006). Few parents bemoan their obligation, and most would do anything to keep their child safe, healthy, and happy. However, all is not well as parents attempt to juggle family, employment, and long-term care.

Few obligations are more demanding than single-handedly providing 24/7 care to an ID adult “child” who has a multitude of needs, and traditional employment is often inflexible and uncompromising in terms of accommodating a caregiver’s needs. Similarly, the academy is ill-adjusted to supporting and nurturing a doctoral student who is a parent caregiver, as I am.

At a time and stage of life when most people are well-established in their careers or close to retirement, I returned to higher education approximately 23 years after finishing high school, and immediately following a divorce. I have been trying to increase my competitiveness in a labor market that favors youth, technological savvy, and impeccable credentials. I have also been attempting to overcome the gap on my CV that is unacceptable to employers and is the result of my lengthy parenting and caregiving obligations.

I am a single parent, and head of household to three adult children, one of whom is my 30-year-old, ID son. He has been given no specific diagnosis and has merely been classified as “cerebral palsy,” a catch-all label for a continuum of developmental conditions. My son has a uniquely scientific understanding of the universe and chemistry, and yet struggles to follow a schedule without prompting. He also has a limited understanding of the value of money. He can read and understand certain complex concepts, as well as crack a joke, yet he remains socially “unaware.” He needs help with some of his daily bathroom needs, meal-making, computer maintenance, and general safety. My son needs me. He has and always will need help from me or some other care provider.

## Purpose

My “layered” experience, though not necessarily unique, is complicated. Few first generation, “immigrant”<sup>1</sup>, single parents of an ID adult, simultaneously provide care and participate in a doctoral program at a “late” age. It is tempting to begin my autoethnography by venting every slight and “ill” that I have experienced as a “mature,” first generation student and parent-caregiver in academia, and several drafts have begun that way. After all, writing about trauma is difficult without sounding unstable and broken (Tamas, 2009), and publishing what might be considered academic “low hanging fruit,” ---an account of my personal pain and caregiver “burden,” elicits fear of academic scorn (Bochner, 2001). Despite this, academic activism requires vulnerability and risk-taking (Bochner & Ellis, 2016), and while the purpose of “doing” ethnography and autoethnography is to ethically provide insight and knowledge about human relations and experiences (Roth, 2009), finding the balance between empirically “shedding light” on an experience and indulging in personal catharsis is difficult when the situation is in the present and ongoing.

By embracing an evocative or “story-telling” methodology that is encouraged by Bochner and Ellis (2016), the intent of this narrative, is to provoke a visceral understanding of my challenges, to make my audience “feel stuff” and hopefully encourage them to *do* something (Bochner & Ellis, 2016). Using an evocative autoethnographic methodology, I can break the traditional academic rules of disengaged reason and distanced analysis (Bochner & Ellis, 2016, pp. 60-62), and it permits me, the researcher, to unashamedly locate myself at the center of the “story” or “research.”

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<sup>1</sup> Lorraine Hutton was born in Canada, left at the age of two years, grew up in New Zealand and returned to Canada in 2016. Her familiarity with Canada is not unlike that of a new immigrant.

## Methodology

Authors Bochner and Ellis (2016) portend that through evocative autoethnography an author can describe or reveal additional layers or complexity of experience beyond a traditional post-modernist approach. Bochner and Ellis (2016) suggest that when an author takes a post-modernist approach, they tend to make a clear “point” about a situation (for example, they will describe a specific, problematic situation) from a subjective positionality or context. But the narrative often ends there. Instead, utilizing an “evocative autoethnographic” methodology, an author can emotively present a problematic situation, or situational experience, provide knowledge (and context), and recommend a practical response or “call to action,” ---without sacrificing traditional analysis (p. 85). The author can share detailed insight into what has “happened” (the problem or trauma), guide the readers’ “thinking,” and elicit an emotional response or “feeling.” More importantly however, by using this approach, the author can indicate what the reader should *do*.

By supporting my own experience (autoethnography) with ethnography and academic literature, I will allow the reader “privileged insight” into my innermost thinking, the externalities and relationships that have influenced my thoughts, and the larger structures that have shaped my experience.

“Actively recalling thoughts and feelings from a social standpoint,” or “emotional recall,” has been coined “systematic sociological introspection” by Bochner and Ellis (2016), and it is increasingly used in the social sciences (p. 167). By applying this method to my lived experience, I have been able to reveal some of the linkages between external influences and my internal conflicts, and between structural systems and my day-to-day challenges as a caregiver.

## Data Sources

My data were compiled through reflections on my academic experiences, observations in the community, and digital interactions online. This is an account of my “truth,” ---drawn from my experiences as “data” that can be analyzed (and will be) to the extent that I might offer a few, constructive remedies. To corroborate my experience and provide a degree of traditionality, I have referred to academic literature using a method described by Bochner and Ellis (2016) as narrative-under-analysis that employs various compositions of experiential and theoretical “sandwiching” (p. 187).

