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CIRCUMVENTING ABLEISM: A GROUNDED THEORY STUDY EXPLORING
CAREGIVER STRATEGIES TO PROMOTE A POSITIVE IDENTITY

A Doctoral Dissertation
Presented to the Graduate School
of Clemson University

In Partial Fulfillment
of the Requirement for the Degree
Doctor of Philosophy
Rhetorics, Communication, and Information Design

By
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May 2023

Accepted by
Dr. David Blakesley, Committee Chair
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ABSTRACT

This qualitative research study explores how caregivers and persons with disabilities navigate the rhetoric of disability and caregiving through the interviews of fifteen caregivers and fifteen persons with disabilities using the lens of grounded theory and Burke's (1952) dramatic pentad. Significant findings describe how focused disability description can circumvent ableism when rhetorical resources that assist caregivers and persons with disabilities to navigate the rhetoric in disability descriptions are provided. *Disability description theory* includes the three stages that *define, collaborate and revise*, and *practice and apply* a disability description. This qualitative research offers an introduction into the phenomenon of disability description with an emphasis on where resources can be located, or what steps can be taken to help caregivers provide or persons with disabilities access rhetorical support. *Disability description theory* frames the production of a caregiving guide for disability descriptions as a crucial missing resource to determine a disability description style to develop and curate a disability description that assist caregivers and persons with disabilities to claim the rhetorical power and freedom to compose their own narratives, transform their identities, and enhance their lives.

DEDICATION

I wholeheartedly dedicate this dissertation to my mother, Sylvane, an immigrant in the United States that dreamed of a higher education for her children. To my father, Charles Herman who taught me to never give up, and to my son, Bryan, who smashed the educational graduate ceiling for our family and became the first person in our family tree with an MBA degree. To my sister, Mysty, who embarked on this graduate school journey with me, endured her Juris Doctor, J.D degree and is now a health attorney, and to my friends who have endured me pontificating about my PhD research for the last six years.

Thank you to my daughter, Holly, who taught me that disability is far more than a list of limitations. You inspired my personal growth challenging me to see the world differently through the enthusiastic and eager eyes of a caregiver. I am a better person because of you.

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I would like to thank my dissertation chair, Dr. David Blakesley and my dissertation committee Dr. Clare Mullaney, Dr. Cynthia Pury, and Dr. Kristen Okamoto for the constant support and guidance throughout this project. My enduring gratitude to the thirty research participants without whom I would not have been able to complete this research. I would also like to acknowledge people with disabilities who endure more than we will ever understand, and the caregivers who support them with the best possible care.

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CHAPTER ONE

INTRODUCTION

I embarked on my personal caregiving journey when my daughter was seven years old on a Monday morning of October in 1990. My daughter Holly sustained a traumatic brain injury as the result of my collision with a drunk driver who crossed the center lane of the highway and flipped my Jeep Cherokee. Holly was airlifted to the hospital and underwent emergency brain surgery to evacuate the blood and relieve the pressure. With twelve days in ICU and forty-five days in a coma, Holly clung to life—yet survived. I slept on the floor of the emergency waiting room for twelve days watching the door for the hourly medical update on her condition. I slept in a chair in her hospital room for the next thirty-three days. The medical portion of my caregiving education, guidance and expertise began in those forty-five days.

These first forty-five days were like a boot camp grounded in an ideology based on the medical model of disability. The Medical model of disability provides the specialists of disability who are entrenched in the medical world with the goal of repairing the broken parts of a human being (Olkin, 2002). In my daughter's case these broken parts were right side of her brain that controls the left side of her body. According to the medical model, I was receiving guidance from the experts in the field, and I should focus on the repairs if possible. Every conversation included a medical professional with the focus on level setting my expectations. I was given a set of instructions, a list of expectations, and a probability of lifespan. I took Holly home with guidance focused on the data set I was given. I understood that she was lucky to survive, would never recover fully from the disability, and would have a shorter lifespan. In my thirty-three years of caregiving, I have never been provided with guidance from any professional outside of the medical world that differed from the original medical model of disability orientation.

Caregivers' most frequent interactions are with members of the medical community are focused on the impairment of the disability and fixated on coping skills (Singh et al., 2016). For example, my first interactions as a caregiver for a person with a disability included learning new medical terminology, assuming health related responsibilities focused on physical repairs, and mitigating potential deficit outcomes. According to Schulz and Eden (2016), "physicians, nurses, social workers, therapists, and other providers routinely initiate an encounter with a new patient by asking about their health history, the medications they are on, past diagnoses, previous treatments and surgeries, adverse reactions to any drugs, and so on. When family caregivers accompany an older adult, as they often do, they help provide or supplement this information" (p. 6). This method of using concepts of diagnosis and impairment in disability descriptions happens naturally for caregivers and becomes the standard over time.

Like a sponge, I soaked up every piece of the medical terminology outlined in my daughter's diagnosis, frequently repeating the terms to assure best practices as the caregiver. Each day brought more shocking news accompanied by supplementary medical terminology and followed by subsequent impairment descriptions. For thirty years, the message I received remained steady: my daughter was considered broken and would remain damaged until we found a way to repair her. According to Campbell (2008), "The corporeality of the disabled body is constantly in a state of deferral, in a holding pattern, waiting for the day it will be not just repaired but made anew (cured)" (p. 155). It was twenty years or more into my responsibilities of caregiving when I realized on my own that disability medical care was only part of the resources I needed as a caregiver.

I began to realize the power of words that I selected in conversations with my daughter made a tremendous impact. For example, if I commented on her posture, she was impacted either

positively or negatively depending on what I said. According to Kittay (2019), what most caregivers want is to find a future with possibilities to thrive for the person they are providing care for, so caregivers are responding to the guidance available to support the person they care for. Dolmage (2014) states, “disability is often used rhetorically in history as a flexible form of stigma to be freely applied to any unknown” (p.4). This personal shared experience of disability rhetoric between caregivers and persons with disabilities is the reason I selected this area of research for my dissertation.

Disability studies is a growing area of research that began in the social sciences and has since moved to humanities- based disciplines like rhetoric and composition. Disability is now studied in most academic disciplines, such as language arts, philosophy, communication, and psychology (Watson, Rhoustone. and Thomas, 2019). The scholarship covering a diversity of challenges persons with disabilities face is often under the umbrella of disability studies and spans many schools of thought (Gerber, 2011). However, one central issue is frequently mentioned through the disability rhetoric scholarship: the effects of ableism (Cherney, 2011). The most significant scholarship on disability rhetoric examines how to navigate and move forward from disability’s disastrous ableist history. Crue (2016) states “disability – as a category and as a label – has a social meaning influenced by well-established conflicts internal to the disability field. Some of these stems from the complex relationship between disability and its two most important ‘membership criteria’: having an impairment and having a chronic illness (p. 961).” Key demoralizing medical terms describe the narrative of disability as a significant challenge that is to be avoided.

The caregiver and person with a disability share a reality full of words that shape the possibilities for the future, so the rhetoric, communication, and psychology of this messaging

plays an integral part in how the individual's future unfolds and evolves. This reality of words delves into a world of vulnerability as caregivers are often providing the most intimate of care such as assisting with showering or dressing. We are discussing topics that many consider private such as hygiene. Thomson and White (2019) remind us that the most influential relationship a person with a disability has exists with his or her caregiver(s). The overwhelming majority of caregivers are friends, family, or acquaintances often with familial ties, absent compensation, specialized instruction, or any consideration of available time (Moore & Gillespie, 2013).

Caregivers for persons with disabilities inherit a challenging and complex task encompassing health care, education, advocacy, and activism (Singh et al., 2016). To further exacerbate the complexity of the caregiver/persons with disabilities relationship, existing literature often focuses on an overarching one-sided critique of the impact of caregivers on persons with disabilities, often highlighting the negative results from these relationships. The inattention fails to give caregivers the knowledge and understanding that would help them care for people with disabilities. Yet the need for caregivers continues to grow even though support is lacking, guides and other resources scarce, and training in communication largely unavailable.

Jay Dolmage (2014) explains that contemporary disability scholarship outlines the tremendous value of positive rhetoric describing what an individual can accomplish regardless of a disability, and positive contribution to society because of the disability. Being aware of the history, concepts, and theories of how persons with disabilities can move past these barriers that exclude belonging and participations is important and often never communicated to caregivers. Reynolds (2018) asserts that disability education should be at the forefront of dismantling the embedded negative descriptions of disability. Is it possible to accomplish the task without

including the educational resources for caregivers to address ableism without research focused on the narratives of the shared caregiver/person with disabilities experience? Preliminary evidence in my research reveals the gap in understanding how disability rhetoric can shift when the focus is on positive or helpful rhetoric that describes how a person with a disability can succeed. In short, the positive and helpful rhetoric that describe the people with disabilities as individuals with purpose and motivations has not yet impacted caregivers and the quality of care they provide to people with disabilities. We need rhetoric for caregivers to assist persons with disabilities in rhetoric that describe value in the disability in lieu of a deficit, and how these unique abilities of person with disabilities are simply another mode of existing in the world.

Purpose

The purpose of this study is to show how caregivers can provide persons with disabilities the rhetorical power and freedom to compose their own narratives, transform their identities, and enhance their lives. This study is unique because I am invested in understanding the rhetoric and I am not a social scientist. Specifically, I will explore the following:

- How do the rhetoric of disability and the rhetoric of ableism define identity for persons with disabilities, and how do caregivers understand this identity?
- How do caregivers make rhetorical choices when supporting persons with disabilities, and do these choices foster the desired effect? What are these rhetorical strategies' outcomes?
- When and how do caregivers' access and distribute rhetorical resources for persons with disabilities?

Chapter one will offer an introduction to the study by first considering the background and context of disability rhetoric, and the rhetoric of caregiving, followed by the presentation of the

research problem and its aims, the key questions that are answered, and value of the study for understanding caregiving's key role in the life of a person with a disability. At the end of the dissertation, I discuss the study's limitations and where future researchers might focus their attention.

Background

While at the salon for a hair appointment recently, I overheard a fascinating and troubling conversation between one of the stylists and his client. The client was in despair, describing his new experience caring for his teenage son who recently underwent the surgical procedure of amputating his leg from the thigh down to stop the spread of cancer. For over twenty minutes, the father described all the things his son will never do and the opportunities he believed his son would never have despite accomplishments that we see amputees perform all the time, such as running, playing sports, getting married, finding employment, and graduating from college. Consider Jessica Long who is a world-class swimmer and Paralympic Games star with twenty-three medals and an international fan following.

In the twenty minutes of anguish expressed by this new caregiver, the worry about the effects of the cancer is ironically secondary to the loss of his son's leg. It is as if having a disability was worse than death for this father. Reynolds (2018) states, "disability is rhetorically paralleled with death, crime, war, and genocide" (p. 4). Reynolds (2018) further asserts that his transformation of the body represents a semiology of societal regression accompanied by a lifetime of pain, suffering and isolation reinforced by "ableist conflation" embedded in society as a cautionary tale guiding the abled to fear the label of disability over dying (p. 4).

I remember at the beginning of my caregiving journey when I had these same feelings of despair for my daughter's future. Our mental programming has led to this conclusion, with ample

rhetorical reinforcement. According to Watermeyer (2014), “In the popular imagination, disability is firmly associated with loss. Disabled people tend to be viewed as lonely, depressed, and struggling with feelings of inadequacy, damage, and shame” (p. 1). The identity of a person with a disability includes being told who they are, how they will be described, what their treatment will be, and what level of success they can achieve (Watermeyer, 2014). Although the term *ableism* is contemporary, the practice is ancient. In *Disability Rhetoric*, James Cherney explains that throughout our history, disability has been at the top of our list of things to be avoided, so it is not surprising that this new caregiver is reacting in this way.

Cherney (2014) explains that describing a person with a disability through a single story of deficit or impairment is a leftover practice from a problematic ableist history, extending the concepts of unnatural and abnormal to describe disability. Dolmage (2014) suggests that history has given privilege to the body that is considered able. This concept of able is tied to an ideal normality that has been loosely defined throughout history. Ableism historically rooted in science and religion with a concept that a body achieves normal through ambiguous descriptions of ability (Dolmage, 2014). I am not considered disabled, yet I can think of at six things I cannot do that render me unable. For example, I cannot straighten my left leg completely.

This systemic rhetoric holds persons with disabilities back from realizing his or her full value in society, as well as the value he or she might contribute to society. Hall (2016) states, “understanding disability requires understanding its social construction, and social construction can be read in cultural products (p. 2).” As a caregiver for thirty years, I consider what cultural products have been in the mainstream at my disposal to help me reconsider the rhetoric of disability. Both the medical description of disability has been consistently grounded in the rhetoric of limitations, and the media descriptions in movies and theater have been historically

associated with horror creating rhetorical vulnerability for the person with a disability and the caregiver (Hall, 2016).

The odds of becoming a caregiver are high, and people often resist that identity because of the complexity, and stigma (Thomson & White, 2019). Caregivers for persons with disabilities inherit a challenging and extremely complex task encompassing health care, education, advocacy, and activism (Singh et al., 2016). All families will experience illness, and most include family members with disabilities. That means the odds are high that most families include caregivers, people who in addition to having roles as parents and providers may also play a role as a primary caregiver to person with a disability. As a caregiver I have been excluded from social events. I have felt the effects of discrimination. (Thomson & White, 2019).

Frequently on the front lines of disability identity, caregivers often view themselves in a negative light compared to those for whom they care because they operate in a care capacity outside of health care expertise with the expectation of possessing the aptitude to provide adequate care (Moore & Gillespie, 2013). Caregivers for persons with disabilities inherit a challenging and complex task encompassing health care, education, advocacy, and activism (Singh et al., 2016). Despite all these challenges with disability that I watched my daughter Holly endure, my heart was always invested in a better life for her. According to Kittay (2019) this life of open opportunity with a society that sees value of the person they care for is the dream of most caregivers.

Some of my first experience as a caregiver were with psychology professionals focused on anguish and managing the struggle my daughter was facing. The traditional models of psychology address and focus on coping with the grief of the deficit (Watermeyer, 2014). According to Beveren, Rutten, Roets, & Buysse (2021), rhetoric should be more of a focus in the

education of clinical psychology students because of the mental health relevance. Caregivers are overwhelmed by a significant learning curve because they grapple with vast emergent demands; therefore, more priority given to build positive rhetoric for persons with disabilities, and caregivers might assist both parties to move beyond coping and surviving to thriving (Beveren et al., 2021). My interactions with medical, education, and government institutions highlighted my inadequacies as a caregiver, which affected the rhetorical messages that might have transitioned my daughter far sooner from coping to thriving.

Rare Rhetorical Guidance in Crip Camp

Positive examples of giving rhetorical care are a difficult journey for caregivers. The struggle of what to say or do for caregivers is not commonplace. While watching *Crip Camp* (Lebrecht & Newnham, 2020), I found myself contending with the rhetorical impact I could make for my daughter, Holly. The film highlights what is possible for persons with disabilities when they experience rhetorical opportunities and scenarios that facilitate bold choices like leading with an introduction to new people. Central character and writer Jim Lebrecht is a paraplegic with extraordinary confidence and impressive accomplishments (Lebrecht & Newnham, 2020). He is a sound designer for Berkeley Repertory Theatre, the writer and producer for *Crip Camp*, and a major social activist for critical disability civil rights legislation. Lebrecht is an excellent example of a person with a disability that has the rhetorical resources to move beyond a disability description that limits.

Lebrecht emphasized what rhetorical opportunities that build a strong positive identity might look like (Lebrecht & Newnham, 2020). Throughout *Crip Camp*, he recognized how having a caregiver who afforded him more opportunities led to his having identity advantages over some of the other campers. In addition, he recalled crucial early advice from his father when

he entered first grade with nondisabled children: “You know. Jimmy, you are going to have to be outgoing. You are going to have to go up and introduce yourself because they are not gonna come up to you” (Lebrecht & Newnham, 2020, 01:46).

A positive identity requires support for self-determination, and this is not a passive exercise learned from reading a book or watching a movie (Murugami, 2009). This rhetorical scenario fostered Lebrecht’s confidence and resilience by providing this strategy, leading him to take chances and keep trying to develop approaches for building relationships. He did not question whether his son was capable of this action or whether the vulnerability would lead to pain; instead, he placed the focus on rhetoric, presenting a scenario for a potentially successful outcome (Lebrecht & Newnham, 2020). This is typical advice for making friends for abled child. This begs the question — does positive rhetoric around disability demand recognizing the disability or erasing it. Why must there be a choice? I believe this is a great moment to consider in the participant responses of the study and include in resources.

Similarly, I recall guidance from my mother as an abled person encouraging me to introduce myself and initiate relationships in new environments. She advised, “Don’t begin with rejecting yourself.” This rhetorical opportunity was powerful, as I learned through trial and error to be successful at making friends and connections. In contrast, I assumed my daughter with a disability would be rejected, so I never suggested that she take this bold chance and did not create such an opportunity.

Yu (2017), CEO of Diversability, made an important remark about such assumptions: “When I think about what the real issue is in the disability space, I think it’s rooted in assumptions—assumptions that kids with disabilities can’t achieve and can’t dream . . . and because of that, we’re not even given the chance to succeed” (6:58). Camp Jened’s campers

describe caregiver overprotectiveness stemming from fears and limitations being among the most problematic barriers to an independent and purposeful life (Lebrecht & Newnham, 2020).

Caregivers address multiple problems with little or no training, leaving them little time, knowledge, or confidence with which to circumvent the ableist rhetoric of deficit—a necessary aspect of providing rhetorical scenarios or opportunities that build identity. Overwhelmed with medical information and potentially negative outcomes, caregivers naturally focus on what is not possible. The preliminary evidence indicates that the rhetorical problem of disability identity extends far beyond meaningful to emergent. At the crux of one of the most significant identity struggles an individual can face, caregivers receive no guidance on what to say, how to describe the individuals for whom they care, and how to move the discussion from what is not possible to what is possible.

Swift (2020) describes how the world of caregiving is full of fear, uncertainty, with a lack of guidance, yet there is an intrinsic desire to provide hope and opportunities for the individual they care for. In 2018, my second year of the PhD in Rhetorics, Communication, and Information Design Program, I produced my first essay film as an assignment. My professor suggested I describe my reflective narrative as a caregiver. I battled with myself to escape telling this story for a long time. Although I had poured my heart and soul into caregiving, I never felt successful. Moore and Gillespie (2013) suggest that a caregiver wrestles with disability along with the individual for whom she or he cares by examining every single decision and outcome. My essay film, *The Walk*, describes a great battle to find personal acceptance that my daughter's disability, or her unique style of walking with a limp could not medically repaired and how I learned to love her walk over time and the unique perspective this journey has gifted to both of us. My acknowledgment and acceptance of the disability as something that brought positive

things to our life. For example, how she has moved me to be more open about my emotions, and she has inspired other people to reconsider their insecurities. My recognition of the positive aspects of her disability provided the necessary ingredient in her ability to thrive.

Shortly after the release of my essay film, emails, texts, and private messages began to pour in from caregivers describing a similar journey of trying to reconcile how to move forward. What each of these caregivers were looking for was what I realized when meeting Temple Grandin two years earlier: I was comfortable with her neurodiverse pattern of normal. As I poured through the literature, the confusion for caregivers and the individual they provide care for has become much clearer. The gap in disability rhetoric scholarship is significant when trying to understand the rhetoric behind these co-narratives. The caregiver and person with disability narratives could be shared yet competing. I found only one study that interviewed caregivers and the persons with disabilities for whom they provide care (Dan Goodley and Katherine Runswick-Cole's *The Violence of Disablism*). The authors in this study evaluate the effects of caregiver stress amidst behavior issues of the individuals for whom they provide care, and the societal shunning experienced by both caregivers and person with disabilities. As a caregiver of thirty years, I have experienced the violence of disablism Goodley et al. (2011) describe a casual prejudice that is imposed on persons with disabilities that might even be considered as kindness, yet in my personal experience such encounters are a tiny part of the shared experience. Surely, the caregiving narratives of disability success are waiting to be told by both caregivers and the people they care for.

According to Cherney (2011), disability studies continue to challenge the rhetoric of deficits normally stemming from the medical model of disability within the ableist context, highlighting an emerging disability population striving for a more positive identity and the

opportunity to join society as a participant and contributor. Overwhelmed with medical information and potentially negative outcomes, caregiver interactions with the medical community tend to follow the funnel of information focused on what is not possible. At the crux of one of the most significant identity struggles an individual can face, caregivers struggle with what to say, how to describe the individuals for whom they care, and how to move the discussion from limitations to possibilities.

