A PORTRAIT OF THE COUNSELOR AS A YOUNG CAREGIVER: AN AUTOETHNOGRAPHIC EXPLORATION OF THE LIVED EXPERIENCES OF FAMILY CAREGIVERS OF ADULTS WITH IDD

By

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ABSTRACT

In this autoethnographic research, I explore the complex interplay of voice between caregivers and adults with intellectual and developmental disabilities (IDD). Adults with IDD often collaborate with caregivers, usually family members, to meet their daily needs, especially when they have complex communication and support needs. Caregivers are frequently asked to serve as vocal proxies for these individuals, leading to an entanglement of voice that impacts various life domains for both parties. This dynamic necessitates an understanding of the unique needs of family caregivers, including navigating service systems and maintaining wellbeing to provide sustainable support. Yet, their voices and needs are often overlooked. My research, therefore, seeks to understand their lived experiences. The central question I investigate is: What can my experience as a family caregiver uncover about the entanglement of voice among family caregivers of adults with IDD who have complex communication and support needs? Using an inductive approach to reflexive thematic analysis and writing narratively around my data, I generated three main findings: Entangled Voices Across a Variegated Landscape of Care, Monopolizing Knowledge and Conferral of Who is Expert, and Caregiver Currency: How Much do You Have to Spend? These findings contribute to a more nuanced understanding of the caregiving experience. I conclude by discussing implications for research, education, and practice.

Keywords: autoethnography, intellectual and developmental disabilities, caregivers, reflexive praxis, qualitative inquiry, rehabilitation counseling

For my brother,
and to those who provide care for their loved ones.

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LIST OF ABBREVIATIONS

AE	Autoethnography
CCN	Complex Communication Needs
CRC	Certified Rehabilitation Counselor
DD	Developmental Disability
DSP	Direct Support Professional
FSP	Family Support Practices
ID	Intellectual Disability
IDD	Intellectual and Developmental Disabilities
RC	Rehabilitation Counselor
rTA	Reflexive Thematic Analysis

CHAPTER 1: INTRODUCTION

The purpose of this dissertation is to use autoethnography to reflexively examine how voice and voicelessness (i.e., an entanglement of voice) impact the care needs and the overall well-being of family caregivers of adults with intellectual and developmental disabilities (IDD). The central question of this inquiry is: *What can my experience as a family caregiver uncover about the entanglement of voice among family caregivers of adults with IDD who have complex communication and support needs?*

In this chapter, I introduce the topic of family caregivers of adults with intellectual and developmental disabilities (IDD), exploring their lived experiences as caretakers, and sometimes, as vocal proxies, for their loved ones who have complex communication needs (CCN) and support needs. I explain my philosophical commitments and chosen methodology of autoethnography (AE) and provide background on IDD and the caregiving role. I address the need to explore the entanglement of voice between family caregivers and their loved ones with IDD through a qualitative, autoethnographic lens, and articulate my intended aim and primary research question. I summarize the interpretive lens for my data and finish with defining key terms: intellectual and developmental disabilities (IDD), family caregiver, entanglement of voice, and complex communication needs (CCN).

Overview

One of the most overlooked groups in the field of disability studies are the parents and primary family caregivers of individuals with disabilities (Green, 2015). These parents and caregivers face multiple challenges and barriers in a society that often stigmatizes and excludes them and their loved ones with disabilities. Parents and caregivers have valuable insights and experiences that can enrich our understanding of disability, parenting, and caregiving across the lifespan; yet caregiver voice tends to be unheard and undervalued in the interdisciplinary disability studies discourse, including within professional counseling.

Sarah Green is a scholar who explores the experiences and perspectives of parents of children with disabilities. She argues that these parents occupy a marginal position both in society and within disability studies, and that their voices are often silenced or ignored. Her research agenda has focused primarily on bringing the voices of these parents from the margins to the table in interdisciplinary discourse on disability, parenting, and caregiving across the lifespan. She hopes that by deepening understandings of parenting and disability, she can contribute to the emancipatory potential for parents and their children. Green's work is informed by disability studies, environmental humanities, and dance studies.

Consistent with Sarah Green (2015) – family caregiver to a child with a disability and researcher of caregiver experiences – this dissertation is aimed at addressing this gap by centering the perspectives and stories of family caregivers of adults with IDD. In this research, I use an autoethnographic approach to explore how I make sense of my caregiver identity, role, and relationships in the context of being not only a family caregiver to an adult with IDD, but also as a researcher-counseling practitioner focused on identifying factors that promote caregiver wellbeing and quality of life (QoL).

This knowledge has the potential to empower parents and family caregivers of individuals with disabilities and their loved ones with disabilities. By recognizing and honoring caregivers' lived experiences, we can challenge the dominant narratives and assumptions that oppress and marginalize them alongside their loved ones. We can also create more supportive and responsive policies and practices that meet their diverse needs and aspirations. Ultimately, elevating caregiver voice holds the emancipatory potential of humanizing the repository of counseling and disability-related research in several ways.

By providing a platform for caregivers to share their experiences, perspective, and knowledge, the dominant narrative that often focuses on the opinions of outsiders such as medical personnel, counselors, educators, and yes, researchers, is challenged. This emancipatory potential has several implications, including shifting power dynamics, promoting diverse perspectives, contextualizing disability, impacting policy, and ultimately, empowering caregivers.

Shifting Power Dynamics – Caregivers' voices can challenge and change power dynamics in research and counseling. They have valuable knowledge and experiences that can inform and direct research goals and methods. This way, they can participate more actively and fairly in creating and sharing knowledge (MacGregor, 2022).

Diverse Perspectives – Caregivers offer a wealth of diverse perspectives to the field of counseling and disability-related research. Their unique insights into the needs, challenges, and strengths of individuals with disabilities, as well as the impact of counseling interventions and support systems, are invaluable. By incorporating the voices of caregivers into research, the scope of inquiry is broadened to encompass a more comprehensive range of experiences and perspectives (Nierse & Abma, 2011; Vurgun et al., 2022).

Contextualizing Disability – Amplifying the voices of caregivers serves to more fully contextualize disability-related experiences within a system of interdependence that exists between caregivers and their care recipients. Caregiver insight into the environmental, social, and relational factors that shape the counseling and support needs of individuals with IDD offer a more nuanced picture of the breadth of disability and disability-related experiences. This perspective moves beyond individual pathology or deficit models and acknowledges the role of systemic and interpersonal factors in the lives of individuals with IDD (Green, 2015).

Advocacy and Policy Impact – The elevation of caregiver voices contributes to advocacy efforts and informs policymaking related to disability. By bringing attention to the challenges faced by caregivers and the needs of individuals with disabilities, research findings can influence policy decisions and drive improvements in counseling services, disability support systems, and inclusive policies. Caregiver voices serve as a catalyst for change (The Arc, 2017; National Alliance for Caregiving [NAC], 2017; Torjman, 2011).

Empowering Caregivers – Elevating caregiver voice empowers them as active agents in the research and counseling process. This recognition of their expertise and validation of their experiences encourages self-advocacy and can have transformative effects on caregivers themselves. By promoting their well-being and resilience, caregivers are enabled to advocate for their own rights as well as those of the individuals for whom they care (Pompon et al., 2018; Vurgun et al., 2022)

Coming to this Research

I come to this research from a place of care — care as a researcher, care as a counselor, care as a sibling, care as a guardian. Yet even as I sit here to write this piece, my attention is split, not wholly focused. Part of my attention is on the research – the literature, the people potentially impacted, the methodology. But a fraction of my attention is where it almost always remains – with my brother. He sits next to me in his rocking chair as I work, quietly humming and smiling while watching the latest, churned-out holiday movie released on one of many available streaming services. He typically remains line-of-sight with me throughout the daytime regardless, but especially so this particular week.

We are both getting over our illness with COVID-19, and monitoring symptoms such as "difficulty breathing", "chest pain", "aches and pains" and "loss of taste and smell" is extremely challenging with someone who is predominantly non-vocal in their communication. I ask him if anything hurts, if anything is "ouch" on his body, to which I am met with the American Sign Language (ASL) approximation for "no". Because he uses this sign to communicate a variety of intimations (e.g., "No, I don't like this question."; "Leave me alone. Stop asking."; "I don't understand what you're asking."; or possibly "No, nothing hurts."), I look to other tools and cues, concrete cues that definitively inform me of some of what I am hoping to know – a thermometer to check for the presence of fever; an otoscope to determine if pain or infection might be present in the ear he seems to be favoring since getting sick; a pulse oximeter to make sure his blood oxygen and heart rate are within normal limits. While an element of split attention is a natural part of being a caregiver, regularly serving as a vocal proxy for someone, attempting to interpret – often guess – what they may need and feel, especially when they are sick, adds a sense of prolonged, vigilant responsibility to this proxy status that can be difficult to maintain and manage.

As you can see, my story is not just mine. It is also the story of my adult brother with intellectual and developmental disabilities (IDD), who utilizes me as a resource for his daily care, support, and quite often, communication. As a counselor and a family caregiver, I have a dual role that shapes my identity and my perspective on family caregiver experiences. I have experienced the joys and challenges of caring for someone who has different needs and abilities than me, and who often has challenges expressing his own voice. I have also consistently witnessed the stigma and discrimination that he and other people with IDD face in our society, and how, in turn, this affects not only their own opportunities and well-being, but also of the opportunities and well-being of the family members functioning as their primary caregivers.

In this autoethnography (AE), my intent is to use my own autobiographical data to explore the complex relationship between care provider and care recipient and assess how my understanding of this relationship influences my personal and professional experiences, development, and ultimately, my own well-being. By doing this, I am embracing my presence as an observer and producing the very phenomenon I seek to record – rather, this is not "me-search", but a way to situate my experience within the broader phenomenon of family caregiver experiences, especially as it relates to family caregivers of adults with IDD. I also want to use AE as a method of inquiry that allows me to critically reflect on my own assumptions, biases, and values, as well as to examine the intersection of power, oppression, and social privilege that shape the lives of caregivers, the individuals for whom they provide care, and the systems of support in which they operate. By sharing my story in an evocative and engaging way, I hope to add a humanizing element to the cartography of counseling research as it relates to caregiver experiences, and to disrupt the normative knowledge production <of what?> that often marginalizes and silences the voices of people with IDD and their caregivers.

Researcher Role and Position

I have served as primary caregiver and legal guardian to my brother, a young man with IDD, for nearly 10 years, but more importantly, I have been his sister for over 25 years. I have worked in direct care serving families and individuals with IDD for over 17 years, and I have been a certified rehabilitation counselor (CRC) for over 10 years. It is within these intersecting experiences, personal and professional, that I was moved to pursue a doctorate in rehabilitation counseling. I wanted to learn how to approach some of the knowledge translation and service delivery gaps that I was regularly witnessing and experiencing.

Upon entering the Academy, where institutionalized knowledge of the profession is housed and disciplinary competence is constructed, I began to encounter the role of the researcher as one of several things - notably, the “publish or perish” researcher, the researcher as detached observer, and the researcher as savior (e.g., Arstein-Kerslake et al., 2020).

Admittedly, I was drawn in some form or fashion, no matter how small, to each of these positions. “If we do not publish,” I initially thought to myself, “how do practitioners access evidence-based treatments? If we do not remain detached, how do we stay “objective”? And as far as the unspoken sentiment of ‘researcher as savior is concerned, what other purpose is there for a researcher if not to create a solution-focused research repository that benefits the people we serve? Yet as I progressed through my journey, I began to experience dissonance. Dissonance between how I was cognitively approaching my early research while knowing in my gut that it felt disengaged, that I was designing work in the way I was trained, yes, but also in a way that I felt strongly was not going to get at the heart of the issues I experienced as a practitioner, family member, and caregiver. I also began to encounter the work of several scholars – for example, Riyad Shahjahan, Mignolo and Walsh (2008), Albert Quijano (2001), and Tuck and Yang (2013) – that left me deeply unsettled with my approach to knowledge construction and how I conceptualized subjectivity. This unsettling – at once blissful and uncomfortable – left me in a space of wondering if and how I was going to be able to conduct research in a way that aligned with my values. It was not until I engaged deeply with the works of scholars such as Edna Szymanski (e.g., 1994, 2012), Berger and Lorenz (e.g., 2015), Arthur Bochner (e.g., 2000), and Jones, Adams, and Ellis (e.g., 2007, 2011, 2013) that I began to feel hopeful about the many forms that disability-related research could take and how I as researcher could move forward from an orientation of value-laden inquiry.

I therefore approach this study as a researcher who seeks to interrupt and build bridges, fully committed to considering what an alternative cartography of disability-related counseling research might look like when it embraces the ontological and epistemological multiplicity necessary to fully capture the vast breadth of disability and disability-related experiences.

Researcher's Philosophical Commitments

Scientific inquiry can be broadly understood as a "systematic quest for knowledge" through observation and evaluation, the philosophies of which form "the conceptual roots undergirding the quest for knowledge" (Ponterotto, 2005, p. 127; Kazdin, 2017). Within these conceptual roots are the domains of ontology, axiology, epistemology, and methodology (Creswell & Poth, 2016), where epistemology refers to the field of philosophy concerned with the nature, origin, and possibilities of knowledge construction; ontology is concerned with the nature of being and reality; methodology is concerned with how the research is conducted; and axiology examines how the values, or ethics, of the research are conveyed (Pennington & Hughes, 2017; Sumner, 2006; Szymanski & Parker, 2001). Together, these philosophical domains form the foundation of our basic belief systems and worldviews, or paradigms of knowledge. While these domains may be typically thought of in academic circles as belonging strictly in the realm of theory and philosophy, John Creswell suggests that one's philosophical commitments can and should be actively applied in both the design and writing of one's research (Creswell & Poth, 2016, p. 6). This belief is echoed among some disability scholars who argue that paradigms of knowledge form the foundation of research and, correspondingly, professional praxis.

Szymanski and Parker (2001) postulate that paradigms of knowledge, or ways of knowing, are at the core of professional counseling. They note that counselors' worldviews are shaped by how they perceive, understand, and value the etiology of knowledge and whose knowledge is considered real. These paradigms of knowledge have social power implications given that the institutionalized knowledge within the counseling profession is directly applied to social issues affecting the individuals we serve. For example, Cottone (2013) traces the evolution of counseling theory from psychological to systemic-relational to social constructivist paradigms. He explains how each paradigm has different philosophical, professional, and political implications for counseling practice. He also gives examples of how counselors can use broad theoretical frameworks to guide their specific interventions in different settings, arguing that counseling has matured as a profession and that counselors should be open to new developments in theory and research.

Consequently, counseling research must consider the welfare of the individuals we serve as paramount to professional inquiry. Two fundamental philosophical perspectives in which this work is heavily grounded come from two separate professional calls to practicing counselors; one is specific to disability (i.e., rehabilitation counselors) and one is a general to counseling professionals (i.e., the counseling field as a whole). These perspectives emphasize the importance of considering the needs and well-being of individuals served by the counseling profession.

More broadly, the American Counseling Association (ACA) calls upon counselors to "…develop knowledge of theories that explain how their privileged and marginalized status influences their experiences and worldview" (ACA, 2015, p. 5). Similarly, Szymanski, Parker, and Patterson (2012) call upon rehabilitation counselors to "…reconsider and reflect upon the sociopolitical context of [their] practice and embrace the paradox, think divergently, and continually challenge the institutional practices that castify and disempower people with disabilities. Without such vigilance and critical thinking, counselors can become instruments of castification rather than agents of empowerment" (p. 381). They posit this call highlights the need for critical, professional reexamination in the topic areas of paradox and divergence; understanding insider and outside perspectives; an awareness of the philosophies of knowledge in practice; differing perspectives on disability; models of disability; professionalism, power, and castification; and ultimately, recognizing that there are **multiple ways of knowing**.

Szymanski et al.'s (2012) discussion of multiple ways of knowing in practice considers the question "Whose knowledge counts?", an essential consideration in that many rehabilitation counselors occupy an outsider perspective in the disability community, and 'expert' knowledge within a profession "confers power to the professional" (p. 370). Philosophies of knowledge, or ways of knowing, in practice bring specifically to the fore the scientist-practitioner and reflective practice models as two primary approaches to professional knowledge, representing the positivist and constructivist-interpretivist frameworks, respectively. Of these, **I align with the constructivist-interpretivist paradigm that informs a model of reflective practice**. Where the positivist paradigm assumes reality is objective and directly observable, the constructivist-interpretivist paradigm recognizes the complexity of human interaction and perception, thereby acknowledging the social construction of multiple, subjective realities (Glesne & Peshkin, 1992; Mcleod, 2013). In terms of scientific traditions, the positivist paradigm aligns with quantitative traditions, whereas the constructivist-interpretivist paradigm is consistent with qualitative research methodology and the methods falling under the qualitative umbrella (Hayre & Muller, 2019).

Stubbins (1982, 1984) and Skrtic (1991) consider **professionalism to be inherently positivistic** given that professions operate under the assumption that knowledge can be institutionalized and accessed by a group of individuals who identify themselves as professional experts. The premise that professionalism is inherently positivistic is echoed by Kazdin (2017), Hayre & Muller (2019), and Szymanski and Parker (2001) who note that positivist and postpositivist paradigms have formed the breadth of contemporary counseling research. This is a concerning connection in that the positivist tradition continues to maintain and advance the hegemonic position of the disease model of biomedical science, and it is one that ultimately views disability as something to be cured or fixed (Hayre & Muller, 2019). McLeod (2013) correspondingly notes that the majority of therapy researchers have been so deeply ingrained and professionally socialized within the positivist paradigm that **"researchers need to be challenged to rethink their underlying (or taken-for-granted) assumptions about ontology and epistemology if they are to engage effectively with qualitative methodologies"** (p. 50).

The professional implications of a solely positivist perspective for rehabilitation counselors would be one of presumed convergence of a singular, objective, all-encompassing viewpoint of disability. Contrarily, the constructivist-interpretivist paradigm embraces divergent reasoning, thereby allowing for a professional research repository that represents a vast topography of disability related perspectives. Rumrill, Bellini, and Koch (2019), for example, note that the increasing number of qualitative studies conducted within the field of rehabilitation counseling highlight the growing acknowledgement of how critical it is to develop a repository of research within interdisciplinary disability studies that captures the breadth of lived experiences across the landscape of disability. Given the importance of capturing the breadth of lived experiences across the landscape of disability, I have chosen autoethnography as the method to explore the lived experiences of family caregivers of adults with IDD. The experiences of family caregivers of adults with IDD are an important area of study within the field of disability. By exploring these experiences through autoethnography, we can gain a deeper understanding of the challenges and triumphs faced by family caregivers.

Background and Significance of the Problem

Intellectual and Developmental Disabilities (IDD)

Intellectual and Developmental Disability (IDD) is a broad disability category that encompasses both Intellectual Disability (ID) and Developmental Disability (DD). DD refers to a chronic disability with an onset before the age of 22 and can include intellectual, physical, or both types of disabilities (NIH, n.d.). ID is a chronic disability with an onset before the age of 22 and is characterized by significant limitations in both intellectual and adaptive functioning (American Association on Intellectual and Developmental Disabilities [AAIDD], 2023). Intellectual functioning refers to the capacity for skill acquisition and problem-solving, with an IQ of less than or equal to 75 indicating significant impact. Adaptive functioning includes conceptual, social, and practical skills such as activities of daily living (ADLs) (AAIDD, 2023). The term IDD refers to individuals who fall under the broader umbrella of DD but may also have co-occurring ID. Examples of disabilities that fall under the IDD category include Down Syndrome, William’s Syndrome, and Phelan-Mcdermid Syndrome.

According to Anderson and colleagues (2019), just over 7 million individuals with IDD currently reside within the United States. Anderson et al. (2019) reviewed US studies on intellectual or developmental disabilities (ID/DD) since 2000 and found only one study of ID in adults and one study using DD Act definitions. Both studies used the 1994/1995 National Health Interview Survey on Disability (NHIS-D), a supplement to the CDC's National Health Interview

Survey (NHIS). The NHIS-D measured disability with social, administrative, and medical factors. The studies estimated a prevalence of 7.9 per 1,000 for ID/DD in US adults. While these studies provide insight into the prevalence of IDD in the US population, it is important to note that the support needs of individuals with IDD can vary greatly.

Individuals with IDD may have a wide range of support needs. These can include assistance with daily living skills, access to nutritional resources, childcare, early intervention services, counseling, and basic academic education for parents (The Arc, 2019). They may also have complex communication needs, such as difficulty with expressive or receptive language, social interactions, or understanding abstract concepts (Singh, 2016). In addition to communication needs, individuals with IDD may require support with activities of daily living (ADLs) like bathing or dressing, managing finances, and accessing healthcare (Singh, 2016). Given the wide range of support needs for individuals with IDD, family members often play a crucial role in providing care and support.

Family Caregiving and IDD

In the U.S., caregiving for adults with IDD is provided by a variety of sources. Family caregivers are often the primary source of support for these individuals and play a crucial role in supporting their complex communication and support needs (Braddock et al., 2015; McKenzie et al., 2016; NAC, 2020; Power, 2016;). In addition to family caregivers, adults with IDD may also receive support from paid direct support professionals (DSPs) (Friedman, 2021). However, DSP turnover is extremely high, which can impact the quality of care provided to individuals with IDD and helps to explain why family caregivers continue to be the most frequent providers of direct care (Friedman, 2021). Given the crucial role of family caregivers in supporting adults with IDD, it is important to understand the characteristics and experiences of these caregivers.

Caregivers of adults with IDD represent about 12 percent of all caregivers and have an average age of 51 (NAC, 2020). They are more likely to be caring for a child (58 percent), to be employed (64 percent), and to have lower household incomes (42 percent have less than $50,000) than other caregivers. Additionally, they provide care for longer periods of time, with an average duration of 16 years and a median duration of 10 years. These caregivers experience unique challenges and needs such as finding appropriate services and supports for their care recipients, planning for future care, and supporting communication difficulties. They also report higher levels of emotional stress (45 percent) and physical strain (24 percent) than other caregivers (NAC, 2020). Given the unique challenges and needs faced by family caregivers of adults with IDD, it is important to understand the support needs of the individuals they care for as well.

There is extensive variability in the intensity of an individual's support needs influenced by factors such as intellectual functioning, adaptive behavior, and mobility status. Individuals with IDD tend to have more significant support needs than their peers without disabilities (Chung et al., 2019), so family caregivers typically fall into the higher-hour/high support-need category. While family caregiving can provide numerous benefits for both individuals with IDD and their caregivers, it also presents unique challenges for caregivers.

Benefits and Challenges of Caregiving

Several aspects of family caregiving can have an empowering impact on the overall well-being of the family. For example, Beighton and Wills (2019) conducted a systematic review and narrative synthesis that aimed to identify positive aspects of parenting a child with intellectual disability (ID) from parental perspectives. The review included 22 studies that used qualitative methods and reported parental views on positive change, personal strength, and growth and development. These themes were mostly related to how parents coped, adapted, or grew from their experiences. However, the review also recognized that positive aspects did not negate the challenges or distress that some parents faced, and that not all parents reported positive aspects. Results from the review identified no clear theoretical framework or predictors for positive aspects of parenting. The authors suggested that future research should investigate underlying mechanisms and contextual factors that influence positive aspects of parenting, and that professionals should support parents' well-being and resilience by acknowledging and validating both the positive and negative aspects of parenting. Despite the potential for positive aspects of parenting a child with intellectual disability, it is important to recognize that family caregivers also face significant challenges and may experience negative impacts on their well-being.

The experiences related to caregiving, including emotional, physical, and financial aspects, greatly impact the quality of life of both the individual providing support and the individual receiving support (Livneh, 2001). Family caregivers who have a higher degree of unmet support needs consistently report higher levels of stress (Estes et al., 2013), caregiver strain (McGrew & Keyes, 2014), lower life satisfaction and well-being (Jackson, Wegne, 2010; Sullivan, Wino, 2012), and decreased optimism about their future (Crabb, 2019). These challenging caregiver outcomes have a direct impact on the quality of care and support they can provide for their loved ones.

Recognizing the impact that identifying positive outcomes can have on caregiver support can assist practitioners in assessing the availability and accessibility of resources. This can then help them implement informed, context-based supports that increase positive outcomes such as quality of life and general well-being among caregivers (Shogren et al., 2020). This approach focuses on increasing positive outcomes rather than only examining ways to reduce negative outcomes such as caregiver burden, stress, and anxiety. Given the critical role that caregivers play in the progress of their clients and the interdependence that exists between adults with IDD and their family caregivers, it is important to focus on addressing the needs of caregivers in addition to clients.

Pompon and colleagues (2015) discuss the importance of focusing on caregivers in addition to clients in order to improve treatment outcomes. The authors argue that caregivers play a critical role in the client's progress and their health and well-being can affect clients' outcomes. Addressing the needs of family caregivers reciprocally increases the likelihood of successful psychosocial outcomes for themselves and the individuals they care for. This includes positively framed outcomes such as family social support (Caton et al., 2019), family coping (Lee, 2009), family resiliency (Caldwell et al., 2018), and family quality of life (Claes et al., 2012). Addressing caregiver needs through this lens also recognizes the system of interdependence that exists between adults with IDD and their family caregivers (Chronister & Chan, 2006; Elliott et al., 1999). Despite this research, service provision for individuals with IDD continues to largely be available and directed solely toward the individual with IDD, leaving family caregivers to navigate a positive-yet-challenging role with little guidance or assistance.

Understanding the Support Needs of Family Caregivers of Individuals with IDD

There have been some attempts in the past to determine the types of resources and supports that are needed by family caregivers of IDD. The Family and Individual Needs for Disability Supports (FINDS), for example, was conducted by the Arc and the University and Minnesota in 2017 and aimed to understand family experiences related to providing care for a family member with IDD. The findings from this survey indicate that supports provided are highly variable and include interventions to support people in areas of behavior, health and medical supports (e.g., physical or occupational therapy), transportation, assistive technologies (e.g., augmentative and alternative communication (AAC) devices), and assistance with activities of daily living (ADLS), such as preparing meals, personal care, and going shopping. Ultimately, the report raised important questions about families, and specifically family caregivers, who provide such support. Rather, we as a scholarly community are still asking the same questions: What are the challenges families face meeting the support needs of their family member? What are the economic implications of caregiving (The Arc & Research and Training Center on Community Living, 2017)?

Crabb and colleagues (2019) conducted a longitudinal appraisal of family caregiving for people with disabilities enrolled in Medicaid managed care. Their study examined the impact of public family support on appraisals of caregiving burden, satisfaction, and self-efficacy among families of adults with disabilities. The study found that family members with more unmet family support needs had increased caregiving burden and decreased satisfaction and self-efficacy. Family members providing more unpaid care also reported higher burden, and parents had significantly lower satisfaction and self-efficacy. Their study highlights the importance of family support in improving caregiving appraisals, and clearly demonstrates a need for including family needs for services within assessments for disability services and policy. Despite the evidence that family support can improve caregiving appraisals, the voices and experiences of caregivers are often not adequately represented in counseling literature. In response to the need for family support highlighted by studies such as that of Crabb and colleagues (2019), initiatives such as the Family Caregiving Advisory Council have been established to address the needs of family caregivers.

The Family Caregiving Advisory Council was established by the RAISE Family Caregivers Act to provide recommendations on effective models of family caregiving and support to family caregivers. The council adopted 26 recommendations aimed at establishing a national approach to addressing the needs of family caregivers. These recommendations address critical priority areas including awareness and outreach to family caregivers, strengthening community-based supports for family caregivers, ensuring workplace and financial security for family caregivers, and greater focus on data, research, and the development of evidence-informed supports for family caregivers (AARP Praises Recommendations from RAISE Family Caregiving Advisory Council Calls on Congress to Act Now to Help Caregivers, 2021).