## Data Analysis

Due to the nature of the data, that is,  $n=1$  (with my own experience being the primary source of data), I utilized the “creative analytic practices” (CAP; Richardson, 1999) described by Bochner and Ellis (2016) by first analyzing my thoughts and written experiences through a conversation with myself, if you will (p. 188). I reflected on why certain details (for instance; structural, biological, or emotional) stood out more prominently in my experience and considered what relevance they had to my feelings as a doctoral student in an academic setting. By laying the synthesis of my thoughts alongside substantiating academic literature, I was able to tease out the areas of my greatest concern that could then be translated into meaningful calls to action or remedies.

## **Ethical Considerations**

Before publication of this manuscript, Queen's University (Kingston, Ontario, Canada) General Ethics Research Board (GREB), reviewed and approved the project. However, the seriousness and responsibility of respecting and protecting the characters or participants whom I have written about, (after obtaining "participant" publication permissions), has remained uppermost in my mind, ---knowing that anonymity could not be maintained (Renzetti & Lee, 1993). Cognizant of the fact that I have a researcher's ethical obligation to (reasonably) minimize risk to my participants, I have given careful thought to what details have been disclosed and the necessity of their inclusion.

## **My Life Story as Context or Data**

### ***My Son's Early Years***

My son's entrance into the world was late, ---induced 3 weeks after his due date, and after an apparent, uneventful pregnancy. I was a healthy, 26-year-old mother with no underlying health issues or "bad" habits. I ate a healthy diet, exercised regularly, and was not over-weight. I was married to an American man, and he and I were not related.

My son did not reach the typical childhood milestones as most children do, and few people could understand why his behaviors failed to match his unusually tall and large stature. The reluctance of doctors to diagnose my son's condition resulted in the loss of services and support in the early intervention years, and while most children begin school at age five, that did not happen for my son. Teachers at the three local elementary schools expressed an unwillingness to work with or accept my son into their classrooms for one reason or another. With no other option, I took responsibility for my son's education, and I enrolled him in a public, home school program in California (USA) where we lived.

The home school program did not offer special education support, and therefore creating and developing learning materials became my responsibility. Mothers who educated their Downes syndrome children and wrote "how to" books established some of the pedagogical approaches I adapted to my son's needs. My son's memory was exceptional, and I focused on leveraging that ability to incrementally increase his reading capacity. Our family had purchased our first computer and printer, and with the new technology, I was able to produce flashcards and later, simple reading books that combined pictures of items with simple words and sentences. I began a similar process to teach him the value of low denomination money, simple addition and subtraction, how to read an analog clock, and follow a calendar. His progress was expectedly slow, but steady.

When my son "failed" the California aptitude test, and came to the attention of the education authorities, an individual education plan (IEP) that would introduce and integrate my son into the formal, middle-school system was implemented. His transition began with half-days, which obligated me to a 20-mile (round trip) drive to collect him from campus at lunchtime. However, most disappointing, was the stagnation of his learning, as most of his peers had not experienced customized education and functioned at a much lower level. School mostly consisted of social and practical skill-building with the intention of training independent adults; however, it was clear that many of the students would never enjoy independence.

### ***My Return to Higher Education***

It was during my son's transition to middle school, that I returned to higher education, something I felt I needed to do to improve my sense of self-worth, to increase my limited social network, and to expand my intellectual capacity in addition to my employability.

I had not attended any educational facility in the USA, as I grew up in New Zealand and my transcripts (the pre-computer era) were held there. Community college personnel in California were understanding and waived the school records requirements. Later in New York however, and despite having a significant number of credits with a grade-point-average (GPA) of 4.0, the personnel were unhelpful and demanded a full international application. Had it not been for my Californian math instructor I would have quit after my first day on campus as a returning student. Low self-esteem that stemmed from years of "put downs" by strangers, doctors, teachers, and close family, caused me to question whether I was smart enough to learn or that I might be too old to "go back to school". My math instructor reassured me that older, returning students are some of the best, most dedicated students, and they do very well. His encouragement is the first reason that I persevered and remained in higher education. My partner's emotional and functional support is the second reason. His tutoring early on, allowed me to excel in math (the calculus route), complete my bachelor's degree, challenge myself with a master's degree program, and finally, to believe that I was smart enough for, and capable of completing a doctorate.

### ***The Challenges of "Doing School" and Providing Care***

During our earlier undergraduate years, my three adult children and I planned our courses in such a way, that someone was always at home to help and supervise my ID son; however, in our final year, most of our courses were scheduled for the same time of day. The university iterated that they did not have childcare [services] for "kids like mine" because their "daycare" (for which I paid fees) was only available to children of elementary school age.

Unable to afford a care provider and given that my son could not be left alone, my son traveled by train with me each day and sat outside my lecture halls while I attended my classes. In my final undergraduate year, I was (also) employed as an undergraduate, peer mentor, a high-GPA student who facilitated two to four mentor sessions per week to fellow undergraduate students. This "job" allowed me to receive my tuition free with a small stipend that covered my student medical insurance. In addition, I won a few scholarships which helped with the purchase of my textbooks and fees, as well as some of the tuition for my young adult children.