Caregivers address multiple problems with little or no training, leaving them little time, knowledge, or confidence with which to circumvent the ableist rhetoric of deficit—a necessary aspect of providing rhetorical scenarios or opportunities that build identity (Thomson and White, 2019). The preliminary evidence indicates that the rhetorical problem of disability identity extends far beyond meaningful to emergent. In fact, identifying and addressing the rhetorical needs of persons with disabilities who are depending on caregivers is an opportunity for those who give care and those who receive it. Moore and Gillespie (2012) remind us that caregivers have a high goal of being great at their tasks while often feeling misinterpreted, helpless, unsuccessful, and invisible in their roles. Many studies traditionally focus on the individual with a disability while often leaving the caregiver role in a negative light or in the shadows. This body of theory presents a problem when over 80% of persons with disabilities rely on caregivers for multiple modes of support.

Harter et al. (2006) suggest that when defining disability identity, society follows a script. This script of disabled, unable, half than, less than (dis/un/half/less) is repeated and reinforced through all societal systems starting with the caregiver. The eager caregiver dutifully follows the instructions of the medical experts without rhetorical guidance because the benefit of guidance is unstudied. As a result, the existing research is incomplete and inadequate for addressing

disability rhetoric because it ignores the role of providing rhetorical resources for the caregiver essential to building the confidence and skills necessary to thrive in a constantly and rapidly evolving society. Assuming that these identity challenges can be met without understanding the caregiver/disability relationship leaves those in need ill-equipped in terms of strategic approaches to developing positive disability rhetoric.

Linton (1996) explains that disability does not need to be defined in medical terms. The descriptions have room to be reconceptualized and clarified for better outcomes. Imagine the difference in the introduction describing a father who saw only obstacles in his son's disability if he learned to see the possibilities and the accomplishments. Should we not be defining and unpacking these powerful descriptions for caregivers to offer guidance?

Exploring the Gap

The characterization of persons with disabilities as unable to reach an accepted physical standard in systemic ableist rhetoric blocks the positive narratives that inspire hope, success, accomplishment, and happiness (Waugh, 2014). Yu (2017) stated, "No one asks me how I want to be viewed" (07:09). Positive stories about life with disability are difficult to find, even though they exist (Cafferky, 2016). However, some people with disabilities have fought their way through the appropriated labels of deficit and embedded limitations of society to lead full, happy, and purposeful lives (Waugh, 2014). The power of choices made in descriptions and disclosure of disability is a frequently discussed topic in disability rhetoric, uncovering a need to further the shared rhetorical experience of persons with disabilities and caregivers. Revealing strategies to navigate these challenges accompanied with guidance could counter the rhetorical effects of the medical model of disability on identity assisting persons with disabilities seize the independence to create their own stories of success.

The lack of research describing this phenomenon indicates a significant gap crucial to not only persons with disabilities, and caregivers but also to the U.S. population overall because disabled persons comprise the country's largest minority (CDC, 2018). If scholars are to achieve the noble goals of disability rhetoric and disability studies reconceptualizing the benefits of disability, a better understanding of what is missing in the rhetorical pipeline is necessary. A deeper dive into the major relationships of persons with disabilities and caregivers could reveal strategies to improve the rhetoric of disability. Exploring the authentic answers to these research questions could open a new dialogue within the academic community.

This dissertation address two primary research questions with qualitative research:

1. Research Question 1 – Qualitative: What rhetorical themes emerge from opportunities or scenarios that consistently support persons with disabilities in developing a positive identity, and rhetorical themes emerge that block opportunities from developing a positive identity?
2. Research Question 2 – Qualitative- What actionable rhetorical strategies do or can caregivers offer that help persons with disabilities transition from coping to thriving?

. I will examine and interpret the interviews of fifteen persons with disabilities and fifteen caregivers through grounded theory and Burke's (1952) dramatistic pentad while comparing my own autoethnographic examples as a caregiver to help uncover the important but absent shared rhetorical experiences of persons with disabilities and caregivers to understand the phenomenon of creating positive rhetorical opportunities. Grounded theory is a qualitative research tool that consists of initial or open coding, and axial coding that are used in data to organize themes, and stages to help understand the responses from the thirty qualitative interviews with caregivers and persons with disabilities (Strauss & Corbin, 1990). Burke's (1952) dramatistic pentad is an

empirical tool to evaluate the motivation through examining the act, agent, agency, scene, and purpose of a scenario (Burke, 1952). These research instruments will be utilized together to analyze and develop theory producing results that can provide a framework to create guides for caregivers to assist in building a rhetorical roadmap that champions a positive disability identity.

Chapter Framework

This study consists of six chapters to address the research problem, significance, academic scholarship objectives, instrument, analysis, results, and discussion of rhetorical opportunities to thrive for persons with disabilities revealed in the research.

Chapter 1, the introduction, describes the historical tendency to define disability purely in medical terms, which equates it with a disease to be cured. That in turn puts caregivers into the role of nurse or doctor but with no medical training. More recent studies of disability argue for the importance of disability identity, which helps us reimagine the role of caregivers as coaches. Building on this foundation, Chapter 1 introduces these two research questions: Chapter 1 explains why answering the research questions will improve our understanding of caregiver experience, and the person with a disability receiving care.

Chapter 2 details a thorough and rigorous examination of the literature surrounding the disability experience including disability rhetoric, the rhetoric of caregiving, and disability identity to reveal evidence of rhetorical support for persons with disability. The literature reviewed in Chapter 2 explores historical context of disability rhetoric including the medical model of disability, and ableism to understand how rhetoric has shaped disability identity in the disability and caregiving experiences. Understanding the scholarship of disability and caregiving rhetoric reveals the gap describing the disability/caregiving shared rhetorical experience.

Chapter 3 introduces the survey instrument which is a grounded theory study combined with Burke's dramatisic pentad and examples from my ethnographic experience as a caregiver. Fifteen semi-structured forty-five-minute interviews from caregivers, and 15 interviews from persons with disabilities conducted individually is examined to understand the trends in rhetorical choices, challenges, benefits, and rewards in this shared narrative of disability.

In Chapter 4 the interviews are analyzed with detailed explanations and examples of trends in the qualitative data is interpreted detailing the narrative examples. The interviews describe how caregivers and persons with disabilities introduce and describe the disability experience both individual and shared. This analysis in Chapter 4 provides a candid snapshot of how the rhetorical experience of disability unfolds. Additionally, Chapter 4 discusses what is revealed and not described. This chapter considers how the commonalities of the interviews and the differences from caregiver to person with disabilities such as the power of introduction or repeated descriptions can empower or block rhetorical opportunities for persons with disabilities. Chapter 4 will introduce and discuss theory created from the research.

Chapter 5 outlines and summarizes from the research drawing comparisons from my autoethnographic experience as a caregiver along with examples from scholars in the field. Additionally, chapter five 5 discusses implications and limitations of the research. This chapter considers how the commonalities of the interviews and the differences from caregiver to person with disabilities such as the power of introduction or repeated descriptions can empower or block rhetorical opportunities for persons with disabilities. The motivations and choices revealed from the analysis of the narratives from Chapter 4 is discussed with suggestions for further research.

Chapter 6 features a brief rhetorical guide affording a directional approach to the results and discussion of the study. This chapter uses the results to describe an introduction of a person

with a disability being cared for that creates opportunities for empowerment. The guide is based off the theory created from the interview analysis and results discussed in chapter four and five. This guide utilizes the results of the research to inform the caregiver how to foster a positive disability identity.

Summary

The literature reviewed in Chapter 2 thoroughly evaluates ableism as a practice that has historically dominated disability narratives throughout our history. The framework of the medical model of disability has endured despite the recognition of the negative results of this systemic rhetoric. Cherney (2011) reminds us that *disability* is a word chock full of assumptions and barriers for persons with disabilities, whereas Dolmage (2014) suggests that society needs to define the positive side of disability to move forward because overlooked and undefined advantages exist for everyone in the population.

We acknowledge the past, try to understand the present, and look for opportunities in the future to understand how we can effect meaningful change in disability rhetoric. Dolmage (2014) advises to learn from the past yet counsels to look at new stories for strategies to improve disability rhetoric. The most frequent exchanges in disability rhetoric are between a caregiver and an individual with a disability for whom he or she provides care.

Prior research has often focused on how persons with disabilities cope or adapt and how ableist rhetoric in society contributes to disability identity, but it has largely ignored the significant and challenging role of caregivers. Little research has focused on how caregivers process and circumvent ableist disability rhetoric to facilitate or create opportunities for more positive empowering disability rhetoric. Enabling these individuals' ability to thrive is urgent because it affects all Americans culturally as valuable and productive members of society with

important experiences to share and economically in the workforce with a unique point of view from a diverse perspective. This research fills a need to understand what if any rhetorical strategies for caregivers are currently in place to help persons with disabilities build positive identities and how these strategies might create opportunities and scenarios encouraging persons with disabilities to push past coping to thrive. Qualitative research offers a unique perspective to understand the potential problems and solutions in narratives (Strauss & Corbin, 1994). This grounded theory study through the lens of Burke's (1952) dramatistic pentad can potentially produce theories that inform quick guides containing effective rhetorical strategies or scenarios for persons with disabilities to move past the roadblocks of ableism. Such information can help caregivers shorten the learning curve to provide more effective and expeditious assistance.

CHAPTER TWO

REVIEW OF SCHOLARSHIP

The Centers for Disease Control and Prevention (CDC; 2018) report that disability affects everyone in United States because one in four individuals in the country has at least one form of disability. Based on this figure, 26% of the population, or sixty-one million people, comprise the largest minority group in the United States (CDC, 2018). Disability permeates all walks of life spanning race, religion, cultures, and traditions, yet quite frequently the members of this growing group find themselves on the outside looking in.

The concept of normal is deeply rooted in historical human thought dating back to the beginning of human evolution, creating a systemic stigma that limits persons with disabilities in crucial opportunities of belonging, including work, school, and social activities (Dolmage, 2014).

From the concept of disability being monstrous in the medieval period of history to a requirement of an ambiguous requirement of a normal body for societal belonging, the label of disability became an overarching barrier to survival. (Nielson, 2013). According to Nielson, “Disability was defined as the inability to “maintain” oneself economically, and those unable to do so were discouraged from ever boarding ship for North America (p. 13).” If care was needed for the disability, family members were responsible for the care, for the impact on society. If the care could be provided, the community was assessed the responsibility (Nielson, 2014). The disadvantage of disability over the next two hundred years was reinforced by religion, government, and science making the construction of a positive identity difficult (Koenig, 2012).

Although persons with disabilities are frequently separated from an identity that encourages belonging and success, the exclusion of the largest minority in the United States is also expensive. Although the CDC statistics show 27% of the U.S. population has a disability,

only about 17% of the disabled population are employed, making the creation of strategies and opportunities for persons with disabilities to thrive monetarily and socially a principal issue for every person in the United States. The likelihood of landing in a category of disability within an individual's lifetime, as Linker (2013) explains, becomes increasingly higher as the U.S. population ages. It is exceedingly likely that most individuals will deal with a disability or being a caregiver during their lifetime. Learning from real-life experiences how people can provide opportunities to participate and belong in society for persons with disabilities to thrive benefits everyone, whether abled or disabled. Every individual needs to create opportunities for persons with disabilities in the same way that people provide for retirement.

Within the last thirty-two years since the major passage of disability reform in 1990 with The Americans with Disabilities Act (ADA), we have seen extraordinary positive policy changes in access for persons with disabilities (Grim, 2015). This historic reform provides a framework or outline for access that continues to challenge where the gaps of economic and societal belonging can be closed. Despite these sweeping reforms providing line of sight to disability inequities and needs, for much of the disability population, the polite acknowledgement of inclusion from the abled population does not typically come with equal or even fractional societal belonging and/or professional opportunity (Goodley, & Runswick-Cole, 2018).

My most vivid and cringeworthy recollection of student teaching years ago was of a disabled student in a wheelchair parked in the corridor every day waiting for someone to return and wheel him to the next learning opportunity. As he was collected and transported from classroom to classroom the escort focused on technical issues and problems with the student such as a repeated description of what the student cannot do despite existing disability documentation. This repeated exchange is like the delivering of a broken equipment item or an inter-office memo

with challenging information. I can picture his expression of dread to hear his limitations repeated every day, and I frequently considered if this is a common introduction for persons with disabilities. This impairment-based disability description seems an apt metaphor for understanding the progression of disability rhetoric's horrible beginnings. The reforms of the ADA might not have progressed for everyone lulling us into believing that we have succeeded in providing tools for equal access and opportunity while not always examining the complete picture, rendering an incomplete solution.

This literature review examines the historical and contemporary scholarship across disability rhetoric to understand the shared experience of disability rhetoric between caregivers and persons with disability informing guidance and resources to empower persons with disabilities to thrive.

Experiencing Disability Rhetoric

Disability studies provides an excellent lens to understand the choices being made, actions taken, and results of rhetoric (Dolmage, 2014). As an early caregiver in the 1990s, I did not consider that the choices I made in describing my daughter persuaded people in one way or another. I did not understand that my disability rhetoric has a result other than my audience understanding that I had knowledge about the medical condition of my daughter. Burke (1945) states, "Rhetoric is an art of persuasion" that also appeals to an audience's desire for identification (P. 45). My daughter Holly has learned that lesson as a person with a disability for thirty-one years in a text-driven world where language is of considerable significance. Rhetoric is a valuable tool employed for various purposes, and it can play an essential role in victory and defeat. My daughter, Holly, who survived an open head injury that resulted from a fatal accident involving a drunk driver, utilizes a combination of her disability and rhetoric to persuade high

school audiences to reject drinking while intoxicated. The message is powerful because she employs rhetoric that uses the visual aid of her disability to persuade. As she drags her body across the room slowly with her unique gait, she calls attention to her distinctive talent for capturing a room and asks for a show of hands from those who have learned to master the ability to capture the attention of everyone in a room. She shares her forgiveness letter to the intoxicated driver, who died in the collision, thanking him for her novel abilities, which include resilience, extraordinary comedic timing, remarkable patience, being memorable, and captivating one-handed skills. This rhetoric is meant to teach how to rise in the face of challenge.

Burke (1945) states, “A speaker persuades an audience by the use of stylistic identifications; his act of identification may be for the purpose of causing the audience to identify itself with the speaker’s purpose (P. 46).” While everyone watched Holly walk through the room, students indicated after the speech how they related to the act of having a difference in ability on display. Additionally, students shared first experiences of a limp as powerful. Recently while watching the seventh episode of the first season of the *House of Dragons*, a prequel to the very *Game of Thrones series*, the character King Viscerys defiantly, yet slowly walks to the throne to defend his daughter. With his head held high his limp in unhurried and deliberate, and I noticed that his gait exhibits a dramatic similarity to Hollys. *Game of Thrones* fans across the world are calling this one of the most powerful scenes across the catalogue of the immensely popular *Game of Thrones* franchise (Saqib, 2022). Yet this scene like Holly’s scenario is coming from an individual who is not considered physically powerful.

It is not easy to define rhetoric. Rhetoric can be literal or figurative and is not always considered moral, immoral, popular, justified, or true (Herrick, 2013). A gray area of rhetoric offers kinder, understated, and more serene moments that can foster unlikely alliances, create

commonality, and shared understanding (Burke, 1950). Holly's speech to high school students about bullying blurs the lines of bullying by focusing on the struggle of popularity, suggesting a shared identity of struggle between students who are bullied and those who identify as bullies. The pressure that students feel to become bullies to achieve popularity and the struggles students who are bullied face when seeking ways to appeal to popularity can establish an unlikely commonality between these two typically opposed groups. The issue of popularity shifts the rhetorical focus of the dichotomy of bullying to a shared pain that can be unpacked more easily.

According to Burke (1969), "Rhetoric deals with the possibility of classification in its purest aspects; it considers the way that individuals are at odds with one another or become identified with groups more or less at odds with one another" (p. 23). During Holly's speech about popularity and bullying, audience members nod in agreement; then, the auditorium grows silent, students begin to glance at each other, and intermittent tears fall, revealing something extraordinary. These first visible signs of shared pain centered on the topic of popularity reveal that bullying is an outcome. Each time, at the conclusion, students all along the popularity spectrum share an awakening with Holly regarding their membership in the collective of popularity pain due to her successful rhetoric. Dolmage (2013) states, "One simple way to define rhetoric is that it is the study of all communication" (p.2). The communication privileges the larger group with the more powerful communication placing individuals in different classifications at different times. In the above example, Holly accessed a different rhetoric that placed her in a larger category of being bullied in the audience she addressed instead of the usual classification of having a disability.

Dolmage (2014) suggests that the rhetoric of body image can be closely mapped to the rhetoric of disability over time. Disability has always had a role in rhetoric; however, the role has

been consistently entwined with stigma and deficit. The idea or concept of abnormality falls into the extremely rhetorical category (Dolmage, 2014). According to Cherney (2011), most humans fit within the desired standard of normality, which is tied to ability, leaving those outside this standard to accept the deficit label of abnormal. This is a problematic rhetoric of disability connected to the medical world. This pervasive negative rhetoric of disability from ableist society overlooks the value of diversity offered by persons of disability (Dolmage, 2014). For example, my daughter has learned that failure does not necessarily lead to the end of things. The problems she has faced because of disability have taught her resilience, which is a different pathway to overcoming the struggles of her disability. This is a key skill and an important lesson for many.

Exploring Disability Rhetoric: The term *disabled* encompass human beings with at least one impairment of a significant life function, such as walking, talking, or learning (Furr et al., 2016). As I continue to mature in my caregiving role, the concept of at least one impairment becomes more confusing for me as everyone I know has at least one thing they cannot do. The spectrum of ability within this classification of disability is as diverse as characteristics that lie outside it, making the classification ambiguous (Dolmage, 2014). Additionally, Dolmage (2016) states, that an expanded understanding of a wider range of disabilities has led to a rhetorical outpouring of troubling language” (p. 30). Adding more descriptions that are medically based does not necessarily solve any rhetorical issues for a caregiver. According to Kittay (2019), “often the first thing felt by an able parent who is confronted with the information that her child has a disability is the terror that her child will not live a “normal” life” (p. 27). For example, repeating my daughter’s diagnosis was my effort to make everyone understand what she was working through her disability, and it did not solve one problem that I can recall medically or

socially. However, I never imagined that the repetition of my daughter's diagnosis could be the attention given to a malicious rhetoric that might have created limitations. This ambiguity in classification of ability across the disability spectrum has always been rhetorically challenging for all stakeholders (Dolmage, 2014).

Across the spectrum of disability categories is a smattering of ambiguous descriptions closely tied to the origins and arguments of rhetoric making a researcher question if rhetoric has shaped disability or has disability shaped rhetoric. According to Murphy (1990),

The long-term physically impaired are neither sick nor well, neither dead nor fully alive, neither out of society nor wholly in it (. . .) They are not ill, for illness is transitional to either death or recovery . . . The sick person lives in a state of social suspension until he or she gets better. The disabled spend a lifetime in a similar suspended state. They are neither fish nor fowl; they exist in partial isolation from society as undefined, ambiguous people. (p. 131)

Classifications based on ambiguous principles can lead to labels with unintended meanings with unintended consequences (Glaser & Ryan, 2013). Yergeau (2017) states, autism resides far beyond diagnosis" (p. 20). Yet this is where the classifications are originating from, the ambiguous diagnosis. Yergeau (2017) further explains that disability rhetoric is dishonest, elusive, and wielded by people are not disabled. The shifting sands of neurology dominate rhetoric, inaccurately defining disability with an intention of division. These labels, description, and classifications are at the heart of what persons with disabilities face in every interaction. Crue (2016), states disability in public may be viewed as a prototypical category—a category of identity with some typical and some atypical members, none of whom share a single defining feature. (p. 960)." The preface to assumptions about disability have been embedded in our

history and reinforced in nearly every conversation or request for a description of the disability for generations. For example, my daughter and I are constantly being asked to explain her disability. It happened this past Saturday at the farmer's market.

The Rhetorical Origins of Ableism: The rhetoric of disability has a significant importance in understanding the endurance of stigma, the shifting narratives, and the importance of the concept of normal in the rhetoric of the past and the future. Although the term *ableism* is contemporary, the practice is ancient. Cherney (2019) explains the rhetorical origins of ableism in Aristotle's conceptual foundation link the idea of what is considered natural to what is believed normal. This links the concept of normal and natural to ableism asserts that the deviance from the intended goal of nature to repeat patterns is unnatural. Aristotle states, "The equal is a mean between excess and deficiency—every science or art, if it is to perform its function well must regard the mean and refer its productions to the mean (Aristotle, ca. 350 B.C.E.,352a13). Accordingly, successful productions are those to which nothing can be added." The Aristotelian concept based on the deviation from natural or the mean evolved throughout history to portray people with a disability as aberrations or freaks of nature who fulfill the Aristotelian concept of a monster who is less than human (Frey, 2020). An unbroken line from the Aristotelian concept can be seen in the recent movie, *Witches*, which portrays an individual with limb differences as an evil monster who hates children. Frey (2020) explains that this rhetoric is powerful because it is under the guise of science, expanding ableist concepts of unnatural and abnormal through subsequent religious practices, persecution, scientific classification, and scholarship. Religion expanded the monster identity of Aristotle's ableism with notions of disability's perceived limitation on one's ability to achieve the higher good, and in countless cases persons with

disabilities were guilty, evil monsters that deserved their plight, transporting the Aristotelian concept of disability as monstrous across generations.