To increase awareness of family caregivers, the council recommends increasing public awareness and recognition of the diverse needs, issues, and challenges family caregivers face. Additionally, the council recommends increasing family caregivers' self-identification and awareness of information, services, and supports. The council also recommends improving outreach efforts to family caregivers to ensure early identification and access to services and supports (Family Caregiving Advisory Council Final Recommendations Adopted November 18th, 2020). Despite the council's recommendations to increase awareness and outreach to family caregivers, there is still a need for greater representation of their voices and experiences in the counseling literature, particularly for those who provide care for someone with complex communication needs, which the council did not address or define.

Caregiver Voice

Caregivers clearly play a critical role in supporting individuals IDD in varied and nuanced ways. However, their voices and experiences have not been adequately represented or addressed in the counseling and rehabilitation counseling literature. While there have been some studies about caregiver needs (e.g., Crabb et al., 2019; Williams & Perkins, 2014), there have been extremely few that directly relate to the caregiver voice and even fewer related to the caregiver voice for those who provide care to individuals with IDD who have complex communication needs.

The concept of caregiver voice has not been well-defined in the literature. However, recent studies have begun to recognize the critical role that caregivers play in the outcomes of their care recipients. Salmiranta et al. (2023) conducted a scoping review to explore the voice of caregivers by collating available research with the participation of caregivers of children and adolescents with spinal cord injury (SCI). The review found that participation in SCI research with caregivers can occur in a range of different ways and explores the extent to which caregivers' participation is connected to what might be called a voice.

The review identified 29 articles and found that in most of them, the caregivers were invited to participate in the research to complete or develop measures. The authors concluded that the voice of caregivers of children and adolescents with SCI in research is limited by representativeness, the pre-determined emphasis, a lack of involvement in the process, and the reported narrative. By reflecting on voice, caregivers can have their experiences and perspectives acted upon to a greater extent to bring change, ultimately leading to improved care and health for children and adolescents with SCI (Salmiranta et al., 2023). While the review by Salmiranta et al. (2023) highlights the limitations of caregiver voice in research, there are some articles that specifically address caregiver voice and knowledge specifically for family caregivers of individuals with severe ID.

In her article "Mingled bodies and voices: Maternal reflections on caregiver expertise and intellectual disability," MacGregor (2022) argues that caregiver knowledge must be viewed as essential expertise, even though it may be unconventional within the medical paradigm. She notes that people with profound intellectual disabilities (ID) often have complex medical issues and that optimal care rests upon the ongoing presence and expertise of their primary caregiver. MacGregor argues that medical professionals risk patient care by excluding the essential expertise of family caregivers. She draws on her personal experience and uses a postmodern view of the body to show how caregivers and their family members have mingled bodies and voices that enable them to communicate in ways that medical professionals cannot. She also discusses **the ethical challenges of balancing autonomy and dignity with the need for caregiver advocacy and support**. These ethical challenges highlight the importance of recognizing and valuing the expertise of caregivers in providing optimal care for individuals with disabilities. MacGregor's argument that caregiver knowledge must be viewed as essential expertise aligns with the rehabilitation counseling philosophy of considering individuals within the context of their family systems and communities.

Rehabilitation counseling philosophy is anchored in viewing disability through an asset-oriented lens and understanding the impact of environmental variables on one's functional capacity (Wright, 1972, 1983). This socioecological understanding sets rehabilitation counselors apart as uniquely skilled professionals to address contextual barriers encountered by family caregivers of individuals with disabilities. It is a core value definitive to our practice that we emphasize a commitment to considering individuals within the context of their family systems and communities (CRCC, 2018). It is therefore incumbent upon professionals in the field to employ this unique set of knowledge and skills to facilitate an understanding of issues related to the entanglement of voice experienced by family caregivers of adults with IDD. This can inform practices that support overall family empowerment, adaptation, and adjustment to the lifelong role of caregiving. As a rehabilitation counselor and a family caregiver, I write for a cross-disciplinary audience of caregivers, counselors and other professionals involved in the caregiving process. I hope to share insights and information that can benefit everyone in this role.

Brief Summary of Methodology

As a family caregiver of an adult with IDD who has complex communication and support needs, and as a counselor working alongside family caregivers of adults with IDD, my identity and lived experience provides valuable insight to understanding the entanglement of voice between family caregivers and the individuals with IDD for whom they provide care. I am therefore using autoethnography, a qualitative method of narrative inquiry that centers critical, cultural analysis and interpretation through storytelling, to investigate the above research question.

Autoethnography is a research method that "seeks to describe and systematically analyze personal experiences in order to understand cultural experience" (Ellis, Adams, & Bochner, 2011, p. 273). This approach combines elements of autobiography and ethnography to produce a rich and nuanced understanding of the cultural context being studied. By using their own experiences as a primary source of data, autoethnographers are able to provide an insider perspective on the culture or phenomenon being studied. A more detailed account of this method will be provided in chapter three (methodology) of this dissertation.

Interpretive Framework Considerations

It is after much deliberation, consideration, and intention that I have chosen not to include an apriori framework in which to bind and border this inquiry. My rationale for this choice is to maintain an open stance throughout the data generation process and prevent the imposition of preconceived themes or constructs on the data, as well as to remain true to my epistemological and ontological commitments (e.g., Bhattacharya, 2017; Ellis, 2004). That said, it is impossible to divorce myself from my training, my experience, and my pull toward specific frameworks that invariably have influence over my intellectual meaning-making. I am therefore including a brief introduction to the following three lenses that have informed how I have come to this research and how they may potentially inform my data analysis and discussion: (a) Bronfenbrenner's (1979) ecological systems theory, (b) Simplican and colleagues (2015) ecological model of social inclusion, and (c) an emancipatory paradigm. My purpose in sharing these perspectives is to show how they have shaped my inquiry and to acknowledge their potential relevance for the analysis, interpretation, and discussion of the data generated in this study.

Ecological Lens

Bronfenbrenner's (1979) ecological systems theory describes the interactional environment as being comprised of nested, interdependent systems and subsystems. These include the microsystem, mesosystem, exosystem, macrosystem, and chronosystem.

Microsystem. The microsystem includes the individual's immediate setting such as home or school (Bronfenbrenner, 1979). Some possible events that would be part of the microsystem for individuals with IDD might include interactions with family members, caregivers, and peers, participation in educational, vocational, and/or recreational and leisure activities, and engagement in self-care and daily living skills.

Mesosystem. The mesosystem is a set of interrelations between two or more settings in which the individual actively participates. For an adult with IDD, some examples of mesosystem events might include a meeting between their case manager and support team, a social outing with their peers from a day program or a support group, A family gathering where they interact with their relatives and friend, or a a visit to their doctor or therapist where they receive health care and guidance.

Exosystem. The exosystem includes settings that impact the individual indirectly, such as interactions between a case manager and their supervisor. The macrosystem reflects elements of culture and subculture such as belief systems and values (Bronfenbrenner, 1979). Some examples of exosystem events for an adult with IDD might include the policies and practices of a school system or adult day program, the availability and quality of community-based programs and facilities that provide recreational, social, and vocational opportunities for individuals with IDD, the attitudes and beliefs of the general public and the media regarding individuals with IDD and their rights and needs, and the economic and political conditions that influence the funding and legislation for disability services and advocacy.

Chronosystem. In 1986, Bronfenbrenner proposed the chronosystem as an addition to his ecological theory. The chronosystem refers to the temporal dimension of an individual's ecological contexts and how they influence development. It encompasses both the changes that occur within the individual and the environment over time, as well as the historical and socio-cultural events that shape the individual's life course. For instance, the chronosystem includes events such as family transitions (e.g., divorce, remarriage, birth, death), residential and educational mobility, and socio-economic fluctuations. It also includes historical events such as wars, economic crises, and social movements that affect the individual's opportunities and challenges.

Ecological Lens within IDD

To further contextualize IDD and caregiving, I will be considering the ecological systems framework from an IDD perspective. In their proposed ecological model of social inclusion for individuals with IDD, Simplican and colleagues (2015) describe how the variables embedded within each level of an individual's ecological system interact and influence personal outcomes, having either an enabling or disabling impact on overall individual functioning. Further, while the elements of Simplican and colleagues' (2015) system levels are conceptually similar to Bronfenbrenner (1979) they appear nominally different (i.e., instead of macro-, exo-, meso-, and microsystems, they alternatively describe each level as sociopolitical, community, organizational, interpersonal, and individual, respectively).

Emancipatory Lens

An emancipatory paradigm in disability research is a framework that promotes the voices of people with disabilities to make possible transformative changes to their lives. This approach takes a political position and is based on the social model of disability, which views disability as a socially constructed experience rather than an individual medical problem. Emancipatory research aims to empower people with disabilities by including their voices and perspectives in the research process (Barnes, 2003; Oliver, 1992; Zarb, 1992). Of further note is that while some scholars within interdisciplinary studies argue that nondisabled people possess a worldview that prevents them from doing research that has emancipatory potential for disabled people (e.g., Charlton, 1998), others acknowledge the "marginal position both in society at large and within disability studies" that the parents (or guardians or primary family caregivers) of individuals with disabilities occupy, and therefore find the emancipatory potential and value of sharing these stories of "individuals with different perspective on the disability experience and who occupy different social positions with respect to disability" (Green, 2015, p. 58)

There are several examples of scholars using and/or articulating the dynamics of an emancipatory approach to disability and disability-related inquiry in literature. For example, Doan (2020) discusses the emancipatory approach in hospitality research on employees with disabilities, suggesting guidelines for conducting qualitative research that includes their voices. Zarb (2007) distinguishes between participatory and emancipatory research and discusses how both differ from other research practices. Barnes (2003) provides a broad-based overview of the development of emancipatory disability research in the UK since its emergence in 1992, discussing key elements of this approach including accountability, choice of methods, empowerment, dissemination, and outcomes. As it relates to caregivers of individuals with developmental disabilities (DD), Vasquez and colleagues (2019) discuss strategies for including individuals with DD and their caregivers in qualitative, community-based research studies; for example, including family caregivers on advisory committees. These examples illustrate how an emancipatory approach to disability research can challenge the dominant paradigms and empower marginalized groups, including family caregivers of individuals with IDD, within the cartography of counseling and disability-related research.

I envision using the systems lenses to frame my understanding of my caregiver experiences and how both my brother and I are impacted across different levels of the system. This includes immediate support available through friends (micro) as well as supports and services provided by HCBS waiver (meso- and macro). I see the Simplican model as a way to understand how my impact as a caregiver is directly related to how my brother with IDD is impacted individually across each level of our shared ecological systems. Additionally, autoethnography aligns with an emancipatory approach to disability-related research, specifically for family caregivers of adults with IDD.

Definitions

Throughout this dissertation, I will be referring to terms such as IDD, complex communication needs, family caregiver, and entanglement of voice. I reiterate them here for clarity:

***Intellectual and Developmental Disabilities (IDD)* –** a disability that occurs before age 22 and is characterized by significant limitations in intellectual functioning and adaptive behavior as expressed in conceptual, social, and practical adaptive skills.

***Complex Communication Needs (CCN)* –** A term used to describe the situation of individuals who have difficulties with verbal and non-verbal communication, thus requiring specialized support for effective communication (e.g., an AAC device or PECS). For example, individuals with CCN may encompass individuals who have the ability to speak, yet experience challenges with comprehension or expressing their wants and needs; individuals who may not have the ability to speak but convey their thoughts through gestures and behaviors; individuals who have sensory and physical support needs that impact their capacity to engage in communication; and individuals who require additional time to process information and to respond.

***Family Caregiver* –** An individual who provides unpaid or informal care to a family member with a disability or medical condition, and who is related to their care recipient by blood, marriage, adoption, or other social or cultural bond.

***Entanglement of Voice* –** A situation where a caregiver speaks on behalf of a care recipient who has complex communication needs (i.e., difficulty expressing themselves verbally and/or nonverbally). This may happen because the care recipient relies on the caregiver for various aspects of daily living, and because vocal communication is often valued more than other forms of communication in society. Entanglement of voice affects both the care recipient and the caregiver in many ways, and it may change over time depending on the individual needs and circumstances of each person.

CHAPTER 2: REVIEW OF THE LITERATURE

To adequately address the previously stated research question, it is necessary to conduct a comprehensive review of the extant literature pertaining to the relevant concepts and ideas of this inquiry. This literature review begins with an overview of intellectual and developmental disabilities (IDD), including definition, prevalence, and characteristics such as complex communication and support needs. Finally, the landscape of family caregiving in the United States is discussed, with a focus on why it is necessary to explore and understand the needs of family caregivers who experience an entanglement of voice with their care recipients with IDD.

Intellectual and Developmental Disabilities (IDD): A Breakdown of Terms

Intellectual and developmental disabilities (IDD) is a broad disability category that can be more easily understood by breaking down the terms into their component parts (i.e., intellectual disability and developmental disability, respectively). Developmental disability is the broader of the two terms and refers to a category of chronic disability with an age of onset that is before 22 years, and can include the presence of intellectual disability, physical disability, or both (American Association on Intellectual and Developmental Disabilities [AAIDD]; 2023). Intellectual disability is also a category of chronic disability with an age of onset prior to 22, with the primarily differentiating factors of the presence of significant limitations to both intellectual and adaptive functioning (AAIDD, 2023). Intellectual functioning includes things like skill acquisition, problem solving, and critical thinking. Adaptive functioning includes skills such as conceptual skills, social skills, and practical skills).

The term IDD, then, refers to individuals who fall under the broader umbrella of developmental disability but may also have co-occurring intellectual disability (AAIDD, 2023). For example, an individual with autism spectrum disorder (ASD) would fall under the IDD umbrella, as ASD is a developmental disability, but note that ASD does not inherently include the co-occurring presence of ID. Down Syndrome, on the other hand, is a developmental disability that also falls under the IDD umbrella, but does include the co-occurrence of ID.

IDD and Level of Support Needs

People with IDD may have complex communication needs (CCN), meaning they have difficulties or disabilities that affect their ability to communicate effectively with others and they may have trouble expressing or understanding verbal, non-verbal, or written messages (Light & Drager, 2009). Communication Rights Australia (2018) defines complex communication needs (CCN) as a broad term to describe people who have severe speech, language, and communication impairments, and may include individuals who have the ability to speak, yet experience challenges with comprehension or expressing their wants and needs; individuals who may not have the ability to speak, but convey their thoughts through gestures and behaviors; individuals who have sensory and physical support needs that impact their capacity to engage in communication; and individuals who require additional time to process information and to respond. CCN can result from various factors, such as developmental disorders, brain injuries, degenerative conditions, or sensory impairments. CCN can impact a person's social, educational, and vocational opportunities and outcomes, as well as their quality of life and human rights. Therefore, it is important to provide people with IDD and CCN with appropriate support and intervention that enhance their communication skills and autonomy, and that are tailored to their specific needs and goals.

One study that examined the quality of life and support for individuals with severe ID and complex needs, including those with CCN, is Beadle-Brown and colleagues (2016). They define complex needs as having additional sensory or physical impairments, autism, challenging behavior, or mental health problems. Data was collected from 110 people living in different types of services in England using structured observations and staff questionnaires. Quality of life was measured using indicators such as engagement in meaningful activities, social inclusion, choice and control, and well-being. Quality of support was measured using indicators such as active support, person-centered approaches, communication support and positive behavior support.

The findings suggest that individuals with severe ID and complex needs have relatively poor quality of life (QoL) and support compared to those with less severe disabilities. They spend a lot of time isolated and disengaged and receive little contact and assistance from staff. However, about one-third of the participants receive consistently good active support, which enables them to participate in meaningful activities and relationships. Active support is associated with other aspects of quality of support and is the strongest predictor of QoL outcomes.

The article concludes that active support is key in improving the quality of life and support for individuals with severe intellectual disability and complex needs. It recommends implementing and monitoring active support in services for this group and further research on how to adapt it to meet their specific needs and preferences. Since family caregivers are often the most frequent providers of active support to their family members with IDD, these outcomes are directly related to family caregiver outcomes. By providing active support, family caregivers can improve the quality of life and support for their loved ones with severe intellectual disability and complex needs. However, in order to provide that active support, caregivers need to be supported themselves. This is especially important when their loved one has complex communication and support needs, as they may serve as a vocal proxy or voice for their loved one with IDD. It is important to note that the terminology used to describe individuals with intellectual and developmental disabilities has evolved over time and can impact how support is provided and perceived.

Historical Context of Intellectual Disability

While intellectual disability (ID) is now recognized – both diagnostically and colloquially – as the accepted term of use, the former diagnostic term of *mental retardation* (MR) is a historically loaded label of which it is essential to be cognizant when considering inclusivity, service provision, and individual support needs within the IDD community. Prior to its official use, Schalock, Luckasson, and Shogren (2007) extrapolated on the professional trend in the preferred use of ID and the corresponding degrees of impacted functioning as a replacement for mental retardation by outlining how both the construction and definition of a term influence the understanding of the term itself.

The construct of mental retardation (MR) was based solely on IQ score and included categories of severity such as borderline, mild, moderate, severe, and profound. These categories were based on a range of IQ scores: borderline intellectual functioning (IQ = 71-84); mild MR (IQ = 50- ~70); moderate MR (IQ = 35/40-50/55); severe MR (IQ = 20/25-35/40), and profound MR (IQ < 20-25) [^First & Tasman, 2004; DSM-IV; APA, 1994^]. The American Association on Mental Retardation (now known as the American Association on Intellectual and Developmental Disabilities (AIDD)) has provided substantial guidance in informing the conceptual understanding of ID over the past several decades. They were the first to suggest an adaptive functioning component in the ID diagnosis in conjunction with IQ score [^American Association on Mental Retardation, 1992]. This inclusion of adaptive functioning acknowledged that certain supports (or lack thereof) contributed to the overall functioning of the individual, either improving or exacerbating the nature of the disability simply by access to resources.

Since its inception, the AAIDD has produced several manuals to inform practice, service provision, and the conceptual understanding of IDD, the most recent of which is the eleventh edition of *Intellectual Disability: Definition, Classification and Systems of Supports* (Schalock et al., 2010; American Association on Intellectual and Developmental Disabilities [AAIDD], 2010). According to this edition, intellectual disability is defined by intellectual functioning *and* adaptive behavior, where adaptive behavior includes 1) conceptual skills, 2) social skills, and 3) practical skills, and has an age of onset prior to eighteen (AAIDD, 2010). Components of adaptive behavior formerly contributed to AAIDD's conceptualization of what constituted mild, moderate, severe, and profound IDD, and while these identifiers are no longer utilized by AAIDD, note that the diagnostic specifiers of severity for *mild, moderate, severe*, and *profound*, as set out in the Diagnostic and Statistical Manual for Mental Disorders (5th ed.; DSM-5; American Psychiatric Association [APA], 2013), maintain that *adaptive functioning*, rather than IQ score, dictate degree of severity based on the *level of one's support needs*. This is not solely, but especially because the lower the IQ score, the lower the construct validity of that score.

The historical context of terminology provides a foundation for understanding how services have been allocated in the past and continue to be informed (and misinformed) by oppressive and disabling criteria meant to rank and categorize. It also highlights how the power of language lingers long after policy shifts and how rehabilitation counselors can target the most salient issues faced by the IDD community as they arise. Specifically, it is important to consider how the degree of an individual's support needs with IDD influence post-school service provision, social engagement, community access, and ultimately, quality of life (QoL) outcomes.

Family Caregiving and IDD

The Landscape of Caregiving

Caregiving is on the rise in the United States. Between 2015 and 2020, the number of individuals providing unpaid care to an adult with health or other functional needs increased from 43 million (18 percent of Americans) to 53 million (21 percent of Americans), resulting in nearly 10 million more caregivers today than eight years ago (National Alliance for Caregiving [NAC], 2020). The National Alliance for Caregiving (NAC) and AARP have published a series of reports based on their Caregiving in the U.S. 2020 study, which provides a comprehensive overview of the current state of family caregiving in the U.S. Each report covers various aspects of caregiving, including demographic characteristics, types of care provided, length of caregiving, and the impact of caregiving on individuals' health and well-being. Some examples of these reports are the Millennial Caregiver, the Feeling Alone Caregiver, the African American Caregiver, and the Student Caregiver.

Of the individuals who provide care for adults 18 and older, nearly 90 percent provide care for a family member. Of these, nearly 60 percent are providing care to an adult family member residing in the caregiver's home (NAC, 2020). The NAC executive summary notes some of the most common challenges faced by caregivers, including coordinating care, managing finances, finding information and resources, balancing work and caregiving, and coping with emotional and physical stress. Along with this, caregivers are reporting outcomes that are comparatively poorer than in 2015, with 23 percent of caregivers reporting that their caregiving role has had a negative impact on their health.

The Taxonomy of Caregiving

According to Singer, Biegel, and Conway (2014), the "taxonomy of caregiving" for "vulnerable family members" is defined according to functionality. Family support is approached according to category, with categories traditionally defined by medical diagnostic categories. The authors suggest a cross-categorical conceptualization of disability and family support based on a functional analysis of disability and caregiver support needs. A perusal of measures of caregiver burden developed in categorical research suggests that many functions that caregivers perform are likely to be more similar across conditions than different. For example, a cross-disability approach to understanding and supporting the caregiving functions of families. Caregiving due to chronic illness and disability represents something that is not very different from traditional tasks and activities rendered to family members. The difference is that "caregiving" here represents the increment of extraordinary care that goes beyond the bounds of normal or usual care (Singer et al., 2010).

At the same time that the need for family caregiving is increasing, the demographic makeup of families has undergone extensive change. Families have grown smaller over the past century, meaning there are fewer individuals available to provide care. Family caregiving also impacts employment in ways that create a need for community supports designed to reduce the number of work hours caregivers miss.

There are different professional journals and associations that include family support as part of their areas of concern. These include separate approaches for caregiving families falling into each of the broad disability categories: chronic illnesses, developmental disabilities, mental illness, and the conditions associated with old age.

Ultimately, Singer and colleagues (2014) propose a cross-categorical approach to understanding and supporting family caregiving based on a functional analysis of disability and caregiver support needs. This approach recognizes that many functions performed by caregivers are similar across conditions and suggests that caregiving due to chronic illness and disability represents an increment of extraordinary care beyond normal or usual care. As the need for family caregiving increases and families grow smaller, there is a need for community supports to help reduce caregiver burden.

Family caregivers are the main source of natural support for adults with IDD (Braddock et al., 2015; NAC, 2020; McKenzie et al., 2016). More and more individuals with IDD are living with their family members. The National Residential Information Systems Project (RISP) in 2016 reported that the number of individuals with IDD living with a family member rose by 120 percent from 1998 to 2016, from 325,650 to 714,910. Most of them (78 percent) were 22 years old or older. This age is important for individuals with IDD because the Individuals with Disabilities Education Act (IDEA) guarantees that children with disabilities from 3 to 21 years old who live in the State have the right to a Free Appropriate Public Education (FAPE) (34 CFR § 300.101).

When adults with IDD age out of school at 22, they are no longer entitled to services under IDEA. Instead, they may become eligible for other services, such as vocational rehabilitation, which are not entitlements but rather are based on eligibility criteria and availability of funding (U.S. Department of Education, Rehabilitation Services Administration, n.d.).Unlike IDEA, which guarantees services to all eligible children with disabilities, vocational rehabilitation services are subject to availability of funding and may have waiting lists (U.S. Department of Education, Rehabilitation Services Administration, n.d.).

Benefits and Challenges of Caregiving

This shift in service provision can create additional challenges for caregivers of adults with IDD. Caregivers of adults with IDD represent about 12 percent of all caregivers and have an average age of 51. They are more likely to be caring for a child (58 percent), to be employed (64 percent), and to have lower household incomes (42 percent have less than $50,000) than other caregivers. They also provide care for longer periods of time, with an average duration of 16 years and a median duration of 10 years. Caregivers of adults with IDD experience unique challenges and needs such as finding appropriate services and supports for their care recipients, planning for future care and supporting communication difficulties. They also report higher levels of emotional stress (45 percent) and physical strain (24 percent) than other caregivers (NAC, 2020).

Several aspects of family caregiving have an empowering impact on the overall well-being of the family unit creating a "system of interdependence" between the individual with IDD and their family caregiver(s) (Grossman, 2018). Beighton and Wills (2019), for example, conducted a systematic review and narrative synthesis that aimed to identify positive aspects of parenting a child with intellectual disability (ID) from parental perspectives. It included 22 studies that used qualitative methods and reported parental views on positive change, personal strength, and growth and development. These themes were mostly related to how parents coped, adapted, or grew from their experiences. However, the review also recognized that positive aspects did not negate the challenges or distress that some parents faced, and that not all parents reported positive aspects. Results from the review identified no clear theoretical framework or predictors for positive aspects of parenting. The authors suggested that future research should investigate the underlying mechanisms and contextual factors that influence positive aspects of parenting, and that professionals should support parents' well-being and resilience by acknowledging and validating both the positive and negative aspects of parenting.

While there are positive aspects to parenting, it is important to also acknowledge the challenges that caregivers may face. The emotional, physical, and financial experiences related to caregiving can greatly impact one's quality of life (QOL; Livneh, 2001) and ultimately the psychosocial adaptation and adjustment of both the individual providing support and the individual receiving support. For example, family caregivers of individuals with IDD who have a higher degree of unmet support needs consistently report higher levels of stress (Estes et. al., 2013), caregiver strain (McGrew & Keyes, 2014), lower life satisfaction and well-being (Jackson, Wegner, & Turnbull, 2010; Sullivan, Winograd, Verkuilen, & Fish, 2012), and decreased optimism about their future (Crabb, Ownen, Stober, & Heller, 2019). These challenging caregiver outcomes have a direct impact on the quality of care and support they can provide for their loved ones.

Recognizing both the positive and challenging aspects of caregiving is important for practitioners to assess the availability and accessibility of resources. This can help implement informed, context-based supports that focus on increasing positive outcomes such as quality of life (QOL) and general well-being among caregivers (Shogren et al., 2020). This approach moves away from a deficit-orientation that only examines ways to reduce negative outcomes such as caregiver burden, stress, and anxiety.

For example, Pompon, Burns, and Kendall (2015) discuss the importance of focusing on caregivers in addition to clients in order to improve treatment outcomes. The authors argue that caregivers play a critical role in the client's progress and that their health and well-being can affect the client's outcomes. Addressing the needs of family caregivers reciprocally increases the likelihood of successful psychosocial outcomes for themselves and the individuals they care for, including positively framed outcomes such as family social support (Caton, Koivunen, & Allison, 2019), family coping (Lee, 2009), family resiliency (Caldwell et al., 2018), and family quality of life (FQOL; Claes et al., 2012). Addressing caregiver needs through this lens also recognizes the system of interdependence that exists between adults with IDD and their family members (Chronister & Chan, 2006; Elliott, Shewchuk, & Richards, 1999). Despite this research, service provision for individuals with IDD continues to largely be available and directed solely toward the individual with IDD, leaving family caregivers to navigate a positive-yet-challenging role with little guidance or assistance.

There have been some attempts in the past to determine the types of resources and supports that are needed by family caregivers of IDD. The Family and Individual Needs for Disability Supports (FINDS), for example, was conducted by the Arc and the University and Minnesota in 2017 and aimed to understand family experiences related to providing care for a family member with IDD. The findings from this survey indicate that supports provided are **highly variable** and include interventions to support people in areas of behavior, health and medical supports (e.g., physical or occupational therapy), transportation, assistive technologies (e.g., augmentative and alternative communication (AAC) devices), and assistance with activities of daily living (ADLS), such as preparing meals, personal care, and going shopping. Ultimately, the report raised important questions about families, and specifically family caregivers, who provide such support. Rather, we as a scholarly community are still asking the same questions: What are the challenges families face meeting the support needs of their family member? What are the economic implications of caregiving (The Arc & Research and Training Center on Community Living, 2017)?