During my master's degree program, not much improved. It was the same campus, and I continued mentoring students in the same program. Half of my campus life was spent in the undergraduate world of mentoring, and the other half in my master's program with mostly, middle-aged, returning students—two very different worlds and experiences.

I completed my master's degree in 2016 and immediately began seeking employment. The challenge of breaking into the workforce with an empty resume (except for the verifiable years spent completing my bachelor's degree and eventually my master's degree) appeared to be more difficult than I had imagined. Most jobs were in far away cities and were either part-time "gigs" or they paid so poorly that I would not be able to support myself (and my children). Furthermore, locations that would suit me, did not offer work opportunities for my partner, and *vice versa*.

### ***The Move to Canada***

Research I undertook in 2013 (as an undergraduate), ---comparing the fundamental institutions of Canada to the fundamental institutions of the United States of America (Hutton, 2013), revealed some important differences between the two countries. These discoveries became instrumental in our family's decision to move to Canada in 2016. While rugged individualism underpins the U.S.A.'s institutions, "collectivism," or socialist-leaning qualities define Canada. Canadian collectivism was appealing philosophically and economically. The concerns that "ate away at my mental health," especially concerns about access to healthcare for my son and myself, (I felt), would be lifted if I lived in Canada. And I was hopeful that my anxiety could decrease.

Because I had been a stay-at-home mom and caregiver during my marriage, I had not paid into the social security system in the U.S.A. As a divorcee, this would mean that in late life, unless I had worked full time for a minimum of 10 years, I would pay the full premium for Medicare (medical insurance for people over the age of 65 years of age). In 2014, the premium I would have been required to pay would have been approximately \$900 per month (before co-payments and deductibles, which can amount to hundreds or thousands of dollars).

Healthcare in the U.S.A. is mostly tied to employment, with an employer paying most of an employee's medical insurance premium. Alternatively, the government-provided medical insurance for very low-income households (Medicaid), has such a low-income threshold, that it is difficult to qualify for the benefits, and government medical insurance "subsidies" (provided through "Obamacare") often do not provide a sufficient contribution to afford a robust or comprehensive plan through the private market. Noting that obtaining a job in the U.S.A. as an older woman is increasingly difficult, (especially with a lengthy gap on a resume), securing a comprehensive medical insurance plan outside of employment is difficult and financially prohibitive.

After completing my undergraduate and master's degrees, finding a job that would pay well enough to afford a caregiver for my son (to provide care while I worked) seemed impossible, as most entry level jobs in 2016 were paying between \$30,000 to \$40,000 per year in wages. Hiring a caregiver would have cost me a minimum of approximately \$35,000 per year and left me with little or no income after paying the caregiver's wage. Furthermore, service coordinators (brokerages) and group home placements had lengthy waitlists that were years-long. I had few feasible or affordable options, and therefore, moving back to my birth country of Canada seemed to make good sense. While the move was socially costly (in terms of disconnection from long-time friends and other networks), it afforded me a degree of financial security and guaranteed healthcare.

Settling into a new country with so many unfamiliar systems can be emotionally and financially disruptive. My partner suggested that I begin a Ph.D. program at a Canadian University where I could find an academic network while easing into our "new" home. However, four more years of school seemed intimidating and daunting, as caring for an ID adult has numerous responsibilities. None-the-less, the opportunity to assist with educating "the world" about my caregiving population's immense burden was also a motivation that overshadowed my hesitancy. I felt that if I could do this for other mothers like me, then I should.

Due to unforeseen issues with Ontario Canada's tertiary education centralized application process, my partner was compelled to accept his place at the University of Toronto, and I accepted the offer from Queen's University, at Kingston. Although the universities are both in Ontario, Canada, this "long distance" scenario was not what we had planned or hoped for. However, despite the issues of distance, we have learned to adapt to a life spent mostly apart. What then, is my caregiver's "problem" now?



## Analysis

### Identity, Role Conflict and Cognitive Dissonance

The “problem” layers or foundations of mental burden, and other challenges (cumulative burden) that I experience now, began during my undergraduate years when I was referred to as a “geriatric” by an elderly professor during a lecture and “stupid” by another. Neither of these professors had known me for more than a couple of weeks and did not know that in both cases I had registered for classes late due to ineffective guidance from school counselors. In one case, I had registered for a fourth-year class in a different discipline, after moving across country and changing universities. The adjustment to a new city, new institution, and a new academic discipline takes time. As a student who was (visibly) older than my peers, it felt as if the professors saw me as a person who had “bummed around” in my early adulthood, and that I was now attempting to repair the damage. As an undergraduate, there is often no opportunity to explain one’s life-context or seek understanding and sympathy, and professors tend to be less accepting of older students, and their expectations greater (Wyatt, 2001). Fortunately, at the graduate level, particularly the doctoral level, there are fewer opportunities to be disrespected by undergraduate students and faculty and appearing to be “the wrong age” or off-time becomes less noticeable or negative.