Clapton and Fitzgerald (2015) describe how religion and science have played parallel roles in the concept of the history of disability by identifying persons with disabilities as “others.” This medical model of disability extends the need for miracle cures to escape the consequences of being considered abnormal. As science emerges with a leading role in disabilities’ medical-centric-identity, theorists such as Darwin suggest that persons with disabilities are locked in a persistent state of dependency and burden. This unfortunate scientific update synonymized disability with affliction, deficit, stigma, and a constant identity of an inability, and incapacity to thrive. Campbell (2009) states, “medical professionals have been accused of contributing to discrimination experienced by disabled people” (p.223). Campbell further states that, “the most serious assertion is that doctors represent one of the disabling professions, which contributes to the social exclusion and dependence of disabled people” (p. 223).” In my own experience as a caregiver, the issue of considering the disability as a burden or struggle conflates when persons with disabilities are excluded from interactions of any part of society outside of the medical community.

One of the most moving examples of the medical model of disability oppression materialized in the development of institutions meant to provide professional caregiving. In the documentary film *Crip Camp*, James Lebrecht describes these places as horrific institutions of neglect and prosecution, explaining that individuals arriving at Camp Jened from these institutions were the most socially removed and psychologically wounded.

The concept of institutional caregiving has had a conflicting past. Many believed initially that institutional caregiving would offer an opportunity for those with disabilities to receive a

better level of care from qualified caregivers (Nielson, 2012). Brignell (2010) explains that institutional caregiving focused only on the medical side of disability, removing all responsibilities and benefits of social belonging such as the ability to relate, establish commonality, find skills, establish independence, or experience joy. These individuals were segregated from the abled population and systematically robbed of the very life force of humankind, a future that offer the benchmarks of belonging or thriving. Lebrecht explained that it took the full Camp Jened experience for these individuals to engage socially or show signs of joy or hope, while explaining that his experience as a child was what he considered a normal experience compared to this alternate situation. Jane Clapton and Fitzgerald (1996) explain how this period of institutionalized disability was a time in the history of disability that used prognosis to determine the potential for a person with a disability.

Finkelstein (2007) describes how independent living created opportunities for persons with disabilities to reimagine identity in integrated housing situations with different caregiving circumstances. This independent group living situation gives persons with disabilities more opportunities to explore new prospects and take more chances. One of the problems in these situations is the lack of government support, the high unemployment rate among persons with disabilities, and the inability to sustain disability communities and support groups. In *Crip Camp*, independent living is discussed frequently, and the opportunities are described as plentiful with an enjoyment of independent living, but consistent caregiving was a challenge. There is a regularly discussed desire to have opportunities to experience independent living under the care of their informal caregivers.

Confronting the Ableist Medical Model: According to Campbell (2009), "The medical profession still plays a powerful role in the lives of disabled people" (P. 235). As a caregiver, the

medical world is my frequent interaction with a reality full of descriptions. Maggio (1997) suggests that descriptive words tied to what is possible or not possible are the most impactful in language and have the power to open or close doors of opportunity. These descriptive words hold the most sway with access to opportunity. Dolmage (2014) explains that the language of disability is dominated by the concept of difference, yet the members belonging to the classifications of disabled are more diverse and adaptable than their abled counterparts. However, the language surrounding this diversity highlights the challenges instead of the opportunities. Society tends to perceive every member of the disabled groups as united under an umbrella of disadvantage.

After thirty years of caregiving, I am not certain what disability really is anymore. It is a very complicated idea. I personally know people who are considered able who are not as able as my daughter who is classified as disabled. We were shopping at the farmers market on Saturday and multiple people with disabilities were at the same booth, and it was fascinating watching the decision being made about who would step aside and what person would go first. Eventually the lady with a cane was selected to pay first, and then my daughter. Grue (2016) states, “The closer one looks at the category of disability, the more fragmented it appears—and much of the fragmentation likely stems from the now familiar conceptual distinction between bodily and social aspects of disability” (p. 960). The fragmentation of the disability description leaves room for the most qualified disability expert in the room for caregivers. Brownlee (2009) explains how tying the focus of the medical model of disability to explain what is considered natural or normal is one of the leading problems in disability rhetoric and in many cases utilizing inaccurate descriptions of what persons with disabilities can achieve. With the proper care and support,

persons with disabilities can adapt, achieve, and thrive, thereby bringing a multitude of social advantages to the general population.

According to Wolbring (2007), ableism is a belief system with procedures and practices constructed to value individuals' mental and physical capabilities directly tied to the medical model of disability judging and ranking individuals' place of value in society. The ableist standard is a state of superior health, which some individuals possess, and others should strive to achieve (Haller, 2010). Bigotry occurs through casual prejudice without reservations or thought afforded to the bigotry (Goodley, 2014). The casual prejudice imposed on persons with disabilities occurs seamlessly throughout the day, sometimes in subtle ways that escape notice in which others could even intend as kindness or mercy (Dolmage, 2014). Campbell (2009) states, "A person with a disability is required to assume an 'identity' other than one's own" (p. 235.). This might include being automatically assigned a disability that is not a limitation for an individual yet assumed in a scenario with an abled individual. For instance, people often elevate their voices and over articulate their language when talking to my daughter, even though her hearing is perfect. They automatically assume that her physical disability is associated with other challenges such as hearing impairment.

Goodley (2014) stated, "Yet everyone across the dis/ability divide is caught up in the processes and fantasies of ableism. We – the non/disabled, wo/man, black/white, gay/straight, poor/rich – are all knotted up in the process of ableism" (p. 26). Haller (2010) describes ableism as painful rhetoric from the media and society intended to label those considered disabled as less than, unequal, and incapable (Wolbring, 2007). The media frequently extends these negative portrayals of disabled individuals by imbedding name-calling based on cognitive bias (Goodley, 2014). Extending these labels is the harm associated with the terms used as insults. I have

frequently heard self-deprecating statements and casual insults connected to disability related terms. Examples include “Are you an idiot?” “Are you stupid?,” “How can you be so dumb?,” and “I am blind as a bat.” Such terms are widely used to signal unacceptable behavior, deficits, and poor outcomes in society. Daily, my daughter sends me excerpts from several types of media, usually on a political topic, including news articles, tweets, and social media posts, which include blatantly ableist rhetoric. We have a running political rhetoric thread of ableist evidence. Ableist content dominates headlines, making it impossible for persons with disabilities to escape the association with deficit. Ellis (2015) presented a classic example:

CNN described the photo as “tone-deaf” while my local rag, the West Australian, suggested it was a “limp effort from model.” Then the Huffington Post hypothesized the wheelchair symbolized that Kylie was “‘crippled’ by fame.” BuzzFeed thought the imagery was communicating Kylie’s belief that she is “limited” by fame.” (p. 2)

Although changes have occurred, the stigma of those who are not able remains, and these types of “linguistic metaphors” (p. 4) that include a cognitive bias used to shame or humor persist, doing substantial harm to those with disabilities (Haller, 2010). It has now become mainstream in politics to question a politician’s cognitive abilities and retrace their every mistake. The pervasive nature of this bigoted rhetoric has become a running joke between my daughter and me, as the abled population fails to see the bigotry, leaving caregivers like me to unpack the unintended feelings of harm this rhetoric causes.

The characterization of persons with disabilities as unable to reach an accepted physical standard in systemic ableist rhetoric blocks the positive narratives that inspire hope, success, accomplishment, and happiness (Waugh, 2014). Tiffany Yu, a disability activist, and CEO, of Diversability (2017) stated, “No one asks me how I want to be viewed” (07:09). Positive stories

about life with disability are difficult to find, even though they exist (Cafferky, 2016). However, many people with disabilities have fought their way through the appropriated labels of deficit and embedded limitations of society to lead full, purposeful lives (Waugh, 2014).

Contemporary disability studies have challenged the life sentence of stigma in favor of exploring how society can develop inclusive experiences for persons with disabilities. Davis (2006) explains that it is crucial to grasp a comprehension of what seems natural to develop a productive understanding of disability and overcome deficit thinking. This is a confrontation of bias or terministic screen, as Kenneth Burke (1968) theorizes that this screen is composed of the many terms, definitions, symbols, and interactions with words from an individual's experiential view. The word *natural* is tied to a concept of universal good for most, whereas a deviation from natural is tied to a shadowy stigma. An abled person's anxiety over whether temporary prosthetic eyelashes look natural creates a situational problem for an individual who has a body difference labeled a disability and medically defined as not being natural. For example, in a thirty-minute conversation with one of my abled friends about her new prosthetic eyelashes, she used the word natural twenty-one times to describe the eyelashes, her feelings about the eyelashes, and her experience of getting the eyelashes. Of those twenty-one mentions, eleven seemed like questions for the purpose of reassurance that the goal of natural was achieved, seven were described as a goal or desire, and the remaining four were a cautionary tale of the pitfalls of not achieving "natural," including a description of a friend's eyelash extensions she considered not natural. I have eyelash extensions. This conversation was fascinating. Cooper Stall and Egner (2021) assert that body mind differences are tragically tied to the medical world situating and conditioning this status as bad. This very recent article calls out the language as the problem for the body mind differences yet completely omits a discussion of the caregiver language because this scholarship

includes disability and obesity together. While the intensity of the oppression of body mind differences could be like critique of fatness, this is oversimplifying the identity challenges of ableism.

Disability Related Identities

A rhetorical approach to disability psychology is important because the rhetoric of disability has been a major barrier for persons with disability and their caregivers to navigate the language that unlocks monetary and social belonging. Kittay (2019) states, “Speaking for people with disabilities is especially problematic since the agency of people with disabilities has long been suppressed” (p.36). Psychology does not address disability as disability itself, but as a subcategory called rehabilitation psychology (Dunn, 2016). The traditional models deal with the grief of the deficit and focus on coping with an impairment (Watermeyer, 2014). Hartman et al. (2016) describe the relationship between psychology and identity as complicated. Typically, social sciences (e.g., sociology) address constructs such as identity. However, psychology addresses the medical resources associated with such problems through rehabilitation (Dunn, 2016). Because psychology often describes the effects of low self-identity, the vague relationship between an individual and their self-concept is an important and noteworthy disconnect which should be further explored. (Hartman et al, 2016). Kittay states when asked to describe her daughter, “I want to tell people that she is a beautiful, loving, joyful woman. But then people ask me, “And what does she do? Does she have any children?” (p.42). As a long-time caregiver I can relate to this quote from Kittay. I have been in this situations hundreds of times feeling that my rhetorical response of giving medical explanation might be wrong. This is one of the chief goals of the study. I would like to know what rhetoric can be used to navigate these questions in a disability description.

Caregivers do not receive identity training, and for years, my only training came from the medical world. This places us in a constant recovery mode focusing on trying to repair the disability. Aquino (2016) suggested that using a medical model of describing the disability as an impairment is the crux of the problem for people with disabilities. The impairment, although secondary in disability identification, takes over to describe the individual as wholly disabled (Phemister, 2017). According to Watermeyer (2014), “In the popular imagination, disability is firmly associated with loss. Disabled people tend to be viewed as lonely, depressed, and struggling with feelings of inadequacy, damage, and shame” (p. 5). The identity of a person with a disability includes being told they you are, how they will be described, what their treatment will be, how successful they will be, and what outcomes they deserve (Watermeyer, 2014). Hartman et al. (2016) described the relationship between psychology and identity as complicated because loss is a part of the identity formation process. This is problematic, given that it took me more than 20 years to move the caregiving of my daughter beyond the physical loss-centered rehabilitation stage and consider a fresh approach.

Caregiver Challenges and Identity

When my caregiver responsibilities began in my twenties, I had a high school education, no medical knowledge, and no educated support group, so I was unqualified to provide expert care for my newly disabled seven-year-old daughter. My family unit had no prior experience with disability, leaving me terrified. According to Thomson and White (2017),

Most caregivers are loved ones who provide, on average, twenty-four hours a week of unpaid care. Yet the one role most of us will assume at some point in our lives—whether we want to or not—has no deliberate onboarding or socialization process, making it difficult to prepare for caregiving or to even know when the role begins. (p. 3)

As a caregiver, I also faced mounting bills and income loss because caregiving is all consuming (Roland, 2018). Thomson and White (2019) stated, “For all of us, caregiving exists within already existing relationships and obligations. In a world with bills, contracts, expectations, mortgage payments, passions, desires, and ongoing relationships, no one can specialize only in caregiving” (pp. 58–59). In addition, “caregiving is never timely” and “doesn’t concern itself with where you are in life.” (Thomson and White, 2019, p. 209). At no other point in my life have I felt so inadequate or unqualified for a task. As my daughter’s untrained, unpaid, and unsupported caregiver, I was still reeling from her near death while desperately striving to provide the best possible care. However, I struggled to find my footing for more than 20 years of daily self-doubt regarding my fitness for the job. I grappled with the correct approach to every medical and academic challenge every minute of every day. Familial caregiving, despite being the most ordinary form of care for persons with disabilities, offers no professional accolades, and there are no Ivy League schools for these support systems, which often comprise parents, other family members, and friends (Thomson & White, 2017).

The call to provide care for persons with disabilities does not typically come with specialized instruction or any consideration of available time (George, 2017). During my first decade of caregiving, I had to research strategies using my limited available time to help my daughter cope with devastation of having a disability, survive the scrutiny of the ableist world that places limitations of belonging on her, and search for a cure for the impairment that holds her back from thriving. Micromanaging every decision related to my daughter’s care and mourning every misstep became ordinary. Thomson and White (2019) suggested that the weight of being a caregiver can become tremendous and characterized by anxiety and doubt regarding

the ability to provide adequate care. In addition to medical complexity, caregivers face preexisting ableist belief systems based on the deficit of illness (Hutcheon et al., 2017).

According to Rafferty, Hutton, & Heller, (2019), “parents play a central role as the primary caregivers, legal guardians, and advocates for their medically complex child” (P. 1386). I found that most caregivers I have met are parents, but it is important to remember that caregiving community is growing as our population ages with all types of caregivers. The responsibility is overwhelmingly provided by the immediate family. Rolland (1999) touches on the complexity of the caregiving conundrum highlighting the need for familial intervention, however, this Family systems illness model is hyper focused on coping instead of thriving. The partnership between caregivers and persons with disabilities is acknowledged with a laser focus on impairment of stress and challenges related to the medical problem. Having processes in place for caregivers who are not educated across emerging disability studies theories to address and move beyond extraordinary challenges is beneficial to the overall success of individuals with disabilities (Rolland, 2018).

Rafferty & Beck (2019) state, “most parents whose children had been diagnosed for several years the first few years of managing their child’s life were particularly difficult” (P. 1391). The first ten years in my opinion as a caregiver are spent tirelessly seeking guidance. The learning curve on the medical side of caregiving is tremendous with minimum support. Harter et al (2006) states, “understanding disability primarily as a medical condition often works to reify the dichotomy between normality and abnormality’ (P. 7). After the hospital visitation was over, the support left, I was left as the caregiver to navigate on my own. With the vast caregiving responsibilities required to offer the medical support, caregivers are left with little time to support additional necessary skills to succeed (Thomson & White, 2017).

After years of seeking a medical solution to help my daughter take her place in society, I found that altering my view and rhetoric to highlight her advantages and unique abilities created the opportunities she always desired. For example, she captures the attention of people in a room whenever she walks in with her limp. Many people spend a lifetime learning to capture a room. Her disability and unique personality that features the wisdom and humor of a valued community elder makes her memorable. She can perform many tasks such as braiding hair with one hand, whereas some people struggle using both hands. Because she uses every muscle to walk, her body is very physically fit.

I spent years trying desperately to change my daughter's struggles with medical solutions but changing the way I described my daughter empowered her and created the most opportunities to thrive in society. Forber-Pratt et al. (2017) suggested a more comprehensive understanding of how opportunities unfold for persons with disabilities; developing a positive identity allows support systems to adapt interventions or scenarios for persons with disabilities so they can thrive within a large group. Although the tremendous medical education I received as a caregiver helped me understand the task before me, these efforts pale in comparison to the outcome of changing my rhetoric. Rafferty & Beck (2019) suggest that further resources are needed to assist, and potential connect parents of medically complicated children. I would suggest one step further to connect all caregivers to networking resources to collaborate on complete care. Thomson & White, (2017) suggest this concept of further connection as a key need for caregivers and the individuals they provide care for.

The history of disability rhetoric and the intersection and domination of ableism is sordid and dreadful. Yergeau's (2018) discussion of neuroqueerness, an emerging identity term for individuals with a neurological difference, gives a perfect example of an alternative concept of

disability normal that caregivers could contemplate when considering disability rhetoric. However, disability rhetoric can be positive, liberating, and fascinating. Consider my example from Chapter one when working at a technology conference, I took Dr. Temple Grandin, a professor at Colorado State University, to dinner. Temple is one of the most famous people with autism in the world and a leading expert in the cattle industry. When I picked her up from the hotel, she was dressed in a full cowgirl outfit from head to toe. While my coworkers were horrified, I thought it was spectacular and a true example of personal freedom how she owned her sense of self. As we walked through the restaurant, Temple was natural and casual, as if she had the courage and confidence to wear her disability without reservation, as it should be. She mentioned later in the dinner that the stares from people in the restaurant do not escape her, but she does not care. I thought about how my daughter was learning to wear her disability with pride in quite the same way and how long it has taken both of us to not care when people stare. One of the most interesting reflections I have is the advantage of the natural feeling of ease as I walked alongside Temple because walking alongside an individual who is being stared at is my normal. I was trained for this advantage as a longtime caregiver. I pondered what her caregiver might have been like and what advice she might have given to encourage her confidence and independence. What did her caregiving experience look like? This would be an excellent opportunity to examine the rhetoric of caregiving surrounding a disability success story.

What I can reflect on is that as a longtime caregiver, I felt a welcomed ease with Temple's neuroqueerness. This was a realization that I had finally found a place of comfort in a different definition of ability. Epstein and Rosenbaum (2019) suggest that one of the most important leaps for caregivers is conceptualizing beyond the ableist labels and categories describing what it is to be normal or considered normal.

The Circumvention of Ableism in Crip Camp: Hall et al. (2016) proposed that attitudes and opportunities are key to improved identities that lead to a more accessible world for people with disabilities. The documentary *Crip Camp* presents an interesting case study of rhetoric's role as a facilitator of opportunities and scenarios for persons with disabilities to develop and enrich positive identities (Lebrecht & Newnham, 2020). Changing how a population thinks about disability is a key component of the advancement of diversity (Belott, 2015). *Crip Camp* provided a glimpse into the ability of disability for, as Larry Allison said in the documentary, "This camp was an opportunity to do things" (Lebrecht & Newnham, 2020, 01:40). As Camp Jened forged a core group of people who fundamentally transformed their identities of dis/ability to ability, the caregivers at the camp enabled the transition to doers. The campers stated that nothing was ever the same, leading them on a journey from camp to independent living to contributing to social the justice efforts that led to the Americans with Disabilities Act, which remains the core bill of rights for the civil liberties of persons with disabilities (Lebrecht & Newnham, 2020). The discussion with former Jened campers Neal, Steve, and Nancy, in which they described a feeling of being sidelined in their home lives due to sheltering or guarding by their parents because they were "sick," exposed the vast connection between caregivers, the medical world, ableism, disability identity, and the power of the absence of rhetorical opportunities (Lebrecht & Newnham, 2020).

The camp counselors who provided care were a mixture of people from the abled and disabled world, and the difference in care was focused more on what each camper could experience outside of their condition (Lebrecht & Newnham, 2020). At Camp Jened, campers were encouraged to take chances and participate in each other's care (Lebrecht & Newnham, 2020).

King et al. (2018) proposed that having the resilience to push past and deal with negative experiences is at the heart of building a strong identity. According to Forber-Pratt et al., (2017), While acceptance of a disability can be an individual phenomenon, engagement with the disability community involves, by name, a community. This added dimensionality of a disability community is an important shift in a sense of disability identity development: where numerous people with disabilities primarily engage with their disability through the earlier mentioned interventions with “support” people, interaction with the disability community provides a diverse set of identity resources. (p. 18)

Neal, Steve, and Nancy spoke of a great awakening at Camp Jened that included unimaginable opportunities beyond the sideline, such as dating, favorable hierarchies based on favorable disabilities, experiencing heartbreak, and love (Lebrecht & Newnham, 2020). As they sampled a new reality that challenged the past reality of sidelining and sheltering, they experienced a rush of emotion and a world of opportunity in which they could feel everything, whether positive or negative, such as being desired or making poor choices such as taking drugs (Lebrecht & Newnham, 2020). Murugami (2009) stated that “a person with disability has the capability of constructing a self-identity not constituted in impairment but rather independent of it, and of accepting impairment as a reality that he or she lives with without losing a sense of self” (p. 3). The Jened campers had the opportunity to experience an enhanced identity not completely grounded in being sick, unable, or safe (Lebrecht & Newnham, 2020).