These findings are consistent with Green and colleagues' (2013) metanalysis of qualitative studies of parents of children with disabilities from 1960 to 2012. This chapter reviews qualitative research on parenting children with disabilities published over the last 50 years to explore whether shifts in academic discourse and changes in professional training have affected research on parenting and/or the experiences of parents who are the subject of such research. An extensive literature search was conducted, and 78 peer-reviewed, qualitative studies on the experience of parenting a child with a disability were included in the sample. Themes were extracted from the reviewed literature and compared across decades. The findings suggest that some aspects of the parenting experience have changed very little. In particular, parents continue to experience negative reactions such as stress and anomie, especially early in their children's lives, and socially imposed barriers such as unhelpful professionals and a lack of needed services continue to create problems and inspire an entrepreneurial response. In addition, stigmatizing encounters with others continue to be a common occurrence. In contrast to earlier decades, studies conducted in more recent years have begun to use the social model of disability as an analytic frame and also increasingly report that parents are questioning and challenging the concept of "normal" itself.

Crabb and colleagues (2019) conducted a longitudinal appraisal of family caregiving for people with disabilities enrolled in Medicaid managed care. Their study examined the impact of public family support on appraisals of caregiving burden, satisfaction, and self-efficacy among families of adults with disabilities. The study found that family members with more unmet family support needs had increased caregiving burden and decreased satisfaction and self-efficacy. Family members providing more unpaid care also reported higher burden, and parents had significantly lower satisfaction and self-efficacy. Their study highlights the importance of family support in improving caregiving appraisals, and clearly demonstrates a need for including family needs for services within assessments for disability services and policy.

While caregivers play a critical role in supporting individuals with IDD and can provide valuable information and guidance to healthcare providers and other support personnel, their voices and experiences have not been adequately represented or addressed in the counseling literature.

Anchored deep within the foundation of rehabilitation counseling philosophy are the firmly rooted principles of viewing disability through an asset-oriented lens, realizing that the presence or absence of environmental variables can both enable and disable one's functional capacity, and that fully grasping the impact of disability necessarily commands an individualized understanding of the interaction of those variables, including the role of family members (Wright, 1972, 1983). Not only does this socioecological understanding of disability set rehabilitation counselors apart as uniquely skilled human service professionals to address the amalgam of contextual barriers encountered by family caregivers of individuals with disabilities, but it is also a core value definitive to our practice in that we emphasize "…a commitment to considering individuals within the context of their family systems and communities" (CRCC, 2018, p. 1). It is therefore incumbent upon professionals in the field to employ this unique set of knowledge and skills to facilitate an understanding of issues related to the entanglement of voice experienced by family caregivers of adults with IDD to inform practices that support overall family empowerment, adaptation, and adjustment to the lifelong role of caregiving.

IDD Voice

One of the challenges faced by individuals with IDD is the lack of voice and representation in various domains of life. Voice, in this context, refers to the ability to express one's opinions, preferences, needs, and rights, as well as to participate in decision-making processes that affect one's well-being (Voice, n.d.). Literature on IDD and voice has explored various aspects of this issue, such as the barriers and facilitators of voice, the role of information communication technology (ICT) in enhancing voice, and the outcomes and impacts of voice for individuals with IDD and their families.

Barriers and Facilitators of Voice – Some of the barriers to voice identified in the literature include stigma, discrimination, lack of awareness and education, communication difficulties, dependency on others, and power imbalances (Interactions with Individuals with Intellectual and Developmental Disabilities, 2017). On the other hand, some of the facilitators of voice include self-advocacy skills, social support, empowerment programs, accessible information, and legal rights (Interactions with Individuals with Intellectual and Developmental Disabilities, 2017).

Outcome and Impact of Voice –The literature suggests that voice can have positive effects on various aspects of life for individuals with IDD and their families. For example, voice can enhance self-esteem, confidence, autonomy, self-determination, quality of life, social relationships, health outcomes, and human rights (Interactions with Individuals with Intellectual and Developmental Disabilities, 2017). Voice can also contribute to social change by challenging stereotypes, raising awareness, promoting inclusion and diversity, and influencing policies and practices (Interactions with Individuals with Intellectual and Developmental Disabilities, 2017). Therefore, voice is a crucial concept for understanding and improving the lives of individuals with IDD.

Caregiver Voice

The concept of caregiver voice has not been well-defined in the literature. However, recent studies have begun to recognize the critical role that caregivers play in the outcomes of their care recipients. As a result, there is a growing recognition that the voices of caregivers must be considered in order to achieve these outcomes. Salmiranta et al. (2023) conducted a scoping review to explore the voice of caregivers by collating available research with the participation of caregivers of children and adolescents with spinal cord injury (SCI), and synthesizing how the research has been conducted. The review found that participation in SCI research with caregivers of children and adolescents with SCI can occur in a range of different ways. This review explores the extent to which caregivers' participation is connected to what might be called a voice.

Descriptive and narrative information was extracted and factors describing how caregivers participated were identified using an inductive approach. The review identified 29 articles, of which 28 had affiliations connected to the USA. In most of the articles, the caregivers were invited to participate in the research to complete or develop measures. Information from the caregivers was often captured using close-structured questions and summarized quantitatively with little or no exploration of the perspectives of the caregivers. The authors concluded that the voice of caregivers of children and adolescents with SCI in research is limited by representativeness, the pre-determined emphasis, a lack of involvement in the process, and the reported narrative. By reflecting on voice, caregivers can have their experiences and perspectives acted upon to a greater extent to bring change, ultimately leading to improved care and health for children and adolescents with SCI (Salmiranta et al., 2023).

Laura MacGregor's (2022) article "Mingled bodies and voices: Maternal reflections on caregiver expertise and intellectual disability" is one of the few articles that talks specifically about caregiver voice and knowledge. In her article, MacGregor argues that caregiver knowledge must be viewed as essential expertise, even though it may be unconventional within the medical paradigm. She notes that people with profound intellectual disabilities often have concurrent, complex medical issues that are complicated by their inability to self-advocate. Optimal care therefore rests upon the ongoing presence and expertise of their primary caregiver. MacGregor argues that medical professionals risk patient care by excluding the essential expertise of family caregivers at any time, especially during COVID-19. She draws on her personal experience as the mother of a young adult with profound disabilities and uses a postmodern, intersubjective view of the body to show how caregivers and their family members have mingled bodies and voices that enable them to communicate and understand each other in ways that medical professionals cannot. She also discusses the ethical challenges of balancing the autonomy and dignity of people with intellectual disabilities with the need for caregiver advocacy and support.

Ashby (2011) explores the challenges and possibilities of giving voice to individuals who type to communicate in qualitative research. She argues that traditional notions of voice, competence, and agency need to be reexamined and broadened to include the diverse forms of expression that people with disabilities use. She draws on her own research experiences with students who do not use speech as their primary mode of communication and highlights four key issues: a) the question of competence for individuals who do not use speech, b) hearing silence, c) agency and voice, and d) broadening the conceptualization of "voice" beyond speech. She concludes with some suggestions for qualitative researchers who want to facilitate voice for individuals using alternative forms of expression, such as acknowledging the complexity and multiplicity of voice, being reflexive about one's own assumptions and positionality, and collaborating with participants and their supporters throughout the research process. Ashby’s (2011) work speaks to the entanglement of voice that can happen between family caregivers who serve as a vocal proxy for their loved ones who are unable to express verbally or vocally, and how qualitative research can help to disentangle and amplify the voices of those whose primary form of communication is not vocal or verbal. Building on the work of Ashby (2011) and others, I explore in this inquiry the entanglement of voice that occurs between family caregivers and their loved ones with IDD who have complex needs.

CHAPTER 3: METHODOLOGY

This chapter provides a detailed description of the research design and methodology selected for this inquiry, including participants and data sources, data generation methods, data management plan, strategies for protecting participant identity, and strategies for data analysis and interpretation. Finally, I provide an overview of how trustworthiness (similar to reliability and validity) is approached within the autoethnographic tradition, addressing my own subjectivity and bias, as part of the research process in which I engage.

Research Design

The purpose of this research was to use autoethnography to reflexively examine how voice and voicelessness (i.e., an entanglement of voice) between family caregivers and their adult care recipients with IDD impact the care needs and the overall well-being of family caregivers of adults with IDD. As a family caregiver of an adult with IDD who has complex communication and support needs, and as a counselor working alongside family caregivers of adults with IDD, my identity and lived experience provide valuable insight to understanding this entanglement. As a qualitative form of narrative inquiry, autoethnography is well-suited to center critical, cultural analysis through the interpretation of caregivers of adults with IDD's storytelling performances. My primary research question for this inquiry is *What can my experience as a family caregiver uncover about the entanglement of voice among family caregivers of adults with IDD who have complex communication and support needs?*

Philosophical Commitments

As articulated in the introduction of this proposal, counseling research must necessarily consider the welfare of the individuals served as the crux professional inquiry. To reiterate, Szymanski and colleagues (2012) call upon counselors working in the field of disability to

"…reconsider and reflect upon the sociopolitical context of [their] practice… and continually challenge the institutional practices that castify and disempower people with disabilities" (p. 381). This call highlights the importance of considering "Whose knowledge counts?" in rehabilitation counseling, as many counselors are outsiders to the disability community and 'expert' knowledge confers power.

Stubbins (1982, 1984), Skrtic (1991), Kazdin (2017), Hayre & Muller (2019), and Szymanski and Parker (2001) observe that professionalism is inherently positivistic and that positivist and postpositivist paradigms have dominated contemporary counseling research. A positivist perspective in rehabilitation counseling assumes a singular, objective viewpoint of disability. In contrast, the constructivist-interpretivist paradigm allows for diverse reasoning and a broad range of disability-related perspectives. Rumrill, Bellini, and Koch (2019) note the growing importance of capturing the lived experiences of people with disabilities through qualitative research. I align with the constructivist-interpretivist paradigm, which acknowledges the social construction of multiple subjective realities and is consistent with qualitative research methodology.

The methodological dominance of positivist and postpositivist traditions is concerning because they generally uphold the hegemonic position of the disease model of biomedical science, which views disability as something to be cured or fixed. McLeod (2013) adds that therapy researchers have been so deeply ingrained within the positivist paradigm that they need to be challenged to rethink their assumptions about ontology and epistemology to effectively engage with qualitative methodologies.

Promoting researcher reflexivity and diverse epistemes can counteract this methodological hegemony. Therefore, consistent with Hughes and Pennington's (2017) call to researchers to let their epistemologies drive their methodologies, my philosophical commitments led me to choose autoethnography, a form of qualitative inquiry that centralizes the researcher's epistemological and ontological commitments and disrupts normative knowledge production within our research cartographies.

Autoethnography: Method, Process, and Product

Autoethnography (AE) is a qualitative research approach that combines self-observation and self-reflection of the researcher's own experiences and cultural background with the systematic analysis of the sociopolitical context of a specific phenomenon (Boylorn & Orbe, 2021; Ellis et al., 2011; Rumrill et al., 2019). The term "auto-ethnography" was first coined by anthropologist David Hayano in 1979, drawing on the traditions of anthropology and ethnography. AE aims to generate rich and nuanced insights into the personal and social dimensions of human phenomena, while also critically examining the power relations and ethical implications of such inquiry. AE can take various forms of creative expression, such as poetry (e.g., Maurino, 2016); photographic essays (e.g., Küttel, 2021); journals (e.g., Wall, 2008); novels (e.g., Ellis, 2004); vignettes (e.g., Humphreys, 2005), and short stories. As a research approach that combines personal and cultural aspects, AE involves both self-reflection and systematic analysis of the sociopolitical context of the phenomenon being studied.

Autoethnography (AE) is both process and product (Ellis et al., 2011). It is a unique form of inquiry that blends personal and cultural aspects and involves writing about oneself (auto) in relation to others (ethno) and their contexts. By doing so, it aims to explore and understand how one's own experiences are shaped by and shape the culture they belong to – in this case, family caregiving. AE is neither a neutral nor an objective way of researching, but rather a critical and reflexive one that acknowledges the researcher's positionality, philosophical commitments, and values. To better understand the unique nature of AE as a research approach, it is helpful to consider the characteristics of autoethnography as described by leading scholars in the field.

According to Ellis, Adams, and Bochner (2011), autoethnography has the following characteristics:

- *Cultural Commentary and Critique* – Autoethnographers examine how their own experiences are influenced by social and cultural norms, values, and expectations, and how they can challenge or change those norms through their stories.
- *Contributions to Existing Research* – Autoethnographers connect their personal stories to wider social and historical contexts and draw on existing literature and theory to support their claims and interpretations.
- *Embracing Vulnerability with Purpose* – Autoethnographers share their emotions, thoughts, and struggles with honesty and reflexivity, and use them as sources of insight and understanding. They also consider the ethical implications of their stories for themselves and others.
- *Producing a Variety of Writing Products* – Autoethnographers use different forms and genres of writing to convey their stories, such as narratives, poems, dialogues, letters, etc. They also experiment with style, voice, structure, and language to create engaging and evocative texts.
- *Creating Reciprocity to Compel a Response* – Autoethnographers invite readers to enter their worlds and interact with their stories. They also encourage readers to reflect on their own experiences and perspectives, and to respond with feedback, questions, or stories of their own.

- *Acknowledging Epistemological and Ontological Multiplicity* – Autoethnographers recognize that there are multiple ways of knowing and being in the world, and that their stories are partial, situated, and subjective. They also acknowledge the complexity and ambiguity of human experience, and the possibility of multiple interpretations.

Jones et al. (2013) outline the primary aims of AE as disrupting norms of research practice and representation, working from insider knowledge, breaking silence, reclaiming voice, and writing to right. These aims privilege subjectivity and seek to make work accessible. They emphasize that AE challenges traditional research practices by privileging the insider knowledge and subjective experiences of the researcher. By breaking silence and reclaiming voice, AE provides a platform for marginalized or silenced voices to be heard. By “writing to right”, AE seeks to address social injustices and promote change.

Autoethnography in Education, Counseling, and Disability.

Autoethnography is a contemporary research method increasingly used in fields such as education and performance studies. While its use in counseling literature is limited, there are examples of autoethnographic research in counseling and related fields. Below, I have provided one example in counseling and two others in education and disability.

In her 2022 autoethnography, Kristina Hansen explored her own experience of teacher burnout as a female educator and aimed to contribute to the understanding of the emotional labor and power structures involved in teaching. Her goals were to identify the causes, effects, and moderating factors of teacher burnout, provide an honest and personal account of her journey through burnout and recovery, and call for a more supportive and well-being-oriented culture among educators and leaders. Hansen addressed three research questions in her study: how her burnout related to the emotional labor of teaching for female educators, how her burnout related to the power structures in schools that affect female teachers, and what factors influenced her burnout and recovery as a female teacher. To answer these questions, she used four types of data: personal memory data such as a timeline of significant events and artefacts, self-observational data such as recording her emotions while teaching, self-reflective data such as journaling on other autoethnographies and memoirs, and external data such as interviews with colleagues. Hansen analyzed her data using four strategies from Chang (2008): connecting the present and the past, using social constructs for comparison such as positivity and resilience, examining comparison cases such as within a community of practice, and analyzing external data within her chosen theories.

As a counselor and a volunteer firefighter/EMT, Erik Sean (2021) conducted an autoethnographic study of his own mental health and that of his peers. He used reflexive journaling to document and analyze his experiences of serving a rural community. He identified four themes that emerged from his journal: (1) death & dying, (2) brotherhood, (3) counselor and first responder intersectionality, and (4) physical and emotional stress of the job. He connected these themes to Resilience Theory and Trauma-Informed practice to show how counselors can work with this population and address the gaps in mental health services and research. His dissertation has two main implications: (a) Counselors need to understand the environment and culture of first responders to help them heal from trauma exposure. (b) More research is needed on the mental health needs and coping styles of first responders. His goal is to raise awareness and understanding of the challenges and rewards of being a volunteer first responder, and to encourage others to seek support for their mental health.

Carol Shaw (2020) wrote an autoethnographic dissertation that explored her journey of living with disability for over four decades. She used a split-page format to present a layered account of her embodied learning, combining an evocative autoethnography and a critical analysis of disability in an ableist society. She narrated her experiences of being diagnosed with diabetes, coping with the impact of her disability on her identity, marriage, motherhood, friendships, and career, and surviving a near-death experience. She also reflected on her experiences as a researcher and a writer, and situated them within the relevant literature on disability, adult education, and lifelong learning. She examined how the culture influenced her becoming as a disabled person and as a scholar.

In light of nature, characteristics, expressed aims, and the potential of autoethnography to disrupt traditional research practices and privilege insider knowledge, I have chosen this method to make sense and meaning of my experiences as a family caregiver to an adult with IDD with complex communication needs. I have drawn on the autoethnographic examples described above to inform how I will construct this AE. As a caregiver, I have direct, insider knowledge of the experiences and challenges associated with caregiving. By using autoethnography, I am able to draw on this knowledge to inform both my practice and my research. In doing so, I am able to provide a unique and valuable perspective on the experiences of caregiving that could not otherwise be extricated from my experience.

Participants & Data Sources

Researcher Description: Positioning the Self in Autoethnography

Chang (2008) describes three, variable positions of self in autoethnographic research, including (1) using autoethnography to make cultural sense of oneself; (2) as a way to incorporate one's story into the fold of others' stories with similar experiences; or (3) to illuminate topics of personal interest without actually centering self (p. 69). Of these, I have aligned my inquiry within positioning myself as a way to use my story as part of the broader study of those who occupy the primary caregiving role of an adult family member with IDD. Rather, my positioning of self is included alongside others as co-participants.

In this study, I used autoethnography as a method of qualitative inquiry that connects my personal experiences as a primary caregiver of an adult family member with IDD to the wider cultural, political, and social meanings and understandings of this phenomenon. Autoethnography is a form of research that acknowledges and capitalizes on the researcher's insider knowledge, biases, subjectivities, etc. rather than trying to assume an impossible objectivity. It also gives the subject a voice, the opportunity to speak from a first-person "I" perspective. Therefore, I do not position myself as a separate entity from the co-participants of this study, but rather as one of them, sharing my story alongside theirs. Like Sharma (2019), who conducted mental health research as an "insider", I also identify my role in my autoethnographic inquiry as "an articulator of an emancipatory perspective" (p.3), in that I have chosen a method that aligns with the emancipatory approach of foregrounding knowledge that seeks to liberate individuals and groups from dehumanizing cultural constraints (Bagnall & Hodge, 2022).

Data Sources

Consistent with qualitative and ethnographic traditions, autoethnographic data are primarily textual as opposed to numerical (Chang, 2016, p. 67). For example, textual data might include field notes, journals, and transcripts from interviews. Similarly, textual data from external sources may come from items such as professional documents, the personal writings of others, and published literature. That said, non-textual data may also be incorporated, which may come in a variety of forms such as audio recordings, graphics/images, and artifacts. Finally, note that in qualitative and autoethnographic data, **the data-generation plan can be modified accordingly throughout the process**, but it is essential to at least have a plan to frame and guide the inquiry from the onset.

Chang (2008) outlines four primary ways to generate autoethnographic data, including personal memory data, self-observational data, self-reflective data, and external data. Where diving into one's personal memory will generate physical data (e.g., literary/narrative) embedded within past memory, self-observational and self-reflective data will help illuminate the content of one's current worldview. Each of these is introspective and designed to capture the lived experience of the researcher. External data, on the other hand, provides an avenue for the researcher to investigate their own subjectivity by supplementing their introspection with external perspectives and contexts provided by other people, artefacts, literature, and documents. In the following sections, I describe how I will use each of these primary sources of data generation methods – personal memory, self-observation, self-reflection, and – to generate my autoethnographic data and create a data assemblage from which to analyze my findings.

Data Generation Methods: Creating an Assemblage

Autoethnography is a method that is both process and product (Ellis et al., 2011). I will therefore be using a variety of data generation options for this autoethnography. Most notably, once I received IRB approval, I generated data from the following sources: personal memory sources, such as identifying relevant cultural artefacts, creating an autobiographical timeline of events relevant to caregiving, and identifying salient routines; through the collection of textual and non-textual artefacts such as official documents, texts, and photographs; and through external data sources such as self-observational or reflective data, which will ultimately "help triangulation with other data sources, fill in gaps left by self-based data, and connect your private story with the outer world" (Chang, 2008, p. 112).

Before moving on to the next section, I would like to highlight an important aspect of AE. Unlike some methods that follow a linear sequence of data collection, analysis and interpretation, AE is both a product and a process that involves constant reflection and meaning making throughout the entire inquiry. This means that my data analysis and interpretation process did not occur as discrete stages, but rather it was an ongoing and iterative processes that informed and shaped the product that is my autoethnographic narrative (Ellis, 2004).

Generating Personal Memory Data

Autobiographical Timeline. I began by creating an autobiographical timeline. This process consisted of choosing, and then listing chronologically, life events of personally identified significance, including the date and a summary of the event. After completing the timeline, I went back and chose experiences that "led to significant cultural self-discovery" (Chang, 2008, p. 74), describing the circumstances in greater detail and explaining the cultural significance of those experiences. For example, this included things like the date I received guardianship, my brother's transitions across states, finally meeting with a speech language pathologist (SLP) who believed in providing Augmentative and Alternative Communication (AAC) for adults, going through the formalized assessment process with the supports intensity scale (SIS), and specific IEP meetings that I attended.

Identify Routines. I selected an array of time cycles – including daily, annual, and seasonal – and listed chronologically the activities I routinely engaged in within these routines. For example, this included monthly meetings with my brother's case manager, daily routines of ADLs, and annual routines such as person-centered planning and medical appointments (both mine and my brother's). Next, I provided a brief description of each routine. Then, I selected some of the most poignant cultural significance as they relate to my caregiving role and described and wrote around the data I generated – i.e., my narratives.

Generating Self-Observational Data.

Self-observational data captures your behaviors, thoughts, and emotions in real-time as they happen in their natural settings. Chang (2008) notes that "Self-observational data from the present, when compared with personal memory data, can reveal changes and continuity in your life over time" (p. 90). I therefore selected the systematic self-observations of the routines identified in the personal memory data exercise to generate this data.

Systematic Self-Observation.

Using the routines identified in the *Identifying Routines exercise,* I engaged in systematic observation of these routines as they occurred for two weeks. Recordings of these observations included contextual information (e.g., time, frequency, location, mood, etc.) and were primarily focused on those routines in which an entanglement of voice regularly occurs (e.g., medical appointments, rec/leisure choices made throughout the day, and through general ADLs).

Generating Self-Reflective Data

Reflexive Field Journal. Throughout the entire data generation process, I kept a reflexive field journal, which Chang (2008) describes as a metacognitive activity that can "provide purposeful and healthy interruptions during (fieldwork) to help you move into and out of the self-reflective state" (p. 96). Here I included my observations of my routines, reflections on my own meaning making of my caregiving experience, and general notes related to the data generation process. Field journaling also provided a methodical way of distancing myself from constant introspection, thereby helping to avoid reflective self-absorption through the data generation process, which Chang suggested as an added benefit of maintain an autoethnographic field journal.

Generating External Data

Textual Artefacts.

I began by making a list of textual artefacts, which were largely informed by the first round of data generation (e.g., through the *routines* and *cultural artefacts* exercises), as denoted in the data generation table above. I located the artefact and described its function and the degree of importance personally ascribed to the artefact. Examples of textual artefacts included official documents such as my brother's person-centered plan (PCP), his Individualized Education Plans (IEPs), the results of the supports intensity scale (SIS), and written correspondence between myself and his medical providers (e.g., with his primary care provider, his OT, his case manager, etc.). Additional textual artefacts also included my own written reflections on the caregiving process that I have recorded and maintained.

Interactive Interviews.

I conducted interactive interviews with three former colleagues and two family members. On of the interviews with former colleagues occurred in a dyad; everyone else I interviewed one-on-one. Ellis and Berger (2002) and Ellis (2004) refer to interactive interviews as an interview style that involves collaboratively interviewing a small group of people with the ultimate focus on "the understandings that emerge among the participants during interaction – what they learn together" (Anderson & Glass-Coffin, 2013, p. 70). With an emphasis on the developing relationships among participants, interactive interviews are ideal when the researcher has personal experience with the discussion topic. "An interactive interview is like a conversation with friends…It probably works best when participants already know each other well" (Ellis, 2004, p. I therefore conducted interactive interviews with former colleagues with whom I worked in a practitioner/counseling capacity as well as with family members. The participant letter, informed consent form, and the semi-structured interactive protocol for these interviews can be found in Appendices A-C. Ultimately, by using multiple methods, my intent was to capture the complexity and richness of my lived experience as a researcher and a participant.

Data Management

Chang (2008) advises developing a data management plan from the outset of the research will support driving the data generation process toward the overall aim of the study, thereby making the data easier to access and identify during the analysis and interpretation stages. To help manage magnitude and mitigate the potentially seeming randomness of the amassed data, Chang (2008) suggested a variety of data management strategies to utilize while data are being generated. These include labeling, classifying, trimming, and expanding, all of which facilitate data organization and refinement. I followed Chang's (2008) suggestion and template for maintaining a data catalog through the data generation process. Finally, Chang (2008) notes that **data collection, data management, and data analysis as a whole form a dynamic, *non-linear* process**, where each activity informs and modifies the other. This proved true for me throughout my entire data generation process.

Data Analysis

Autoethnographic data analysis does not have a fixed procedure, but Chang (2008) offers some useful guidelines that I will consider in my own process. However, I acknowledge that different autoethnographers may adopt different approaches to their data.

Chang (2008) notes that data analysis and interpretation form the crux of ethnographic research. For this process, she suggests 10 strategies, including: (1) searching for recurring themes, topics, and patterns; (2) looking for cultural themes; (3) identifying exceptional occurrence; (4) analyzing inclusion and omission; (5) connecting the present to the past; (6) analyzing relationships between self and others; (7) comparing yourself with other individual's cases; (8) contextualize broadly; (9) comparing constructs wand ideas within social science; and (10) framing the data with theories (p. 131). The specific strategies I utilized out of these ten are described below.

Searching for recurring themes, topics, and patterns involves perusing your data for repetition "to discover foundational elements of your life" (p. 132). Chang (2008) advises one strategy for this is to holistically review either your entire data set or by scanning small chunks of data to identify recurring topics, which will include people, places, ideas, and/or activities.

Looking for cultural themes has been identified as a final step in traditional ethnography, where a cultural theme is understood as a stance or position that strongly guides one's behavior, which is then either "tacitly approved or openly promoted in a society (McCurdy, Spradley, & Shandy, 2005, p. 78). Themes need to be searched for and extracted from both the "global and holistic readings of data" (Chang, 2008, p. 132).

Identifying exceptional occurrences is a way to structure data analysis and interpretation around unique or rare life occurrences. Chang (2008) notes that life-changing experiences often serve as catalysts for personal development and moving differently throughout the world, and data can therefore be structured around these exceptionalities when they inform the research topic.

Analyzing inclusion and omission is a strategy that recognizes there are many reasons for data omissions, including naturally missing elements that simply did not occur as well as both intentional and unintentional omissions. Chang (2008) advises using every data inclusion to ask a question about data omission. For example, one question I asked after identifying some patterns and similarities about the caregivers I chose to include is why male caregivers were missing from my list. “Omission in data reveals an autoethnographer’s unfamiliarity, ignorance, dislike, disfavor, dissociation, or devaluation of certain phenomena in life” (p. 134).