It was my experience that some school counselors were not well-versed in understanding and providing a suitable degree route for students, and they often took a short-sighted approach to mapping it out. Without understanding the increasing demand and importance of quantitative research in all academic research (statistics-based research), I proceeded into the calculus stream where I excelled. Unfortunately, calculus is (mostly) irrelevant in social science and this has left me open to criticism regarding a lack of familiarity with statistics and data manipulation in general. It has caused me to feel self-conscious and limited. Furthermore, I feel that there is a general assumption that older persons (students in this case) are “bad” at math.

Being mistaken for the professor (in undergraduate school) might seem innocuous to many, but to me, it was a reminder that I was not in the right place or situation for my age, --- that I was “off-time” (Norris, 2011). Furthermore, group projects (that are dreaded by most undergraduate students of similar ages), were a logistical challenge for me. Younger group members were apt to shirk an entire project or exclude me entirely. One instructor held me responsible for a poorly executed group poster project ---because I was older.

Hay, Tan, and Whaites (2010) noted that multi-choice exams are a challenge for older minds in general, and accordingly I found undergraduate multi-choice exams especially challenging. The stress from a very recent divorce, and challenges of single-handedly raising teenagers rendered my memory faulty. In addition, problems with unfamiliar technology such as overhead projectors (which are notorious for their quirks) often caused students to wonder if I was too old to operate the equipment. These feelings of inadequacy and reminders of being off time (cognitive dissonance), have compounded as time goes by, and have carried over into my doctoral experience.

At the doctoral level, youthful and often privileged (doctoral) students begin their program each year with enthusiasm and mostly, unencumbered freedom. They participate in department competitions, they serve on committees, attend campus events, and gather in each other’s offices to strike up comradeships that are cemented by regular social interaction and experiences of their generation. I am old enough to be their mother, yet I am their peer. It is probably more conflicting for me than for them. It is and has been isolating.

## **Cumulative Burden**

I have found that my caregiver burden is not the result of any burden or negative event at any one time, but it is the sum of all daily challenges—past and present (some of which were described earlier). Burden is cumulative. It is a layered experience that compounds over time and in my experience, it has manifested as distrust, resentment, fatigue, and withdrawal from social interactions. While many of my problems are systemic and functional (real), some are likely “in my head” (imagined or misperceptions). It is difficult to not feel excluded, judged as lazy, stupid, old, unable to cope, incapable, and a failure. I also feel that I am automatically assigned the label of “wealthy” and “privileged”; terms that disadvantage me further, merely because of my appearance, and the way I dress.

It is often assumed that by the time a person is in mid-life, they are probably an empty nester (or childless), and therefore have the freedom (and the finances) to pursue higher education unfettered. Noting that many women (or other non-traditional) students return to higher education after a major life event such as a divorce, some will be experiencing financial instability and mental duress (Moloney, 2018). Furthermore, considering the current trend of adult children continuing to live with their parent(s) into adulthood (Burn & Szoeki, 2016; Warner et al., 2017), it is often the case that older students who are also parents, are financially supporting adult children who are facing several employment and health issues (McMillan, 2018). Furthermore, the increase in drug dependent children who may also be experiencing debilitating mental illness and/or disability, often creates a compound and complex caregiving situation (Lunsky et al., 2017). This contributes to parental caregiving obligations and burden that disrupts employment and study (Prouix & Le Bourdais, 2014). Women continue to predominate caregiving roles and they also make up increasing numbers in graduate programs, yet their struggle to balance family life and mothering with the demand for academic output (that leads to fatigue, mental health issues, and dire financial situations) is often ignored or not understood by the academy (Wilton & Ross, 2017).

It is true that I seem overwhelmed by the needs of my personal life and the demands of graduate life ---because the two are not compatible. I become stressed before I walk out the door to catch the bus to campus, because I know that my son will sit in front of his computer until I return. My adult children are present and available to my son while I am gone, and they give him his food and beverages at mealtimes. However, I worry that my daughter or son may have to deal with an adult-sized tantrum, or emergency that she/he is not comfortable with, or for which she/he does not have the capacity to manage. My adult children work and study from home, and my daughter has her own (confidential) medical illness complicating her abilities. We pool our labor, because I do not have the resources to hire specialized (and vetted) care providers ---if such providers are available. My children can phone me any time. I am always prepared to hurry home to manage a crisis, and hope that colleagues and professors will understand. The never-ending task of meeting less-pleasant needs that my daughter (or son) has been unable to manage, is mine at the end of the day, and sometimes it is a “mental mountain” that needs overcoming. Understandably, I am elated to leave the house, if but for a few hours, yet simultaneously I am anxious. I lack confidence, partly attributable to “imposter syndrome” (Chapman, 2017; Clance & Imes, 1978), but also because I feel that I may become the subject of rejection, humiliation, and ridicule in an environment that is oblivious to my (and other) caregiver’s circumstances.