Each Camp Jened participant lauded the freedom from barriers, including the freedom to struggle, participate, and experience a more substantive life (Lebrecht & Newnham, 2020). For many campers, it was the first time they experienced the freedom to live with the same affordances as abled-bodied peers, facing the high and lows of living off the sidelines, including

being thought attractive, taking charge, or being dumped by a love interest (Lebrecht & Newnham, 2020). Landau (2007) suggested that resilience is an important part of self-identity, and this is a component of the whole person with a disability that is overlooked and unaccounted for. Jim Lebrecht, former Jened camper and co-director of *Crip Camp*, said, “The place has got a bunch of hippies in it and some of them looked pretty freaky, and it’s like, wow, I’m not sure who’s a camper and who’s a counselor” (Lebrecht & Newnham, 2020, 01:43). The counselors intentionally created space to experience fewer boundaries, and they encouraged risk.

Various societal and individual situations position shifting hurdles—some overwhelming—some seem impossible, yet with guidance we often evolve our skill sets. There’s decent evidence that our capabilities to be successful in any given space are not at all predetermined. (Oakley, 2017). Camp Jened was described as a utopia not because it was easy or safe, but because it provided the opportunity to make poor choices and feel everything, including the struggle of less-than-ideal self-care and medical consequences such as the pubic lice outbreak from promiscuous conduct without making distinctions from abled to disabled people (Lebrecht & Newnham, 2020). The abled community frequently learns through missteps and consequences, but persons with disabilities are often not afforded the same experiences to make mistakes and deal with the results because medical centered gate keeping focuses on staying safe.

A common takeaway from the campers throughout their journey from Jened to independent living and protesting for civil rights was the opportunity to make bold choices and experience their consequences (Lebrecht & Newnham, 2020). Many campers experienced this freedom from social and medical barriers for the first time (Lebrecht & Newnham, 2020). The expectation of a fixed outcome because of the disability was ignored at Camp Jened. As Oakley

(2017) suggests when people or groups of people consistently cease the activity of clinging to a fixed outcome, the predictability of an outcome shifts.

According to Yergeau (2018), “Rhetorical schemes are inventive schemes, ways of coming to knowledge through habit, compulsion, or echoing” (p. 203). Burke (1950) describes a concept where an individual can reimagine a situation that would originally be considered a failure suggesting a different more advantageous invention. When considering this concept of rhetorical schemes after Camp Jened, the action, activity, and ability related freedoms offered by the caregivers, and disabled people being cared for by other disabled people encouraged campers to leave the sidelines blurring the lines of un/sick and re/abled to completely reinvent the exclusion of ableism (Lebrecht & Newnham, 2020).

Summary

Winding through the labyrinth of rhetoric, disability rhetoric, caregiving rhetoric, and identity scholarship brings me to the classic question of how ableist rhetoric has consistently endured despite rigorous scholarship in disability studies which is at the heart of the inquiry. Rhetoric and disability seem tragically and powerfully intertwined and dependent on each other. The narratives of disability are at the center of the problem and tied to everything (Dunn, 2013). Crue (2016), states, “any signs of disability, along with most identity markers, are inherently ambiguous. An unsteady walk, indications of sensory impairment, or slurred speech may indicate any number of things—though they are all likely to be noticed and thus trigger the need for an explanation” (p. 958). As a caregiver for decades, I have watched this need for a disability explanation play out a multitude of times nearly everywhere my daughter and I go.

According to Murugami (2009), “Society needs to acknowledge the sometimes-elusive boundary between having impairment and being able-bodied’ (p. 5). History suggests that the

rhetoric of disability depends on the victorious and the defeated giving the abled motivation as the obvious victor. Cherney's (2011) discussion of natural law in rhetoric states that "ableism gets reinforced by the everyday practice of interpreting and making sense of the world" (p. 2). Every request that my daughter and I have received to describe her disability situation lacked an understanding of negative implications tied to disability descriptions.

Contemporary disability studies suggest an ideal activist approach to develop tools with a scientific model of natural/normal that is labeled as the problem, yet this model continues to be applied and reinforced everywhere (Dolmage, 2014). These disability rhetorical strategies work for some but not for most because most persons with disabilities have multiple caregivers providing guidance and influence (Spring, 2016). It is impossible to task society with a change or improvement in disability rhetoric without understanding the narratives that exist between the major stakeholders. I am shocked to find the untold story creating a gap in literature between disability and caregiving. The literature describing relationships between disability and caregiving like the labels and descriptions of disability are skewed towards impairment, and coping. Who is shaping the rhetoric of disability on a day-to-day basis for a person with a disability? Caregivers.

Crip Camp gives us a peek at the potential of individuals who receive rhetorical strategies to thrive, and signals how caregiving is or can be involved. It seems that the gray area of rhetoric that Burke (1950) described with opportunities of commonality is where the potential for persons with disabilities to build strategies to thrive exists. This requires nurturing, coaching, and reinforcement. The literature is unclear as to how that can be accomplished and scaled without caregivers. Epstein and Rosenbaum (2019) suggest that one of the most important leaps for caregivers is conceptualizing beyond the ableist labels and categories describing what it is to be

normal or considered normal to provide support. There is a significant, and emergent need to describe how caregivers and persons with disabilities cocreate, recreate, and navigate disability identity to understand the rhetorical opportunity and support that is needed.

CHAPTER THREE

FRAMEWORK AND METHODS

Restatement of Purpose

The purpose of this study is to show how caregivers can provide persons with disabilities the rhetorical power and freedom to compose their own narratives, transform their identities, and enhance their lives. Specifically, I will explore the following:

- How do the rhetoric of disability and the rhetoric of ableism define identity for persons with disabilities, and how do caregivers navigate this identity?
- How do caregivers make rhetorical choices when supporting persons with disabilities, and do these choices foster the desired effect? What are these rhetorical strategies' outcomes?
- “When and how do caregivers’ access and distribute rhetorical resources for persons with disabilities?

Framework

My theoretical base for this study will be Burke’s (1952) dramatisic pentad. Because this theory provides a structural method for comprehending how rhetorical choices can emerge to produce rhetorical opportunities or scenarios, it will provide an important lens for understanding how caregivers can provide or facilitate opportunities and scenarios for persons with disabilities to build a positive identity.

The elements of the pentad (i.e., Act, Scene, Agent, Agency, and Purpose and Attitude) facilitate the examination of the structural progression of a scenario surrounding a rhetorical situation (Burke, 1969). According to Blakesley (2002), “the pentad—Act, Scene, Agent, Agency, Purpose—functions as a form of rhetorical analysis that can help us understand the

presence of ambiguity in any interpretation that guides action” (p. 42). Ambiguity is important to discern when considering the rhetorical exchanges between a caregiver and a person with a disability. A sixth element lends credence to this study, as the element of Attitude could potentially uncover any preparations made for the pentad’s Act element (Burke, 1969).

According to Norman (2002),

Most of us start by believing we already understand both human behavior and the human mind. After all, we are all human: we have all lived with ourselves all our lives, and we like to think we understand ourselves. But the truth is, we do not. Most of human behavior is a result of subconscious processes. We are unaware of them. As a result, many of our beliefs about how people behave—including beliefs about ourselves—are wrong. (p. 63)

According to Blakesley (2002), “Burke intended the pentad to be a form of rhetorical analysis, a method reader can use to identify the rhetorical nature of any texts, group of texts, or statements that explain or represent human motivation” (p. 33). The pentad represents a comprehensive theoretical lens for understanding the questions that need to be answered about the drama of human behavior to provide a more complete context (Burke, 1954). I will use two terministic screens, ableism, and the opportunity to thrive, to understand what the interviewees reveal about their motives. According to Blakesley (2002), “If you think of a word as an act, it would have to be the culmination of something, and as a word, it could also potentially act on something else. A word, then, is both the sign of a motivated act, and a motivating act” (p. 133). Understanding terministic screens helps people deal with the way they view the world through their existing biases, so understanding a comprehensive vocabulary across an important theme reveals a complete reality, enabling more accurate judgements while analyzing motivation

(Burke, 1966). The examination of what human motivation occurs in disability through the narratives of caregiving could provide positive rhetorical scenarios or opportunities, making this framework ideal for this study.

Additionally, as a long-time caregiver, I will be using autoethnographic examples of my own human experience in this topic. Adams, Ellis, & Jones (2017) state that Autoethnography is a research method that uses personal experience (“auto”) to describe and interpret (“graphy”) cultural texts, experiences, beliefs, and practices” (p. 1). Blending these autoethnographic memos can add insider knowledge to trends in research. These experiences can enrich repeated themes in the research to develop a deeper dive in cultural understanding (Adams et al. 2017). Wall (2006) suggests that using autoethnography assists in making sense of narratives that are culturally vulnerable and adds supporting details to help a reader grasp an evolution of comprehension. This is the approach I am taking by including personal narratives from my experience as a caregiver. My goal is to unpack, analyze and develop my comprehension of the experiences of giving care to a person with a disability.

Research Questions

1. RQ1 – Qualitative: What rhetorical themes emerge from opportunities or scenarios that consistently support persons with disabilities in developing a positive identity? What rhetorical themes emerge that block opportunities from developing a positive identity?
2. RQ2 – Qualitative- What actionable rhetorical strategies do or can caregivers offer that help persons with disabilities transition from coping to thriving?

Methodology

For the last two decades, grounded theory has been a diverse qualitative method used across many disciplines, including sociology, psychology, and education. Strauss and Corbin’s

(1990) version of grounded theory is ideal for this study because they have been crucial to the development of theories that use data to give studied individuals and communities a voice. This is a crucial element of my study of caregiver strategies for rhetoric and scenarios that help persons with disabilities develop positive identities. Strauss and Corbin (1990) utilized data analysis to break down, organize, and reassemble data to develop a different understanding of the situation under study.

Participants

Participant Selection: The participants comprise individuals with at least one identified disability and individuals identified as caregivers for persons with disabilities. In total, fifteen participants are people with disabilities ages of 19–69, and 15 are caregivers for persons with disabilities.

Interview Procedure: All names of participants are anonymized to ensure as much transparency on the topic as possible. The recordings and demographic information are stored on a secure computer in a safe place. The participants were debriefed to obtain information on the clarity of the interview questions and their relevance to the study aim. All participants received the interview questions prior to the scheduled calling time and were informed that the interviews would be recorded and transcribed verbatim

Sampling: I use a snowball sampling method via Facebook disability sites, social media web pages, for both the fifteen persons with disabilities and the fifteen caregivers. According to Browne, (2014).

Snowball sampling is often used because the population under investigation is “hidden” either due to low numbers of potential participants or the sensitivity of the topic, for

example, research with women who do not fit within the hegemonic heterosexual norm”.
(p. 47)

Therefore, this method is ideal for the sampling in the disability and caregiving community. The subjects were selected at random but fall within the criteria.

Materials

The materials in the grounded study comprise an interview script that posed twenty-four semi structured interview questions exploring disability identity for persons with disabilities and their caregivers or support systems, along with a demographic survey and a participant release form. I used these materials to gather the data to be analyzed in the study.

Procedure: Data Analysis

I transcribe the thirty recorded interviews and extract the data from that text using Strauss and Corbin’s (1997) version of grounded theory. Strauss and Corbin (1998) found that the “first step in theory building is conceptualizing” (p. 103); conceptualizing with the consideration of the terministic screens of ableism and opportunity to thrive will enable me to identify, understand, and describe the phenomenon through the lens of Burke’s (1952) dramatisic pentad. The process of conceptualizing grounded theory takes a researcher through the following steps of data analysis.

Textual Coding, Axial Coding, and Theorizing

In grounded theory research, the search for the theory begins with the first line of the initial interviews that the researcher codes. I take sections of text line by line while coding with the understanding that concepts useful to the study can be identified by marking key phrases in the interviews. After naming these concepts, I examine another section of text, repeating these steps throughout my initial pass through the interviews. According to Strauss and Corbin (1998), this procedure is called open coding. During this process, I break down data from the research

participants into conceptual components. In the next step, theorizing, examples are extracted from the data to underpin concepts that might lead to a larger concept. Considering how each concept could have a relationship with each other is important during this step. This involves the constant comparative method and continues throughout the grounding theory process and up through the development of complete theories (Strauss & Corbin, 1994).

Memoing and Theorizing

Memoing is the process of identifying the cache of notes that I kept. This is the step between the data coding process and the first draft of the completed analysis. These memos serve as the field notes that describe the identified concepts outlines observations and insights. The process of creating memos begins with the first concept identified during the identification and theory development process (Strauss & Corbin, 1994).

Synthesizing, Refining, and Textualizing Theories

Once the coded categories are identified, they are linked together to create theoretical models surrounding a unifying central category (Strauss & Corbin, 1994). An example of the dramatisic pentad will be used to develop grounded theory with the terministic screens of *ableism* and *opportunity to thrive* to understand motives in a brief interview question example below.

Analysis Example

Q. How do you describe the person with a disability that you provide care for?

Melody (the caregiver) describes the 27-year-old female with a disability in her care: “She is a 30- year- old female with a disability from an open head injury that caused a traumatic brain injury (TBI). She has a disability that affects the left side of her body. Many doctors have given her a diagnosis of spasticity in her left arm and leg as well as dystonia which creates constant

movement in her left arm while not always able to understand where her arm is in space. This creates a lot of mobility challenges for her. Because of these issues she also struggles with her speech. She experiences a great deal of pain from these issues, yet rarely complains. She is strong willed.”

Pentad Analysis

Pentad 1: Medical Description

Act- Uses medical terms to explain the disability

Agency- Medical terms (TBI, spasticity, dystonia).

Agent- A family member that is the primary caregiver

Scene-. Cultural predisposition to describe disability purely in medical terms

Purpose- To explain the challenges that the person with disability faces; to identify the challenges faced by the caregiver.

Pentad 2: Character Description

Act: Saying that a person is strong willed.

Agency: Using terms that describe a person’s personality

Agent: Caregiver who appreciates qualities of the person’s personality or character

Scene: Close relationship in a caregiving situation

Purpose: to focus on the person’s identity in terms of character or personality, not physical limitations.

The use of two pentads offers a clearer understanding of two distinct descriptions revealed in the caregiver description. The analysis of pentad 1 in the caregiver interview, *medical*

description, reveals a predominant diagnostic approach when describing the individual, she cares for. However, pentad two, *character description*, presents an opportunity to reveal character traits of the person with a disability in the description.

Grounded theory Analysis

Textual Coding, Axial Coding, and Theorizing

Limitations (ableism)	Strengths (Opportunity to thrive)	Theorizing
<p><i>She has a disability that affects the left side of her body. Many doctors have given her a diagnosis of spasticity in her left arm and leg as well as dystonia which affects creates constant movement in her left arm while not always able to understand where her arm is in space. (The medical terms highlight weakness).</i></p>	<p><i>She has a great deal of pain yet rarely complains. She is strong willed. (Shows strength and determination?)</i></p>	<p>Memoing</p>

The Grounded theory analysis breaks down trends identified in both dramatic pentads further to identify the underlying ideas and pinpoint the larger concepts. The caregiver used

diagnostic terminology described in pentad one to highlight the deficit/challenge of the disability apart from two passages. The passages, “*she has a great deal of pain yet rarely complains*” and “*she is strong willed*” described in pentad two reveal a rhetorical opportunity to focus on resilience and strength in the face of adversity, characteristics that both the terministic screen *opportunity to thrive* and *ableism* highlight as positive characteristics in drive and determination.

Two main categories, *limitations*, and *strengths* are larger concepts that emerge to compare in the grounded theory analysis. While one answer to one question is not enough data to develop a theory, the research instrument using the dramatic pentad as a lens to develop a grounded theory utilizing the terministic screens of *ableism* and *opportunity to thrive* proves to be a successful form of analysis.

Terministic screens: ableism and opportunity to thrive

Ableism

- ability, lack of ability, unable
- disable, disabled, disability, disabilities
- fix, repair, modify, cure,
- break, broken, lame,
- skill, unskilled, lack of skill
- functional, dysfunctional
- normal, abnormal

Opportunity to thrive

- opportunity, chance, occasion, prospect, opening
- success, achievement, accomplish, victory, triumph, conquest, accomplishment, feat, attainment

- strength, determination, fortitude, resilience, courage, grit, willpower, resolve
- adapt, adjust, acclimate, accustom
- change, alter, modify, transform, amend
- Flourish, bloom, prosper

Summary

Dunn (2013) states, “Powerful stories leave lasting impressions” (p. 1). Understanding the motivation behind these stories is much more complicated. Murugami (2019) states “We are able to choose our identity and ignore and even reject identities forced on us as a result of ascribed characteristics” (p.5). It is important to understand how these characteristics are communicated and intentionally and/or unintentionally forced and how this is reinforced within the shared narratives of persons with disabilities and caregivers. Therefore, I have selected to analyze the narratives of persons with disabilities and caregivers through grounded theory which carefully curates the process in which rhetorical decisions are made. Burke’s dramatisic pentad, the second part of my research tool, will take the process analysis of decisions and choices to break down the scenario where rhetorical situations happen to understand the motivation of these identity narratives shared by caregivers and persons with disabilities.

CHAPTER FOUR

DATA ANALYSIS AND RESULTS

Introduction

The purpose of this study as outlined in Chapter one is to show how caregivers can provide persons with disabilities the rhetorical power and freedom to compose their own narratives, transform their identities, and enhance their lives. The two research questions have produced a theory that will help answer some of the key queries I had as a caregiver when I began my research.

Specifically, I explored how the opportunities and scenarios of rhetorical support for caregivers and persons with disabilities unfold while evaluating the effects and influence of ableism. Clear patterns and themes emerge to assist in understanding the importance of the disability description in disability rhetoric for caregivers to support individuals in their care, the need for helpful guides and resources, and how they might be developed.

This study uses grounded theory to analyze thirty qualitative interviews with caregivers and persons with disabilities at the granular level carefully evaluating the transcript of the interviews to identify themes that explain how the rhetoric of disability in disability descriptions unfold and develop to provide rhetorical opportunities. The research instrument reveals an understanding of the motivation and actions within the scenarios of these themes from the grounded theory study and Burke's (1952) dramatistic pentad.

This chapter will provide interview samples, Tables and Pentads analyzing selections of the samples, execution of the analysis with explanations of the full two-part research instrument, and a discussion of the results with a full explanation of the developed theory based on the research.

Descriptive Findings

A total of thirty participants were interviewed with fifteen caregivers from the ages of twenty-seven to seventy-three. The caregivers come from a variety of cultural backgrounds and reside in seven states across the United States. Fifteen interviews analyzed are with persons with disabilities including ages ranging from eighteen to fifty-six with mix of gender identities, and cultural backgrounds located in six states across the United States. In the interviews samples I have included gender, age, and additional identity details according to participant responses.

Results

Interview Samples

The fifteen caregiver interview samples are labeled throughout the study with identifiers C1 – C15 to allow quick cross-referencing found in the interview sample section, tables, pentads, and examples in analysis and discussion throughout the study. The fifteen interview samples from persons with disabilities are labeled P1 – P15 to accomplish the identical quick access cross reference goal.

C1: Diane- Caregiver. Diane, a forty-one-year-old caregiver said, “my stepmom struggles with health daily, but we try to create a plan that involves some joy. For example, she encouraged her stepmom to downsize to an over fifty-five retirement community and to embrace activities.” Diane said “her stepmom has immunity health problems but tries to be a part of the community. The community center is nearby my house so I make sure that I offer to be a part of the activities so she will continue to participate and instead of getting a house cleaner I come to do the activity with her because cleaning her home was something she always took pride in. I would admit that it would be easier to hire someone instead of dedicating one morning or

afternoon a week, but it is part of her identity and we discussed early on that this would help her feel useful and important in her life.”

C2- Emma- Caregiver. Emma said, “Anya wanted to have fun, to be happy even if it was for a short while. Making friends was difficult but once they let go of trying to keep up to this normal thing. Anya started making friends with other kids with disabilities through support groups.” Emma said “I had to stop relying on what I knew and dig for opportunities for Anya to have relationships and experiences. There were no treatments or medical strategies that made her as happy as that. (example) I asked questions at the doctor. I emailed disability support groups.” Emma said the lack of resources in the topic of independence when a person with a disability is medically dependent as “scarce.” She stated, “I am a loner, a shy person, and have no strategies to help. I wish I had example where I have had good results. The existing help for caregivers that create opportunities is for extroverted people. As a caregiver Emma said I feel constantly judged by others. It is hard to keep from being overprotective. For example, family members always had an opinion about her treatment, I had to hold my tongue and let Emma answer. I am judged for that...made me feel not accepted.”