Connecting the present to the past is a “history-conscious strategy” to facilitate the researcher in making the connection between present thoughts and behaviors with their origins, which are potentially rooted in events of the past (p.4). This connection will be an approximation that is made by the researcher through “logical reasoning, imagination, and intuition to explain the connection between the present and the past” (p. 134). For example, I may identified, or correlated, my chosen profession of rehabilitation counseling with events that occurred while I was a direct care worker supporting adults with IDD in day programming and residential settings when I was a teenager.

Analyzing relationships between self and others involves looking for relationships with others of both difference, similarity, and even opposition to oneself with the aim of identifying the connective tissue between yourself and others. Others of similarity may involve individuals within your profession, those who hold similar identities, and individuals with whom you may identify for various reasons. Others of difference may include those with different value sets, those with different or unfamiliar identities, or even other communities of practice. Within this data analysis and interpretation strategy, Chang (2008) advises considering why certain types of others were included and excluded and using the answers to those questions to help frame your data analysis.

Comparing yourself with other individual's cases allows for identifying similarities and differences among two cases, which might include experiences, events, or contexts. The aim of this strategy is to further the cultural sense and understanding of self by bringing the differences and commonalities one shares with others to consciousness, thus allowing for reflection, analysis, and interpretation.

Contextualizing broadly involves zooming in and zooming out in order to shift attention "to what lies beyond your case" to provide an in-depth understanding of the context one is considering (Chang, 2008, p. 136). Rather, contextualizing broadly involves attempting "to explain and interpret certain behaviors and events in connection with sociocultural, political, economic, religious, historical, ideological, and geographical environment in which they took place and in which data were corded (p. 136). Chang (2008) further noted that a boundary must be set to determine how broadly the context will be defined in order to make the cultural interpretation more manageable through this data analysis and interpretation strategy.

Again, autoethnographers may use different approaches to analyze their data. While some may employ traditional qualitative data analysis methods such as coding and thematic analysis, others view autoethnographic narrative inquiry as a data analytic method in itself. Bhattacharya (2017) is one such researcher who views autoethnography in this light. This highlights the flexibility and diversity of autoethnography as a research method.

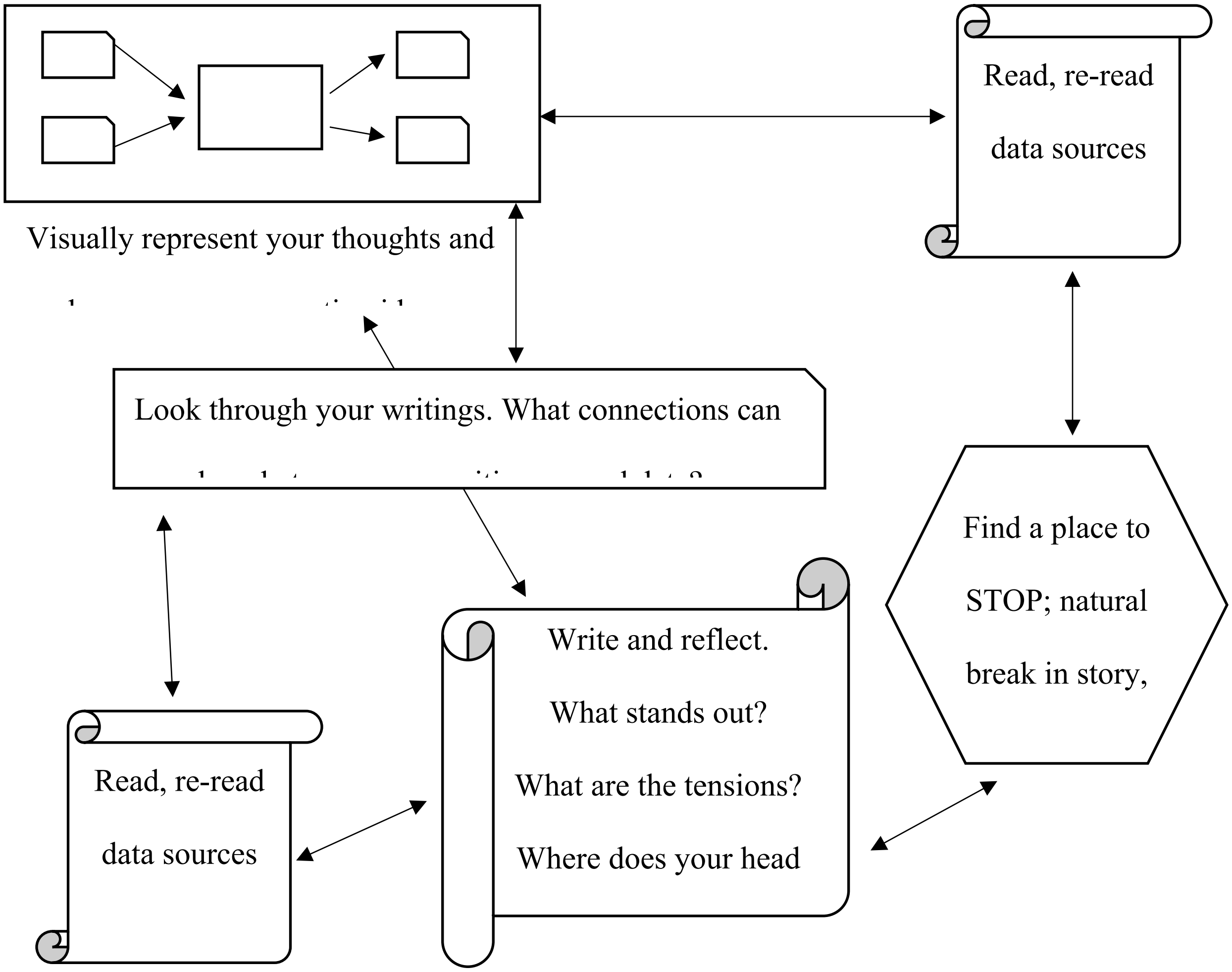
Chang's (2008) strategies were particularly helpful, as they are intended to facilitate making cultural sense of the amassed data, or data assemblage, by fostering a process of zooming in on the personally meaningful aspects of the research while simultaneously being able to zoom out and view the larger social context of your experience (Chang, 2008, p. 136). As I was generating my data, I engaged in these strategies to analyze my data, alongside Braun and Clarke's (2006, 2021) approach of reflexive thematic analysis (rTA) and writing narratively around my data (Bhattacharya, 2017)

In their 2021 work, Braun & Clarke discuss the various versions of thematic analysis (TA), each differing in paradigm, philosophy, and procedure. They identify three primary approaches to TA: Coding Reliability TA, Codebook TA, and Reflexive TA. Of these, Braun & Clarke align with Reflexive TA, an approach that fully embraces qualitative research values, views analysis as an interpretative, reflexive process, and sees researcher subjectivity as a resource for knowledge production rather than a threat to credibility.

In this inquiry, I utilized Braun and Clarke's (2006, 2021) approach to inductive rTA to generate my findings. This approach aligns with my commitments and provides a reflexive way to engage with my personal data to understand how I construct meaning around my caregiving experience. This choice was informed by the understanding that TA is not a monolithic approach and that citing Braun & Clarke's 2006 work requires a thorough understanding of its content. To engage reflexively with my data to generate these themes, I utilized Kakali Bhattacharya's (2017) *Inductive Analysis Process via Mapping and Writing around Data* (p. 156). For clarity, I created a simplified version of Kakali's figure to illustrate this process.

Figure 1

Inductive Analysis Via Mapping and Writing as Inquiry (Bhattacharya, 2017, p. 156)



Trustworthiness

Trustworthiness in qualitative research is a reconceptualization of what quantitative research calls *validity.* Trustworthiness refers to “the degree to which the reader can assess whether researchers have been honest in how the research has been carried out and reasonable in the conclusions they make” (Pratt et al., 2020). It is achieved by ensuring alignment between theory, research question, data collection, analysis, and results. It is also enhanced by using various strategies such as disclosure, auditability, peer debriefing, corroboration, and prolonged engagement.

To ensure the trustworthiness of this autoethnographic inquiry, I followed the criteria of credibility, transferability, dependability, and confirmability (Bhattacharya, 2017; Creswell & Poth, 2016; Schwandt, 2007). *Credibility* refers to the authenticity and plausibility of the researcher's interpretations and representations of the lived experiences being explored. For example, I have outlined how I utilized multiple sources of data, such as journals, interviews, and observations, to triangulate my findings. *Transferability* refers to the extent to which the findings can be applied to other contexts or settings. For example, I provided rich and thick descriptions of the research context (i.e., my layered accounts of my caregiver experience) to allow readers to judge the applicability of this inquiry to their own situations. *Dependability* refers to the consistency and rigor of the research process and subsequent outcomes. For example, I have noted I kept a detailed, reflexive field journal of all the significant research decisions and actions, and I engaged in rTA, reflexively engaging with and writing around my data. *Confirmability* refers to the degree of "structural corroboration" of the research findings (e.g., Creswell & Poth, 2016; Eisner, 1991). For example, through my daily interactions with my data in my reflexive field journal, I engaged in continuous, critical self-reflection and bracketing to identify and address my own biases and assumptions as a researcher and a family caregiver (Bhattacharya, 2017; Schwandt, 2007).

Protecting Participant Identity

One of the ethical challenges of autoethnography is to protect the identity and privacy of the participants, especially when they are family members or close friends. In completing this autoethnography I necessarily considered how I will ethically protect identity. Rather, my brother and other individuals with whom I have an established relationship will be involved. My intention is and must not be to divulge personal information of others, but to explore the nature of the caregiving role in *relation* to others; this autoethnography is about the *caregiver* experience and what is born from the entanglement therein.

In her piece on relational ethics with intimate and identifiable others, Carolyn Ellis (2007) noted that researchers have a responsibility “to act from our hearts and minds, acknowledge our interpersonal bonds to others, and take responsibility for actions and their consequences” (p. 3). She went on to describe relational ethics as recognizing and valuing the “mutual respect, dignity, and connectedness between researcher and researched” (p. 4). In line with Ellis’ (2007) emphasis on relational ethics and the responsibility of researchers to act with mutual respect, dignity, and connectedness towards their participants, I will take several measures to ensure that my autoethnography meets these ethical standards.

In this autoethnography, I used several strategies to protect participant privacy, privacy, and dignity. I obtained informed consent from all the participants engaging in the interactive interviews, which explained the purpose, methods, and potential risks and benefits of the study (see Appendix B). My interviewees had the option to withdraw from the study at any time or to request changes or deletions of any data that they were uncomfortable with (Ellis et al., 2011). Additionally, because my brother is inherently implicated as our stories are intertwined and therefore identifiable to individuals who know me or who may encounter this autoethnography and meet he and I in the future, I made every effort to keep at the forefront of my mind through virtually every layered account I provided as data to focus on *my* perspective and position of the caregiver’s experience rather than assume his voice in the writing. I therefore tried to share minimal details of his story that I felt would compromise his privacy. To help protect the identities of the other voices I shared in the process of my interactive interviews, I provided a collective, brief, and generalized summary of their backgrounds in relation to me, emphasizing only that they have been and continue to be instrumental in my caregiver journey. I also used pseudonyms for each individual I mentioned. By following these strategies, I protected to the extent I am able the participant identity in my autoethnography and produced a trustworthy and ethical account of family caregiver experiences.

Positionality

As a researcher and a rehabilitation counselor who works with individuals with IDD and their family caregivers, as well as being a family caregiver myself, I recognize the importance of being aware of my positionality and how it influences my research. Positionality refers to the social identities and locations that shape one's worldview and perspective (Alcoff, 1988). In this statement, I will describe some of the key aspects of my positionality and how they relate to my research interests and goals.

I am a single, non-parental primary caregiver to my sibling with IDD. The reality of this role is therefore a conflation of sister-parent-caregiver-advocate-case manager. This means that I simultaneously perform the functions of a sister, a parent, a caregiver, an advocate, and a case manager for my sibling. I recognize that this positionality influences my perspectives, values, and interests in relation to the topic of family caregiving.

I have a neurodevelopmental disability, but I do not have an intellectual disability (ID). Additionally, I am able-bodied. This combination of circumstances gives me an outsider perspective when it comes to IDD and physical disability, but an insider perspective when it comes to neurodivergence and caregiving. As someone who is not part of the IDD community, it is neither my place to speak on their behalf nor on behalf of my brother. Instead, my goal is to speak to the experience of family caregivers and the family caregiver community, as we work in tandem and reciprocally with our loved ones with IDD. In this way, I see myself as occupying the status of edgewalker – someone who walks the boundaries between insider and outsider perspectives within this research (e.g., Berkovic et al., 2020).

I am a white, cisgender female and I come from a low socioeconomic status (see the Pew Research Center's income calculator for reference). These identities grant me certain privileges and disadvantages in society and affect how I interact with and understand others who share or differ from these identities. For example, as a white woman, I am not fully aware of the experiences and challenges of family caregivers who are Black, Brown, or Indigenous. Similarly, my socioeconomic status may influence my understanding of those from higher or lower income backgrounds, such as degree of access to caregiver resources. Additionally, being a cisgender female may affect my interactions with those who identify as transgender or non-binary. I need to be mindful of how my whiteness, socioeconomic status, and gender identity may influence my assumptions and interpretations of the experiences of other family caregivers.

I am also a millennial, which means that culturally I belong to a generation that grew up with the internet, social media and digital technologies. Millennials are typically defined as those born between 1981 and 1996 (Pew Research Center, 2020), although some sources may use slightly different ranges. As a millennial caregiver, I am aware of the challenges and opportunities that come with my role. I am part of a generation that is often stereotyped as lazy, entitled, and narcissistic, but also as innovative, adaptable, and socially conscious. I am also part of a growing population that provides unpaid care to a family member or friend with a chronic condition, disability, or aging-related issue (NAC, 2020). I balance multiple responsibilities and expectations, including work, education, personal development, and social relationships, while also managing the physical, emotional, and financial demands of caregiving. I recognize that my positionality shapes my perspective and influences my decisions. I strive to be respectful, empathetic, and collaborative with other caregivers and care recipients who may have different backgrounds, experiences, and needs than mine. I also seek to learn from them and share my own insights and resources. I acknowledge that caregiving is not only a challenging role but also a source of meaning and fulfillment in my life. I value the opportunity to support someone I care about and to contribute to their well-being and dignity.

As a certified rehabilitation counselor (CRC), I am aware of the sociopolitical implications of disability and how it affects the lives of individuals and communities. I recognize that disability is not a fixed or homogeneous category, but rather a dynamic and diverse experience that intersects with other aspects of identity, such as race, gender, class, sexuality, and culture (e.g., Levine & Breshears, 2019). I also acknowledge that disability is shaped by historical, cultural, and environmental factors that create barriers and opportunities for people with disabilities. My position as a CRC is informed by my professional training, personal values, and lived experiences. I have learned to adopt a holistic and strengths-based approach to counseling that respects the autonomy, dignity, and potential of each client.

My positionality also **influences my epistemological and methodological choices**. I believe that knowledge is socially constructed and situated. I value the voices and experiences of people with IDD and their family caregivers, and I intend to conduct research that is participatory, collaborative, and emancipatory. I reject the positivist and medical model traditions that have dominated disability inquiry, and that have often devalued people with IDD and their family caregivers (e.g., Holmes, 2015). I believe that promoting counselor reflexivity is paramount to disrupting the normative knowledge production that we often encounter in disability inquiry, not the least reason of which is a failure to acknowledge how positivist and medical model traditions have found their way into the methods for researching individuals with disabilities, including within the counseling and rehabilitation counseling literature.

I believe the methodological hegemony demonstrated within the counseling literature can be interrogated, problematized, and counteracted by promoting researcher reflexivity and diverse, emancipatory epistemes. Therefore, consistent with Hughes and Pennington (2017) who advise to “let your epistemology determine the methodology” (p. 147), my philosophical commitments and positions of entry into the topic of family caregiving form the foundational impetus for my selection of a form of qualitative inquiry that centralizes the epistemological and ontological commitments of the researcher, and whose purpose is to disrupt norms of research practice and representation; namely, autoethnography (Jones, Adams, & Ellis, 2013; Cunliffe, 2004).

CHAPTER 4: FINDINGS

Whose Voice?

Is it my voice or Anakin 's voice?

I am interpreter only, advocate yes. But what gets lost?

His heart, his feelings, the nuances of his emotions.

Thinking of this loss guts me, leaves a hole. A hole that I inevitably fill with doubt and guilt that my (in)ability and consistent (in)accuracy in discerning his meaning signifies that I may or may not be hitting the right interpretive notes. Does he feel the translative loss? The communicative one?

Have the number of times I've asked him to repeat something, and I not understand, finally taken its toll to the detriment of his vocal interaction? His vocal utterances have only decreased over the years, replaced with gestures, facial expressions, and extremely limited ASL approximations. Attempts with his AAC device, his Nova Chat, have been met with doubt from family members and avoidance from Anakin himself. Does he realize the possibilities with this tool?

My practitioner voice says, "keep working with him to use it, reinforce with high-value activities and items, encourage family to use it with him!" Sister/caregiver voice – do I know which is which? Sometimes – says, "but assistive technology is only as effective as perceived by the user." I also ask myself "is it worth it to push?" There is a level of interpersonal care that must take place, and it means trying to support Anakin's relationships with his friends and family as well as supporting my own. This "advocacy even among family" role takes quite a bit of navigation. I know that I will largely be the one to advocate for the device's use, that other individuals in Anakin's circle find the use of an AAC device too obtrusive, too tedious, not necessary, that I am "pushing too hard" or "overthinking things, he's fine".

Providing interpersonal care also means several opportunities for Anakin to be heard and understood by folks with whom he may have limited exposure and thus may not have the degree of comfortability with communicating differently in forms other than vocalized speech. I therefore want to honor Anakin's voice as much as I am able wherever and with whomever possible. Yet again – and because I am interpreting through multiple voices – I ruminate in and among each internally vocalized perspective, each with its own conductor leading a separate thought train 'full steam ahead!' to a different, conclusive destination.

"Over protection versus dignity of risk" my counseling voice whispers – how hard do I push to use the device? How hard do I push in general? I must balance what Anakin wants with what supports his needs, well-being, and quality of life. I am constantly assessing this from what I can only empathically interpret as his perspective with my perspective, where mine is one of a differently informed adult who loves him and understands things on a different scope than he does, or that he may. ***When his voice communicates "no," when do I listen and when do I override?***

My certainty with the "when" has dwindled within the past few years. Because out of necessity I have gone into currency triage. Every day, the energy I have must be divvied up among interpretive tasks with work tasks with daily living tasks for two adults (prepare meals, brush teeth, give shower, set up an environment he is comfortable and at least semi-engaged in so I can work, while simultaneously trying to create a work environment that I can both work in and perform peripheral care in while Anakin sits with me). Even within this contextualization, I hesitate to provide too much detail; I don't want to over emphasize the degree of Anakin's challenges or the full significance of his support needs, because I respect his autonomy and dignity, and his strengths and capabilities are considerable. This is merely to illustrate that every *day, I am essentially holding and appraising within my consciousness the needs, wants, routines, recreational/leisure activities, and environmental setup for two adults. An 'interdependent dyad', as it were, and this is to say nothing of just the general, everyday engagement he and I relate in that extends beyond caregiver. Rather, it is to say nothing of simply being his big sister, of him simply being my younger brother, of it boiling down to him being one of my truest friends and companions. Of hoping he knows this and understands it and feels it. And of – in those few-yet-sweet moments that remain blissfully devoid of self-doubt – intuitively knowing that he does.*

But I am his primary caregiver, and I am also his legal guardian, which carries added weight and responsibility. I have been legally identified to "speak for him". I understand that I can never truly do this, never capture his full and true voice, and that the sheer nature of the court setup is one that inherently marginalizes Anakin and sets up a perception of social incapacitation. I therefore approach this responsibility with immense care and regard it to be one of utmost privilege. It is also one of great cognitive load. Because I want to do it flawlessly. I do not want him to be subject to anymore loss of his own voice than he is already subject to. I do not want to misinterpret. Yet I know I do. And then there goes a little more of that guilt into that void. Every time he disengages, every time he shrugs his shoulders and raises his arms in the air in polite frustration at my misinterpretation, the resounding feeling of the interpretive failure reverberates throughout my consciousness, reiterating back to me that I must try harder for him so that his voice is not lost, be better for him so that his voice is not lost, learn more from him so I don't conflate his voice with my own, provide more interactive opportunities for him to get communicative feedback and reinforcement.

But it is just me. How do I reconcile in my heart and mind the knowledge that even if I poured every ounce of energy that I have into knowing, supporting, understanding, and nurturing

Anakin's voice it would not be enough to completely bridge the communicative gap between he and his world? Between me and my full understanding of who he is as a wholly individuated young man. To help connect me to his thoughts, feelings, emotions, and ideas about the world. How do I leverage this understanding? How does it impact how I construct, interpret, and actualize my caregiver role and responsibility? I ask again – whose voice?

**

The aim of this research was to use autoethnography to reflexively examine how voice and voicelessness (i.e., an entanglement of voice) impact the care needs and the overall well-being of family caregivers of adults with intellectual and developmental disabilities (IDD). For this inquiry, I examined how I construct my caregiver experience as both a family caregiver to an adult with IDD and as a researcher-counseling practitioner who works with individuals with IDD and their caregivers. The central question of this inquiry was: *What can my experience as a family caregiver uncover about the entanglement of voice among family caregivers of adults with IDD who have complex communication and support needs?*

To critically analyze my personal experience as situated within these broader cultural contexts, I analyzed four types of autoethnographic data: personal memory data through the construction of my autobiographical timeline; self-reflective data recorded in my reflexive field journal; self-observational data through the systematic self-observation of routines relevant to my caregiving role (e.g., meal preparation, hygiene routines, bedtime routines, and travel routines); and external data, such as interactive interviews with family members and former colleagues, and formal documents (e.g., proof of guardianship, Individualized Education Plans (IEPs), and the results from the Supports Intensity Scale (SIS) assessment).

Applying an inductive approach to reflexive thematic analysis across these data, I generated three main findings, each with an associated lens of analysis: *Entangled Voices Across a Variegated Landscape of Care*, viewed through a lens of form and function; *Monopolizing Knowledge and Conferral of Who is Expert*, viewed through a lens of role and identity*;* and *Caregiver Currency: How Much do You Have to Spend*, viewed through a lens of transaction. Because my situated identity as participant-observer is inextricably entangled with my identities as caregiver, guardian, sister, and counseling practitioner, I present my findings in the form of a layered account.

Carol Rambo Ronai (1995) describes layered accounts as a "postmodern ethnographic reporting technique that embodies a theory of consciousness and a method of reporting in one stroke" (p. 396). She notes that in traditional scientific narratives, readers are delivered a specific, fairly monolithic understanding of a subject that is then presented as the general standard of knowing on that subject. The layered account alternatively provides an abstract outline, offering readers various layers of experiences to fill in the gaps and form their own interpretation of the writer's story. This allows readers to reconstruct the subject matter, injecting more of their own perspective into it and, ideally, gaining more from it.

Layered accounts utilize multiple personal perspectives, voices, and vantage points to depict lived experience. These vantage points offer positions of potential understanding, but no one voice is inherently privileged over the other. They are reflective of personal meaning-making in a specific time, space and context. The analysis provided within should therefore not be considered as conclusory or prescriptive. Instead, the layered account is a storytelling technique designed to loosely present and generate for the reader a continuous dialogue of experiences in a way that reflects a stream-of-consciousness, shifting among the temporal, the spatial, the reflective, the abstract, and even the fantastical, should the author so choose. This dialogue arises from myriad reflective voices that concurrently create and interpret a narrative text. That is not to say that in presenting my findings in this form that you will have a comprehensive facsimile of my experiences; but that in breaking free from the reporting parameters inflicted upon the positivist reporter, I invite us together to construct meaning around the conceptual construct of caregiving and invite the possibility of multiple ways of knowing and understanding embedded within these accounts of lived experience.

During this autoethnographic journey, you will encounter voices that have deeply influenced my experiences and perspectives. These voices belong to individuals with whom I share personal and professional connections and all of whom are caregivers in some capacity. They are former colleagues from various practitioner and service backgrounds supporting adults with IDD and their family caregivers, including teachers, behavioral health practitioners, case managers, and a mother of a child with IDD. There are also family members, each referred to by a pseudonym to protect their identity. Among these voices, you will hear from ‘Ahsoka’, ‘Minerva’, ‘Maarva’, and ‘Cassian’. I will also be referring to my brother as ‘Anakin’. These pseudonyms are not arbitrary; they are chosen from some of my brother’s favorite characters from his beloved stories, a small tribute to honor his voice and presence in this work. Each voice brings a unique perspective, adding depth and richness to the exploration of our collective experience. As you read their words, I invite you to consider the complex interplay of our shared experiences and the ways in which they illuminate the entanglement of voice among family caregivers of adults with IDD who have complex communication and support needs.

4.1 Entangled Voices Across a Variegated Landscape of Care

In my analysis of my journey as a family caregiver, I discovered intricate layers of interconnectedness in the voices of caregivers for adults with IDD. This theme paints a vivid picture of a complex tapestry of care, each strand representing different levels of care - intuitive, formalized, interpersonal, and peripheral. Each level is shaped by the caregiver's past and present experiences, as well as their understanding of the experiences of the person for whom they are caring.

The process of appraisal is central to this theme. It involves ongoing interpretation and understanding, serving as the nexus where the entanglement of voices resides. This theme thus provides a nuanced understanding of the multifaceted nature of caregiving for adults with IDD who have complex communication and support needs. It highlights how our voices as caregivers are not isolated but are deeply intertwined with those we care for in this diverse landscape of care.

4.1.1 Intuitive Care

Intuitive Care is an innate, instinctual aspect of caregiving that emerges naturally from the caregiver's deep connection and understanding of the individual they are caring for. It transcends formalized knowledge or prescriptive learning, characterized by an instinctive knowledge or 'gut feeling' about what the person may need or want. This form of care surfaces organically from the caregiver's interactions and experiences with the individual.

The essence of intuitive care is effectively illustrated in the interview excerpt below, where Maarva describes how she was able to effectively support and teach the individual she was supporting without any formal training or direction, relying instead on her natural instincts and intuition. This 'natural thing' she describes is the essence of intuitive care - an inherent understanding of how to provide care that is tailored to the individual's unique needs and circumstances. One might even call this wisdom – a profound insight that transcends traditional knowledge, embodying a deep, empathetic understanding that is instinctively attuned to the nuances of human needs and emotions. This wisdom, often unspoken yet powerfully resonant, forms the bedrock of intuitive care, guiding caregivers like Maarva as they endeavor to provide personalized, compassionate care. This finding points to the importance of personal connection and understanding in caregiving, illustrating how intuitive care can lead to remarkable outcomes even in the absence of formal training or education. It serves as a testament to the power of human connection and empathy in caregiving contexts. As Maarva noted in our interactive interview:

> *"That's really the basis of my resilience, really. Truly. When you drill down to it, it's that experience and knowing that even after – my guy was 40 when I started working with him – even after 40 years in an institution and having really no appropriate intervention whatsoever, with a little bit of attention and just a little bit of natural –* ***I just had a natural thing*** *about, you know, redirecting or teaching or whatever you wanna call it – it just naturally happened. And, because I had no experience, no education, no direction. I had a psychologist who would come and observe me, because he was blown away, right? Because he hadn't, you know, he was like "What are you doing?" and I was like "I don't know... I didn't know what I was doing. But, um, that belief that if everybody had the right stuff, where would they be? Really, it kind of prepared me for my battle for [my child]."*

Despite having no formal training or education in caregiving, Maarva was able to make a significant impact on the individual she was caring for by simply paying attention and responding naturally to his needs. This suggests that caregiving is not solely about professional expertise, but also about empathy, intuition, and adaptability.