## **Self-Imposed Isolation**

I sometimes feel resentment about my life situation (not towards my son), and envious of those around me who have the freedom to travel for work or school. They have the freedom

to focus on their career or studies (without disruption or interruption), to go on vacation, and to visit “family” in foreign places. Getting out of the house is difficult for me (Yantzi et al., 2006), and I feel frustration towards people who think that if I had better coping skills or bothered to make a few phone calls, I could easily “hook my son up” with services and activities. People assume that I have not tried to secure services, and they fail to consider how inaccessible most government provided information is, and how fruitless follow-up can be. They also assume services would take care of all my problems. Even when services are available, they often have a wait list of more than 20 years (especially in the case of supervised housing). Furthermore, unbeknownst to most people, services are almost never provided free of charge.

After spending hours on the phone, year after year, I have only found one occupation that was suitable for my son. It was “employment” at an electronics recycling facility in California, U.S.A. My son was hired to dismantle broken electronic equipment for a token “wage” per hour. This “employment” lasted for only a short period of time, as my son experienced abusive and threatening hostility from another employee. My son has been understandably reluctant and afraid to try anything new since then. Our arrival in Canada has not improved his outlook, and I have been unable to find any program or activity suitable for him.

My frustration (emotional accumulation) can become overwhelming, and many comments from the people who surround me can feel insensitive, ignorant, and judgmental. Housework, yard work, home repairs and meal-making (with attention to special dietary needs) are some of the many chores that consume the hours in my day. To avoid hefty expenses, I only hire “expert or professional” help when the procedure or project is something that I cannot do myself. This is, in addition to doing research, grading, and meeting with students and professors.

Working late into the night allows uninterrupted time to grade student work, study, or write. I often get over-tired, and this leads to depressing or negative thoughts. I feel trapped, judged, and blamed by everyone around me. In the academic setting, comparisons, and competition (which seem to underpin everything) is stressful and ignores the immense burdens and challenges some of us face. The accumulation of these daily stressors causes me to doubt my friendships and to question the point of living. When I fall into this tired, depressed “spiral,” I tend to withdraw and cut social ties. This burden is not visible, as it lies behind the positive façade I am told I project. It is an invisible “energy-sucking” burden that has become “my mental illness.”

### **The Rationale for Staying Home**

Attending conferences during a graduate program offers a student an opportunity to connect with like-minded academics and build social networks. However, for the caregiver, “getting there” can be a worrisome task. Driving on busy, dangerous freeways or taking air transport are anxiety-provoking, as the fear of leaving the ID adult child abandoned is always uppermost in one’s mind. Many parents to ID adults do not have a long-term contingency or “future plan” for their adult child (Band-Winterstein & Avieli, 2017; Lunsky et al., 2014; Mooney & Lashewicz, 2013).

Going on vacation, or attending out-of-town events is complicated by caregiving obligations, and many parents of ID adults who have hired a stranger or received respite, have worried about the quality of the care (Lunsky et al., 2014), or have experienced a negative or abusive interaction. Furthermore, going anywhere, or doing anything that has any amount of risk, has the potential to leave my adult children in the predicament I find myself. They could become caregivers whether (or not) they are mentally, physically, or financially able. Whether

my concern about “risk” is rational behavior might be subjective, but for me, it is a very real concern. To admit this out loud makes me sound paranoid, but to another caregiver, it sounds reasonable.

I worry about falling ill or acquiring and transmitting an illness or disease to my son, and I wonder what will become of him if something happens to me. I do not have any formal, alternative care arrangement established ---aside from relying on my son’s siblings to take on the caregiving responsibility. I, like many other caregiving parents, know that there is no formal help to fall back on. According to the Ombudsman’s report on crisis response for Ontario, (Canada), there are major crisis response deficiencies, and parents like me who fall into a medical or mental crisis are left to fend for themselves (Dube, 2016). Additionally, Dube (2016) noted that when there is a governmental (police or medical) response, the outcome is often inappropriate, and occasionally ID adults are placed into prisons or homeless shelters due to a lack of shelter options. No parent of an ID adult is comfortable with the knowledge that the default plan of governments (during a crisis response) could be either scenario. Our disabled “children” are vulnerable and very dependent people (whether we like this term or not) who rely on us to genuinely care for them and their welfare, and they trust us completely.

I feel that I must take extraordinary precaution to avoid risk of any kind as my adult children are relying on me to stay safe and provide care. My closest relatives live in New Zealand, and if an unfortunate event were to happen, their distance would be a barrier to providing help. Furthermore, due to past experiences, I feel that I could not expect to receive any help from any of them. This lack of trust in family, particularly for support has been expressed by other caregivers who note that they have been promised help from family, however, the help has never materialized (McKenzie et al., 2017). Much of the time, family members do not understand caregivers in any capacity, are not interested in understanding the situation, are uncomfortable with disability, and often ignorantly suppose that caregiving mothers do not work (earn a living). Therefore, friends and family believe that a caregiver does not need help. In my case, female family members have iterated that they must work, which seems to suggest that my “at home time” is a vacation.