C3: Jake – Caregiver. Jake is a fifty-three-year-old male gay caregiver/ Jake’s husband is disabled from a heart attack at forty-two. Jake described his husband as “courageous having battled many medical difficulties from his heart attack and head injury from the fall.” Jake said, “prior to the heart attack they were highly active in the community participating in many events including the yearly Pride events but in the last years, David, his husband has lost interest in everything that connected them.” Jake described “the strain on their marriage over the last 5 years and says he is discouraged and a little lost”. While empowered as a gay man, Jake

expresses being “deflated as a caregiver.” For example, he said. “I have been criticized for not being positive enough. It is impossible to be positive all the time.”

C4: Jessica- Caregiver. Jessica is a thirty-seven-year-old caregiver for her son Alex who has Tourette’s Syndrome. Jessica states, “my son Alex is good kid who makes very good grades and is a wrestler in high school. He is often in interesting situations because he makes different physical and auditory moves. He will often as a condition of his disorder blurt things out. We used to endure negative feedback from other students and parents, I was over communicative in his place not allowing him to speak for himself. I have learned over the last few years—mostly in high school to back off and let Alex manage it. Jessica said, it was the hardest thing I have ever done...to let him struggle through to get to owning his life. I believe the last few years with such a focus on identifying and using descriptions in school have helped empower him to own his life and me to let him.”

C5: Elizabeth -Caregiver. Elizabeth is a fifty-one-year-old recent caregiver of her father, Bob, who just recently moved in with her and her husband. She said her father is a “vibrant, active, and has more friends than her.” He has been diagnosed with Alzheimer’s, so she and her husband wanted her father to have a safe space to continue his life. They created an apartment for him so he can live as independently as possible but with the support needed. She has studied many types of disability resources such as books and blogs to decide how to create opportunities for her father if they are available. She said, “the time they are spending together...the opportunity to continue his independence is a privilege for her.” She said, “it would have beneficial if resources were part of the health experience.”

C6: Victor - Caregiver. Victor a forty-five-year-old single caregiver said I am proud of my son who despite severe epilepsy graduated from college and is successful in his marketing

job. He said Seth has “taken on life despite the bumps in the road. He has taken the disability as a part of his life ...not his entire life. We learned to recognize the qualities we have gained from facing the struggles. We have always talked through the problems...the embarrassment that we both felt in the beginning and turned them into success. We worked through it together. I am not trying to say that it was always simple or easy but communication between us and to everyone else has helped us. We asked a lot of questions and we still do. I speak with Seth more than my other two. I learned that I could be the sounding board and this helped us succeed.”

C7: Donna– Caregiver. Donna is the sixty-three-year-old caregiver of her brother who most recently has multiple complications of COVID 19 and long-term diabetes. She described her brother as an “individual that has many health problems throughout the course of his 52 years because of premature birth.” He has lost limbs to diabetes. And seemed to have given up before their mother died. For most of his life he was stuck. After her mother died, she recently took over the care of her brother, Ethan, she described her caregiving as “promise to her mother and her responsibility as a sibling.” Because her mother always financially, emotionally, and physically supported Ethan, Donna said the care and struggle to help Ethan with Independence has been “real.” Donna said that “Ethan has expressed the desire to be more independent but as a new caregiver Donna is at a loss as to how to help him.” She described the lack of resources in the topic of independence when a person with a disability is medically dependent.

C9: Jan- Caregiver. Jan is seventy-three-year-old recently retired female that described “multiple challenges throughout her life as a caregiver” Her brother was diagnosed with schizophrenia thirty years ago and her mother recently passed away after years of car at 94. Jan said, “what I learned over all these years is that there is no future in describing the medical side of things. I am smart and dedicated so I spent many years describing my knowledge instead of

my brother and mom. What I learned is that was time wasted for all of us. Between my mother and I we made excuses for my brother not to move forward. Now that my mother has passed, I have backed off and offered help instead of excuses. He has made the most progress of his life. Recently during the rise of personal pronouns, she started thinking about descriptions.”

C10: Judy – Caregiver. Judy, a forty-three-year-old single caregiver described her journey as a caregiver as one of the most frustrating and sad times of her life. She said, “watching her daughter lose everything including her health makes me so angry and resentful. I watch all my friends with children the same age going on with their lives and pursuing careers and family while my daughter is stuck ending up in the hospital frequently with complications of her diabetes. I do not know how to get us unstuck. I am worried that I am the problem. Recently I have started visiting a therapist to work through my anger so that I can be healthier mentally to help my daughter. The situation has been dire, But I do want to be the caregiver that empowers.”

C11: Tangy – Caregiver. Tangy, a forty-seven-year-old familial caregiver said, “caring for my son with spina bifida has been one of the great challenges of my life. She said every day I learn something new about myself such as a strength or skill I did not know that I had. When I first started caring for Shane, I felt sorry for myself and him and I am sure that I did many things wrong. I had to forgive myself and give him the chance to be who he was going to be. Do you understand? Over the last 11 years I have learned that despite of all the medical issues we must work through, he is an intelligent, funny, and more often now happy young man that has developed his own way...his own friends. Tangy said the real problem I faced was myself. When he was born with all these health problems, I just wanted him to survive, and then I wanted him to be normal, and then I let that go and I wanted him to be happy. I started looking for advice on how to do that.”

C12: Ian – Caregiver. Ian is a forty-four-year-old caregiver of his spouse who was in a car accident shortly after they were married 8 years ago. His spouse is a 32-year-old paraplegic in a wheelchair. Before the accident Ian and Ani were active participating in activities like cross fit and warrior dashes. Ian described “his situation as challenging at first but increasingly easier over the years.” He stated that “the transition to caregiver was pretty terrible because we lost our friends, our social life, but we made new ones and found a different way to live. He said she fought her way to independence like she was born for the challenge.” He describes his wife Ani, as “fiercely independent and wicked smart. It was a situation and challenge I struggled to rise to, and I will admit that I did not always describe Ani that way. In the beginning for the first 4 or 5 years I got caught up in sounding like a medical expert because I thought that was what I was supposed to do which Ani reminded me over time was not my job as a husband. We have collaborated on her story. This is actually our story. We are still warriors. We recently participated in a rowing competition together and the disability was not the story. The disability was just a small part of our story.”

C13: Olivia– Caregiver. Olivia, fifty-one, and her husband Ralph are the caregiver of her seventy-six-year-old father who has Parkinson’s disease. Olivia described her father “as a once articulate and passionate man, but his extreme health challenges have drained both him and her. She said “I love my father and I feel a deep responsibility for him because he was always there for me. The last couple of years have been rough. He is often difficult to handle, and he is frustrated. Sometimes I wonder if I am doing the right thing by taking on the care. I do not have anyone to go to for advice.” She said, “there is plenty of medical guidance to pursue his physical care”, but she worries about the quality of his life. She said, “I have the desire to help him find a

next step in life but the only conversation I have with doctors is about treatment, medicine, etc.” She said those things are important, but I would like to help him find a happier rest of his life.”

C14: Susan - Caregiver. Susan, a fifty-six-year-old, is the only caregiver for her husband for the last four years due to a spinal cord injury that left him partially disabled. She described her husband Bryce as “partially disabled and clinically depressed. The responsibility has been a tremendous impact on their marriage. They have been married for 18 years and they once had a great relationship, because his care is not shared by other family members. I have been isolated and excluded from the world.” His disability has become hers to bear. She said, “I feel guilty all the time as if she is not doing enough but the resources of hope are so limited in the small town, they live in. I have no example. I am doing the best I can with the care. What is left of our friends have encouraged her to divorce, but I feel that would be the last straw for Bryce and a major shirking of her responsibility.”

C15: Patricia – Caregiver. Patricia is the forty-seven-year-old caregiver of an 11-year-old boy with dyslexia. Pat said Brendan is a sweet thoughtful boy with a severe form of dyslexia that created issues for us during COVID 19. He was afraid to go on the camera for virtual school because of live reading. This is where we found out his diagnosis and he was near serious mental problems including threats of suicide. She said, “the beginning of this problem threw me for a loop, and I felt like I had to disclose every time I mentioned him. He is doing really well now, and I believe the current conversation in the world about identity and personal pronouns along with description helped him to understand that he was not the only one struggling to identify himself. It also helped me to understand that I did not have to advocate for him in every conversation. In the beginning I was working my way through my heartache for him by talking about it. Now we always talk through what he will say instead of me. For example, he asks the

questions—introduces his self. I add support. This has made us stronger. Helping him through this made me a better mother, and better human.”

P1: Kamden – Person with Disability. Kamden, a twenty-six-year-old said, “I am twenty-five years old and up until I was twenty, I never had any health issues beyond a cold. I would describe myself as a nice person who is a dreamer. I dream of being an artist. I am particularly good at portraits. I was diagnosed with diabetes at the height of my college experience. I was a popular sorority girl and a cheerleader at a state university. Everything went downhill very quickly after my diagnosis, and I have been in the hospital so many times in the last four years. My mother is so sad that it makes me sad. There is no one to give me advice because I am the only one of my friends or acquaintances that I know who is going through this. When my family describes me, it is not the description of a twenty something with a bright future. The description is always bad and what might have been. I have lost most of my friends over time and I have recently begun to explore stories of people who survive severe diabetes like mine and go on to live their best life”

P2: Seth- Person with Disability. Seth, a twenty-six-year-old, stated, “I would not include my disability as a part of my description. I believe it stands alone...speaks for itself. Do people go around disclosing what they cannot do...no they do not. Why do I need to do that? My father helped me understand that my disability did not have to be what defines me. He is great dad...the kind of dad that is there every day but in the background. He did not let me make excuses. Sure, there are differences and accommodations but those are ways to help me gave the existence I want. When it came time for every part of my life my dad said go do it. If you need help, I will be there. I believe the best strategy he gave me is the assurance that I would have another chance if I failed. He would love me even more for trying. I always had the belief that trying was the success.”

P3: Shane - Person with Disability. Shane describes himself as a twenty-seven-year-old male with a traumatic brain injury from an issue with anesthesia during an ear procedure when he was four. He said, “being a twenty-seven-year-old with TBI is lonely because it is difficult to make friends who can identify.” He lives with his mother and father and has a part time job at Wendy’s. He has his limited driver’s license and his own car which he is proud of. He stated, “my parents describe me as a hard worker because I am never late for my job. I have overheard them telling my brother that they are concerned about me which sometimes worries me. I also have issues with bipolar disorder which is harder to handle.”

P4: Abbey – Person with Disability. Abbey is a thirty -one-year-old that was recently diagnosed with multiple sclerosis. The symptoms have been escalating over years. She described a real struggle for both her and her caregiver. After a divorce she moved back in with her mom, she said, “my mom is just coming to grips with my disability, and she often describes my situation as dire. I did not want to be disabled. I know that both my mom and I will have to change our attitude to change the outlook. This is why I participated in this study. When there is a problem with money, an emotional struggle, and the future does not have a cure. I know we are going to have to find a different way of thought. Recently, my mom and I have talked more than any other point in our lives trying to come to an understanding about what is next because I want to believe there is a next. We need to find more.”

P5: Ani – Person with Disability. An, a twenty-seven-year-old, I described a “tremendous challenge for her husband Ian.” She said, “we were extremely active outdoors when this happened. We were hiking, camping, running, and into many types of activities. This hit us like a ton of bricks. We could not see our way forward. I know that my husband’s friends were encouraging him to walk away. It was hurtful. My husband who has always described me as

beautiful and sexy was describing me as sick. It seemed hopeless. He did not walk away. He stayed and we figured it out.”

P6: Mary – Person with Disability. Mary, a thirty-five-year-old stated, “I have had a disability for seventeen years and the difficulty has not let up. My mother has not spoken about wishing I was normal but I can sense the desire. She has struggled with me. I have watched her be left out along with me but we started recognizing and pointing out that her friends leave her out. She has many obligations to my health and I would like to not be a burden.” This was a tough conversation with Mary. She spoke about being depressed and the limitations of being in a wheelchair. She is bound to her caregiver which is her mother and she indicated that a change in her mother’s attitude or mood could be an opportunity for her.

P7: David – Person with Disability. David is what he describes as a “forty-seven-year-old proud gay man.” He described “a strong identity as a gay man yet very resistant to his disability identity.” He said, “this has been the most troubling transition of his life. He said that he no longer feels that he fits anywhere and understand the frustration his husband feels.” He describes the “disconnect on disability between he and his husband as a major block and said it has nearly broken them up on several occasions.” He does not feel that his husband is sexually attracted to him anymore, so he shies away from talking about the disability. He said, “I lack the energy to try after years of trying. We discussed guidance.” He said, “to date, the only advice they have received over the last five years is to seek a therapist which we cannot afford since David has lost his job. Some professional guidance to accompany all the medical care I have received would have made the most difference in my life besides surviving.”

P8- Jack – Person with Disability. John, a twenty-five-year-old, said, “my caregiver is my pop who decided from day one that we were in this together. I was injured in high school

sport 8 years ago when I was seventeen. Because my father involved me in decisions that involved me, I never felt disabled. I had a voice in my own life. I have friends that are also disabled so I know this does not always happen. My father is this quiet sensitive man of few words who never cared about what other people thought. When I was younger I did not like that about him. I once wished that he was like one of the funny popular dads...you know the cool dads. I was lucky. No—he did not have the answers on how to help me find a happy life in the beginning. He was willing to explore the options and help me find it. There was never a time when I felt weak because I needed care. He never corrected me when I attempted to identify and describe myself.”

P9: Alice – Person with Disability. Alice is thirty-seven years old and has lived with a disability with severe spasticity since birth. For many years Alice dreamed of being what she described as “less weak.” Alice states “For as long as I can remember my story was wrapped up in the things I cannot do, the permanent problems I was born with. I could not seem to get away from the doom that I felt and brought to my family.” “For the first twenty-one year’s hope was alive for a solution, cure, or some sort of miracle. When I reached my twenties there was a number of years that my situation.my possibilities seemed hopeless. My grandmother was my caregiver for 30 years. She did everything she could to fix me. It was only when she gave up hope for a cure that we made progress. It was harder I think...for her than it was for me. Because she wanted me to be this person that I was never going to be. When I failed, she rushed to explain why and solve problems for me. She made sure everyone knew the struggles I faced medically, and I heard this so many times I lost count.” The real change came when Alice’ grandmother gave up on the cure and began to look for things that Alice could do independently. Alice states, “She began to ask me what I want to do, what I dream about, and she brainstormed

with me on how we might accomplish that. For example. I wanted to learn to cook for myself...my grandmother was an expert cook. She began to include me in preparing meals.” Alice described this “as the beginning of the change in everything.” Instead of her grandmother describing her as her limitations, she talked about their “cooking together.”

P10: Veronica – Person with Disability. Veronica, a twenty-five-year-old, describes herself “as strong determined that can do anything I put my mind to. I might have cerebral palsy, but I am not cerebral palsy. For years I lived with my parents. After going through vocational rehabilitation, I learned to be independent, and I have a job and live in a group home. My parents were afraid at first to let me go but I gained their confidence over the years as I learned to build a support system. I have hardships like everyone else. I do not think being disabled makes me the only one that has problems. In the group home I have friends and I have a boyfriend. I think that was one of the things I did that was most surprising to my parents. They were once focused on what my issues with my disability and now, they describe me talking about what is going on in my life, my job. Boyfriend, or living on my own. They are proud of me. Learning to be independent built my confidence.”

P11: Alex – Person with Disability. Alex is an eighteen-year-old high school student with Tourette’s Syndrome. He said, “my mom was a helicopter parent for a large part of my life. She loved me too much if that is possible. She was fiercely defensive and sometimes hostile to people who did not understand. She often inaccurately spoke for me, but I knew this was from love. The world is not that easy. Because I have a body is always moving and I cannot always control my words it easier for me to describe myself or to talk about my own identity.” He could more easily let the misunderstandings of others about his condition than his mom. For example, during a wrestling match this season he yelled out some bad words. One of the moms from the

other team complained and the coach allowed Alex to explain his condition. The complaining Mom immediately understood diffusing the situation. Instead of his mom handling situations, now they talk through best case scenarios for handling people. Alex said, “it is a work in progress, but it has improved his life.”

P12: Chloe – Person with Disability. I interviewed Chloe; thirty-one years old completely through assisted technology. She is nonverbal. She described herself as “an active part of her community. She has a job in the local school library and lives independently with her mom providing caregiving support.” She said she has been determined throughout her life to find purpose and her mother always found a way for her to be involved. She was always in an inclusive class throughout school and has a college degree in sociology. She loves to travel with her inclusive adventures travel group and has a large group of friends. She said the “most happiness came when she was able to accept myself and practice self-love regardless of her situation.”

P13- Julie- Person with Disability. Julie describes herself as “fun and always ready for a new experience. Julie is a twenty-one-year-old with down syndrome that likes to hike, camp, and have outdoor adventures”. She said her mom and dad would describe her this way because she grew enjoying the outdoors with her family. Julie is taking a little time working at a local grocery store before going to college. She wanted an opportunity to spend time with her boyfriend and take a couple of trips with her family before she explores living by herself. She said, “my family have always included me in everything. I knew I was different, but my parents, brother, and sister never made me feel that way. This made the bullying hard at school, but home was always a place where I could learn to ignore that.”

P14: Kasey – Person with Disability. Kasey is a twenty-three-year-old transgender female with a missing limb from a childhood infection. Kasey has lived with the disability for the last fifteen years and describes herself as lucky to be alive. Kasey describes her mom and Dad as “eager to help.” She laughed when she made that comment. She said, “it was a rough go for a lot of years. My parents really had no experience and no resources or advice with disability. My parents wanted to be supportive and helpful yet were embarrassing. Kids can be so cruel, and when the parents are hovering it can be like a big fat highlighter over anything different. In some way my parents constant outing of my disability helped me come out as transgender identifying as a girl. When personal pronouns became an acceptable idea for the public, it also gave me a way to talk about how I wanted to be described, and not as my disability, but as someone who has much more.”

P15: John – Person with Disability. John is the fifty-six-year-old father of two children. He is very adamant about his story being one of overcoming adversity to be purposeful. He explains, “from the time that my accident happened I knew that I did not want to stay in a moment of sorrow. I wanted to find another way. This was a real difficulty for everyone else. They wanted to be the caregivers. I had no shortage of caregivers from my wife, children to my mother. I am grateful for the love and support, but I wanted that support to be focused on how my life would move forward. I was lucky because I had professional help from a therapist on how to ask for productive help from my caregivers. My caregivers went from describing me as a person with life threatening medical issues to stubborn to eventually focused on living a happy life. This opened doors to the support I need, the advice I would get if I didn’t have a disability. Getting a job. Relationships!”

Data Analysis

The most common responses from participants throughout the interviews continue to draw attention to the significance of disability descriptions, which narrowed the focus of the analysis. Murugami (2009) states, “Self is seen as a universal human property, something that we must all possess and a characteristic that we must all develop (p. 2).” The formation of identity is uniquely tied to how we describe ourselves, which as Goodley (2014) suggests, has no particular definition. As an example, in my caregiving experience, I was always striving to understand what magic words would assist my daughter in finding a happier life, I was offered no pathway to success beyond the medical care I could provide. As *Crip Camp* highlights, the happier life requires a complexity including an exploration of identity.

Initial coding, which is the phrases that describe disability description are highlighted in red throughout the samples in Tables 4.1 - 4.3 used for the *grounded theory* analysis. The bold red text throughout examples reveals the axial codes that outline evolving trends, categories and subcategories developing emerging themes to label the data describing the participant voices. Pentads 4.1 – 4.9 are used for the Burke’s (1952) dramatic pentad analysis to understand what is taking place within the scenario of each disability description to help evolve an understanding of the motivation behind the rhetoric used in the disability description.

The most common categories are revealed when the axial coding is placed in stages within the table and organized in a theme from the memoing to explain the data. These stages are developed through the analysis of the grounded theory coding from the participant voices and analyzed to understand the evolving purpose or motivation through the dramatic pentads of each disability descriptive choice. The two-step analysis helped tell a disability description story developing between caregiver and persons with disabilities.

The Grounded Theory and Pentad Analysis

1. **Research Question 1** – Qualitative: What rhetorical themes emerge from opportunities or scenarios that consistently support persons with disabilities in developing a positive identity, and rhetorical themes emerge that block opportunities from developing a positive identity?