Furthermore, Maarva's story illustrates the transformative potential of intuitive care. Her belief in the individual's potential and her refusal to limit him based on institutional norms challenged the status quo and led to unexpected positive outcomes. This experience not only facilitated a supportive relationship that helped him enhance his communication and engagement, but it also shaped her own approach to caregiving when she later became a parent to a child with a disability.

Maarva's experience illuminates the intricate entanglement of voice within caregiving relationships. Her intuitive approach allowed her to connect with an individual who was previously perceived as non-communicative and non-verbal. By attentively responding to his needs, she facilitated his self-expression in new and meaningful ways. This illustrates that voice extends beyond verbal communication, encompassing agency, participation, and recognition.

4.1.2 Formalized Care

**

'You need to hear that he can stay here.'

The head of special education at Anakin's school speaks to me in what she seemingly believes is a placating tone.

Caregiver Voice in My Head: *Yea, no [expletive] he can stay here, because that's the [expletive] law, lady.*

I was nettled. Bristling immediately, but trying to keep my voice calm and polite (why do we always try to be so polite?) I respond simply, "I understand that."

It was the winter of 2018, and I was sitting at a table in the unfortunately familiar setup I have grown accustomed to at IEP meetings: parents'/caretakers' chairs set up on one side of the table, and the entire school team congregated around the other. At times it feels quite intentional, others, a more implicit setup, the school team failing, I think, to recognize or understand what it might be like, as a parent, to come visually into a room full of professionals, looking like a powerful, unified team ostensibly standing information, banded against you and your cause. And there you are, sitting singularly on the other side, seemingly the only one present in the room that's going to try to represent, to the absolute best of their ability, the closest approximation to the voice of your loved one as possible, the only one to fully advocate for what your loved one needs and is entitled to in terms of full inclusion. It is not supposed to be, and it isn't always, but the sense of the setup as 'us versus them' feels inherent and inevitable.

'We just thought ['x' school] might be more appropriate for him, for his functioning, he'd just have more support.'

Caregiver Voice in My Head: *Yea, what you're really telling me is that you don't want to actually have to do your job. I'm sorry, did I walk into a room full of gen ed teachers? No. No, I did not. Also, I know we all like to speak to levels of functioning in the pro world as a way to understand what we're working with, but it's a bull shit thing to say to parents about their kid. You're telling me someone who ambulates independently, follows directions, helps others when asked, and feeds himself is too 'low functioning' to be in a non-segregated public-school setting inside a special education classroom? *Looks around mockingly* is there a Delorian around here somewhere and I've time-hopped into some time pre-1975 reality?*

Practitioner Voice in My Head: *Use this opportunity to educate. Understand these folks are stuck between a rock and a hard place – their resources are limited; they're doing what they know. Coming at them adversarially or patronizingly will not get you what you want, and it definitely it won't get Anakin what he needs. Be solution-focused, not blame-focused. However, you also need to be clear and direct. Don't sugar coat what you mean in fluff language.*

'I understand that everyone at this table is working to the best of their ability to support your students. I understand it can be extremely challenging to balance and support a variety of needs and abilities at one time. I also want to be transparent with everyone seated here today. I visited ['x' school] last week. There are virtually no neurotypical students at that school. I genuinely do not understand how this setup is legally allowed to continue, and I feel like I've stepped back in time. Students with the most significant disabilities have literally been segregated from their non-disabled peers by placing them in their own building in the next town over. Is anyone able to explain this as anything other than a segregated setting? Able to explain to me how moving him to that school would be the 'least restrictive' environment?'

I am met with an uncomfortable silence. Well, less uncomfortable for me, I am fairly certain. I give it a ten count before interjecting a vocalized reprieve into the heavily saturated silence.

"So, what I am saying that I need each of YOU to hear, is that yes, he will be staying here, and I would like to take the remainder of the meeting to discuss how we can all support his success in this setting."

**

Formalized Care encapsulates the structured, systematized care provided by interdisciplinary teams, including case managers, direct support personnel (DSPs), medical doctors, school personnel, and speech language pathologists (SLPs). It is subject to various systems, from federal to county levels, and individual caregivers must navigate these systems to access care and support for their loved ones. In my exploration of the finding *Formalized Care*, which is nested within the broader theme of *Caregiver Entangled Voices Across a Variegated Landscape of Care*, I took a deep-dived into my experiences as a family caregiver. This journey revealed a multitude of intertwined layers within the voices of caregivers for adults with IDD, each contributing to the diverse tapestry of care. These layers encompassed elements such as power dynamics, advocacy and resistance, emotional labor, legal and ethical considerations, and communication styles. The impact of other voices, such as my practitioner voice, also added further dimensions to this complex landscape. Each layer amplifies the intricacy of how caregivers' voices are articulated, perceived, and comprehended within these systems of care. In the IEP meeting discussed above, I experienced firsthand the power dynamics in services that often feel adversarial. Despite standing as an advocate for Josh, I found myself unexpectedly at odds with a group of professionals who were presumably on the same advocacy path for students with disabilities. The structure of the environment, however, seemed to create an adversarial "us versus them" dynamic, where my voice as a caregiver felt undervalued and overshadowed by these so-called "experts" (but more on that later).

Advocacy and resistance therefore became central to this experience. My internal dialogue reflects my resolve to protect Anakin's dignity and autonomy, even when it challenges the conventional wisdom of the "experts". I do not want to sound smug or arrogant, but rather to express my conviction that I know what is best for my brother, as his caregiver and advocate.

I also experienced the emotional labor involved in these meetings. The effort to remain polite despite frustration reflected the complexities I faced in expressing my thoughts and feelings. This emotional labor impacted how my voice was perceived and received by the other individuals seated at the table.

Legal and ethical considerations added another layer where my voice became entangled with the wider system. By questioning the legality and ethics of isolating students with disabilities, my voice acted as a catalyst for addressing systemic problems pertaining to the domains of ethics. This was not an expression of self-aggrandizement, but rather a manifestation of the principle “all for one, one for all”. It emphasized the idea that advocating for individuals with IDD is not about advocating for a group as a whole, but about advocating for each individual person with a disability. Rather, to support the rights of people with disabilities you must first support the rights of person with a disability.

Transitioning from these broader systemic issues to more personal experiences, the contrast between my internal thoughts and spoken words illustrated how my voice was modulated depending on the context. This modulation was part of the entanglement of voice, reflecting the complexities involved in communicating effectively within these settings.

As I investigated deeper into these complexities, my practitioner voice served as a mediator, providing a more neutral perspective that helped guide my approach. This voice was part of the entanglement, influencing how my voice was expressed and heard. Building on these layers of entanglement, real-life experiences from caregivers like Maarva further illustrated these complexities. The excerpt from Maarva below highlights the challenges of formalized care. She speaks of the rarity and value of finding a cohesive team of high-level professionals who can work together effectively. Maarva also touches on the confrontational aspects of interacting with various systems. As Maarva notes:

> *"We got to a team, and this is another thing when you talk about resources and caregiving, this was huge, because it's almost impossible to find this, where you have a group of people who are all high-level professionals, top of their game, who work as a group, because these people tend to be so focused on themselves and what they're doing and they don't play nice in the sand box usually* ***… I was not a confrontational person. Until the stuff with the schools.*** *There's a price you pay…when you have to interact with all these different systems."*

Maarva's first excerpt highlights the challenge of finding a cohesive team of high-level professionals. This reflects the power dynamics aspect, as caregivers often find themselves navigating a landscape populated by professionals who may not always work collaboratively, or who become quite precious about their professionally established and maintained knowledge. The entanglement of voice here lies in the caregiver's need to communicate effectively with each professional, despite their individual focus and potential lack of cooperation. As I will describe in some of my upcoming layered accounts, this could not be more accurate, especially once Anakin aged out of school. There are innumerable reasons for this, not the least of them being the extremely high turnover in disability agencies that specifically support folks with IDD. For example, we had 3 different case managers assigned to us in a two year period through DHS. Maarva also mentioned that she was not a confrontational person until she had to deal with the schools. This transformation tied back to the aspect of advocacy and resistance. The entanglement of voice is evident as caregivers may find themselves adopting more assertive or confrontational communication styles to advocate for their loved ones, even if this is contradictory to their more natural style.

Furthermore, Maarva's statement about the "price you pay" when interacting with different systems underscored the emotional labor involved in caregiving. This emotional toll contributed to the entanglement of voice, as caregivers must manage their emotions while navigating complex systems of care. These excerpts from interactive interviews further enriched my analysis by providing first-hand accounts that highlight how caregivers' voices become entangled across various systems and situations.

4.1.3 Interpersonal Care

**

We are driving down the familiar stretch of I-94 highway that takes us from northwest Indiana back to Michigan. It is late afternoon in midsummer 2023, and Anakin and I are going home from visiting my grandmother. I steal several glances out of the corner of my eye as he quietly looks out the window, trying to gauge how much speech to throw at him and how much silence and space he might need to process.

Practitioner Voice in My Head: *Should I put on his playlist? Music is the wavelength of language into which you two can typically tune and dial in with each other. This might help him process in his silence.*

Caregiver Voice in My Head: '*So ready to jump in and intervene, Kristin, just let him be for a bit,' I silently reprimand myself.*

But if you're reading this and you're a caregiver in any way, you know how excruciatingly difficult that can be.

In this moment, I am his caregiver, yes, but I am also just an older sister driving home with her younger brother and (I am/we are) trying to figure out how to share and process change as a family. So, while as a caregiver I recognize he's just had a potential shock to his visual system, *he and I experienced together as a family our grandmother's gradual decline in general health and physical capabilities, and now, in her living situation. This is a lot of change for anyone, especially for an individual with IDD who may benefit from consistency in routine and have difficulty in processing these changes.*

Before even visiting, I agonized over the right decision to make, taking into account my grandmother's intimations that she didn't want to scare or worry him and "he won't understand seeing me like this". "But does that just mean he doesn't see her from now until she passes?" I think to myself. Over protection versus dignity of risk, here it is again – the internal negotiation of exposing Anakin to something that may be extremely difficult to process, a large reason of which is because I am neither sure of how much he understands of the situation nor of how to talk with him in an way that's accessible to him about processing the emotions that I know will inevitably come up – confusion, sadness, grief, memories related to the last time he experienced a grandmother under nursing care.

I place my hand over the left side of my chest, tapping it gently as I ask, 'Are you having strong feelings?'

He looks at me, making direct, sustained eye contact. It is in times like these when I know intuitively that he is locked in to our conversation, engaging with me at his highest level of comprehension; there's no vocal stim going on, no staring off in his own thought world while I speak to him. It is just me and him, and we are as dialed in to each other as we are ever able to be. Furrowing his brow and slightly squinting with those sweet, green eyes he puts both hands over his heart and lowers his head.

I want to squeeze his hand, to put my arm around his shoulders in comfort, but this would only be for my benefit if I did so – Anakin is a warm and affectionate young man, but hugs and *physical contact need to be on his own terms, as too much physical stimulation in the moment can be too overwhelming, even aversive, to him. So, I gently pat his left knee, a gesture that he allows and that I have seen him do to himself while smiling and vocally scripting, another indicator that this is a gesture of shared understanding between us.*

'It is okay to feel sad, my buddy. I have strong feelings, too', I say, again tapping gently the space over my heart. 'You love grandma so much, and she loves you so much. I'm so proud of you for being so gentle with grandma, it made her so happy to see her Anakin'.

He smiles at me through the tears beginning to trickle down his cheeks, a reaction that I'm not sure is him trying to tell me it's going to be okay even if he's sad; or if it's because he feels it's wrong to show sadness or any negative type of emotion; or if it is his way of trying to cope through his sadness. I feel it's a combination of all of these.

'I love you so much, Anakin, I will be here with you. We can be sad, and we can love grandma and we can miss grandma. And we will be okay.'

Trying to inconspicuously wipe the tears from my own eyes, I put on his playlist and let us continue on quietly, each immersed in our own thoughts, for the rest of the drive home.

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Within the broader landscape of care is that of *Interpersonal Care,* which encapsulates the care performed in ways that support social inclusion and participation. This includes interactions with other family members, meaningful engagement with the community, and the nurturing of friendships. It also extends to the individuals within the caregiver's personal network who facilitate this care, beyond formalized support systems.

My analysis of my own data alongside interactive interviews with other caretakers and practitioners like me provided rich, firsthand accounts of caregivers' experiences, revealing the complexities and nuances of *Interpersonal Care.* My reflexive field journal served as a repository for my thoughts, observations, and reflections throughout the caregiving journey, offering valuable insights into this finding. For example, this finding highlights how voice is entangled in the interpersonal relationships that shape caregiving experiences. It demonstrates how voice is not just an individual phenomenon but is interwoven with others in the caregiving landscape, influencing and being influenced by the dynamics of *Interpersonal Care.*

Ultimately, *Interpersonal Care* is a finding that is not merely related to providing care; it's about selectively supporting relationships, facilitating social inclusion, and navigating the complexities of interpersonal dynamics across several types of relationships. It's about coming to a greater awareness of how our voices as caregivers become entangled with those we care for, and those who support us in our caregiving journey.

In my layered account above, I illustrate a form of *Interpersonal Care.* I call attention to the interplay of communication and comprehension that takes place between me and Anakin, even in the absence of traditional verbal communication. In this scenario, I am not just a caregiver but also a sister trying to navigate the complexities of familial relationships and shared experiences. The care I provide is not just about meeting Anakin's immediate needs but also about helping him process complex emotions and changes in our family dynamics.

The internal dialogue between my practitioner voice and caregiver voice highlights the constant negotiation that takes place within me as I strive to balance Anakin's needs with my own instincts and what professional knowledge may say counter such instincts. The moment of shared understanding, when Anakin places his hands over his heart, is a poignant example of how our voices become entangled. Despite the challenges, we find ways to connect and communicate, highlighting the power of interpersonal care. This provides a powerful illustration of how care extends beyond immediate, direct interactions to include a broader network of relationships and social participation. It illustrates the complexities and nuances of caregiving for adults with IDD who have complex communication and support needs. It's about supporting relationships, facilitating social inclusion, and navigating the complexities of interpersonal dynamics in caregiving contexts.

4.1.4 Peripheral Care

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'Anakin has been having a good time, but today he just seemed kind of out of it. He doesn't seem unhappy or anything, but he hasn't been laughing or interacting with us as much, and he's just rocking in his chair and humming and kind of keeping to himself.'

As I listened to my sister describe Anakin's behavior, I tried to think back to what she had been telling me they had been up to for the past few days. I mentally listed things off I thought it might be – did he have a headache? He struggles with sleep, and he was in a different space with a different routine, was that it? He does have dietary restrictions, had he possibly eaten something he wasn't used to and didn't feel well? Was he sitting there ruminating and wondering where I was? Was he afraid he wouldn't get to come back home?

It was late into the 2023 spring semester, and Anakin was visiting my sister and her family for a couple of weeks in another state, a setup that was new for all of us. I started my PhD journey in 2018, and for the past five years it had become increasingly more difficult to juggle my caregiving role with my teaching role with my counseling role with my doctoral student role. At this phase, I was working toward the submission and presentation deadline for my dissertation proposal. Seeing my struggle from afar and knowing I would rather do naked cartwheels around my neighborhood than ask for help, my sister had finally stepped in and insisted we figure out *how she could come and get Anakin for a couple of weeks to help me meet my deadline. Several conversations, quite a bit of persuasion, and a lot of planning, full of "Yes, but what about…" and "Well, what if he…." and "No, are you really sure?", all culminated in my breathed sigh of relief in May when I got the text message that she and Anakin's flight had touched down safely and they were on their way to my sister's house.*

And then it hits me. "Didn't you say you guys had all been out and about for several hours today?" My sister proceeds to give me a running account of the day's activities, letting me know the places they had gone and things they had all done together, and this confirms my suspicion. "I actually think he is just overstimulated and needs to decompress. It sounds like he had a great day with a lot of fun things going on. That is just a lot of activity and interaction for him all at once. That can be challenging for him anyway, but he's also not used to it right now. I'd just say let him chill in his spot for a day and keep it fairly low key." I try to say this in a way that doesn't make her feel like my appraisal is an accusation or a judgement. Because it's neither. It is simply my best guess based on the information she's communicating, where she is now also serving as Anakin's voice in an attempt to appraise the situation, and all I can really do is provide a secondary, albeit experientially informed, appraisal.

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Another form of care, *Peripheral Care*, emerged from my data through interviews and reflexive writings in which caregivers reported engaging in a primary responsibility that was alternative to immediate caregiving. As such, peripheral care represents a form of multitasking where the caregiver maintains a level of awareness and responsiveness towards the individual they are caring for, even as they focus on another task. This could occur in situations where the caregiver is physically present with the individual but is primarily focused on another task, such as teaching a class, or when the individual is with someone else who is seeking the caregiver's input. Peripheral care illustrates the constant vigilance and adaptability required in caregiving roles, highlighting how caregivers often juggle multiple responsibilities and roles simultaneously.

In the account above, I am engaged in multiple roles - as a doctoral student, a teacher, a counselor, and a caregiver. Even as I focus on my academic responsibilities, I remain attuned to Anakin's needs and well-being. I intuitively identify overstimulation as the likely cause of Anakin's behavior based on my sister's account of their day. My ability to provide this secondary appraisal, despite not being physically present, also demonstrates peripheral care in a required understanding of Anakin that allows me to provide care and guidance even if from afar. The entanglement of voices in caregiving in this case comes from how my voice merges with my sister's as she seeks my input, and together we strive to understand and meet Anakin's needs.

My experience of peripheral care also draws attention to the complexities and challenges of caregiving for adults with IDD who have complex communication and support needs. It shows how caregivers must constantly adapt and respond to changing situations, often juggling multiple roles and responsibilities. The need for support and understanding from others, as shown by my sister's involvement, further emphasizes the interconnectedness in this landscape of care.

4.2. Monopolizing Knowledge and Conferral of Who is Expert

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Check Your Experiences at the Door…What Do the Experts Say?

This is an autoethnography, yet for the last several weeks I have been putting placeholders in the spaces where I can see elements of my story as a caregiver possibly being included. Even though *it is my story to tell, I stare at my screen and sit fixed with trepidation, doubt, and fairly low efficacy. My hands rest poised over my keyboard, ready to let my fingers fly with a fervor that matches the flow of thought and emotion in my heart and head space related to my experiences. Yet, without fail, just as I start to include a sentence or two about this lived experience, I am immediately pulled to validate a thought I have with something in the literature. "Is this consistent with others' experiences? If it's not, it shouldn't be included, right? My experience doesn't really matter, it's about what the literature says more broadly about caregiver experiences that will really work to inform my own understanding...*

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I Can't Do This...

I can't tell you how many times I've sat down in an attempt to write the pieces of my story, any piece of my story, and I have this immobilizing thought. Immobilizing in the sense that it constrains my ability to construct coherent thoughts around the concept of caregiving, or at least renders them disjointed enough to feel that I'll never be able to articulate them in the way I want to, in the way I need to.

The entanglement of voice I'm attempting to explore – to have a better grasp of not only for my caregiver self, but for myself as counselor-scholar-advocate-researcher – is more than an entanglement of my caregiver voice with the voice of my brother. I now recognize it's also largely an entanglement of my (overwhelmingly) quantitatively trained researcher voice entangled with my (newly) qualitatively exposed researcher voice entangled with my behaviorally trained practitioner voice entangled with my humanistically oriented counselor voice entangled with my plain, everyday old "me" voice. Just when I think I've finally found my jump-off point into the conceptual depths of this inquiry, these voices orchestrate an *inharmonious interlocution of 'tyranny of the shoulds' that anchor me fast and fixed to the perseverative fear of my own future-oriented failure in fully communicating the caregiver experience without further marginalizing Anakin's position.*

Caregiver Voice in My Head: *You shouldn't be doing this. Are you really going to make this about you? It should be about Anakin. His is the story that is compelling. Your part in the story is secondary, you only have a story to tell because of Anakin; you're a character in his story, one he is not able to share, and here you are trying to share yours.*

Quant Researcher Voice in My Head: *This is not real research. This is not credible. This is not generalizable. It is not empirical. This is charlatanism meeting solipsism at its finest (or rather, worst). You mean to tell me there is no systematic process for data analysis? No verifiable way to check reliability? That you just get to more or less "make up" your method of analysis? No demonstrable, positive outcomes for the population? Yea, this isn't a real thing.*

Qual Researcher Voice in My Head: *"Write to right!" You are inquiring narratively which means you must write to know, even if – nay, especially if – you don't know what you're going to write yet. WWKS- What would Kakali say? Feel your way through this by writing your way through this. It's important. Your reactions are so visceral, so mentally, emotionally, and even physiologically ingrained, of course this can be done in a way that provides value. Things to ask yourself, Kristin – would it be okay if the transferability of this work only resonated with a few? Would there be enough significance to the study? What about the implications? You've finally found a way to connect your heart and values to your academic work – where is the real origin of all this resistance you're experiencing to your own work?*

Everyday Critical Voice in My Head: *Hell, no it's not okay – narcissistic much?! And what about ethical praxis of care? You are here to serve others, not yourself. So, keep your sunshine,* *seashells, and butterflies for the art world-this is a space for real, evidence-based research that promotes effective interventions for the people you personally and professionally serve. Get. Over yourself.*

Practitioner Voice in My Head: *Of course, this is complicated to engage with. You know what it's like to sit in a room with a client and their family and for them to be talking to you about things that no amount of training prepares you for. You also know part of that preparation is lacking in the very nature of your training experiences and own reactions following these unprepared-for moments. What it's like to feel yourself a professional failure because the research says 'x' intervention is supposed to work, or 'y' agency is supposed to provide 'a, b, and c' services, but they don't. That you wish you had been able to sit and hear stories from people who have spent years working with clients, gutting their way through the emotional trenches with and alongside them, having the courage to sit with all of the fear, despair, longing, joy, shame, inadequacy, disappointment, hope, excitement, and learning how to situate all of this within the context of your practice in such a way that allowed you to engage deeply, intuitively, and meaningfully while also remaining boundaried in your work. Does the research you've encountered speak to this? Serve this? Prepare future counselors for this? Is the research you're seeing going to benefit your family? What about families in the future?*

Everyday Critical Voice in My Head: *That may be all well and good, but you're not a good writer anymore, or at least not an evocative one. Your academic writing skills may have become more polished, but the heart and soul of your writing has been lost, or at least has gotten considerably weaker. You no longer have the ability to fuse the emotion and love and compassion that you want to inflect in your work. It has instead been replaced with cold, algorithmic, procedural, systematic, truncated, lifeless prose. You're not a good enough* *storyteller, nor are you trained as one. You haven't identified any theories of storytelling, which Kakali says you should consider. You chose an approach that you like but are not skilled enough for. You don't know enough about narrative storytelling yet, how to engage a reader evocatively. Just because you feel this is important, you won't be able to do your, or Anakin's, or any others' stories, justice. You also know you're a rambler- you have knowledge, but do you have the elocution? "Classic millennial" I can hear my critic's voice interjecting. "Of course, she wants to share her story, it's a generation of 'me, me, me; I, I, I'!" Also, do we really need another white woman in academia speaking to a status that's marginalized? Hard pass.*

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> **"***Oh, if these people would have just had somebody in their life that cared about them and tried and worked with them rather than just, you know, 'warehouse' them, I wonder where they'd be… Because, really that's where they had been dropped off as little kids at an institutional setting, and then again landed in this program, but all they knew was the institutional setting." – Maarva*

What does it mean to be an 'expert'? The privilege of being recognized as an expert is often reserved for professionals who have undergone formal processes. Concepts such as gatekeeping are central to discussions about maintaining 'quality control' and 'standards of service'. But who are these gatekeepers protecting, and from whom? Who determines and maintains these standards? Who continuously evaluates them? Who initially established themselves as gatekeepers, under what authority, and who oversees these gatekeepers?

Furthermore, what does it mean to 'know' a thing? What kinds of knowledge are valued and considered in this context? Is knowledge fixed and static, or is it dynamic and fluid? Is there a type of knowledge that we culturally value by default? What kind of knowledge might

Western, American culture prioritize both historically and currently? How does this influence our practice as counselors or caregivers? When should this knowledge be re-evaluated?

We often discuss a research-to-practice gap – is practice-based, experiential knowledge considered less valuable than knowledge derived from the controlled settings required by academia? Is ‘clinical utility’ and ‘clinical significance’ more evidence-based than a caregiver who feels more positively after an intervention but whose p-value is less than .05? Where you are positioned will inform you of your answers to these questions, but what is more important than stating your position is what has informed your position and how did you come about to your current way of thinking – do you even know? Counselors, do you know? Researchers, do you know? Would you consider your training “balanced”? In what ways yes, and in what ways not?

Indeed, almost every interview revealed experiences of being guided in a particular, often incorrect, direction by someone assigned “expert” status – typically teachers, doctors, psychiatrists, psychologists, and therapists. An additional aspect of this conferral is the entanglement of various voices experienced by the caregiver. The professionally ascribed expert status can lead caregivers to question or doubt their own experiences and knowledge. This results in caregivers reevaluating their own experiences and knowledge based on these competing voices.

This process can create a cycle where caregivers continually question their own expertise in favor of professionally ascribed experts. This cycle can undermine the caregiver’s confidence in their own knowledge and experiences, potentially leading to a devaluation of their own expertise. It raises the question: How can we validate and incorporate the experiential knowledge of caregivers into our understanding of expertise?

The voice of the adult with IDD is essential, regardless of if it is difficult to ascertain. It’s not about elevating the caregiver’s voice over the individual with IDD; absolutely not. However, when the comprehension/ability to express voice isn’t available, this creates an entanglement; it’s not about “poor ol’ caregivers need to be heard”, but rather that caregivers need to be heard so our loved ones can be heard. This concern should not be missed or misunderstood. So, how can we ensure that the voices of caregivers are heard and valued alongside those of professionally ascribed experts? These questions are central to redefining our understanding of ‘expertise’ and ‘knowledge’ in this context.

Maarva’s statement highlights the systemic issue of conferring expertise to institutional settings, often at the expense of individual care and attention. The term ‘warehouse’ used by Maarva paints a vivid picture of individuals being stored away, their unique needs and experiences overlooked in favor of a one-size-fits-all approach. This is a poignant example of the monopolization of knowledge, where the institutional setting is seen as the ultimate authority or ‘expert’, often leading to the marginalization of other forms of knowledge and care.

In Maarva’s description, parents, perhaps out of desperation or a lack of alternatives, entrusted these institutions with expertise. This act of entrustment is not merely a thing of the past but continues to occur in the present, often unconsciously. Recognizing this ongoing cycle is crucial to prevent history from repeating itself. Without constant and reflexive examination of our knowledge base, the past will inevitably become prologue. The challenge lies in disrupting this cycle and broadening our understanding of ‘expertise’. Valuing experiential knowledge and individualized care and questioning the power dynamics inherent in our current understanding of who is an ‘expert,’ is a difficult but important step if we are to understand caretakers’ needs. It involves creating spaces where multiple voices can be heard and valued, rather than allowing one voice (in this case, the institutional setting) to monopolize knowledge. In essence, this account calls us to reflect on our own roles in this process. Who are we conferring expertise to in our lives? Are we unconsciously upholding systems that monopolize knowledge? And most importantly, how can we challenge these systems to create more inclusive, equitable spaces?