### **Mental-Health Services and Other Campus Supports**

For most students, stress reaches its peak around exam and final project time. I have similar student issues, but they are graduate-level issues entwined with life-related challenges. My issues involve grading, student concerns, relationships with professors, my research, and my life—mostly my life. Campus mental health counselors are always kind and understanding, but no amount of positive thinking or reframing my problems can change my feelings of anxiety and burden. My problems are mostly not “in my head.” Counselors do understand this, but there is little they can do to alleviate my burden. They have offered me the opportunity to take a medical leave; however, this is merely a band-aid solution that will only kick my Ph.D. responsibilities down the road.

### **Neoliberalism and “Neglect”**

Due to my son’s genetic misfortune, I found myself stuck in an overwhelming role, and I have often felt that I am entirely alone, ---abandoned by society in every regard. I feel that my son and I are considered burdens in a society that values youth, vitality, and contribution. Economists, Wren, and Waller (2017) would likely argue that my feelings are valid, as they note that “care” or caregiving falls outside the “market” (that it is not valorized) due to neoliberal ideology, and that such systems espouse autonomy, self-interest, and personal responsibility. Wren and Waller (2017) add that, “dependency,” or the reliance on care

provided by another is “demonized” by neoliberal ideals, and to forgo one’s self-interest in the quest to care for another, is seen to “diminish one’s own identity” (p. 6). In other words, caregiving undermines personal responsibility. The propagation and perpetuation of this ideology ensures the rejection (by citizens, firms, and leaders) of policies that support or favor social assistance (“welfare”), thereby shifting the responsibility of care and dependency away from the state and to the individual. Indeed, few governmental structures are available to “make it easy” for caregivers to access funding, and functional or emotional support services. The “problem” of providing care to a dependent “other” is seen as an entirely “private problem,” or an individual’s own problem (El-Bialy et al., 2022; McGregor, 2001).

The “wage” that I earn as a teacher’s assistant (TA) is minimal (with the assumed “reward” being an advanced degree), and understandably, I am expected to perform as well as any other student who has significantly fewer life demands. After all, it is not the university’s “fault” or problem that I have an adult “child” who is intellectually disabled, and who depends on me entirely. Until the COVID-19 pandemic forced academic learning to a remote delivery system for all, rigid, traditional-thinking faculty and staff were reluctant to imagine less than a student’s full-time presence on campus. Considering most resources are now available remotely or through a VPN, the expectation to be “always present” and in the office, places unnecessary burden on parents with a challenging life situation.

Most people are employed in occupations that demand a full-time office commitment, however, at the end of the day, they can go home and enjoy a mostly “workfree” weekend or holiday. They are also able to change companies or firm and resign or retire if they choose. I am unable to vacate my caregiving role, and I must fulfil it when I am very ill or tired. I have no “sick days” or substitute worker(s), and I cannot retire from the obligation.

### **Academic Competitiveness**

The pressure to attend conferences adds to my feelings of “missing out” or appearing as a lazy “failure.” It adds pain to my already constrained life, and it also means that my curriculum vitae (CV) lacks the long list of participation that my colleagues can tally. Furthermore, I cannot find time to sit on committees or attend campus social events that are offered with single, young graduates in mind. While I have unwillingly learned to accept these losses, I am unable to quantitatively demonstrate the array of skills and achievements I have accomplished to future employers. Awards are constantly meted out to “high achieving” students who are active at all levels of the academy, and newsletters praise their feats and contributions. I, on the other hand, must tend to household needs for which there is no recognition. Furthermore, the service I provide, that relieves the government (and society) of providing care, is formally recognized as a contribution to society by mere words and data alone. Caregiving “skills” are unlikely to arouse interest from an employer who favors a “traditional” CV, and it is likely an employer would consider caregiving a “red flag” that indicates distraction and disruption.

Neoliberalism (personal responsibility, self-interest, and the market) is an ideology that increasingly permeates administrative and academic policies and structures (Schulze-Cleven & Olsen, 2017), and it is inculcated through institutional practices such as funding and political agendas. This is evidenced via “merit-based” awards, volunteering, exceptional community and or academic leadership, and through special interest agendas. Excellence of scholarship is measured in terms of publication output, and contribution to, or participation in campus activities, groups, committees, (additional) advanced or technical learning, and teaching appointments (Schulze-Cleven & Olsen, 2017).

In the academy and society at large, value is placed on leadership and service to others, however, these “qualities” are only (formally) recognized when they pertain to the academy or

are voluntarily performed in surrounding communities (for strangers, non-profits, and other organizations). Recognition of “service to community,” in the case of parent-to-child caregiving (a self-less act towards another), is not given any emphasis or recognition within the academy or beyond. Furthermore, there are few or no provisions for a caregiver to acknowledge their personal obligations, experience, and contribution to society on their CV, and be respected in so doing. In effect, the academy is like any other business or industry that does not recognize “caregiving” as a contribution to society and dismisses it as something outside of its system.