Table 4.1

Challenge or Opportunity	An Ableist Tale	Alternative Identity
P13: Julie describes herself as “fun and always ready for a new experience.”	P9: Alice said, “For as long as I can remember my story was wrapped up in the things, I cannot do.”	P1: Kamden, I would describe myself as a nice person who is a dreamer . I dream of being an artist. I am particularly good at portraits .
P12: Chloe describes herself as “strong determined person that can do anything I put my mind to. I might have cerebral palsy, but I am not cerebral palsy.”	C14: Susan, described her husband Bryce as “partially disabled and clinically depressed.” She said, “the responsibility has been a tremendous impact on their marriage.”	P15: John is the 56-year-old father of two children . He is very adamant about his story being one of overcoming adversity to be purposeful .
P8: Jack said my caregiver is “my pop who decided from day one that we were in this together.”	P11: Alex said, “She often inaccurately spoke for me, but I knew this was from love.”	C2: Emma said, Anya wanted to have fun.”—to be happy even if it was for a short while.”
C12: Ian said, Before the accident Ian and Ani were highly active participating in activities like cross fit and warrior dashes. Ian described his situation as challenging at first but increasingly easier over the years. He stated that “the transition to caregiver was terrible because we lost our friends, our social life...but we made new ones and found a different way to live	P5: Ani said, “My husband who has always described me as beautiful and sexy was describing me as sick.”	P15: John “Wanted support to be focused on how my life would move forward”

<p>P13: Julie is a 21-year-old with down syndrome that likes to “hike, camp, and have outdoor adventures.” She said her mom and dad would describe her this way because she grew enjoying the outdoors with her family</p>	<p>P7: David is what he describes as a 47-year-old proud gay man. He described a strong identity as a gay man yet very resistant to his disability identity.</p>	<p>P12: Chloe: described herself as an “active part of her community.” *She is nonverbal.</p>
<p>C1: Diane, states, my stepmom struggles with health daily, but we try to create a plan that involves some joy.”</p>	<p>C10: Judy, a 43-year-old single caregiver described her journey as a caregiver as one of the most frustrating and sad times of her life. She said watching her daughter lose everything including her health makes me so angry and resentful.</p>	<p>C6 Victor said, “I am proud of my son who despite sever epilepsy graduated from college and is successful in his marketing job. He said Seth has taken on life despite the bumps in the road. He has taken the disability as a part of his life ...not his entire life.”</p>
<p>“</p>	<p>C3: Jake described his husband as “courageous having battled many medical difficulties from his heart attack and head injury from the fall.”</p>	<p>C4: Jessica, a caregiver, here response to describing the person she cares for is, “Alex is good kid who makes good grades and is a wrestler in High School.”</p>
<p>C5: Elizabeth is a 51-year-old recent caregiver of her father, Bob, who just recently moved in with her and her husband. She said her father is “vibrant, active, and has more friends than her.” He has been diagnosed with Alzheimer’s, so she and her husband wanted her father to have a safe space to continue his life.</p>	<p>P3: Shane said, “my parents describe me as a hard worker because I am never late for my job. I have overheard them telling my brother that they are concerned about me which sometimes worries me.”</p>	<p>P2: Seth stated, “I would not include my disability as a part of my description. I believe it stands alone...speaks for itself. Do people go around disclosing what they can’t do...no they do not. Why do I need to do that?”</p>

Table 4.1 Sample Discussion

While the interview questions focus on different phenomenon in the lives of the caregivers and persons with disabilities, the reoccurring need was a motivation for the participant

to define the condition, or the experience in different way. The initial coding includes example phrases that help organize the direction of the data to understand disability description. For example, C5 describes the Alzheimer's diagnosis, and P2 questions the purpose of disclosing the disability in a description. These phrases set the scene for the categories, and eventually the purpose. The axial coding indicated in bold red text in Table 4.1 reveals a commonality in the terms used when the caregiver or the person with a disability describes the disability. For example, the P12 data has two types of axial coded examples with a description of the disability as cerebral palsy yet a different axial coding descriptor as strong and determined in the challenge or opportunity column. Throughout the fifteen interviews the participants made 1 of 3 choices consistently when initially describing the person they care for, or themselves. The most interesting detail is that once the choice of definition or a description of the individual with a disability was made, the participants remained consistent. This sets the stage for the analysis of Table 4.1 which was a stage that is focused on the need to define the description of a person with a disability and how that choice is made.

Three themes indicated in italics emerge to develop a need accompanied by choices made to define the person with a disability; to offer a description revealing a *define stage* established from research question one: *challenge or opportunity, an ableist tale, and alternative identity*.

The *challenge or opportunity* theme in Table 4.1 exhibits a connection with persons with disabilities and caregivers on common response keywords and phrases to present a disability description that has a precedent of impairment accompanied by additional skills or qualities. For example, in P12, Chloe said, "I might have cerebral palsy, but I am not cerebral palsy." These phrases or the initial are indicated in plain red text. In the axial coding in Table 4.1 with bold red text exhibits how the participants offer labels to describe the disability, but have clear additional

examples like strong, determined alongside a diagnosis or description of the disability struggle. The below example P12 describes a definition that has multiple choices. P13 offers an example of the disability diagnosis of down syndrome but also makes choices to describe hobbies like hiking and camping. There is a challenge or a potential opportunity of introducing the disability accompanied by descriptive details that signal opportunity. Dolmage (2014), suggest that the ability to hope can be self-made with the motivation and information. The shared experience between caregiver and persons with disabilities can be nuanced with multiple levels of information. This is the disability description response most often shared by caregivers and person with disability.

- In example P12, Chloe said “I am a strong determined person that can do anything I put my mind to. I might have cerebral palsy, but I am not cerebral palsy.” This response acknowledges the disability but does not identify as the disability offering information with alternative descriptive options. This example was frequent in the interviews from persons with disabilities.
- In example P13 from Julie who describes herself as “a 21-year-old with down syndrome that likes to hike, camp, and have outdoor adventures.” She said, “her mom and dad would describe me this way because she grew enjoying the outdoors with my family.” The disability description presents alternative qualities in the disability description allowing the person with a disability a path forward.
- In example C5 from Elizabeth who is a 51-year-old recent caregiver of her father, Bob, who just recently moved in with her and her husband. She said, “my father is vibrant, active, and has more friends than her. He has been diagnosed with Alzheimer’s, so she and her husband wanted her father to have a safe space to continue his life.” The multi-

response approach here shows how the disability identity and alternative identity can be blended for opportunities.

Pentad 4.1 Analysis (challenge or opportunity)

In pentad 4.1 listed below the initial coding of the grounded theory method provides a distinct scene with two disability description choices being made. Key phrases in the initial coding reveal a scene with two facets to the person with a disability's description. For example, in P12: Chloe said "I am a strong determined person that can do anything I put my mind to. I might have cerebral palsy, but I am not cerebral palsy." In each of the examples the act of a disability description is to provide a challenge of the disability itself but an opportunity to understand that the individual has more happening in their life. The terms in the axial coding that give the diagnosis like cerebral palsy yet offering follow-up identity details with a personality trait like determined reveal a definite act that has a purpose for these individuals to acknowledge the disability in the description but to list skills, qualities, or attitudes that can be developed offering a prospect for the future. This choice can provide step one of a rhetorical guide for disability descriptions. This scenario of owning the disability while presenting alternate skills and qualities opens possibilities for the persons with disabilities and caregivers to consider the disability description as a story instead of a label. For example, when Julie from example P13 describes her diagnosis of down syndrome accompanied with her hobbies. This choice is a human narrative instead of a diagnosis.

- *Act-* Description that acknowledges disability with highlight of other descriptive priorities. For example, P13 from Julie who describes herself as "a 21-year-old with down syndrome that likes to hike, camp, and have outdoor adventures."

- *Agency*- Disability description accompanied by activity description. In Table 4.1 the axial coding identifies two distinct patterns in agency. For example, C1: Diane, states, my stepmom struggles with health daily, but we try to create a plan that involves some joy.”
- *Agent*- caregiver and person with disability
- *Scene*-. *Making a choice that offers a disability description that includes supporting details about the person.* P12: Chloe said “I am a strong determined person that can do anything I put my mind to. I might have cerebral palsy, but I am not cerebral palsy.”
- *Purpose*- Descriptions of the person with a disability that represent a style representing both challenges and opportunities.

An *ableist tale* theme introduces a straight medical model response offering the disability description as a diagnosis, condition, or burden. This response does not mean that the individual responding is an ableist but rather recognizes the ableist foundation from the medical model of disability which underpins the response. The initial coding in Table 4.1 in column two reveals that frequent focus solely on the difficulty of the disability exhibited in C3 below, or the impairment or diagnosis exhibited below in examples from P5 and P7. The axial coding reveals the act of describing disability in terms like sick, loss, or impairment. Goodley (2014) states, “too often disability is found and medicalization aroused. (P. 16). A personal example would be how my first experience as a caregiver was with the medical world but focused on loss. The ratio from medical-related experiences to outside-encounters has been staggering. This approach was more commonly used by caregivers and mentioned frequently as an issue for persons with disabilities and never cited a solution to move forward. The straight *ableist tale* theme approach to disability description can produce an excellent part of a rhetorical guide for disability description on what not to do.

- In example C3 one from Jake who described his husband “as courageous having battled many medical difficulties from his heart attack and head injury from the fall.” The description is grounded in the impairment and diagnosis leaving the shared reality of the description without a positive destination. Interestingly, I asked a follow up question that was not answered inquiring about other areas where Jake is courageous. The absence of a response left C3 definitively in the ableist tale theme.
- In example P5 from Ani who said, “my husband who has always described me as beautiful and sexy was describing me as sick.” The shared disability description of impairment causes a feeling of loss.
- In example P7 from David describes himself as “a 47-year-old proud gay man. He described a strong identity as a gay man yet very resistant to his disability identity.” This is an interest parallel. David is familiar with description as a gay man yet struggles in the disability identity and description. I used example P7 because the disability identity was constantly used as an example of doom with this participant. It was not a shared identity of being a gay man with a disability. The response was a regret of the disability identity replacing the gay identity, which could be a topic for another study.

Pentad 4.2 Analysis (ableist tale)

In Pentad 4.2, the initial coding consistently informs a scene of description that is focused on the inability, or the challenges associated with disability. The axial coding is grounded in terms like struggle, resistant, sick, battled, medical difficulties described in above examples from P7, P5, and P3 revealing the act of focusing the disability description of inability. The purpose is clear with an emerging theme of a disability description that is based on an ableist narrative that the person with a disability is described as the disability instead of the many facets of their

personality not associated with a disability. According to Hall (2016), “The meanings of disability are not understood to be contingent or discursive but are instead assumed to be exhausted by medical diagnosis (p. 2).” As you can see below in Pentad 4.2 the act, scene, and purpose stay firmly grounded in the motivation to define the diagnosis or the struggle with the disability.

- Act- focused on ability or inability. In example P5 from Ani who said, “my husband who has always described me as beautiful and sexy was describing me as sick.”
- Agency- Medical terminology and level of burden used in diagnosis
- Agent- caregiver and person with disability
- Scene -Providing a disability description that focuses on inability. In example P9: Alice said, “For as long as I can remember my story was wrapped up in the things, I cannot do,”
- Purpose – To provide a disability description that details the medical description and/or the challenges that are faced

The *alternative identity* theme is most frequently utilized in a description by persons with disabilities. The initial coding sets the scene for the possibility of a different disability description with phrases like example P12 from Chloe, she described herself as an “active part of her community.” The axial coding in Table 4.1 reveals a definitive trend among the participants with a disability. Frequent descriptions in the coding to self-describe for participants with disabilities were fun, happy, active, and avoiding language that describes a diagnosis or negative emotion. Other descriptions recognize the absence of necessity to explain a disability such as the below example from P3: Seth. These descriptions focused on the person with disability as an individual offering alternate rhetorical elements of his or her story. Murugami (2009) states,

“Despite daily experiences of oppressive practices by non-disabled peers, there are persons with disabilities who do not incorporate disability in their identity (p. 4).”

In my own caregiving experience, I realized over the course of many years that disability description focused on the disability was not always necessary. In P12, P2, and C4 examples below the responses question the need for a disability description to be a definition and delve more into the disability as part of the human story.

- In example P12 from Chloe, she described herself as an “active part of her community.”
*She is nonverbal. Despite needing assisted technology to communicate her description, she did not use disability in her description.
- In example P2, Seth stated, “I would not include my disability as a part of my description. I believe it stands alone...speaks for itself. Do people go around disclosing what they can’t do...no they do not. Why do I need to do that?” This individual recognizes he has choices about description questioning why it is necessary to state the obvious.
- In example C4 from Jessica, a caregiver, her response to describing the person she cares for is: “Alex is good kid who makes good grades and is a wrestler in High School.” This is a rare initial description response from a caregiver in my interviews. She makes a choice to focus on other aspects of the identity of the person she cares for.

Pentad 4.3 Analysis (alternative identity)

In Pentad 4.3 the initial coding focuses mainly on a scene that describes alternative characteristics of a person with a disability. C4 in the above examples uses words like “good kid with good grades and describes wrestling as an activity.” P12 highlights “activity in the community.” P2 questions the necessity for a description that includes the disability. The axial

coding begins to describe the act of offering an alternative disability description, which was a response mainly from persons with disabilities with a few caregivers responding in this theme. The clear purpose gleaned here is a glimpse at additional or alternative disability descriptions for persons with disabilities recognizing qualities that recognize opportunity beyond the disability. This data analysis offers an opportunity for caregivers to understand how persons with disability desire to be described, and an option in the disability description guide in chapter six for adding details to the disability description.

- Act- description focused on other life experiences. For example, C4: Alex is described as “a good kid who makes good grades and is a wrestler in High School.” In example P13: Julie describes herself as “fun and always ready for a new experience.”
- Agency- Terminology like hiking, camping, making good grades, father, artist, and active in community used to describe other skills or activities
- Agent- caregiver or person with disability
- Scene-. Q1: Making a descriptive choice that introduces skills or activities to describe the individual.
- Purpose- Discovering the alternative descriptions of an individual with a disability.

Grounded Theory and Pentad Analysis

2. Research Question 1 – Qualitative: What rhetorical themes emerge from opportunities or scenarios that consistently support persons with disabilities in developing a positive identity, and rhetorical themes emerge that block opportunities from developing a positive identity?

Table 4.2

Stuck	More	Next
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<p>C3: While empowered as a gay man, Jake expresses being “deflated as a caregiver.” For example, “I have been criticized for not being positive enough. It is impossible to be positive all the time.”</p>	<p>P4: Abby said, “I know we are going to have to find a different way of thought. Recently, my mom and I have talked more than any other point in our lives trying to come to an understanding about what is next because I want to believe there is a next. We need to find more/”</p>	<p>C15: Patricia said, “he is doing really well now, and I believe the current conversation in the world about identity and personal pronouns along with description helped him to understand that he was not the only one struggling to identify himself. It also helped me to understand that I did not have to advocate for him in every conversation.”</p>
<p>C7: Donna said, “I have the desire to help him find a next step in life but the only conversation I have with doctors is about treatment—medicine—etc. She said those things are important, but I would like to help him find a happier rest of his life.”</p>	<p>P8: Jack said, “no—he did not have the answers on how to help me find a happy life in the beginning. He was willing to explore the options and help me find it.”</p>	<p>C4: Jessica said, “it was the hardest thing I have ever done...to let him struggle through to get to owning his life. I believe the last few years with such a focus on identifying and using descriptions in school have helped empower him to own his life and me to let him.?”</p>
<p>P7: David said that he “no longer feels that he fits anywhere and understand the frustration his husband feels. He describes the “disconnect on disability between he and his husband as a major block and said it has nearly broken them up on several occasions.” He does not feel that his husband is sexually attracted to him anymore, so he shies away from talking about the disability. He said, “I lack the energy to try after years of trying.”</p>	<p>P11: Alex said, instead of his mom handling situations, now they talk through best case scenarios for handling people. Alex said, “it is a work in progress, but it has improved his life.”</p>	<p>C11: Tangy said, “when he was born with all these health problems, I just wanted him to survive...then I wanted him to be normal...then I let that go and I wanted him to be happy. I started looking for advice on how to do that.”</p>
<p>C7: Donna said, he has lost limbs to diabetes. And seemed to have given up before their mother died. For a large part of his life, he was stuck. After her mother died,</p>	<p>C9, Jan said, “Now that my mother has passed, I have backed off and offered help instead of excuses. He has made the most progress of his life. Recently during the rise</p>	<p>P14: Kasey said, “In some way my parents constant outing of my disability helped me come out as transgender identifying as a girl. When personal pronouns became an</p>

<p>she recently took over the care of her brother, Ethan, she described her “caregiving as a promise to her mother and her responsibility as a sibling.”</p>	<p>of personal pronouns, she started thinking about descriptions.”</p>	<p>acceptable idea for the public, it also gave me a way to talk about how I wanted to be described—not as my disability, but as someone who has much more.”</p>
<p>P5: Ani said, “My husband who has always described me as beautiful and sexy was describing me as sick. It seemed hopeless.”</p>	<p>C10: Judy said, “Recently I have started visiting a therapist to work through my anger so that I can be healthier mentally to help my daughter. The situation has been dire, But I do want to be the caregiver that empowers.”</p>	<p>C11: Tangy said, “I had to forgive myself and give him the chance to be who he was going to be. Do you understand? Over the last 11 years I have learned that despite of all the medical issues we must work through, he is an intelligent, funny, and more often now happy young man that has developed his own way...his own friends. Tangy said the real problem I faced was myself.?</p>

Discussion of Table 4.2 Data

Collaborate and Revise. In the *collaborate and revise* stage of Table 4.2, the axial coding and purpose from the Pendads 4.4 – 4.6 align to three themes emerging from disability description and application: *stuck, more, and next*. Caregivers and persons with disabilities consider the disability description or narrative and how it can be either individually or collectively revised and owned by the persons with disabilities. Additionally describing what is often desired but has not happened, or the reason a recognized or desired result will not occur. The *collaborate and revise* stage details an excellent example of how the disability description can be recognized as valuable collaborative opportunity leading to planning and practicing in the disability description guide

The theme *stuck* exhibited in Table 4.2 presents interview responses that indicate how persons with disabilities and caregivers describe themselves as stuck or similar descriptions. The

initial coding features phrases that describe how the caregiver and person with a disability are recognizing where they are positioned in disability rhetoric. The axial coding describes being stuck in example P7, given up in example C7, hopeless in example P5, or deflated in example C3. This *stuck* theme response came from caregivers and persons with disabilities who are struggling to provide/find guidance or opportunities that enable a person with a disability and in some cases a caregiver to move forward. Thomson and White (2009) assert that caregivers are struggling to provide support. For example, I experienced an uphill battle from my first day as a caregiver. I had the desire but could not locate the support. The interviewees in this category sometimes acknowledge a similar desire to finds opportunities to thrive but cannot recognize or are not acting on the desire.

- Example P7 from David said, “I no longer feel that I fit anywhere” and understand the frustration his husband feels. He describes the disconnect on disability between he and his husband as a major block and said it has nearly broken them up on several occasions. He does not feel that his husband is “sexually attracted” to him anymore, so he shies away from talking about the disability. He spoke. “I lack the energy to try after years of trying.” This narrative describes withdrawal from the disability description, and a block from thriving.
- Example C7: from Donna said, “He has lost limbs to diabetes. And seemed to have given up before their mother died. For a large part of his life, he was stuck. After her mother died, she recently took over the care of her brother, Ethan, she described her caregiving as a promise to her mother and her responsibility as a sibling. This description is heavy with blocked opportunities.” The disability description is stuck.

- Example P5 from Ani, stated, “my husband who has always described me as beautiful and sexy was describing me as sick. It seemed hopeless. This disability description focuses on the impairment and regret.”

Pentad 4.4 Analysis (stuck)

In Pentad 4.4 the initial coding in the data unpacks key phrases in the scene of disability description. For example, “it seemed hopeless” from P7, and C7 describes how “for a large part of his life, he was stuck’ offers a glimpse into the scene where caregivers and persons with disabilities describe a persistent motivation towards the limitations. The axial data reveals a *stuck* theme derived from the categories such as stuck, not fitting in, hopeless, lack energy, and given up. The agency continues the grounding in language of limitation from the caregiver and person with disabilities that blocks pursuing opportunities. The act is giving up because of the challenges of disability create a purpose that explains and describes the negative effects of being stuck with a disability. This scene of disability description is mired in the medical model of disability but recognizes being stuck. The motivation of this analysis is to signal those caregivers and person with disabilities acknowledge a struggle to find assistance to move forward.

- Act- To give up on a solution and describe the frustration. In example P7, David said, “I no longer feel that I fit anywhere.”
- Agent- caregiver and persons with disability
- Scene-. descriptions that signal frustration like stuck, hopeless, disconnect on disability, major block. In example C7, the frustration is described as Donna said, “For a large part of his life, he was stuck.”
- Agency- Medical terminology used in diagnosis, limitations the focus

- Purpose – To describe the struggle of disability in the description of both caregivers and persons with disabilities.

The theme *more* indicates that the caregiver and person with disabilities have a desire to explore different elements of the disability description such as hobbies, personality traits, or accomplishments that would describe the various foundations of a human story. The initial coding looks forward to what could be done in key phrases such as example P7 where Abbey describes a need to find “a new way of thought.” In example P8 Jack is willing to explore. These phrases build the case for the axial coding categories to understand what style of disability description this theme is outlining. Murugami (2009) states, “We are able to choose our identity and ignore and even reject identities forced on us because of ascribed characteristics (P. 7). These disability description responses explain how the respondents recognize opportunity and are searching for answers. It is acceptable to ask for more.