In my journey as a family caregiver, I've encountered an entanglement of voices that sometimes conflict, challenging my judgment and experience. This entanglement is central to the main finding of *Monopolizing Knowledge and Conferral of Who is Expert,* as it reflects my struggle of determining who the real expert is in the caregiving landscape.

Each voice, whether it's my *Caregiver Voice*, *Quantitative Researcher Voice, Qualitative Researcher Voice, Everyday Critical Voice*, or *Practitioner Voice*, carries its own perspectives, doubts, and criticisms. This creates a complex dialogue that can be both enlightening and challenging. The distinction between these voices often becomes blurred, making it difficult for me to disentangle them completely.

I do not aim with my analysis to arrive at specific conclusions. My goal is to instead recognize and bring to the fore the interplay of these voices. It highlights the discord between my headspace and heart space, stemming from the experiential dissonance between my encounters in the Academy, as a practitioner, and as a caregiver.

Many of these voices I report existing in my head carry a harsh, critical tone, reflecting self-frustration. This frustration arises from the feeling of being unable to control certain aspects of caregiving, despite having extensive training. It's the frustration of not being able to leverage this training in a way that significantly improves Anakin's social opportunity and connection. Reconciling academic knowledge with practical experience and personal emotions in caregiving contexts means to discriminate more purposefully what these voices are trying to say, what kind of experiential wisdom emerges in conflict, in the entanglement of family caregivers' voice and the voice, buried, of those they care for. The exacerbation of this conflict points out to the various roles and identities that emerge in the lived experiences of caregiving, each with its own perspectives, expectations, and socially constructed forms of criticisms. This entanglement adds a layer of confusion and self-doubt but also provides a rich tapestry of experiences that can offer valuable insights into the caregiving experience. Take for instance what Maarva states about this: *"He did apologize to us later, but it was too late.... If he would have just listened to me. To just. Listen to me. That's what he should have done. That's what he could have done a year before. But he was still dismissing me. And you know, we say well you know that was rough and oh my gosh, but no, it was even worse than that, because my [child] suffered longer than he needed to."* Maarva's experience highlights the struggle caregivers often face when interacting with professionals who are supposed to support them. Despite her intimate knowledge of her child's unique situation, Maarva's insights were dismissed by the professional, leading to an extended period of difficulty for her child.

This situation also highlights the tension between professionally ascribed expertise and the experiential or intuitive knowledge of caregivers. The professional in this scenario assumed a position of authority based on their formal qualifications, neglecting to consider Maarva's unique insights gained from her lived experience. This not only undermined Maarva's confidence in her own expertise but also had tangible negative impacts on her child's well-being.The professional's failure to listen and validate Maarva's concerns resulted in a delay in appropriate care for her child. This is a stark reminder of the potential consequences when professionals monopolize knowledge and dismiss the voices of caregivers. It raises questions about the ethical responsibilities of professionals and the need for a more inclusive understanding of expertise.

The disregard for Maarva's intuitive and experiential knowledge is not just an oversight; it is professionally unethical and irresponsible. It negatively affects the quality of life and health of both caregivers and their loved ones. This incident I recounted here recognizes the need for professionals to respect and value the insights caregivers bring to the table, recognizing them as legitimate contributors to the understanding and management of care. The urgent need to redefine 'expertise' in this context takes us to move away from a narrow focus on professionally ascribed status towards a more inclusive approach that values experiential knowledge. This shift is crucial for improving outcomes for both caregivers and those they care for.

4.2.1 Elevation of Caregiver Load by Way of Multiple Roles

As caregivers, we often become a 'jack of all trades', developing skills across various professional disciplines such as case management, social work, education, medicine, and technology. This is not because we have become what would be professionally considered as "experts" in these fields, but rather out of necessity to meet the diverse needs of our loved ones.

This necessity arises from the reality that services for people with IDD often fall short of what is promised or expected. Policies and funding sources vary by state, affecting the availability and quality of local agencies to provide adequate supports to their community members. Furthermore, the staff and providers of these agencies, such as case managers, DSPs, and day program providers, influence the quality of available services. The support needs of the person attempting to access these services also play a role in their eligibility.

However, this necessity is also driven by the monopolization of knowledge and conferral of expertise in caregiving contexts. Often, so-called "experts" in the field do not respect our intuitive or experiential knowledge as caregivers, as mentioned earlier. This lack of respect can lead us to doubt our own expertise as it relates to our loved ones, especially when the "experts" differ from what we want, say, and need. As a result, we are compelled to become sort of mini experts across several fields.

For example, when I moved from Indiana to Michigan with Anakin, I discovered that the state was largely doing away with adult day programming in favor of more community-based and integrated settings. At first glance, this sounds fantastic, yet in the world external to this on-paper policy is the reality that these agencies end up having to prioritize activities related to things like employment, for example, which inevitably leaves behind people with more significant support needs. As Ashoka stated in one of our conversations:

> *"I have a whole lot more folks who are nonverbal and don't really have great communication methods to be able to express what they want all the time as far as decisions go, where they live and who they live with, and medical concerns and all of that.* ***All the big stuff is put on a caregiver****, whether it be a parent or guardian or a staff. They're the ones that do a lot of the daily '[here is] where we're going' and '[here is] what we're doing' and 'here's the options for lunch'. I think that they do the majority of the choice making, honestly, even though that's not where we always want it to be - our folks should definitely have a lot more choice than they have sometimes. But I do think that's probably what I see the most."*

On another occasion, when we discussed the role of interdisciplinary teams, she also noted:

> *"I would say, I think when [family caregivers] have a supportive team who is… who they feel like is taking some of the load, is taking on some of the responsibility. I think they're a lot more likely to be invested in all of the things if they feel like they don't have*

> *to. They're not the only person doing everything about everything. Like if they have a staff, if they have a good day program, if they have a good job or job coach, I think I see…I feel like I see parents when they feel like they can relax a little bit or guardians like, when [their loved one] goes with that person, 'I know they're taken care of and I can spend those 3 hours on something else and not having to be constantly worried about that person that they're going to be okay or not'. I think part of that is* ***they have to do a whole lot of work to get to that point****. ... And parents are tired, like they've been potentially fighting for their kid for a long time. They're tired and they don't want to have to keep fighting with people. ...because* ***I think their whole life is worrying about what may happen to them or, you know, what could happen****. You see stories and things on the news or things everywhere, or just, you know, historically it just is what it is and they just know that that's always a possibility that they're going to be hurt or taken advantage of. And so, I feel like they're able to relax when they have something else in their life that they're comfortable with. But that comes with a whole lot of work. I mean, the parent or guardian is the one finding those things and keeping that team. And honestly, I think the parent or guardian is the one who keeps that team together."*

As these excerpts illustrate, caregivers are often the primary decision-makers, even in areas where the individual should ideally have more autonomy. This reflects the monopolization of knowledge and conferral of expertise in caregiving contexts, where caregivers are often seen as the primary decision-makers due to their extensive knowledge and understanding of the individual's needs.

Ahsoka's statements also touch on the emotional toll of caregiving. She notes that caregivers can relax a bit when they feel supported by a good team, but getting to that point requires a lot of work. This highlights how the caregiver load is elevated not just by the multiple roles caregivers play, but also by the emotional labor involved in ensuring their loved ones are well cared for and safe. The constant worry about what may happen to a loved one is a constant companion, influencing every decision made as a caregiver. It’s a clear example of how the “expertise” conferred upon caregivers can sometimes lead to self-doubt and second-guessing, further elevating the caregiver load.

Ahsoka ’s words resonate deeply with me. The constant worry about what may happen to Anakin is a reality I live with every day. This worry extends to all situations, including when considering staff support. Anakin will never be able to report to me if he was harmed, if his staff was kind to him while he was out, if he felt safe with them while he was out, or even if he feels safe with them in his home.

This is why I absolutely refuse to send him into a public men’s restroom by himself; if there isn’t a family restroom available, I take him into the women’s. I understand that some might question this approach, but I ask you to consider how you would handle the situation if you had a young man who is extremely friendly, trusting, and compliant, who requires some support and prompting to not immediately hug and/or shake the hands of ‘friendly’ strangers, and who has no way of communicating to you if something happened to them in the bathroom. Would you send him in alone?

This situation presents a recurring dilemma – overprotection versus dignity of risk. But I know too much. I know that roughly thirty percent of adults with IDD experience sexual abuse (Tomsa et al., 2021). In this instance, I consider the risk far too great. On the flip side of that, if Anakin and I are out by ourselves and he is not able to stay alone, so if I need to use the restroom, our only option is for him to come with me.

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The DSP Carousel

In the past 11 years of guardianship, I can legitimately count on one hand the number of direct support professionals (DSPs) Anakin and I have had to assist in his support and care. This is despite having "access" to waiver funds that are supposed to support care along with social participation and meaningful inclusion.

Now, it's 2023, and Anakin has been on these waitlists across several DSP staffing agencies since his approval for waiver services back in 2019. In this entire time, we have never had a consistent caregiver, but we have had two who started and quit for one reason or another within 2 weeks of starting, and one who quit due to DSP and agency-specific burnout.

One was a teenager who had never worked with an individual with a disability before. They started and quit in 2019 within 2 weeks. We had a woman who had been in direct care her entire life but was so burnt out with her agency that she opted after decades in the DSP field to work somewhere else that would be more pay, more support, and less stress. Even when we had her, she was only able to work for a few hours one Saturday a month.

And in the most recent experience this summer, we started to get our hopes up that this time we might have found someone consistent. I would like to note that an aspect of this is me playing case manager throughout this entire process by calling agencies, trying to vet agencies, getting on waitlists at agencies, and hoping one of them calls you back with staff.

Back to this summer. In July I hear back from the staffing director at an agency advising there is someone who can work with Anakin. This individual comes to our home, and we do a mini meet and greet. Even this takes coordination and explaining this to Anakin (i.e., yet another stranger *coming into his home that he may or may not see again) and trying to gauge if this staff person will be a good match.*

I meet this person who advises they don't have experience with individuals with IDD outside of the new client they just took on. The individual tells me this was not their first choice in working, but they hadn't been able to find a job to match their degree, and this one will allow them to be at home with their kids when they get home from school.

I say let's give it a go, knowing that for the first month or two I will be staying with Anakin and this staff to monitor and train and make everyone feel comfortable (it's an element of peripheral, interpersonal, and formalized care, all rolled into 1, while also wearing hat of "case manager".). The day this person is supposed to start, they are a no show. The second day they show up I stay with them, and they spend the entire three hours on their phone and watching TV with Anakin.

The next day, I get a call from the staffing agency saying the staff quit. But I don't want to be a pessimist, even though this process is exhausting, frustrating, seemingly worthless because at this point I know how it will end. It's almost more exhausting to keep hopping on the carousel rather than just saying "screw it, you can keep coming with me everywhere I need to go". But this is not fair to Anakin either. He needs interaction beyond me; he needs his own day, his own activities, his own experiences beyond hanging out with his sister all the time.

And so continues the cycle of systemic challenges that caregivers face in navigating the DSP landscape. With each turn of events, we find ourselves stepping back onto the carousel, ready for another round in our relentless pursuit of consistent, quality care for our loved ones.

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I am navigating the complex landscape of securing direct support professionals (DSPs) for Anakin. This process involves multiple roles - not just as a caregiver, but also as a case manager, a trainer, and an advocate. I am constantly juggling these roles in an attempt to secure consistent and quality care for Anakin. The monopolization of knowledge and conferral of who is an expert is also evident in this process. While DSPs are not necessarily considered experts, they are often entrusted with the care of individuals with IDD despite potentially lacking the necessary training or experience. This puts me in a difficult position - I want to entrust Anakin's care to the DSPs, but I also have to be wary due to their high turnover rate and potential lack of experience or training. I am also faced with the challenge of balancing my role as the expert on Anakin's needs by giving the DSPs the tools they need to support him effectively. However, I also know from my professional experience that pushing too hard for the implementation of an individualized support plan (ISP) can lead to DSPs not wanting to stay and work with us.

How I receive this layered account is that my voice as a caregiver is entangled in my multiple roles and responsibilities. My voice is not just about expressing my needs or concerns, but also about advocating for Anakin, negotiating with professionals, and navigating complex systems. This entanglement can make it challenging for my voice to be heard and recognized in our pursuit of consistent, quality care for Anakin.

Excerpt from Cassian: *"I've equated you being a caregiver as being a single mom. This is somebody who comes as a 'packaged deal'... Like, I know you're his sister but it's still, you know, the role is that of a mom. So, I just know that he'll always be first. So more often than not, I'm going to have to learn to not say anything because I'm assuming caregivers are the same as single mom's when it comes to as far as dating that. And I don't have any kids, so it would be seen as me just imposing my thoughts and ideas on you."*

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Sure, I'll go on a Date with You ... Cool if my Brother Comes?

Have you ever gone on a date with your little brother tagging along? Oh, yea? Were you both over the age of 22 and it wasn't a double date?

I have. A couple of times. And let me tell you, the physiological gymnastics that takes place once this question is asked for the other party to fastidiously fix their facial expression in such a way that doesn't denote disappointment, reticence, or confusion while still displaying interest is fairly amusing.

On the one hand, I suppose I could say, 'Well, at least that's one way to separate the men from the boys from jump'; but that would, I think, be slightly unfair.

Again, the nature of my caregiver role means that unless I have someone else who can hang out with Anakin, he goes where I go, and I go where he goes. Generally, we are both golden with this. It's in the times – which is more often than not – when it's the only option we have, and an alternative would be more ideal for one or both of us. Like, I can't imagine Anakin loves having to tag along with me on my own errands, appointments, classes, and in this case, dates. It is actually part of the reason why dating is just not something I messed with in my 20s, and something I approached with a certain degree of my own reluctance, even into my early 30s.

Now, can this reluctance be wholly attributed to my caregiver role? Not fully, no. However, my career focus has, in large part, been fueled by my need and desire to put myself in a position to be financially stable enough, and to have a position flexible enough, to be able to support Anakin and myself over the long term. Not only this, but I am a fairly private person (yes, I know, the irony of doing an autoethnography when this is the case is not lost upon me) and going on a date *with Anakin in tow automatically opens he and I up to sharing extremely personal elements of our lives.*

Fast forward to my current situation, where I'm navigating my only long-term relationship while balancing my single caregiver status. What expectations should there be for my partner to share in my caregiving role? This dynamic is different from parenting a child, even if, as Cassian observes, my role appears similar to that of a single mother. How will my caregiver responsibilities influence potential family planning? What impact will this have not just on me and my partner, but also on my relationship with Anakin? As Cassian points out, I sometimes find it challenging to accept feedback about caregiving. A whirlwind of emotions arises when advice is offered – how can I ensure that my partner's voice is heard and valued without feeling subordinated? He could also provide valuable insights into my caregiving role. However, I'm also aware of the longevity of the role and the possibility of my partner not fully understanding what it entails – such as the DSP carousel. There's also the fact that we will never be able to go on dates alone unless we find another caregiver. This means that my partner and I have had an extremely limited amount of time for just the two of us across our nearly three years together. My caregiver identity seems to trump all other roles in my life at this point – how do I negotiate these roles, whose voices are to be considered, and when and how much do I consider them? When and how much does my partner consider them?

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In this account, I've emphasized the multifaceted nature of my role, which extends beyond caregiving to other aspects of my life. Cassian's comparison of my caregiving role to that of a single mom speaks to this complexity. He acknowledges that Anakin and I come as a 'packaged deal' and that Anakin will always be a significant part of my life. I've also discussed the challenge of processing feedback from various sources, which can often lead to self-doubt about my decisions. It's not just about having difficulty accepting feedback, but the overwhelming volume and conflicting nature of the advice received. I'm receptive to my partner's input, but sometimes grapple with how to incorporate it, or feel that he may not fully grasp Anakin's needs and abilities or understand the journey I've embarked on.

As a caregiver, I've taken on a range of responsibilities to support Anakin's diverse needs. However, my role as a partner exists independently and wasn't formed in response to Anakin's needs. Despite maintaining distinct roles outside of caregiving, the caregiver role has inevitably become my most prominent role, in large part due to systemic shortcomings. These systemic failures, such as the lack of adequate adult day programs and the challenges in finding another caregiver, often leave me with no alternative but to include Anakin in personal activities, impacting both our experiences.

My account also reveals the monopolization of knowledge in caregiving contexts. I've mentioned the challenge of accepting feedback about caregiving and ensuring that my partner's voice is heard and valued, which also reflects the struggle to reconcile professional expertise with my intuitive or experiential knowledge as a caregiver. The long-term nature of the caregiving role and its impact on my life is underscored in my account. I discuss the longevity of the role and its implications for my relationship, potential family planning, and my own identity; the added layer of my partner's conferral further complicates this dynamic.

4.3 Caregiver Currency: How Much do You Have to Spend?

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It's March of 2020. The pandemic is in full swing. Masks are newly required everywhere. Groceries are being washed or left in garages overnight. Public building occupancies are being *restricted to one visitor per family. Social distancing enters the social vernacular. And Anakin and I are alone. Alone with no family in the state. Alone without a way for him to tell me if he begins getting COVID symptoms. How will I know if he starts getting sick? How do I go to the store and get us what we need? He isn't able to stay by himself; if I leave anywhere, he has to come with me, and I don't want him exposed. What about masks – how am I going to get him to wear a mask? We can't afford grocery delivery, and we're supposed to be staying in isolation – do I ask a school colleague to sit in the driveway in their car while I run to the store to get essentials?*

**

Cyanotic fingernails. "Low oxygen," I think out loud. I put my hand to his head. No temperature. "Anakin, do you feel okay?" He just looks at me. I look to his face, body, and mannerisms to interpret what I perceive as lethargy. I have no other tool at my disposal to discern how he may be feeling. This is the case for virtually any question whose response does not require a simple "yes" or "no" response. Even then, the comprehension is not always there for him to discern my meaning, and sometimes the desire to response or engage with my question isn't there either. But he looks at me as if to say, "I need help, I don't feel good." I intuitively know this is the more likely intimated sentiment, because my question is not met with an immediate no – when this is the case, it usually tells me something's up.

It's roughly 8:00pm on a mid-April evening in 2020. We've been in isolation for over a month now. The cognitive load of the daily assessment and check for invisible symptoms on top of the emotional weight of the pandemic concurrent with the weight of the reality that if anything goes wrong, it is on me, weighs heavier each day. It is a two-adult household, but I am the only adult in the household who can assess an emergency; I am the only adult in the household who can *keep us in supply of essentials like groceries, clean water, toilet paper, and cleaning supplies; the only adult in the household to maintain and sanitize our living space; the only adult in the household with an income to sustain and support us both; the only adult in the household who needs to report to work, to continue to attend virtual meetings, to spend and maintain enough currency to keep us both going. It's the reality that I can only imagine hit every single caregiver in the middle of the pandemic. It's you. It's just you. Figure it out. Because if you don't ....*

'Hold on, Anakin, I'm gonna go grab my phone and I'll be right back up here, okay?'

Fumbling to find the right contact, I dial his PCP and speak to the physician on call. She doesn't know Anakin, his diagnosis, his communication or support needs, so I hurriedly try to jam as much context as I can before she cuts me off. 'Excuse me, ma'am, you need to stop talking and listen to me.' I take a breath, hold it in my rib cage for a few beats, and exhale slowly. I know she's right. To say I talk fast on a good day is like saying a bullet train moves at a reasonable pace, and if I'm anxious?

'I'm sorry about that, go ahead, please.'

She tells me she thinks I should take Anakin to the ER immediately.

I hang up the phone and tell Anakin we're going to visit the doctor to help him feel better. He gives me a half-hearted thumbs-up, which worries me even more. I don't know if he's ever 'thumbs-upped' going to the doctor, before or since.

I grab our masks, help each of us get bundled up and into the car, and we drive to the emergency room. Anakin seems lethargic, laying his head on the back of his seat, another uncharacteristic move for him.

We are pre-screened at the door and then taken to the COVID-19 testing tents that are outside in the parking lot. I try to speak calmly and soothingly to Anakin. I know if I get worked up, or *appear worked up, it will only stress him out more. Being at the doctor or the hospital is already a stressful situation for him, regardless of the amount of prep or talking about it beforehand, because ultimately it's a lot of unknown to him, so I try to narrate what is happening as we go; explaining why we're outside in a tent; explaining they're going to put something up his nose; explaining that the thing squeezing his finger 'is just to let us know about your deeeep breath, my guy' I say as I take an exaggerated deep breath, exhaling it out as I speak to help demonstrate what I mean; explaining why everyone's wearing masks; and explaining why, as he keeps asking to take his off by pointing to it and looking at me questioningly, we absolutely need to keep ours on; explaining that they will let us into a room soon and he will be able to lay down; assuring him that I will stay with him; and wondering the whole time how much he is able to grasp of what I'm saying and how much of my monologued dialogue is as much for myself as for him.*

A few hours later we're in a room, and Anakin is laying back in the hospital bed, yet another behavior completely uncharacteristic of him – if we're in a doctor's office and there's a chair available over the bed, he'll always choose a chair. If the bed is the only option for a seat, he'll sit cross legged until it's time to go, and it typically takes quite a bit of coaxing to convince him to lay back when needed. He's hooked up to a monitor keeping track of his blood oxygen (SPO_2*). He is borderline for hypoxia, oscillating between 88-91%. A nurse comes in to tell me he's negative for COVID and pneumonia, and because he's only borderline hypoxic and they have limited beds, they were sending us home with the recommendation to keep an eye on his* SPO_2 *and if it fell any lower to bring him back in.*

I asked the nurse if there were any SPO2 monitors available to buy, and was advised to check the local pharmacies, as there were none available at the hospital. So, I took Anakin, still lethargic, home. I then embarked on a frantic search, calling pharmacy after pharmacy. It soon *became clear that there were virtually no SPO2 monitors left for purchase within a 3-hour radius of our home. Even the medical supply stores I called were out, some telling me 'We just sold our last one today, they're in extremely high demand.' Online searches also hit a dead end. Feeling desperate, I reached out to a colleague from my program, asking if they by chance had one or knew someone who did. Graciously, my colleague created a Facebook post for us (as I have no social media accounts for such) explaining our situation and asking if anyone could help.*

Thanks to a kind stranger with no connection to Anakin and me, we were lent a pulse oximeter so that I could monitor his blood oxygen levels. With this crucial tool in hand, I spent the next two nights camped out with my pillow and blanket outside of Anakin's bedroom door, listening intently to make sure his breathing wasn't labored and that he was okay.

**

Caregiver Currency emerged from my data as an articulation of the metaphorical and literal capital that caregivers expend in the process of providing care. This capital is not solely monetary but also consists of personal resources such as time, energy, emotional capacity, and even health. However, it's important to acknowledge that literal capital, such as socioeconomic status, can significantly influence a caregiver's capacity to provide care.

The transactional nature of caregiving is inherent but often unrecognized in daily interactions. Caregivers 'spend' their currency on tasks that require effort, attention, and emotion, while 'earning' or 'recharging' their currency through rest, motivation, and confidence-building activities. The value of this currency is subjective and dynamic, fluctuating based on a variety of factors including the caregiver's mental and physical state, life experiences, social identities, socioeconomic status, and the demands of their caregiving role. These factors can significantly influence the amount of currency available for caregivers to expend each day. As Minerva stated in our interview:

> *"I think. I mean, as a family member, especially if the client's living with the family member, it's a 24/7 responsibility, so they don't get to go home after shift, you know what I mean? And deescalate, especially if it's a really difficult person, difficult client with lots of needs and behaviors, medical, whatever, they don't get that break. I also think that sometimes that leads to caregiving fatigue where we run up against it as [professionals], because we want to implement the plan consistently. But by hour 12, the parent has had it, and it's like, "I don't care, have the ice cream bar." And it's not that they don't care, they're just... Very tired."*

Similarly, Ahsoka told me:

> *".. if it's a staff person who is on a shift and being paid to do what they're supposed to be doing, I definitely am a lot less forgiving than I am with a family who just like that; Like, I know that they're exhausted and they have three other children, or they have this or that, and somebody else has a basketball game and, you know, this person doesn't want to go. I mean, there's just, there's so many other aspects to if it is a family member [providing care] and they're living at home that I definitely I understand that more I guess, or I'm more forgiving in that realm than I am with a staff who is being paid to do what we're asking them to do."*

In my account above, expenditure of *Caregiver Currency* suggests that I am seen constantly assessing Anakin's health, managing our living situation, and maintaining my professional responsibilities. This expenditure is echoed in Minerva's excerpt, where she talks about the 24/7 responsibility of caregivers and the fatigue that can result from it.

The transactional nature of caregiving is also evident in my layered account. I am ‘spending’ my currency on tasks like taking Anakin to the hospital, searching for an SPO2 monitor, and staying up nights to monitor his health. However, there are few opportunities for ‘earning’ or ‘recharging’ this currency. The value of *Caregiver Currency* also fluctuates based on various factors. For instance, the pandemic increases the demands on me as a caregiver, thereby reducing my available currency. Ahsoka’s excerpt also touches on this, highlighting how different circumstances can affect a caregiver’s capacity to provide care. My layered account further highlights how literal capital or socioeconomic status can impact a caregiver’s ability to provide care. For example, I struggled to afford grocery delivery and had difficulty finding an SPO2 monitor due to high demand and limited availability.

The emotional toll caregiving can take is highlighted in the final part of my layered account. For example, I needed to remain calm and reassured for Anakin, despite my own (extreme) anxiety and stress. This emotional labor is a significant expenditure of *Caregiver Currency*. My health becomes a form of currency when Anakin’s health is at risk. For example, I needed to monitor Anakin’s health closely, even staying up nights to ensure his breathing isn’t labored. This takes a toll on my own health and well-being. This account also illustrates times when almost all of my currency is consumed by my caregiving role, leaving little to no resources for other tasks and roles. As a student, I would need time and mental energy to attend classes, complete assignments, and engage in academic discussions. However, the demands of caregiving leave little room for these activities. My role as a counselor also requires emotional capacity to empathize with clients and provide effective guidance. Yet, the emotional demands of caregiving can deplete this capacity, making it challenging to fulfill this role effectively.

Self-care is also an important aspect of maintaining one's well-being and ability to care for others. However, in my layered account, we see that there is little time for respite. I spend nights monitoring Anakin's health instead of resting, and I spend the day worried about how he is doing. This lack of time for the self further depletes my currency over time, thus highlighting the challenges faced by caregivers like me and the need for strategies to help us manage our resources effectively.

4.3.1 Temporality

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Split Attention/Split Time

Since I was 25 years old, I've had legal guardianship of Anakin. I've had primary caregiver status – for us, this means he and I have lived in the same home – for the last 8 of those years. From the beginning of the shift into this status, when I was working in a '9-to-5' type clinical setting, to now being a 35-year-old in my final year of doctoral study, a zoomed- out appraisal of the differences in my role, experiences, and energy reserves are stark. But even when I think back to when I was 18 and beginning my undergraduate study in psychology, and how the shift of me leaving the house slightly restructured the nature of my role, I have always considered Anakin's care. I legitimately do not remember a time where I wasn't thinking about it, worried about it, prioritizing it.