In the capitalist system, disability (dependence) and caregiving are considered “pathological,” and both need to be overcome (Wren & Waller, 2017, p. 6). Furthermore, in this system, “failure to overcome” (the dependent/dependency relationship) is seen as an indictment on the character (weakness) of the caregiver or care-recipient. Similarly, the dependency relationship between the Ph.D. student/caregiving-parent and their ID adult, becomes a hindrance and failure in the academic system.

To be competitive in the academy, one must be autonomous and able to realize self-interest, that is, be unincumbered and delivering “goods” to the market (recognized here as academic contribution through publication and voluntary services). A caregiving parent, particularly a single parent providing care to an intellectually disabled adult (who has outgrown the K-12, comprehensive, support system), is logistically and emotionally challenged to provide care and deliver the “goods” to the academy, and there are few occasions when a parent in this situation can meet both obligations without support.

With emphasis on the number of academic publications as the qualification for prestigious scholarships and awards, and community participation as the criteria that elevates a student to a place for leadership recognition, the caregiver may find it difficult to be competitive. A caregiver is relinquishing freedom and (rewarding) opportunities to provide unconditional love and care that is not recognized as a civic contribution or leadership achievement. The lack of “service” recognition in conjunction with the market’s dismissal of the value of care puts a caregiver’s CV in jeopardy of appearing meager and non-competitive (Wren & Waller, 2017). Furthermore, Preece and Stoddard (2015) suggest that women are more likely to shy away from competitive careers, in part, due to parental responsibility. Given that most caregivers are women, it is highly likely that these women will be reluctant to embrace a competitive and demanding career in the academy. Due to this reluctance, the attainment of a professorial tenure is poor (Kulp, 2019), and rather, the tendency for women providing comprehensive and long-term care is to drop out of the workforce entirely (Prouix & Le Bourdis, 2014).

Relocating to assume professorial tenure as a parent-caregiver is constrained by services for the ID adult that are fixed to “place” (Torjman & Makhoul, 2016). Services and income support are provided by the state or province of residence, and they are not portable across geographic borders and boundaries. Many newly graduated Canadian doctoral students accept post-doctoral appointments at international institutions, using the experience to segue back into the highly competitive Canadian academic market (which sometimes values international experience and broader “world views”; Bauder et al., 2017; Chen et al., 2015; Schulze-Cleven & Olson, 2017). The ability to benefit from an international experience is unlikely for a parent of an ID adult, particularly a lone, caregiving parent.

Pitman-Brown and Brown (2015) found that women were more likely to attain (professorial) tenure if they attended a prestigious university with strong department and professor affiliations, if they did not work part time jobs, if they were awarded scholarships, and if they performed TA positions. Unfortunately, a parent-caregiver and doctoral student does not always experience some, or all these important advantages. Parent-caregiving doctoral students are likely to find it difficult to relocate to a more prestigious university (which would

improve their opportunities to acquire a tenure track position), and the needs and services of the ID adult often places limits on the caregiver's entire household that must consider affordable living costs, and disability service options that are tied to "place" (Pitman-Brown & Brown, 2015).

### **Resilience in the Academic Caregiver's Context**

Increasingly, institutions of higher education are learning to recognize and understand challenges experienced by non-traditional students (Buglione, 2012; Moore et al., 2020; Van Rhijn et al., 2016; Wraight & Giordano, 2018); however, my own experience at several colleges has indicated a weakness in the institutional understanding of the non-traditional student who is also a parent providing care to an ID adult or other disabled adult "child." This is likely attributable to the scarcity of academic literature on the topic, and the rarity of a parent undertaking the two careers simultaneously. Met with "pity" instead of qualified, professional understanding and strategizing, I have leaned heavily on my partner, close friends, and withdrawal/avoidance to "get through" my most over-burdened moments. It has been insufficient.

The theory of resilience that portends intrinsic strengths are well-springs of resilience, has found fertile ground across disciplinary practice and academic literature, and while it is essential for individuals and larger populations to be somewhat self-sufficient and able to take care of themselves, resilience is difficult when basic needs are unsatisfied (Levine, 2009; Masten, 2001; Zimmerman, 2013). Levine (2009) writes that, positive and concrete "assets" (mentoring, guidance, and other formal and financial supports) are essential for a person to be truly resilient. Cobbled, weak support systems, and employment precarity are exacerbated by the abandonment, passivity, and disinterest of political and other structures including the academy (McKeown & Glenn, 2017).

It is apparent that the academy has specific political agendas that garner financial and therefore academic attention for certain populations. This has negative implications (for funding and other supports) for those of us with mundane and/or under-valued research. It also has implications for my future in the academy. Is there a place in health geography for parent-caregiving research if funding is politically awarded? Is there any political, institutional, or even personal *will* to care about parent-caregivers, ---mothers like me who are challenged in numerous ways? What is the Indigenous or immigrant experience of parent-caregivers of ID adults? There are many gaps in our understanding, and appreciation of parents who provide long-term care to adult children across all industries and occupations. Does the importance of this unrepresented community stand a competitive chance in the research milieu?