- Example C10 from Judy, who stated, “recently I have started visiting a therapist to work through my anger so that I can be healthier mentally to help my daughter. The situation has been dire, But I do want to be the caregiver that empowers.”
- Example P8 from Jack stated, “No—he did not have the answers on how to help me find a happy life in the beginning. He was willing to explore the options and help me find it.”
- Example P3 from Shane exerted, “I know we are going to have to find a different way of thought. Recently, my mom and I have talked more than any other point in our lives trying to come to an understanding about what is next because I want to believe there is a next. We need to find more.”

Pentad 4.5 Analysis (More)

In Pentad 4.5 the initial coding analysis gleans key phrases in the data revealing a scene where the individual is looking for more options. For example, P3 describes “needing to find more,” P8 is looking to “explore options,” and C10 “wants to empower.” The axial coding breaks these phrases into expressive terms that describe the purpose such as more, explore, and options. These revelations often happened in the middle to end of the interviews with inquisitive language used to describe situations of hope. This analysis indicates a readiness to try to describe outside of the disability. This is not a surrender to just a diagnosis or a medical term to describe a disability. The caregivers in this theme are acknowledging the possibility of an alternate description. This stage brings the disability description to a pinnacle with a purpose of possibly making a choice to turn the corner in the disability description with guidance and should be included in the guide in Chapter 6.

- Act- Description with acknowledgement and desire for information about opportunities
- Agency- Inquisitive language used with situations of hope
- Agent- caregiver and person with disability
- Scene- A disability description that opens the door for the exploration of more opportunity. In example P3, Shane said, “I know we are going to have to find a different way of thought.” We need to find more.”
- Purpose- A disability or caregiver description that explores more hopeful options for the person with a disability. In example C10 from Judy, she said, “I do want to be the caregiver that empowers.”

The theme *next* from Table 4.2 directs that disability identity does not require for the caregiver or person with disability to focus on impairment. A necessity for the disability description to focus on the past or the present does not exist. According to Murugami (2009),

The universal construct of the self is the product of the fact that every human being is aware of his individuality” (P. 2). Samples from the theme *next* illustrate the shift to an understanding of the creation of identity through disability description. This shift is one of the significant themes in *Disability description theory*. If it can be imagined, it can be accomplished. Both the caregiver and person with disability are free to imagine an alternative to the disability description. The disability description can be considered in a discussion of what is next and what is possible. Looking at the personal pronoun responses here prompts an excellent question about the importance of description and the disability description role within an introduction.

- Example C11 from Tangy stated, “I had to forgive myself and give him the chance to be who he was going to be. Do you understand? Over the last 11 years I have learned that despite of all the medical issues we must work through, he is an intelligent, funny, and more often now happy young man that has developed his own way with his own friends.” Tangy said, “the real problem I faced was myself.”
- Example P14 from Kasey asserts that in “some way my parents constant outing of my disability helped me come out as transgender identifying as a girl. When personal pronouns became an acceptable idea for the public, it also gave me a way to talk about how I wanted to be described, not as my disability, but as someone who has much more.” The personal pronoun answer responses for transgender were not surprising because of the gender related discussion in current politics and academics. However, it was interesting the frequent mentions in this study signaling an acknowledgement of the importance for future research in disability description.
- Example C15 from Patricia states, “he is doing really well now, and I believe the current conversation in the world about identity and personal pronouns along with description

helped him to understand that he was not the only one struggling to identify himself. It also helped me to understand that I did not have to advocate for him in every conversation.” As I stated in the more theme the pronoun discussion came up from disability description frequently. In a brief scholarship search after these interviews, I did not find research on how personal pronouns are navigated by persons with disability. Another interesting concept in this description is finally coming to understand that Patricia in example C15 indicates that her caregivers does not have to advocate for her in every situation.

Pentad 4.6 analysis (next)

In Pentad 4.6 the initial coding aligns perfectly with the scene of the pentad in key phrases in examples P14 where Kasey said, “personal pronouns became an acceptable idea for the public, it also gave me a way to talk about how I wanted to be described, not as my disability, but as someone who has much more.” The notion of description is evolving in the world. We can look forward and into the public realm for answers. The axial coding offers terms like work through, give, going to be, developed his own way divulge that the act of disability description is signaling the move towards pursuing opportunities with an agency that is outside of medical terminology. Both the caregivers and persons with disability in the *next* phase are poised to seek and consider alternate possibilities in the disability description. The responses including personal pronouns that are typically aligned with gender is a fascinating reoccurring theme in the interviews that indicates respondents are considering what these descriptors means in the disability description. This is an excellent point of guidance for the disability description guide which offers an example of how the discussion about description can evolve through conversation.

- Act- description that signals the move towards pursuing opportunities. Example C11 from Tangy stated, “I had to forgive myself and give him the chance to be who he was going to be. Do you understand?”
- Agency- Terminology that is grounded outside of diagnosis
- Agent- caregiver and person with disability
- Scene-. The caregiver and person with a disability discover they do not have to follow a rigid medical disability description. In example C15 from Patricia states, “he is doing really well now, and I believe the current conversation in the world about identity and personal pronouns along with description helped him to understand that he was not the only one struggling to identify himself.
- Purpose – To explore what can be next in the disability description for both the caregiver and person with a disability. Example from C11 from Tangy said, Over the last 11 years I have learned that despite of all the medical issues we must work through, he is an intelligent, funny, and more often now happy young man that has developed his own way with his own friends.”

Grounded Theory and Pentad Analysis

1. Research Question 2 – Qualitative- What actionable rhetorical strategies do or can caregivers offer that help persons with disabilities transition from coping to thriving?
2. Research Question 1 – Qualitative: What rhetorical themes emerge from opportunities or scenarios that consistently support persons with disabilities in developing a positive identity, and rhetorical themes emerge that block opportunities from developing a positive identity?

Table 4.3

No Resources	Create a Plan	Shift to Independence
<p>P7: David said, “to date, the only advice they have received over the last 5 years is to seek a therapist which they cannot afford since David has lost his job. Some professional guidance to accompany all the medical care I have received would have made the most difference in my life besides surviving.?”</p>	<p>4.3f: Diane said, “the community center is nearby my house so I make sure that I offer to be a part of the activities so she will continue to participate.”</p>	<p>C12: Ian said, “We have collaborated on her, actually our story. We are still warriors. We recently participated in a rowing competition.”</p>
<p>C7: Donna said, “Ethan has expressed the desire to be more independent but as a new caregiver.” Donna is at a loss as to how to help him. She described “the lack of resources? in the topic of independence when a person with a disability is medically dependent.”</p>	<p>P2: Seth said, “When it came time for every part of my life my dad said go do it. If you need help, I will be there.”</p>	<p>P6: Seth said, “I believe the best strategy he gave me is the assurance that I would have another chance if I failed. He would love me even more for trying. I always had the belief that trying was the success.”</p>
<p>C13: Olivia said, “he is often difficult to handle, and he is frustrated. She said sometimes I wonder if I am doing the right thing by taking on the care. I do not have anyone to go to for advice. She said there is plenty of medical guidance to pursue his physical care, but she worries about the quality of his life that does not involve medical care.”</p>	<p>P15: John said, “my caregivers went from describing me as a person with life threatening medical issues to stubborn to eventually focused on living a happy life. This opened doors to the support I need, the advice I would get if I didn’t have a disability, like getting a job, or relationships.”</p>	<p>C5: Elisabeth said, “they created an apartment for him so he can live as independently as possible but with the support needed. She has studied text and media to decide how to create opportunities for her father as long as they are available. She said the time they are spending together...the opportunity to continue his independence is a privilege for her.”</p>
<p>C13: Olivia said, I feel guilty all the time” as if she is not doing enough but the resources of hope are so limited in the small town, they live in. She said, “I have no example. I am doing the best I can with the care.”</p>	<p>P9: Alice said, “She made sure everyone knows the struggles I faced medically, and I heard this so many times I lost count.” The real change came when Alice’ grandmother gave up on the cure and began to look for</p>	<p>P9: Alice said, “for example. I wanted to learn to cook for myself...my grandmother was an expert cook. She began to include me in preparing meals.” Alice described this as the beginning of the change in</p>

	<p>things that Alice could do independently. Alice states, “She began to ask me what I want to do, what I dream about, and she brainstormed with me on how we might accomplish that.”</p>	<p>everything. Instead of her grandmother describing her as her limitations, she talked about their cooking together.”</p>
<p>P14: Kasey describes her mom and Dad “as eager to help.” She laughed when she made that comment. She said, “it was a rough go for a lot of years.” My parents really had no experience and no resources or advice with disability.”</p>	<p>C15: Patricia said, “In the beginning I was working my way through my heartache for him by talking about it. Now we always talk through what he will say instead of me. For example, he asks the questions, and introduces his self instead of me introducing him. I add support. This has made us stronger. Helping him through this made me a better mother...a better human.”</p>	<p>P10: Veronica describes herself “as strong determined that can do anything I put my mind to. I might have cerebral palsy, but I am not cerebral palsy. For years I lived with my parents. After going through vocational rehabilitation, I learned to be independent, and I have a job and live in a group home. My parents were afraid at first to let me go but I gained their confidence over the years as I learned to build a support system. I have hardships like everyone else. I do not think being disabled makes me the only one that has problems. In the group home I have friends and I have a boyfriend. I think that was one of the things I did that was most surprising to my parents. They were once focused on what my issues with my disability and now, they describe me talking about what is going on in my life...job. boyfriend...living on my own. They are proud of me. Learning to be independent built my confidence.”</p>

	<p>C6: Victor said, “we have always talked through the problems...the embarrassment that we both felt in the beginning and turned them into success. We worked through it together. I am not trying to say that it was always simple or easy but communication between us and to everyone else has helped us. We asked a lot of questions...we still do. I speak with Seth more than my other two. I learned that I could be the sounding board...this helped us succeed.”</p>	<p>C1: Diane said “her stepmom has immunity health problems but tries to be a part of the community. The community center is nearby my house so I make sure that I offer to be a part of the activities so she will continue to participate and instead of getting a house cleaner I come to do the activity with her because cleaning her home was something she always took pride in. I would admit that it would be easier to hire someone instead of dedicating one morning or afternoon a week, but it is part of her identity and we discussed early on that this would help her feel useful and important in her life.”</p>
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Discussion of Table 4.3 Data

Practice and apply. In the *practice and apply* stage three themes emerge established from research question two: *no resources, create a plan, and shift to independence*. All three themes indicate how the evolution of the description is or can be an actionable element of thriving with a crucial role in the pursuit of personal power, happiness and belonging through disability description independence.

The *no resources* theme from the *practice and apply* stage of *Disability description theory* indicate both caregivers and persons with disabilities in this theme recognize he or she needs rhetorical resources. This was a frequent point of conversation in these interviews. The initial coding in example C7 below, Donna is describing being “at a loss” in the search for guidance. The axial coding sets up categories with terms like resources, and guidance. The medical

resources do not solve all the problems. Grue (2016) states, the social meaning of disability—and the precise way in which the category is understood in social interaction—deserves further attention (p. 968).” The desire is building for caregivers and persons with disabilities in this theme to claim a more powerful identity, yet the resources are limited. The caregiver priorities have shifted in the *no resources* theme by recognizing the resources as an essential step to achieve disability description independence.

- Example C7 from Donna said, “Ethan has expressed the desire to be more independent but as a new caregiver Donna is at a loss as to how to help him. She described the lack of resources in the topic of independence when a person with a disability is medically dependent.” This example highlights the recognition that independence is the goal, and that Donna does comprehend a correlation between the need to find resources beyond the medical description to gain independence.
- Example P14 from Kasey describes her mom and Dad as eager to help. She laughed when she made that comment. She said, “it was a rough go for a lot of years. My parents really had no experience and no resources or advice with disability. Kasey recognizes that lack of resources was the struggle behind the delay of independence.” The desire to be helpful was key, the lack of resources was the barrier.
- Example P7 from David said, “to date, the only advice they have received over the last 5 years is to seek a therapist which they cannot afford since David has lost his job. David stated, “some professional guidance to accompany all the medical care I have received would have made the most difference in my life besides surviving.” The need for therapist to find professional resources beyond medical care was one of the key themes. The participants often talked about the need for resources that are not based on medical

care but focused on how to help the person they care for to navigate the world during both description and resources questions.

Pentad 4.7 Analysis (no resources)

In Pentad 4.7 in the initial coding, frequent phrases describing the frustration of having limited resources are described in P7 when David said, “some professional guidance to accompany all the medical care I have received would have made the most difference in my life besides surviving,” and P14 from Kasey, describing how here parents had “no resources” to help. What is interesting here is that frequent responses from caregiving and persons with disabilities recognizes the lack of guidance. The axial coding exposes the terminology that describes complaints about a lack of resources including lack of resources, need for therapist, medically dependent. Individuals in the *no resources* theme indicate that further resources would offer a move towards independence, the purpose of gaining resources is clear in the scene of complaining about no resources, and the motivation is to describe no resources as a barrier to disability opportunities.

- Act- Medical descriptions because of lack of guidance. Example C7 from Donna said, “Ethan has expressed the desire to be more independent but as a new caregiver Donna is at a loss as to how to help him. She described the lack of resources in the topic of independence when a person with a disability is medically dependent.”
- Agency- Medical terminology offered as only resource
- Agent- caregiver and person with disabilities
- Scene-. In example P7 David stated, “some professional guidance to accompany all the medical care I have received would have made the most difference in my life besides surviving.”

- Purpose- To find resources that assists caregivers and persons with disabilities to develop disability descriptions that lead to independence.

The *create a plan* theme of the *practice and apply* stage of *Disability description theory* is a major turn in the disability description. The caregiver and person with disability have realized a key understanding and transformation in disability descriptions. The caregiver has moved into a different stage by providing the support and becoming the resource. Participants in the *practice and apply* stage frequently indicate actions of talking things through or making a plan for the disability description. The person with a disability is in practice mode telling his or her own story and owning the narrative while the caregiver offers support and encouragement. The initial coding features key phrases like example in P7 where “she began to ask me what I want to do, what I dream about, and she brainstormed with me on how we might accomplish that,” and from example C6, I learned that I could be the sounding board.” The axial coding revealed key terms like brainstormed, make a plan, sounding board. The process of disability description is not fully formed; however, the power has been transferred to the person with a disability to own their story.

- Example P9 from Alice stated, “she made sure everyone knows the struggles I faced medically, and I heard this so many times I lost count.” The real change came when Alice’ grandmother gave up on the cure and began to look for things that Alice could do independently. Alice states, “she began to ask me what I want to do, what I dream about, and she brainstormed with me on how we might accomplish that.” This is an excellent example of practicing the new disability narrative and applying to real life situation.
- Example C6 from Victor stated, “we have always talked through the problems, and the embarrassment that we both felt in the beginning and turned them into success. We

worked through it together. I am not trying to say that it was always simple or easy but communication between us and to everyone else has helped us. We asked a lot of questions, and we still do. I speak with Seth more than my other two. I learned that I could be the sounding board, and this helped us succeed.” The concept of talking through the problems seems like a simple answer yet surfaced frequently in the interview. The medical caregiving dynamic creates a barrier to simple actions like collaboration. A caregiver is often tasked with being the instructor or facilitator in medical care without a guide that most instructors would have on how to collaborate for authentic results.

- Example C15 from Patricia said, “in the beginning I was working my way through my heartache for him by talking about it. Now we always talk through what he will say instead of me. For example, he asks the questions, and introduces his self instead of me introducing him. I add support. This has made us stronger. Helping him through this made me a better mother, and a better human.” The same concept of disability collaboration emerges in this example.

Pentad 4.8 Analysis (create a plan)

In Pentad 4.8, the initial coding develops a scene from the phrases. In example C15, Patricia describes “talking through what he will say instead of me.” In C6, Victor said, “I learned that I could be a sounding board.” The theme and purpose quickly emerge in the axial coding with terms like talk through, support, plan, sounding board, and brainstorm. The purpose in the grounded theory and pentad point to creating a plan for the disability descriptions. This stage sets up the shift to independence with the promise of ongoing advice and support. This also teaches the person with disability how to navigate support outside the caregiver relationship. The

caregiver in this conversation begins to unpack what it is to be the resource. This is a key theme to include in the disability description guide in chapter 6.

Pentad 4.8 Analysis: Create a Plan – (Theme two)

- Act- Description supported by engagement that creates a platform for practice. Example P9 from Alice stated, “she made sure everyone knows the struggles I faced medically, and I heard this so many times I lost count.” The real change came when Alice’ grandmother gave up on the cure and began to look for things that Alice could do independently. Alice states, “she began to ask me what I want to do, what I dream about, and she brainstormed with me on how we might accomplish that.”
- Agency- Cocreated/curated collaboration
- Agent- caregiver and Person with Disability
- Scene- Collaborating to find a positive way forward in the disability description. Patricia in example C15, said, “now we always talk through what he will say instead of me. For example, he asks the questions, and introduces his self instead of me introducing him. I add support. This has made us stronger. Helping him through this made me a better mother, and a better human.”
- Purpose – To collaborate on the disability description in providing details that empower. In example P9, Alice states, “she began to ask me what I want to do, what I dream about, and she brainstormed with me on how we might accomplish that.”

The *shift to independence* theme from the *practice and apply* stage introduces narratives where persons with disabilities are building the actionable identity and disability description. These moments of the interviews where I heard stories of caregivers and persons with disabilities who had ran the disability gauntlet and developed strategies to succeed were a highlight for me

as a caregiver. The persons with disabilities are taking the resources provided from caregivers and applying to various life situations forging a pathway forward in the disability description. The *shift to impotence* theme is an excellent example of a rebranded disability description. In example P9 from Alice when she said, “for example. I wanted to learn to cook for myself...my grandmother was an expert cook. She began to include me in preparing meals” inspired a change in my own caregiving relationship with my daughter. My daughter and I are now going to the farmers market together and discussing recipes. She has been married for ten years yet is now cooking on her own because of what I learned in this study. These narratives have power to be shared in a caregiver guide to disability description.

- Example C12 from Ian states, “we have collaborated on her, actually our story. We are still warriors. We recently participated in a rowing competition.” This examples how taking the disability description discussion leads to opportunities as they resumed an activity, they once believed reserved for the abled.
- Example P9 from Alice, “for example. I wanted to learn to cook for myself...my grandmother was an expert cook. She began to include me in preparing meals.” Alice described this as the beginning of the change in everything. Instead of her grandmother describing her as her limitations, she talked about their cooking together.” The story of Alice and her caregiver presents the successful results of disability description rebranding. The new disability description is applied successfully.
- Example P10 from Veronica describes herself “as strong and determined that I can do anything I put my mind to. I might have cerebral palsy, but I am not cerebral palsy. For years I lived with my parents. After going through vocational rehabilitation, I learned to be independent, and I have a job and live in a group home. My parents were afraid at first

to let me go but I gained their confidence over the years as I learned to build a support system. I have hardships like everyone else. I do not think being disabled makes me the only one that has problems. In the group home I have friends and I have a boyfriend. I think that was one of the things I did that was most surprising to my parents. They were once focused on what my issues with my disability and now, they describe me talking about what is going on in my life, my job, my boyfriend, and living on my own. They are proud of me. Learning to be independent built my confidence.” Collaboration between the caregiver and this person with a disability led to independent living. She is successfully described as qualities beyond the disability allowing her to thrive through visualized and practiced opportunities.

Pentad 4.9 Analysis (Shift to Independence)

Pentad 4.9 indicates a purpose of creating descriptions from the act of advice that produces scenarios of participation. In the initial coding the scene is set with phrases from P10 from Veronica that states, “now they describe me talking about what is going on in my life, and in C12 that states “we have collaborated on her, actually our story,” and in P9 where Alice states, instead of her grandmother describing her as her limitations, she talked about their cooking together.” In the axial coding, you can recognize the act, with terms like instead, collaborated, learned, independent, began to, living on my own. The purpose here is to shift gears to a practice of a disability description that signals a move to independence. This places the caregiver firmly as a resource of rhetorical support that leads to freedom. The purpose is a shift to claim power of the disability narrative to act on it. Pentad 4.9 outlines how the motivation of creating an actionable disability description can be accomplished. The rhetorical support is not conjoined to only medical support but is giving the persons with disabilities the power over his or her own

narrative and opportunities. This theme provides excellent examples for the disability description guide in chapter six.