Growing up in a single-parent household meant the nature of my and Anakin's sibling role had always been slightly blurred between that of caretaker and just good ol' fashioned older sister. While I am not the oldest child in my family, I had been the oldest in the household from 10 years old onward, and therefore functioned more as 'the oldest', and all that implies. For our family, it meant a shift in our family system, where I shared more of a partner role with my mother; this *correspondingly resulted in the dual, caretaker-sister role with Anakin. Our family was a team. My mother worked nights as a nurse and brought home the proverbial bacon, and I helped take care of my brothers at home – make meals, straighten house, do laundry, go to school, go to practice, come home, study (sometimes), hang out with/take care of my brothers, rinse, and repeat. My grandmother stepped in and filled in the gaps whenever and wherever she was able, which was a lot, so please let that be emphatically noted. We had help. I had help.*

This time in our lives is genuinely precious to me. It's the foundation of my and Anakin's bond, impenetrable and everlasting. The time when my intuitive knowledge, my insights into who Anakin is as a person – what and how he communicates, what he likes, what he doesn't, the subtle signs that intimate more nuanced feelings, like anxiousness, frustration, and shyness – began to develop and crystallize. It's why I started attending his IEP meetings when I was 14 (he was 7). It's why I knew as I started nearing the end of high school that I needed and wanted to stay near Anakin, so I only considered colleges that were within a two-hours driving distance from our home (and that also had basketball scholarships so I could pay for school, a necessary, albeit limited, two-fer). It's why from undergrad until now I have worked in disability services, primarily alongside folks with IDD.

Every school experience I've had – undergraduate in Indiana from 2006 to 2010; master's in Utah from 2011 to 2013; PhD in Michigan from 2018 to 2023 – has entailed Anakin being factored into the equation. During undergrad I would pick him up on evenings and weekends, either to come hang out with me and my friends on campus, to go on community outings, or to attend my home games. There were a couple of times he even attended classes with me out of necessity (i.e., not having another caregiver available to hang out with him). Flashforward to now, and it's a recurring jest in my program that Anakin deserves an honorary PhD just as much *as I do when I graduate., because he's (quite graciously) attended so many of my doctoral classes with me. Not only this, but he's also been in my classrooms with me when I've been teaching undergraduate courses. Again, this is out of necessity, as finding and retaining direct care staff has been (and will always continue to be) difficult, inconsistent, and unreliable. This is true in virtually every state he and I have lived in.*

In 2015, I obtained full, primary caregiver status and Anakin came to live with me permanently. I immediately began the process of setting him up for services – in Indiana, this entailed signing up for what was called the Family Support Waiver, the state's HCBS waiver – but he was waitlisted for over a year. I had also enrolled Anakin in school, but his school day didn't fully coincide with my on-site work hours. This meant that the full-time position I had in a clinically based setting wasn't going to work, so I took a consulting position that would allow me both scheduling flexibility as well as the option of taking Anakin with me if and when I needed to on-site visits or staff trainings. It was also around this time that I had originally gotten accepted into this doctoral program, but leaving at that time would've meant starting the guardianship and services process completely over again, a process I had neither the bandwidth nor the financial resources to start again, so I deferred acceptance.

From then until now, the load feels epigenetically compounding. It's not noticeable daily, perhaps, but the longevity of it, knowing the need to maintain it for literal decades to come if I am so fortunate, weighs heavily. The caregiving role is not just about the present moment; it's a long-term commitment that extends far into the future. It's about navigating the complexities of systems and services while also managing personal and professional responsibilities. It's about making difficult decisions and sacrifices for the well-being of Anakin. And through it all, it's *about finding ways to replenish my caregiver currency, to ensure that I can continue to provide care without compromising my own well-being.*

**

Temporality refers to the enduring nature of the caregiving role and its impact on the expenditure of *Caregiver Currency*. It is not merely the daily tasks of caregiving that deplete the currency, but the cumulative effect of providing intensive support day after day, month after month, and even decade after decade. As I age alongside the adult I am caring for, the level of support required remains high, further impacting my currency expenditure.

This long-term commitment to caregiving is a journey that moves from past to future, as aptly described by Jones, Adams, and Ellis (2013): “The present self is a temporal condition, always coming from the past and moving toward the future” (p. 565). This journey involves navigating systems, finding support staff, and addressing new concerns related to aging. Each step on this journey represents an expenditure of my *Caregiver Currency*.

It’s extremely important for me to note here that it is not Anakin that is a burden. The challenge lies in the systemic failings to provide consistent, meaningful, and engaging support for both caregivers and their loved ones. The strength of caregivers lies in their resilience and ability to navigate these challenges over time. In essence, *Temporality* emphasizes the importance of acknowledging the long-term nature of caregiving and its impact on Caregiver Currency. It highlights the need for strategies to help caregivers like me manage our resources effectively over time, ensuring we can meet our caregiving responsibilities without compromising our own well-being.

From the moment Anakin came back to live with me permanently, things necessarily began to shift. I immediately began the process of setting him up for services, but he was waitlisted for over a year. This delay was the first of many systemic shortcomings that would impact my *Caregiver Currency.*

My role as a caregiver didn't just affect my personal life; it also influenced my professional decisions. I needed to leave a full-time position in a clinically based setting for a consulting position that offered scheduling flexibility and allowed me to bring Anakin with me when necessary. This decision was a direct result of the caregiving role's demands and its impact on my time and energy. This is true even now. As I approach graduation, I am very uncertain about the viability of obtaining a faculty position. It has already been extremely difficult to navigate a course and teaching load without having an alternative caregiver; as of now, Anakin and I continue to have no additional staff support. This again will mean that when I am assigned classes to teach, it will either be bring Anakin with me (which I am assuming most tenured positions are not going to allow), find positions that are completely remote, or continue to piece-meal instructor positions together to get myself enough hours and a steady enough income to support us. The reality is that working as a teacher/professor/counselor, or rather utilizing my education/PhD may not even be viable right now. Honestly, I am looking for any work at this point, including food service and retail.

The longevity of the caregiving role is not just about the daily tasks; it's about the cumulative effect of providing intensive support day after day, month after month, and even decade after decade. As I age alongside Anakin, the level of support required remains moderate-to-high, further impacting currency expenditure.

4.3.2 Boundarilessness

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It had not even been 10 minutes since my grandmother passed.

Not 10 minutes from the time I was resting my hand gently on her arm while I watched and felt the rise and fall of her chest for the last time, and from my back pocket I felt my phone buzz. Conflicted, drained, sad, and to be honest, irritated, I reached for my phone and looked at the screen. It was a member of the research team I was on at the time. It was the fall of 2019, and I was the lead facilitator of an online telehealth pilot intervention for adults with IDD. We were only halfway through the study, and a 90-minute group session was scheduled for later that day. The team leads knew I would be with my grandma for the remainder of her time in hospice, but as I had helped develop a significant portion of the intervention and was the only clinically trained facilitator at the time, there were limited options to fill my role. This was also a timed and funded intervention, and when it comes to intervention research in the Academy, the show must go on.

I didn't want to answer the phone, to have to negotiate this conversation, to sound professional, to put on my practitioner's hat and think about treatment fidelity or how to frame the conversation for the group about why I wasn't there that day. But my co-facilitator was an undergraduate research assistant, and they were doing their best to make the most out of the situation as well. It was not this person I was irritated with; not their fault that the situation had unfolded this way. So, I took the call.

We reviewed the plan for the day's session and talked out some potential scenarios for the breakout sessions. As we're talking, I can hear movement from the bedroom upstairs, letting me know Anakin is now awake and about to come down into the living room. Several thoughts flash *in succession across my mind like a sped-up film reel. Oh my God, grandma Jan's body is still right there. He just saw her yesterday; he won't understand why she won't rouse if he walks into the living room. Everyone down here is crying; how do I shield him from that? Should I shield him from that? Grief can be communal, can be shared, will that help him process this? Will he experience what I understand as grief if he doesn't understand the concept of the finite? Should we leave the house for a bit until the rawness of everyone's emotions settles?*

"So, is there anything else you want to make sure I cover today?" Pulled from the panic of my reverie, I came back to the phone conversation, apologizing for the inconvenience and thanking them for covering for me for the day. And then I turned the power off on my phone.

I have flashbulb memories of the rest of the day: of knowing Anakin is upstairs while my grandmother passes with a few of us surrounding her in her living room bed; of stretching my 6'0 frame as wide as it can go in every direction to physically and visibly shield him from the paramedics zipping her up into a black body bag as he comes downstairs to see what all the commotion is about, all the while keeping a high-pitched, animated tone in my voice while I suggest we go into the kitchen and grab a snack and see what Aunt Lily might be up to.

**

It's the day of the funeral. It will be an open casket. To bring Anakin or not to bring Anakin? How do I help him understand this situation, and what is there for him to understand? He's experienced the death of loved ones before, but only in the sense that there are people in his life he simply no longer gets to see. What does he think of this? How does he experience the loss? I cannot believe it's simply "out of sight, out of mind", regardless of if that's the feedback I continually get from others, often unsolicited, perspectives.

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Boundarilesness is a finding that illustrates the omnipresent nature of caregiving, a role that permeates all facets of life and occurs everywhere, at all times. The nature of the interdependent dyad I have with Anakin is formed by my specific caregiver identity – single, primary, legal guardian – and Anakin's support needs, exemplifying this boundless aspect of caregiving. The constant requirement for a caregiver for Anakin means that I must always be present for him or identify an alternative caregiver when I'm not with him. This results in a caregiving experience that is continually taking place, whether peripherally or directly.

When viewed from a distance, this can feel like an 'everything, everywhere, all at once' vortex that becomes almost impossible for me to compartmentalize. In essence, it's a role without boundaries. Over time, the lack of boundaries can lead (and has lead) to a system overload and currency over-expenditure. When all currency reserves have been depleted, it raises the question: what do you do next? This has led me to a sort of currency 'triage'. This calls to mind Maslow; rather, I can focus on meeting the bottom layers of the hierarchy (food, water, shelter, sleep) and anything outside of that becomes ancillary, extra, a luxury. This is where *Boundarilessness* intersects with *Temporality*. The constant demand for my time and resources, coupled with the unending nature of the caregiving role, can lead to a sense of timelessness or an altered perception of time, an element of which is illustrated in my layered account above.

On the day of my grandmother's passing, I was pulled in multiple directions. I was grieving the loss of a loved one, coordinating a research intervention, and ensuring Anakin's well-being. The phone call from the research team member served as a stark reminder of the constant demands on my time and energy. Despite the personal loss I was experiencing, I switched emotional gears out of necessity and discussed the day's session plan. The moment Anakin woke up added another layer to this boundless caregiving role. I had to quickly strategize how to shield him from the raw emotions in the room and the sight of my grandmother’s body. These rapid-fire thoughts and decisions speak to the ‘everything, everywhere, all at once’ nature of caregiving. The day of the funeral brought forth similar challenges. The decision to bring Anakin or not, and how to help him understand the situation, further emphasized the lack of boundaries in caregiving. Even in moments of personal grief, considerations for Anakin’s needs were always at the forefront.

These layered accounts and shared experiences serve as a tangible backdrop to the findings I presented in this chapter. My analysis of my caregiver experience of entangled voices was guided by three overarching findings: (1) Entangled Voices Across a Variegated Landscape of Care; (2) Monopolizing Knowledge and Conferral of Who is Expert, and (3) Caregiver Currency: How Much Do You Have to Spend? These findings have shed light on the caregiving experience, uncovering much about the interconnected elements influencing this entanglement within the caregiving landscape.

In the next chapter, I will interpret these findings more broadly and use this understanding to inform my implications for research, education and training, and practice. Through this discussion, I hope to find ways to support holistic care, recognize different types of voices, and balance the needs of individuals with IDD and their caregivers. I aim to inform practices that allow family caregivers to embody roles beyond caregiving or care management, enabling them to simply be and enjoy engaging in relationship with their loved one that extends beyond the constellation of care.

CHAPTER 5: DISCUSSION

In this autoethnographic dissertation, I examined the multifaceted nature of the entanglement of voices among family caregivers of adults with IDD who have complex communication and support needs. My experiences as a family caregiver, legal guardian, and practitioner-researcher serving adults with IDD and their family caregivers, allowed me to explore this entanglement alongside other caregivers, family members, and practitioners who have significantly influenced my experiences. In this exploration, I aimed to contribute to an emic and deeper understanding of the complexity of the lived experience of the family caregiver through a description and systematical analysis (graphy) of my personal experiences (auto) to make sense of a cultural experience related to my positionality and intersectional identities as a female counselor and caregiver (ethno; Ellis, Adams, & Bochner, 2011).

In the previous chapter, I discussed three main findings that emerged from my systematic analysis of the many voices present across caregiving experiences: (1) *Entangled Voices Across a Variegated Landscape of Care*, (2) *Monopolizing Knowledge and Conferral of Who is Expert*, and (3) C*aregiver Currency: How Much do You Have to Spend?* Each finding, along with its associated insights, offered a nuanced view of the phenomenon of voices entangled in caretakers decision-making processes. Alongside my layered accounts, the shared experiences and insights by Maarva, Ahsoka, Minerva, and Cassian, added greater depth to my understanding of these experiences as polyphonic events that are dynamically affected by and that affect caregivers' culture.

Through my autobiographical experiences, I interpret the essence of this inquiry – the entanglement of voice among family caregivers of adults with IDD who have complex communication and support needs. As my layered accounts illustrate, this is not just an entanglement of voice between Anakin and me, or family caregiver and their loved ones. Rather, I respond to a multitude of voices – systems, institutions, practitioners, historiographies, medical terminologies – to name a few, at times aware of their presence and sometimes unaware of it. Through this interpretation, I attempted to make sense of the structure and process of my own meaning-making as it relates to my lived experience and the lived experience of a community of individuals to which I belong, both as a caregiver and counselor. By situating my voiced data alongside the voices of other caregivers, I hoped not only to generate awareness but to collectively deepen our understanding of the phenomenon I describe. It was also my intent to engage in a dialogue with professionals in the counseling field about "best practices" as they relate to IDD and the accompanying constellation of care. Through this dialogue, I hope to challenge and potentially reconceptualize our understanding of whose knowledge counts and what knowledge is considered legitimate in the development of these practices.

As my research shows, the caregiving landscape encompasses various forms of care, each representing a different facet of the experience, particularly for family caregivers of adults with IDD who have complex communication and support needs. This multifaceted nature calls for a holistic approach that acknowledges the diverse factors and challenges involved, such as navigating personal relationships and coordinating among interdisciplinary teams who often hold divergent perspectives on care. In this sense, my voice surfaces at times as a distinct layer in this landscape, intermingling with others' and echoing their shared experiences.

The nature of my role as a caregiver forms an interdependent dyad with Anakin. Our shared experiences and evolving needs shape our journey with each communicative interaction, adding a layer of individualized complexity to our relationship's evolving narrative. Central to my caregiving is the process of appraisal and attunement to the voices that influence my decisions, a complex task that involves deciphering not only what my experiences lead me to interpret but also understanding and interpreting Anakin's needs, wants, and emotions. His communication is often constrained by environmental barriers and societal emphasis on verbal and written communication, leading me to assess and articulate his voice as ethically as I can. Simply put, our voices are not solitary phenomena; they are entwined in a complex dialogue of reciprocity, reflecting the intricate dynamics of our interdependent dyad. This interplay demonstrates the reciprocal nature of caregiving, where both parties actively shape each other's experiences. Ultimately, my journey as a caregiver illuminates this interconnectedness, dynamism, complexity, and diversity with the broader caregiving landscape. As such, it adds variegated layers to the landscape, enriching my understanding of the interplay of voices among family caregivers of adults with IDD worth considering.

As I made sense of my narratives alongside Maarva's, Ahsoka's, and others' throughout this research, I recognized the potential stress and emotional toll that navigating formalized care systems can have on caregivers like me. Systemic improvements to make the process more supportive and less adversarial for caregivers ought to pay attention to how caregiving voices, including researchers', interact with one another in ways that may produce and reproduce injustices. As I read Maarva's experiences alongside my own, I began to understand more presciently the effectiveness of intuitive, individualized care, something that the precision medicine movement has begun to acknowledge (Ashley, 2016). This approach stands in contrast to institutionalized, one-size-fits-all methods, offering a more customized and adaptable way of caregiving. While the experiences of caregivers like me, Maarva, and Ahsoka underscore the emotional toll of navigating formalized care systems and the need for more supportive, individualized care, it's crucial to also consider the consequences overlooking or dismissing caregivers' voices in these systems.

Indeed, when caregiver voices are not taken into account, or worse, completely disregarded and devalued, it can lead to misinterpretation, a violation of rights, even, of the individual with IDD. This was the case in my IEP meeting with Anakin's school team, described in the previous chapter, where a team of professionals technically educated in supporting individuals with disabilities made a prescription of segregation based on "*professional* opinion". Maarva's intimation that the egregiousness of the disregard of her voice ultimately resulted in her son bearing the consequences also comes to mind, an event that negatively impacted her son's quality of life in the moment. The fundamental question we need to grapple with here is: how can we ensure that the voices of caregivers are heard and valued alongside those of professionally designated experts?

This finding draws attention to the systemic issue of attributing expertise to professionals and considering institutionalized knowledge as *the* definitive knowledge. This happens often at the cost of individualized care and attention. As we saw in Maarva's account, the term 'warehouse' was used to depict a stark image of individuals being sidelined, their unique needs and experiences overlooked in favor of a one-size-fits-all approach. The monopolization of knowledge in this case, where the institutional setting was seen as the ultimate authority, leads to the marginalization of other forms of knowledge and care worth considering.

As I reflect on findings like this, I also consider the implications for how 'expertise' and 'knowledge' are defined and valued in this context. The monopolization of knowledge in institutional settings can marginalize the caregiver's voice, and by extension, the voice of the individual with IDD. By recognizing and validating the caregiver's voice as a form of ‘expertise’, we can begin to broaden our understanding of what forces shape knowledge and whose voices are prioritized in the development of best practices for IDD support and care. The presumed end-all be all expertise embedded within professionalism can compromise the care of our loved ones, something I hear from other caregivers in circumstances similar to mine.

In her reflections of her caregiver expertise, Laura MacGregor (2022) speaks to the failure of medical personnel to recognize her intuitive knowledge that was inaccessible and unconsidered in her son’s care during the beginning of COVID-19. She describes how she was asked to leave her son, a non-verbal adult with ID, by himself in the ICU the day he was to be extubated, without any exception or consideration for her to be able to stay with him due to the “no visitors allowed” policy. As she mentions:

> “...what the new visitor policy failed to acknowledge was that as the mother and lifelong caregiver for my son ... my unique knowledge was both inaccessible to health care providers operating within the context of the medical model, and indispensable to providing optimal care. Preventing access to my son during his hospitalization would compromise his care.... I was not a visitor, I was an expert able to glean unique and indispensable insight into my son’s body that was necessary for his care (p. 595)”.

From MacGregor’s assertion above, it becomes clear that caregivers play a crucial role in the healthcare journey of their loved ones, particularly those with IDD. Her account shows, in particular, how the COVID-19 pandemic dramatically affected how she was able to provide care in the context of interacting with more formalized systems of care. This is also reflected in the National Alliance for Caregiving’s (NAC, 2020) statement on the pandemic noting it likely amplified the difficulties caregivers encounter in their roles, such as a sense of isolation, financial burdens, emotional stress, and juggling employment responsibilities alongside caregiving duties. These accounts call for a more inclusive approach that views caregivers as partners in care, not just visitors.

Echoing MacGregor's sentiments – who importantly notes that her intent is not to devalue medical knowledge or evidence-based practices – I, too, am not attempting to create a dichotomy between caregivers and professionals; especially considering that to do so further ignores the voice of Anakin and other adults with IDD, thus further placing them at risk for their own stories being constructed and voiced by authors other than themselves. I also am an edgewalker within these spaces, toeing the line of incorporating my caregiver knowledge with my professional knowledge, not only with Anakin, but with the individuals and families I serve as a counselor. My intent is therefore to promote a greater awareness of power operating through the voices involved in caregiving and how our awareness of it may facilitate a more collaborative environment where the insights and knowledge of family caregivers are considered critically alongside professional medical expertise.

From my research, I also came to more consciously understand that the caregiver load becomes elevated by way of multiple roles. The experiences I depicted alongside other caregiver and practitioner voices point to some of the complexities and challenges caregivers face, highlighting how caregiving load becomes elevated by way of multiple roles we play. Pompon and colleagues (2015) reach a similar conclusion in their work, noting that "Although traditionally we have viewed caregivers as communication partners, we now realize the caregiver's role is so much more: advocate, interpreter, "therapist," case manager and more" (para. 6). Accordingly, in Chapter 4, I also illustrated how the monopolization of knowledge and conferral of expertise in caregiving contexts can sometimes lead caregivers like me to doubt our own expertise and second-guess our decisions, further elevating our caregiver load. Part of this is because, due to failings, whether big or small, at virtually every level of a system that purports to support individuals with IDD, we end up developing a set of "generalist" knowledge and skills across several disciplines, all because several of the professionals we encounter in these disciplines can give us conflicting advice and care, lackluster advice and care, or neither advice nor care.

Like all individuals in society, caretakers occupy multiple identities, some of which have have been historically gendered, racialized and marginalized, which further exacerbates the challenges of caregiving. For example, in the IEP meeting I described in the previous chapter, where I was physically separated from the team of professionals, I walked into a PWI and a classroom full of individuals who occupied several similar statuses and looked like me – namely, a bunch of educated white women. As a white, disabled student, Anakin also experiences some degree of privilege afforded by his whiteness, and therefore I benefit from this as well. Here it is important to address that Black and Brown students with IDD and their families frequently face disparities in support and care, an issue that has been largely overlooked. This observation aligns with the insights shared by Ocasio-Stoutenburg and Farkas (2023). They noted that while many people understand the discrimination and systemic inequity faced by individuals with disabilities—evident in areas like housing and employment opportunities—there's less awareness about the intersectional experiences of these inequities, and the challenges are even more profound for Black families of children with IDD. Recognizing these differing conceptualizations and definitions of equity was one of their initial challenges as former chairs of the Multicultural Concerns Committee (MCC), which underscores the importance of acknowledging and addressing intersectional disparities in our work as counselors and advocates for ethical care. Reflecting on these experiences and the systemic challenges they reveal, it becomes clear that the caregiver's load extends beyond the immediate relationship with the individual they are caring for. It is deeply intertwined with the broader institutional and social landscape.

As demonstrated in my research, load has *nothing* to do with my interactions with Anakin, and everything to do with interacting with systems of care, with voices from individuals who may be well-intentioned but who, in their positions of authority, may create extra layers of burden for caregivers that have nothing to do with the provision of direct care. "The families major challenges are less likely to be a direct result of the presence of an intellectual impairment or its sequelae and more likely to be due to the underwhelming, poorly matched, uncoordinated, and potentially adversarial response to the various services systems that they have encountered over the years (Hanley-Maxwell, Molfenter, & Maxwell, 2014, p. 109).

I would love to be able to turn to professionals in my field and say "Oh, but Rehab Counselors, they'll get it, they will help us, they'll understand how to provide support in the midst of these competing forces." But in my experience, this has not been the case. I do not bring this up to collectively shame us, my fellow rehabilitation counselors, but to call our attention to opportunities for growth, me included, in the context of these findings. I have professionally worked with several Rehabilitation counselors over the years for individuals I was serving on my caseload, and the support that folks with IDD received differed greatly from the support received by the folks with physical and/or psychiatric disability. Over the years, in the one time (yes, one) that I interacted with an RC for Anakin's support, I was met with the familiar "he's not able to develop independent work skills, so he is not 'appropriate' for our services." Note I added the quotes around appropriate. I hate this word. It ranks right up there with "high" and "low" functioning. I understand we use these terms professionally to help contextualize our understanding of disability and support needs, but I believe it also results in a cognitive default of category-based thinking and assumption that undermines our ability to effectively implement individualized, needs-based supports. I think it's also important for us to recognize here that our profession was foundationally formed to support individuals with physical disabilities returning from war to find meaningful, gainful employment (Tarvydas & Hartley, 2018) and the needs of individuals with IDD have consistently gone under-addressed. Macgregor (2022) notes, for instance, this is a form of intellectual ableism. I will take this a step further and argue that, as disability 'experts', we will be continually complicit in this until we fully embrace aspects within our ethical code that go *beyond* finding meaningful and gainful employment for the individuals we serve and are also called to support independent living goals. I will discuss this further in the *Implications for Practice* section. For now, suffice to mention that the elevated caregiver load, a consequence of the disparities in support for individuals with IDD, necessitates a shift in our understanding towards the concept of 'caregiver currency'. This concept, as discussed in Chapter 4, encompasses the expenditure of resources, time, and emotional energy in caregiving, often leading to a state of 'currency triage'.

Caregiver currency surfaced as a finding in my research through my analysis of experiences showing caregiving for individuals with IDD as transcending traditional boundaries of time, space, and roles. Indeed, it is an activity that permeates every aspect of life, occurring everywhere and at all times. It also brings to light how systemic shortcomings can lead to an over-expenditure of caregiver currency, resulting in a sort of currency 'triage'. This boundarilessness intersects with temporality as caregiving demands are unending and can lead to an altered perception of time.

In my experience—and I've noticed the same with others as well—the different types of expenditure include physical energy, such as supporting Anakin with instrumental activities of daily living (IADLs); emotional energy, such as interacting with formalized systems like education, healthcare, and social services that don't always "play nicely" with one another; time, for example, I must build significant time buffers into my own schedule to accommodate Anakin's pacing; and financial resources. For instance, my ability to work is dependent upon my ability to find consistent adult care, which has been next to impossible. Social capital is also a factor. Anakin is wonderful about rolling with me wherever I need him to go, but I experience significant guilt in continuing to make him come on social outings with me when I engage with a friend or colleague. This also makes my own self-care challenging because activities like "going on a walk with a friend", attending classes, teaching classes, going to the doctor, etc., must always include Anakin.

Factors influencing the amount I must spend include my own currency related to my health and wellbeing beyond just the caregiving role. My caregiving role has become my most salient role given all of the systemic shortcomings I have already addressed. The expenditure is therefore compounded by the fact that few other identities (sister, partner, friend, counselor, colleague) can be reasonably supported because my caregiving role takes ultimate precedence. Over time, the consequences of over-expenditure have resulted in me engaging in currency triage. I have been less and less able to focus on higher-level goals and have focused only on the immediate necessities - food, shelter, heat, safety.

My exploration of the entanglement of voices across a variegated landscape of care that includes the monopolization of knowledge and conferral of expertise, and caregiver currency expenditure has shed light on the complex dynamics at play in caregiving roles. As I transition next into the implications of this research, these insights will guide my discussion on potential strategies and interventions to address the challenges I've described.

Implications for Practice

My main findings lead me to four primary implications for practice:

1. Development of Family Support Practices (FSPs) within the field of Rehabilitation Counseling. Although supported by existing policies and services, consistent implementation remains a challenge.
2. A revisit and reflection upon the 2023 CRCC Code of Ethics. This involves working with clients to establish goals related to hobbies, independent living, and community integration. These goals should align with the clients' abilities, interests, cultural background, needs, and welfare, emphasizing the importance of culturally responsive accommodations.
3. Federal recognition of Direct Support Professionals (DSPs) as a distinct occupational category in the Department of Labor (DOL). This includes advocating for the DOL's investment in the DSP workforce.
4. Incorporating autoethnography as a supplemental psychotherapeutic approach alongside complementary approaches such as narrative therapy.

These implications highlight the need for continued development and refinement in the field of Rehabilitation Counseling. Here is where state Home and Community-Based Services (HCBS) waivers play a significant role in shaping the landscape of support services.

State HCBS waivers include Individual and Family Support Services (IFS) for various support areas, backed by the Developmental Disabilities Assistance and Bill of Rights Act of 2000 (DD Act; P.L. 106-402). However, the consistent implementation of these services is a challenge (Kyzar et al., 2012). Funding for IFS is relatively low, as highlighted by Projects of National Significance (PNS) from The Administration for Intellectual and Developmental Disabilities (AAIDD, 2012). In 2013, only a small portion of total IDD spending in the U.S. was for IFS, with a decrease in family support allocation (Braddock, 2015). The 2011 Wingspread Conference proposed a national agenda to improve support for families of individuals with IDD, emphasizing the need for state service systems to focus on supporting families and for the development of National Supporting the Family Initiatives (Hecht et al., 2011).