## **Discussion**

### **I Am Living My Research**

My research was inspired by my ongoing experiences with caregiving and the lack of understanding and support. My line of inquiry has changed somewhat as I have realized that the issues that have become more "pressing" for me, (as both my son and I grow older), are the same issues that concern and debilitate other caregivers as they too, age. I am worried about our future. I am not sure how I can find a way to work and care for my son (as a single parent). I am not sure how I will provide for us both in old age, or should I become ill. Building a support network is difficult, as caregiving peers, and community resources are overwhelmed.

Local support groups are difficult to organize, and few caregiving parents attend. Parents' (personality) compatibility with other caregivers is rare and finding a trust-worthy

sitter is difficult in the evening when most meetings take place. Parents are tired and getting older, and they mostly just want to stay home, ---especially after dark. Online resources offer few realistic or useful solutions to long-term caregiver burnout, and burgeoning social media groups are silos of distraught, desperate, and suicidal mothers. Group members are posing complicated medical and legal questions to each other and offering up “prayers” as a form of non-committed, yet helpless support. Most are middle-aged, often divorced, and often dealing with poverty, life-stage, and health issues.

Monitoring social media is part of my research, however, the regular exposure to online “caregiving platforms” has been a depressing activity that has compounded my feelings of hopelessness. It has been upsetting to see so many women managing their burdens alone and feeling misunderstood while sometimes being mistreated by husbands and family. Some are medically uninsured, and financially distressed. Despite their need, many are reluctant to participate in my research, as confronting their reality and sharing their experience is difficult, and possibly humiliating.

### **Learning Acceptance, and to Some Degree, Resilience**

The mission statement of some blogging mothers caring for ID or autistic children and adults, state that blogging has been a way to make sense of the situation they have found themselves “stuck in.” It is cathartic. It is also a way to yell into the vast, virtual world to find sympathetic “ears” and voices who “get it.” Likewise, I have found that by throwing myself passionately and authentically into my research, this life that has dealt so many disappointments, has given me a purpose. I am motivated and dedicated to making the parent-caregiver’s life struggle known to the academy and beyond. I am trying to *do* something.

Caregiving parents to ID adults have been forgotten by society as their energy to protest or picket, ---to be heard, wanes with time. Many of their voices have fallen silent after years of fruitless fighting and pleading, and they have become resigned to the fact that they are on their own. Young mothers of ID and disabled children who are coming along in our footsteps, are more adept at social media, and they are still optimistic, as we used to be. They are putting their collective voices out there on blogs and social media sites. Maybe they will be the change we need. Yet, if timely change is not implemented, these women who began their life-long caregiving journey with optimism and spirit, will become disillusioned as we have. I know that many caregivers resent academics who have solicited their story and then disappeared. Recounting and retelling their emotional experiences, again and again, has been traumatizing and exhausting. They are tired. They are worn out.

I am tired too, but the needs of my research population have been the impetus to “get this thing done,” for them and for me. Finding and recruiting a population that is in distress (exacerbated severely by COVID-19) has taken patience, and the establishment of trust between members in the boundary-less virtual world. It has helped me find other strong women who are forging on, connected through virtual networks of understanding, ---sisterhoods of sorts. We are experiencing many of the same issues. Through finding these women, I have come to understand that the feelings I have are normal, common, and understood in these circles. I am constantly reminded, that my son’s medical complexities are minor compared to some conditions that are managed by some caregiving mothers. I also realize that my research is important, and it will be appreciated by marginalized caregivers and their ID adult children who are being left behind.



## Conclusion

While this autoethnography is an account of my experience as a doctoral candidate and parent-caregiver to an ID adult, it may not be shared by another parent in a similar situation. However, many of the challenges I have experienced are likely to be shared by parent-caregivers in numerous employment and other occupations, in most areas of the world.

Understanding that caregivers are fully engaged with their care obligation(s) is essential to developing strategies and contingencies that increase equity in the academy and other workplaces. There should be no guilt, shame, or retribution for the inability to be “geographically present” on campus (or the workplace), when virtual attendance is a viable option. More effort to work with a caregiving parent should be encouraged from all academic members and employers. Sensitivity, social support, recognition, and respect (all of which cost nothing), are responses we should expect and receive from our colleagues, family, and friends. Furthermore, functional, or real supports should be societal givens, and until caregiving is recognized as a respected occupation that deserves remuneration and recognition across and within all structures, caregivers will be stuck on an eternal, stress-fraught, isolated, and lonely treadmill. Every one of us will become a caregiver or be cared for at some point in our life. It is imperative that our collective actions press for change that will deliver necessary financial support, respect, and understanding to the millions of caregivers, who provide life-long care.

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