At this juncture, rehabilitation counselors play a crucial role. Our roles involve coordinating services, advocating for change, and developing programs, which are all essential components of FSPs (Leahy, 2018; Leahy, Chan, Sung, & Kim, 2013). This aligns with the call from the 26th Institute on Rehabilitation Issues' (IRI; 2000) to recognize the family as a crucial partner in rehabilitation outcomes (Millington, Jenkins, & Cottone, 2015). In essence, rehabilitation counselors are well-equipped to create effective FSPs, given our multifaceted roles and the emphasis on family involvement in the rehabilitation process. Our unique position allows us to bridge the gap between policy and practice, ensuring that the support provided is not only consistent with existing policies but also responsive to the needs and welfare of individuals and their families. This highlights the significant role of Rehabilitation counselors in enhancing the implementation of FSPs and improving outcomes in the field of Rehabilitation Counseling.

Building on the significant role of Rehabilitation counselors in enhancing the implementation of FSPs, it's important to note that our work is also guided by the CRCC ethical code (2023, p. 5). Our code emphasizes the importance of developmentally and multiculturally appropriate communication, accommodating accessibility needs, and collaborating with clients to adjust practices accordingly. This includes working with clients to establish goals related to **non-**

vocational activities, independent living, and community integration that are in line with their abilities, interests, cultural background, needs, and welfare. Certified Rehabilitation Counselors (CRCs) are ethically obligated to incorporate effective communication systems when interacting with adults with IDD who have complex communication needs. It is crucial for CRCs to consider the voice of the caregiver, but never at the expense of the voice of the adult with IDD. This approach ensures a comprehensive understanding of the individual's needs and promotes a more effective support system. In the same vein as the role of Rehabilitation counselors, the National Alliance for Direct Support Professionals (NADSP) is also making significant strides in the field. They are actively working towards improving the training protocol for Direct Support Professionals (DSPs).

The National Alliance for Direct Support Professionals (NADSP) has been actively working towards improving the training protocol for Direct Support Professionals (DSPs). They have proposed the development of policy guidance that sets minimum requirements for competency-based credentialing for DSPs, aiming to ensure consistency across states (NADSP, 2021). In addition to this, the NADSP has emphasized the need to differentiate and standardize occupational categories that are similar to DSP work. This is to improve the quality of data collected in this field (NADSP, 2021). They also recommend that state reimbursement rates should be structured in a way that supports adequate wages and benefits for DSPs and reflects a pay scale based on levels of training and experience (NADSP, 2021). The NADSP also offers a variety of training events and presentations that cover a range of topics. These include the emerging roles and changing expectations of the DSP workforce, as well as practical applications for hiring, developing, and empowering DSPs (NADSP, 2021).

This aligns with the Institute on Community Integration’s (ICI) call for the creation of a unique occupational category for DSPs at the U.S. Department of Labor. The ICI, which is part of the University of Minnesota, argues that none of the existing occupational categories accurately describe the work of DSPs, and that a unique occupational code is needed to recognize the additional skills DSPs bring to their roles, particularly in supporting people with disabilities to engage with their communities (ICI, 2022). Despite the recognized need for more sophisticated skills and comprehensive training, it’s important to note that there are currently no federal minimum training requirements for DSPs (U.S. Department of Labor’s Office of Disability Employment Policy, 2021). However, the development of career pathways that provide DSPs an opportunity to increase competency and professionalism is seen as a key strategy to improve retention of the workforce and the quality of support they provide (U.S. Department of Labor’s Office of Disability Employment Policy, 2021).

Building on the Institute on Community Integration’s advocacy for recognizing the unique skills and roles of Direct Support Professionals, there is a parallel in the academic world where scholars are pushing boundaries to enrich our understanding of human experiences. This is evident in the work of Carolyn Ellis, Arthur Bochner, and Tony Adams, editors of the series “Writing Lives, Ethnographic Narratives.” They are striving to blur the lines between humanities and social science research, much like the ICI’s efforts to redefine occupational categories. A key text in this series, “Reimagining Narrative Therapy Through Practice Stories and Autoethnography” (Heath, Carlson, and Epston, 2022), presents a pedagogical strategy deeply rooted in autoethnography and storytelling. This approach, advocated by Heath, a psychologist and cultural democracy scholar, Carlson, a licensed marriage and family therapist, and Epston, a co-originator of narrative therapy, mirrors the ICI's call for a unique occupational category, as it emphasizes the importance of unique narratives and experiences in both fields.

The authors, Heath, a psychologist and cultural democracy scholar, Carlson, a licensed marriage and family therapist, and Epston, a co-originator of narrative therapy, advocate for the use of autoethnography and practice stories as both an educational tool for pre-service and new counselors and a method for practitioners to write what they term "practice stories." These stories, which transcend mere clinical description and incorporate artistic expression, aim to engage readers with the ideas and practices being narrated, bringing them to life in a way that traditional clinical writing cannot. In another example, McMillan and Ramirez (2016) champion the use of autoethnography as a therapeutic method for trauma. They argue that the healing process should not be private, as this could perpetuate existing discourses of shame associated with trauma. Instead, they propose making visible the oppressive, gendered, and structural acts that are often overlooked by medical approaches. In light of these findings, it becomes clear that the field of Rehabilitation Counseling is on the cusp of significant evolution. The development of Family Support Practices, the reevaluation of the 2023 CRCC Code of Ethics, the recognition of Direct Support Professionals by the Department of Labor, and the incorporation of autoethnography as a therapeutic approach all point towards a future where the needs and experiences of individuals are more deeply understood and addressed.

Implications for Research

My findings have led me to four primary implications for research in the field:

1. Promoting an Emancipatory Episteme: This calls for a shift beyond community-based research, advocating for a more inclusive understanding of the field.

2. Making Research More Accessible: There’s a need to make research findings readily accessible and understandable to both professionals and non-professionals in human services.
3. Humanizing Data: This involves privileging individual experiences and elevating voices through the medium of storytelling to bring a human touch to the data within our research repositories.
4. Encouraging Multi-System Dialogue: This suggests fostering dialogue across service providers to enhance communication and understanding.

Each of these implications represents a critical area for further exploration and holds the potential to significantly influence the future direction of disability and caregiver-related research. Building on these implications, it’s important to consider the existing literature that discusses the disconnect between research and practice. This disconnect is particularly evident in the experiences of caregivers, whose stories often go unnoticed and unaddressed. The need for more inclusive, empathetic, and humanizing research practices is clear, and this need aligns with the call for an emancipatory episteme. This paradigm, which seeks to remove social barriers and empower individuals, extends beyond community-based participatory practices and embraces emancipatory practices.

There is extensive literature discussing the weak connections between research and practice (e.g., Szymanski & Parker, 2001, p. 461; Tracey, 1991; Savickas & Walsh, 1996). Indeed, part of the gap identified in the literature and voiced by caregivers is that their experiences often go unacknowledged and unaddressed. This lack of recognition and response is emblematic of the disconnect between research and practice, highlighting the need for more inclusive, empathetic, and humanizing research practices. This highlights the need for an emancipatory episteme, a paradigm that seeks to remove social barriers and empower individuals, that goes beyond community-based participatory practices (CBPP) and embraces emancipatory practices (Ocasio-Stoutenberg, Hernandez, & Jackson, 2023). An emancipatory episteme foregrounds knowledge that is seen as informing the radical liberation of individuals and groups from dehumanizing cultural constraints (Bagnall & Hodge, 2022).

While CBPP has its merits, it often privileges certain voices, underscoring the need for a more inclusive approach. Emancipatory practices address this by humanizing the knowledge base and ensuring that all voices are heard and valued (MacPhee & Wilson Norad, 2021). Szymanski & Parker (2001) argue for the importance of both quantitative and qualitative methods in counseling research, viewing them as two sides of the same coin or ends of a methodological continuum. They emphasize that high-quality, methodologically diverse research is essential to advance knowledge in the field and inform practice (p. 461, 464).

In addition to the points previously mentioned, Rumrill, Bellini, and Koch (2019) advocate for the incorporation of diverse forms of qualitative research into the rehabilitation counseling knowledge base. They suggest moving beyond traditional methodologies like grounded theory and phenomenology, and specifically cite collaborative autoethnography as a promising approach. This methodology allows for the development of more consumer-driven practices, informed by the rich, detailed descriptions of lived experiences it provides.

Adding a narrative element and elevating story and voice are crucial aspects of this approach. They allow us to humanize our research repository and provide access to insider experiences that would otherwise remain inaccessible. This not only enriches the knowledge base but also ensures that the research is grounded in the realities and experiences of those it aims to serve. Part of the gap identified in the literature and voiced by caregivers is that their experiences often go unacknowledged and unaddressed. This lack of recognition and response is emblematic of the disconnect between research and practice, highlighting the need for more inclusive, empathetic, and humanizing research practices. Thus, the call for research is not just for high-quality, practically relevant research, but also for research that is inclusive, empathetic, and humanizing. In this pursuit, the guidance provided by Blue-Banning and colleagues (2004) and others becomes particularly relevant. Their identification of key themes that facilitate successful collaborative partnerships between families and professionals can inform and shape the development of such research practices.

Research conducted by Blue-Banning and colleagues (2004) identified six key themes that facilitate successful collaborative partnerships between families and professionals: Communication, Commitment, Equality, Skills, Trust, and Respect. These themes point to the importance of respectful and positive interactions, shared goals, equitable decision-making, perceived competence, reliability, and valuing family input. In 2018, Kennedy-Lizotte and colleagues emphasized the need for robust interagency collaboration to support employment and community engagement outcomes for individuals with I/DD at different life stages. They argued that federal and state agencies need to collaborate on service design, resource sharing, and provider development, with a focus on life stages, to ensure integrated competitive employment and community participation for people with intellectual and developmental disabilities. Antosh and colleagues (2013) outlined elements of effective interagency collaboration, including involving parents and families across the life course, addressing collaboration at local and state levels, establishing comprehensive transition legislation, and expanding the transition planning team. They suggested using Kohler’s Taxonomy for Transition Programming (Kohler et al., 2016) as a framework for defining interagency collaboration. This taxonomy includes five primary practice categories: Student-Focused Planning, Student Development, Interagency Collaboration, Family Engagement, and Program Structure. It emphasizes cultural relevancy, empowerment, family preparation, and collaboration with service agencies in school and post-school transitions (Kohler et al., 2017).

Despite these insights, challenges in interagency collaboration persist. Therefore, there is a pressing need for research that explores practical ways to promote interagency collaboration. Extending Kohler's taxonomy across the life course could be a beneficial approach to fostering this intersystem dialogue throughout an individual's lifespan. This would not only enhance our understanding of the complexities involved in interagency collaboration but also contribute to the development of effective strategies and practices that can be implemented in real-world settings.

Implications for Education

From my research, I have identified four primary implications for the education and training of pre-service practitioners who support individuals with disabilities, particularly those with IDD. These implications also extend to the direct support workforce. They include:

1. A broader interpretation of marginalization when contextualizing disability.
2. The teaching of critical reflexivity as a method of best, ethical practice among pre-service practitioners.
3. The development of a more comprehensive training protocol for the Direct Support Professionals (DSP) workforce.
4. The development and provision of more comprehensive support for pre-service and practicing counselors to help mitigate burnout and to constructively deal with it if and when it occurs.

Building on these identified implications, it’s necessary to explore more deeply and with greater nuance the complexities of marginalization within the context of disability. This leads us to the intersectional ecological approach suggested by Levine and Breshears (2019), which provides a broader lens to view disability through multiple marginalized identities. This approach not only aligns with the Multicultural and Social Justice Counseling Competencies (MSJCC) outlined by Ratts and colleagues (2016), but also enhances our understanding of systemic paradigms that perpetuate marginalization and discrimination. Therefore, it’s instrumental in improving the training of pre-service practitioners and aligns with the need for a more comprehensive training protocol, one of the key implications identified from my research.

As discussed, individuals with IDD often embody multiple identities that have been historically marginalized. Levine and Breshears (2019) suggest teaching an intersectional ecological approach. While we frequently receive instruction on various models of disability, discussions about disability through the lens of multiply marginalized identities are less common. Therefore, Levine and Breshears (2019) advocate for an intersectional ecological lens to challenge the entrenched prevailing ideologies within our professional institutions. This lens is instrumental in understanding, discussing, and researching the interactions of multiple marginalized identities, with the goal of enhancing social justice activism in the field of rehabilitation. Importantly, this approach can significantly improve the training of pre-service practitioners This also directly aligns with the Multicultural and Social Justice Counseling Competencies (MSJCC) outlined by Ratts and colleagues (2016) which call counselors to “reflect a more inclusive and broader understanding of culture and diversity that encompasses the intersection of identities” (p. 29). By cultivating a deeper understanding of the systemic paradigms that perpetuate marginalization and discrimination, it equips future practitioners with the knowledge and skills to effectively address these issues in their practice.

I also see the need to promote critical reflexivity (CR) at the preservice level. This will encourage pre-service practitioners to embrace CR as a best practice, becoming empowering agents rather than further marginalizing those whom we serve. Therefore, I envision CR as a response to Szymanski and colleagues' (2012) call to rehabilitation counselors, where they urged us to "…reconsider and reflect upon the sociopolitical context of [their] practice, embrace the paradox, think divergently, and continually challenge the institutional practices that castify and disempower people with disabilities" (p. 381). In line with this, Ann Cunliffe (2004) describes reflexivity as the critical analysis of our actions, their implications, and the prevailing norms of effective management. This perspective aligns with the call from Szymanski and colleagues, reinforcing the importance of CR in our practice. Cunliffe further emphasizes that journals can be instrumental in fostering students' abilities to become critically reflexive practitioners, as they provide a platform for students to actively participate in their own learning process. These insights shed light on the significance of critical reflexivity in counseling, suggesting that it can enhance self-awareness, improve therapeutic relationships, and promote ethical and responsive practices. This highlights the need for pre-service practitioners to adopt and integrate critical reflexivity into their practice from the onset of their training.

My personal journey and findings also underscore a need for more comprehensive support for both pre-service and practicing counselors. This support is essential for mitigating burnout and providing constructive strategies to deal with it when it occurs. Yet, there's a noticeable gap in the literature regarding how to provide this support at the training level for pre-service counselors. Throughout my career, I’ve encountered assumptions from professionals that, as a counselor, I should inherently know how to mitigate burnout. Phrases like “self-care is important, be sure to implement self-care” are often advised, but the practical application of these words is rarely modeled or explained. This lack of practical guidance is a significant issue. Research indicates that burnout can lead to decreased productivity, increased absenteeism, and health problems (Practice Research and Policy Staff, 2018). It is important that counselor education programs provide explicit instruction and modeling of effective self-care strategies (Abramson, 2021; Bourne, 2021).

However, my findings suggest that this practical instruction is often missing from current training programs. This aligns with the literature, which indicates that while the importance of self-care is often discussed in the abstract, there is a lack of concrete strategies and practices being taught to pre-service counselors (Abramson, 2021; Bourne, 2021). These findings highlight the need for a shift in how we approach counselor education and training. We need to move beyond abstract discussions of self-care and start providing concrete strategies and practices that pre-service counselors can use to mitigate and manage burnout. This isn’t just about improving the quality of counselor training programs, but also about ensuring the well-being and effectiveness of future counselors. This is a path forward for our field.

Study Limitations

As I pursued autoethnography related to my experience as a caregiver and the multiple voices entangled with and constitutive of it, I found myself navigating a complex entanglement of emotions, knowledge, experience, and introspection. The methodology is not concerned with generalizability, but rather with transferability, reflexivity, and ethics. In my personal and professional life, the most meaningful mentors and individuals with whom I’ve interacted as it relates to caregiving have been women and that is particularly telling. The predominance of female voices in this study was not a deliberate choice, then, but a reflection of the overall caregiver landscape. However, this inadvertently led to a limitation in my study – the absence of male caregivers' perspectives. Their voices and experiences, while equally valuable, remained unheard and unexplored.

Conclusion

In this autoethnographic journey, I sought to uncover the phenomenon of the entangled voices of family caregivers of adults with IDD who have complex communication and support needs. The findings of my research were threefold: the entanglement of voice across a variegated landscape of care, the monopolization of knowledge and conferral of expertise, and the concept of caregiver currency. Each finding, enriched by the shared experiences and insights of Maarva, Ahsoka, Minerva, and Cassian, offered a nuanced view of the caregiving experience.

My findings have significant implications for education, research, and practice. In terms of education, it emphasizes the need for a broader interpretation of marginalization, the teaching of critical reflexivity, comprehensive training for DSPs, and more robust support for counselors, especially at the preservice level. For research, it advocates for an emancipatory episteme, accessibility of research findings, humanizing data through storytelling, and fostering multi-system dialogue. In practice, it calls for the development of Family Support Practices, reflection on the 2023 CRCC Code of Ethics, and federal recognition of DSPs. Bridging the practical implications of my findings with the personal journey of autoethnography, I now turn to the reflective nature of this work.

Goodall's (2000) discussion on ethnographic texts speaks to the essence of my autoethnographic journey, which is marked by a tension between my ongoing personal evolution and my aspiration for scholarly completion. “To speak and write from this tension – a tension between incomplete personal evolution and the desire for complete scholarly arrival – is part of the new ethnographic text. Writing that tension honors the incompleteness, the desire, the learning. It shows the self, and the self’s construction of knowledge, as a jointly produced work in progress” (Kindle Locations 42-43). This autoethnography is therefore a reflection of this historical moment, as referred to by Sperry (2001); it is a testament to my becoming in this particular time period. It is a manifestation of my situated identities, my interactions based on my current modes of knowing and being, and my constant evolution. When I look at this work as a composite whole, I recognize that my conclusions are not static. They are dynamic, much like the process of autoethnography itself, which is both a process and a product.

Writing this autoethnography was a transformative experience in many ways, and yet, it still feels incomplete. This product is representative of this timepoint, a snapshot of my journey thus far. I can only hope that in embracing the vulnerability required of the autoethnographic tradition, I can consistently and ethically embrace and model within my own practice as a counselor and caregiver the critical reflexivity required to make professional and personal moves that are reflective of ethical care and praxis.

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APPENDIX A: PARTICIPANT LETTER

Dear Former Colleague/Family Member,

As you are likely aware, I am currently working on my dissertation, which focuses on the lived experiences of family caregivers of adults with intellectual and developmental disabilities (IDD). To do this, I am using a research method called autoethnography, which allows the researcher to engage in critical, cultural analysis by examining their own lived experiences within a particular phenomenon to gain a better understanding of the sociocultural environment in which they exist. To fully capture and analyze these experiences, I will be utilizing a strategy called "interactive interviewing" with individuals who know me and who have been a part of these experiences, both personally and professionally.

I am therefore writing to ask if you would be willing to participate in at least one interactive interview session with me so that I may incorporate the critical input you provide about the shared memories of experiences we have had as it relates to family caregiver experiences of adults with IDD. Please note this interview will be more like a conversation than a formal interview. Our conversation will last approximately 45-60 minutes, and I will come to the interview with discussion starters related to the research topic. Attached to this email is a letter of consent that outlines the procedure, purpose, participation, confidentiality, and risks/benefits of this research.

If you could please **reply to this email within 5 business days** as to whether you would like to **decline or accept participation** in this research, I would be most appreciative. If you accept, I will then coordinate a time with you for this interview. I am also happy to discuss any questions or concerns you may have prior to deciding whether or not you would like to participate in this research. Thank you for your time and consideration of this request!

Warmly,

Kristin Houck

APPENDIX B: PARTICIPANT CONSENT FORM

You are being invited to participate in a research study conducted by Kristin Houck, a doctoral candidate in the Rehabilitation Counselor Education program at Michigan State University. Researchers are required to provide a consent form to inform you about the nature of their proposed study, to convey that participation is voluntary, to explain risks and benefits of participation, and to empower you to make an informed decision. You are encouraged to please ask the researcher any questions you may have at any time during the research process.

Study Title: A Portrait of the Counselor as a Young Caregiver: An Autoethnographic Exploration of the Lived Experiences of Family Caregivers of Adults with IDD

Researcher and Title: Kristin Houck, MS, CRC, Doctoral Candidate

Department and Institution: Department of Counseling, Educational Psychology, and Special Education at Michigan State University

University Address and Contact Information: 620 Farm Lane, Erickson 460, East Lansing, MI 48824; houckkr1@msu.edu; (317) 402-2269

RESEARCH PURPOSE

Adults with intellectual and developmental disabilities (IDD) frequently utilize family caregivers to support their daily needs. For adults with complex communication needs, caregivers are regularly asked to serve as vocal proxy for numerous intimations, resulting in an entanglement of voice between the individual and their family caregiver. However, the voices, experiences, and needs of family caregivers are often subordinated by service providers, medical personnel, and even within disability studies. The purpose of this dissertation is to examine how this vocal entanglement impacts the care needs and overall wellbeing of the family caregiver.

You are being invited to participate in this study by the researcher, as you have been involved with or related to the researcher in some way, and your input will be essential in informing how she has been shaped, both personally and professionally, by her caregiver experiences. You will be asked to participate in an interactive interview with and facilitated by the researcher, which will take place online via video (e.g., Skype or Zoom). The conversation will take approximately one hour of your time.

WHAT YOU WILL BE ASKED TO DO

In the event you choose to participate, you can expect the interactive interview to take place more as an interactive discussion, where the researcher will facilitate the discussion by posing some discussion starters related to caregiver experiences. This interview style is designed to facilitate a more open, natural dialogue between you and the researcher. The interview will be recorded, and notes will be taken by the researcher. You will have the opportunity to read any notes and transcripts of the interview prior to inclusion in the study. Any study revisions will also be sent to you for your input. You may withdraw your participation in this study, including within the interview, at any time without penalty.

Examples of the questions that may be asked during the interview may include, but are not limited to:

As you reflect on our experiences together, what stands out in your memory as it relates to:

Former Colleagues

The most challenging/successful times in our workplace supporting adults with IDD and their caregivers?

A time where you remember serving as the voice for an individual with IDD?

A time where you remember witnessing me serve as the voice for an individual with IDD?

Family Members

The most challenging/successful times in our sibling caregiver journey?

A time where you remember serving as my sibling's voice?

A time where you remember witnessing me serve as my sibling's voice?

POTENTIAL BENEFITS

It is the researcher's hope that developing discussion questions from a strengths-based and exploratory orientation will facilitate personal reflection and insight into participants' caregiving experiences, both their own and of others.

POTENTIAL RISKS

Potential risks associated with participating in this study are that you may experience emotional stress or conflict in recalling and/or expressing your beliefs related to your own memories and experiences of caregiving and caregiver voice, as well as discussing and being exposed to the researcher's memories and experiences related to caregiving and caregiver voice. Because this study is being presented from the researcher's lens, there may be disagreement about the perceived details and impact of past events, which has the potential to result in hurt feelings or interpersonal conflict. To help mitigate this, you will be asked to be transparent about any of these feelings as the study develops. The researcher will also engage in ongoing, reflective consultation throughout the entire research process, with the aim of remaining response neutral during the interactive discussion**.**

PRIVACY AND CONFIDENTIALITY

Your confidentiality will be maintained throughout the study. Data will be kept for no more than 1 year following completion of the study. No physical data will be recorded or maintained during this study. All electronic data will be kept on a password-protected computer and in a HIPPA-compliant folder in OneDrive. Individuals who will have access to this information include members of the dissertation committee and the MSU Human Research Protection Program (HRPP). Any identifiers will be removed to protect privacy and confidentiality.

You may choose a pseudonym for yourself to be used in the study, or the researcher will provide one for you. The researcher may also amalgamate responses to further maintain anonymity. Identifying information will be kept separate from the recordings and transcripts of the interactive interviews, and individual's specific responses will therefore be known only to the researcher. Any recordings of the interview will be destroyed upon conclusion of the study. The interview will be recorded, transcribed, and analyzed. These recordings will be destroyed upon the conclusion of the study. Your individual privacy will be maintained in all publications or presentations resulting from this study. However, please note that full anonymity may still be limited due to a participant's direct connection to the researcher.

FUTURE RESEARCH

All data collected as part of the research, even if information that identifies you is removed, will not be used or distributed for future research studies.

YOUR RIGHTS TO PARTICIPATE, SAY NO, OR WITHDRAW

Participation in this research is completely voluntary – you have the right to say no to participating. You may also change your mind and withdraw your participation at any time during the study. You have the right to refuse to answer any of the questions asked, and the right to stop participating at any time during the interactive interview process. There will be no penalty for choosing not to participate and/or withdrawing your participation from this research.

COSTS AND COMPENSATION ASSOCIATED WITH YOUR PARTICIPATION

There are no foreseeable costs for your participation in this study. There is no compensation for your participation; your participation is completely voluntary.

CONTACT INFORMATION FOR QUESTIONS AND CONCERNS

If you have concerns or questions about this study, such as scientific issues or how to do any part of it, please contact the researcher, Kristin Houck, at houckkr1@msu.edu, or at (317) 402-2269.

If you have questions or concerns about your role and rights as a research participant, if you would like to obtain information or offer input, or would like to register a complaint about this study, you may contact (anonymously if you wish) the **Michigan State University's Human Research Protection Program** at 517-355-2180, Fax 517-432-4503, or e-mail irb@msu.edu or regular mail at 4000 Collins Rd, Suite 136, Lansing, MI 48910.

DOCUMENTATION OF INFORMED CONSENT

Your signature below indicates that you have read the information provided above and have decided to participate in this study. If you later decide that you wish to withdraw your, you may notify the researcher at any time. You will be given a copy of this document for your records.

____	________________________
Printed Name of Participant	Date
____	________________________
Participant Signature	Date

APPENDIX C: INTERACTIVE INTERVIEW- SEMI-STRUCTURED PROTOCOL

Former Colleagues

As you reflect on our experiences together, what stands out in your memory as it relates to:

- The most challenging/successful times in our workplace supporting adults with IDD and their caregivers?
    - Presence of systemic barriers/supports that facilitated/restricted caregivers and their adults?
- Differences in supporting caregivers of adults with more significant support needs (e.g., non-verbal, line-of-sight, etc.)?
    - Unique challenges?
- A time where you remember serving as the voice for an individual with IDD?
- A time where you remember witnessing me serve as the voice for an individual with IDD?
    - What do you think is lost/gained by this verbal proxy status?
- What do you remember about me most as a working caregiver?

Family Members

As you reflect on our experiences together, what stands out in your memory as it relates to:

- The most challenging/successful times in our sibling caregiver journey?
- What elements do you consider to be essential to the role of caregiver?
    - How would you define it?

        - E.g., Elements where you consider difference in the social construction of what is considered caregiver vs. how you would define it in the context of your experience?
    - In what contexts is it most salient?
    - Elements unique to being a caregiver + a family member?
- A time where you remember serving as my sibling's voice?
- A time where you remember witnessing me serve as my sibling's voice?
    - What do you think is lost/gained by this verbal proxy status?
- What are some moments that stand out to you about me as a working caregiver?
- Do you believe I've changed in any way since transitioning into the primary caregiver role?
    - How has our relationship changed or been impacted?
- Please tell me what you have noticed about my adaptation to my caregiving role.
    - Times when I've been successful/less successful at managing my personal and professional life?
    - If/how did I manage my physical and mental health?
    - If/how did I ask for help from others when I was struggling?