- Act- advice that creates scenarios of participation. Example C12 from Ian states, “we have collaborated on her, actually our story. We are still warriors. We recently participated in a rowing competition.”
- Agency- Language that reinforces effort as success or practice that can lead to success.
- Agent- caregiver and persons with disabilities
- Scene-. Moving to an actionable disability description. Example P9 from Alice, “for example. I wanted to learn to cook for myself...my grandmother was an expert cook. She began to include me in preparing meals.” Alice described this as the beginning of the change in everything. Instead of her grandmother describing her as her limitations, she talked about their cooking together.”
- Purpose- To develop rhetoric that assists the person with disability in claim power over their personal disability description and apply. In example P10 from Veronica, “she states, now, they describe me talking about what is going on in my life, my job, my boyfriend, and living on my own.”
- Attitude- identify the person with the disability as an individual that can live independently, contribute, and belong

Results Summary

My original goal of this study was to understand what rhetorical resources are missing for caregivers and to create a guide that fills the gap in these resources. As a long-time caregiver, I wanted to learn from these narratives on how I can help my caregiving community and the disability community of my daughter in building a shared rhetoric that inspires thriving beyond

diagnosis or struggle. The interview responses in this study reinforce a key appeal for caregivers to help with a necessity to explore the rhetoric of disability within the shared experience of caregivers and persons with disabilities. As I conducted the thirty qualitative interviews with fifteen from caregivers and fifteen from persons with disabilities, the need to unpack disability description choices and narrow the focus to understand the phenomenon of disability description became clearer. The most interesting elements of the interviews outline a process of stages, and a pathway to guidance for improving disability description.

The stages evaluated and described in the data analysis offer a framework to create guidance for caregivers in each step of disability development with three distinct stages revealed in the data outlined in the grounded theory and pentad analysis: *define, collaborate and review*, and *practice and apply*. Each one of the three stages has three themes uncovered in the coding described in Tables 4.1, 4.2, and 4.3, and Pentads 4.1 - 4.9. The themes outline the conversation surrounding the myriad of choices in which disability is being described, how caregivers and persons with disabilities are making phrases in initial coding and word selections in axial coding for the disability descriptions.

The grounded theory and pentad analysis work well together to understand, describe, and glean actionable disability description next steps from the data. The most difficult part of grounded theory is to develop the process of initial coding narrowing into the axial coding to reveal the themes. The pentad studies helped me organize the stories and understand that once the caregivers and participants with disabilities began describing the disability, the patterns emerged to describe the purpose or motivation of each description.

The initial coding is easy to understand in the context of a scene, and the axial coding reveals the acts, or the choices which revealed the purpose of the description. The pentad

analysis reveals a deeper understanding of potential motivation or purpose of these acts within the scenes described in the initial coding of grounded theory. Disability description goes through a transition when the caregiver and person with a disability begin looking for answers outside of the medical community, and a transformation when the conversation evolves beyond the medical descriptions, and blocked resources to collaborative conversations and ultimately acting on an alternate disability description path. The merge between both grounded theory analysis and pentad analysis reveals more details in the stages of a shared experience of disability description between caregivers and persons with disabilities.

The pentad analysis assists in unpacking the scenario in each stage of *disability description theory*. Understanding how the scenario of disability description unfolds when examining the act, agent, agency, scene, and purpose assists in building a theory that is reinforced with the accurate analysis of the data pointing to the purpose of each disability description theme. The initial coding with key phrases set the scene of choices made when the caregivers are describing the person with a disability and the individual with the disabilities are describing themselves. For example in P9 when Alice describes how her caregiver was asking what she wanted to do, what she dreams about, and how she brainstorms with her in the pentad helping me to understand how this phrase in the initial coding of grounded theory is a scene where a disability description is being formed, and I am able understand how the act reveals a purpose in the axial coding to develop a category of brainstorming which fit into a theme that describes the example in P7 above of how to *create a plan* for disability description. Each scenario of disability description unfolds to describe what the purpose and ultimately the motivation is. Understanding the motivation in descriptions helps determine how the purpose could change and evolve.

From disability description in the beginning with resources grounded in a motivation to define the person with a disability. The themes *challenge or opportunity* that detail the challenge of disability with a follow-up details outlining an opportunity to see something different in the story like a hobby. *an ableist tale* theme is a straight definition of the disability diagnosis, and/or the challenge or struggle. The *alternative identity* offers different personality traits, hobbies, or skills dissected from the disability. set story in the *define* stage. The define stage holds back on details with a simpler description that does not tell offer the complexity of a human that typically offer about our story. For example, in P9 of an ableist tale theme: Alice said, “For as long as I can remember my story was wrapped up in the things, I cannot do.” The most frequent interaction that a caregiver and a person with a disability have been with the medical world that is designed to repair. Without additional resources, it is easy to get caught up in the definition of the disability description. This kind of definition-oriented disability description was frequent.

The *collaborate and revise* stage has a new element. The participants are either recognizing they are *stuck* and need resources, identify the need to provide or find *more* in the disability narrative, or to collaborate and decide what is *next* in the disability description. The act in this theme is to understand what is missing. The participants are constantly describing what is missing. In the *more* stage, an example from C11 describes how a caregiver recognizes the need to find answers and help as Tangy said, “when he was born with all these health problems, I just wanted him to survive, and then I wanted him to be normal, and then I let that go and I wanted him to be happy.” In my own experience when I first become a caregiver, the goal was to give the best possible medical care, to be qualified for the task, and then I realized that is not the perfect pathway to happiness for my daughter. The *collaborate and revise* stage is moment of

realization for both caregivers and persons with disabilities revealing they are in a cycle of trying to find collaboration and understand how to edit and revise the disability description.

Finally, the *practice and apply* theme brings the journey to an inflection point as both caregivers and persons with disabilities understand resources are missing. The need to have a more purposeful and positive disability description is recognized. The *no resources* theme is an important distinguishable moment in the study that unpacks a realization that help in describing a disability is needed. The *create a plan* stage is the study group of disability description. We can talk about how the person with a disability is described in a way that empowers and validates. We can rewrite that story together. That choice can be made and evolved. The final stage of *shift to independence* reveals the purpose of evaluating, revising, creating a guide for, and ultimately transforming a disability description. This is the shift in a disability description that is actionable. I was personally moved to action as a caregiver in example P9 when Alice said, “I wanted to learn to cook for myself, and my grandmother was an expert cook. She began to include me in preparing meals.” Alice described this as the “beginning of the change in everything. Instead of her grandmother describing her as her limitations, she talked about their cooking together.” I called my daughter after this interview and asked her if she would like to go to the farmers market with me. I find myself talking about us converting to a healthy lifestyle together with my friends instead of descriptions that include disability. After thirty years of caregiving, I learned something completely new from this study that changed our story through a disability description. We revised our disability description to create an actionable narrative as my daughter has been cooking her own food independently from our weekly farmers market trips for several months now.

Summary

Dunn (2016) asserts that “powerful stories leave lasting impressions” (p. 2). This is the rationale for including qualitative interviews. Trying to understand the shared experience between caregivers and persons with disabilities without those stories is nearly impossible. As a caregiver for over 30 years, prior to this study I could only speak from my experience, yet I know there is such a diversity of other caregiving experiences that could enrich the disability and caregiving experience. I have been in countless waiting rooms and heard innumerable stories different from my own. While thirty interviews including fifteen from caregivers, and fifteen from persons with disabilities can not capture the entire story of disability description, this study initiated the conversation discussing the shared reality between caregivers and persons with disabilities. I have successfully analyzed a snapshot of the rhetorical description dance between the two to begin the task of finding and providing rhetorical resources for those who care for persons with disabilities and for persons with disabilities to utilize for themselves. Wilson (2012) states “I have learned that disability pushes us to examine ourselves and the question about our American past (p. 1).”

The three stages in *disability description theory* establish a crucial framework which can inform a useful guide to assist caregiver in transforming ableist description disability rhetoric into powerful descriptive rhetoric of independence. These three stages, *define*, *collaborate*, and *revise*, and *practice and apply* offer an instructive framework with steps to empower and assist caregivers and person with disabilities. The quick guide created from *disability description theory* will inform caregivers on how to assist persons with disability to thrive in an ableist world.

Chapter 5 will discuss how Chapter 4 answered the research questions with a discussion of limitations, implications, bias, and suggestions for future research in the topic of disability descriptions in disability rhetoric.

Chapter 6 will reinforce and realize the essential goal of the study to provide caregivers a disability description guide outlining steps to provide rhetorical opportunities and scenarios based on *disability description theory* developed in this study.

CHAPTER FIVE

SUMMARY, CONCLUSIONS, AND RECOMMENDATIONS

According to Harter et al (2006), “By envisioning inclusion and integration as a product of the ways we “do disability” in our personal interactions, and institutional and societal scripts, we seek to visualize where and how we can change our discourse practices and social interactions’ (p.4). The scholarship reviewed in Chapter 2 often points to this vision of a new way of seeing disability, yet rarely envisions the caregiving role in accomplishing this goal. As a caregiver, I have lived this reality of expectations without answers, solutions, or guidance for over thirty years looking frequently to the medical community for answers. I have attempted to navigate the maze of disability rhetoric primarily unsuccessfully.

In Chapters 1 and 2, I posed the question of why ableism has endured despite inspiring a genre of scholarship in disability studies. At the heart of my inquiry was a hopeful qualitative exploration of information to find caregiver resources focused on persons with disabilities thriving in a dominant ableist world. Chapters 1 through 3 capture ten essential points to describe what has been discussed in the rhetoric of caregiving. This conversation reveals what needs to be discussed to understand how caregivers might align to the goals of mitigating the impact of ableism on the identity of persons with disabilities:

The ten essential points include Caregiving Point 1 (CP1) which describes a disability identity with description that exclude people with disabilities. Caregiving Point two (CP2) outlines how the world of opportunity is aligned to an ideal based on ability. Caregiving Point Three (CP3) defines how societal belonging is manufactured and distributed through the lens of ableism. Caregiving Point four (CP4) is a reminder that science is a major resource in the disability identity narrative for caregivers, yet Caregiving Point Six (CP6) reinforces an

alternative in a very large community for caregivers to learn to build disability identity knowledge among other caregivers. Caregiving Point Seven (CP7) is a reminder that the medical influence in disability identity through disability description is embedded and pervasive in society. Caregiving Point Eight (CP8) reminds us that, the caregiver is usually the most impactful relationship in a person with a disability's life and future research could reveal alternatives to the medical descriptive resources for caregivers. Caregiving Point Nine (CP9) shines a light on the need to help caregivers in accessing and developing empowering disability identity resources.

The tenth and perhaps the most essential Caregiving Point (CP10) is that a disability description does not have to be based on science or reinforced by what an individual can or cannot do. It is a rare thing for an abled person will introduce themselves with a description that outlines ability. The disability description can be based on the accomplishments, hopes, dreams, or ideas of the person being described. For example, after learning about Alice's in example P9 describing her cooking transition with her caregiver sharing how they cook together which is a strategy stemming from the collaboration on her dream of cooking, I use that collaborative strategy successfully with my daughter, Holly, who now cooks and talks about her dreams of new ingredients she will purchase at the farmer's market. I talk about her cooking and dreams of new recipes instead of her challenges.

My first key point (CP1) describes a narrative of disability description that excludes and marginalizes. Ableism is a product of a false medical-based narrative focused on undefined abilities that ignores the physical impairment of some humans, while defining other humans as the impairment. This places classification and description is at the heart of the problem of disability rhetoric.

Harter et al (2006) states “The world is structured to support the ideally shaped and intellectually gifted” (P. 19). My third point (CP3) from previous chapters is societal belonging and inclusion is distributed according to the undefined rules of ableism. The person with a disability is uniquely positioned to never be considered the ideal shape or intellectually gifted. I was inside Starbucks last week with my daughter watching the interaction of assumptions people have with her disability. It is alarming how many people talk slowly to her as if she cannot comprehend simple words. She slurs her words because the left side of her body has spasticity yet can hear perfectly and is very educated. After a barista shouted very slow questions to her, she said, “I understand you perfectly at a regular speed and volume. The problem we have here is that you do not understand me. Would you like for me to speak louder and slower?”

According to Goodley (2014), “disability is normatively understood through the gaze of medicalization” (p. 1). My fourth point (CP4) presents discussion of how the narrative of disability is reinforced by science and history punishing individuals who fall in the disabled classification. According to Murugami (2009), “impairment should be seen as part of the human condition rather than a basis for setting someone apart, or a characteristic diminishing one's humanness” (P. 5). To accomplish this goal, we would need to examine the resources from the source of care for persons with disabilities. Goodley (2014) suggest that disability studies have been ongoing for 30 years and persons with disabilities continue to struggle.

Essential point five (CP5) reminds us that disability studies has rose in popularity and significance across genres of academic research. I have been a caregiver for those thirty years and my knowledge of disability studies only grew within my academic experience. There is a community of caregivers who only know what they learn from the medical interactions. This project offers an opportunity to bridge academic and non-academic communities of care by

utilizing theory gleaned from scholarship to create a disability description guide. This explains why my sixth point (CP6) is that the medicalization of disability continues to present the most significant challenge in disability identity. Dolmage (2014) suggests that ableism is the product of the medical model of disability which focuses on the ambiguous concept of an able body as the normal standard. For example, I have had three surgeries on my knee and the ligaments are completely gone, yet I rarely mention it. We do not have to focus on our inability to perform a task if it has no role in the conversation.

My seventh essential point (CP7) is disability rhetoric has been represented in a great deal of scholarship yet is rarely connected to the rhetoric of caregiving. The very few examples of caregiving rhetoric focus mainly on autoethnographic experiences of caregivers which is important. However, studies with narratives of both caregivers and persons with disabilities are needed. The academic community must begin to explore the shared experience of caregiving and persons with disabilities. Rafferty et al. (2020) explain my eighth point (CP8) when reminding us that caregivers are the most significant relationships persons with disabilities have. Thomson & White (2019) describe the journey of caregiving as heavy in responsibility, and expectations with the minimum resources or support. Caregiving is in the forefront of the person with a disability's life. It can be a useful place to collaborate and revise the disability story with useful rhetorical resources.

In my ninth point (CP9), the research points out the uphill battle of caregivers to find resources beyond medical care. As a long-time caregiver the importance of this need cannot be understated by me. This study exemplifies the fact that I continue to learn after thirty years. If belonging is underpinned by words that describe ability as many scholars suggest, caregivers need to be able to understand the words. We can use a guide that offers strategies with words

with motives that empower the disability description. Finally, in (CP10) there is no rule that requires the disability description to be dominated by a diagnosis or described as a struggle. The accomplishment of the Camp Jened participants described in *Crip Camp* are a glowing example of what can be accomplished when disability is not the obstacle but rather the advantage as these campers went on to be leaders, politicians, administrators, and doctors by focusing on each of their abilities.

Murugami (2009) states “Despite daily experiences of oppressive practices by non-disabled peers, there are persons with disabilities who do not incorporate disability in their identity” (P. 2). My decisive point from previous chapters is the importance of understanding what role caregivers have played in assisting persons with disabilities to champion his or her own identities. Rafferty et al. (2020), acknowledge that familiar caregivers, most frequently parents, are the heart and soul of support for persons with disabilities. The most frequent identity marker comes from the description of disability, which is most commonly part of the shared experience between caregivers and persons with disabilities. The power is in harnessing the disability narrative beyond diagnosis and that requires caregivers to understand what stage of the disability description they are in.

Summary of Findings and Conclusion

There is no guide or set of directives that exists requiring the disability description to be defined in a definite way. According to Grue (2016), If there is a single, easy way to define disability, it has yet to be found (P. 1468). Caregivers are left to navigate the disability description on their own and often judged for it. The study assembles an outline of the phenomenon of disability description offering guidance from real stories: a snapshot of how the rhetoric of disability description in the caregiver/persons with disabilities shared experience

falters, fails, escalates, and succeeds. By using a two-step research instrument in grounded theory and Burke's (1952) dramatic pentad, the emergent themes can be applied to a situation or scenario. The similarities between caregivers and persons with disabilities are evident in the interview analysis. Likewise, the most emergent rhetorical situation surrounds the disability descriptions including the primary ownership, transfer, permanent ownership, and application of the disability description.

Rafferty et al. (2020) describe a critical challenge for caregivers finding resources in providing essential care focused on social support. The above ten essential points outlined to describe what I learned in Chapter 1 and 2 describing what has been researched in the rhetoric of disability and caregiving, and what is aligning to what revelations have been revealed in the thirty qualitative interviews in this study. Caregivers continue to struggle to find the support that leads to social belonging, and identity building for the individuals they care for and themselves. As a caregiver for thirty years, I found that I relate to many of the narratives that were shared, but I did not understand where I am currently exist with the stages and themes of disability description.

Grue (2016) states, "the social meaning of disability is in flux (P. 1468)." The responses from this study certainly paint the picture of that fluidity yet provide a clearer path forward for caregivers. The research questions are keenly focused on the search for how to find, where to find, and how I might develop resources for caregivers. This study delivers by revealing some preliminary answers through outlining the challenges and steps toward finding a resource that helps caregivers and the people with disabilities they care for to develop an actionable collaborative disability description that describes that moves this shared story forward. This was

my goal, and the stages and themes of *disability description theory* begin that process in scholarship.

Three stages emerged to form disability description theory assisting me in understanding where different participants were in the act of describing a disability. Each stage exists at a different level of disability description. The stages have three themes each to describe the location of the disability description at that level. In the *define* stage, the disability description is a simple definition being delivered in 3 different behaviors. The *challenge or opportunity* theme presents the diagnosis or impairment with additional details unrelated to the disability. *An ableist tale* only describes the diagnosis, impairment or struggle, and the *alternate identity* ignores the medical condition of the description giving other details of the individual such as a hobby or emotion. The commonality in this stage is that the definition is not seeking resources.

The *collaborate and revise* stage is a disability description seeking or sampling resources. The themes *no stuck*, *more*, and *next* are all actively looking for answers to the problem in the disability description. Each theme is actively questioning the function of the disability narrative. The participants are moving through that stage in act of identifying being *stuck* in a situation they do not understand, to collaborating and communicating the need for *more*, and revising the disability description to understand what is *next*. This stage is about more than a simple definition with a medical term or added detail to gloss over what a disability description is. The data is now indicating movement in the disability description.

The final stage of *practice and apply* is where the participants describe taking control of the disability narrative. The *no resources* theme is a cry for help and a recognition that something is wrong. This is no longer accepting the label from the doctor or glossing over the description with more details. In this study I learned that the *create a plan* theme is most likely

where I was before this study. We were actively talking about how my daughter wanted to be described. This is a cocreation of the disability description between the caregiver and the person with a disability.

The *shift to independence* is the actualized level of the disability description where a caregiver is providing guidance and support that leads to independence. One of the fascinating details is how an open conversation in some cases broached by the person with disability can evolve the disability description to a story with more supporting details like a job, skills, or even strengths not often possessed by the caregiver. In example P15, John led the conversation about how he wanted to be described with his caregivers. This disability description theme is based on a purpose of creating opportunities to talk about other cocreated details like the example P9 when Alice's mother taught her to cook and began to talk about that in the disability description instead of the struggle. The disability description has a motivation, there are no rules about the ambition of that motivation. The disability description can be a choice to transform and transfer power. For example, just yesterday when my daughter and I were at the farmer's market and she was sharing her future cooking plans with a local farmer, I stood there silently amazed at all the possibilities of her narrative as she described her one-handed cooking strategies. As we walked away, she said, "I never knew how powerful I was until I took the reins of my story."

Disability description theory presents a framework for a disability description guide and offers a beginning of the necessary resources for caregivers and/or persons with disabilities in describing a disability that empowers which is the primary purpose of my study.

Implications

The implications of this study offer a new theory, *disability description theory*, with significant research in disability rhetoric and the rhetoric of caregiving based on qualitative data

outlining the shared experience of caregivers and persons with disabilities. The shared experienced of rhetoric within the most significant disability relationship is no longer absent from scholarship providing a lens for future research. The importance of the disability description, and the role of caregiving in disability rhetoric can be examined further to identify and outline future resources. Additionally, this study paves the way for scholars to further examine how caregivers can navigate disability rhetoric to provide guidance for those whom they care for.

Strengths and Weaknesses of the Study

Disability is a complex term for a population that is diverse (Grue, 2016). Often the problems associated with a disability are oversimplified for caregivers pointing to the most frequent professionals in the medical world as description guidance and authority (Goodley, 2014). These descriptions are often a diagnosis or the explanation of a struggle for the caregiver, the person with a disability, or often both. The major limitation of this study is the lack of comparison to other studies, which naturally creates an oversimplification of the issue. The phenomenon of shared experience between caregivers and persons with disabilities is largely undefined beyond medical care and needs more examination. Because the demand for resources is a key part of thriving and a frequent thread in the analysis, the gap in scholarship needs to narrow.

Thirty qualitative interviews offer a beginning but falls short of fully describing a comprehensive solution which could be universally applied. Caregiving is often addressed in scholarship by a single caregiver, in an autoethnographic approach or a few studies generally describe the challenges caregivers face with medical care. The qualitative studies with both caregiver and persons with disabilities addressing the rhetorical challenges can be a long and

arduous process. For example, transcribing the forty-five-minute interviews with a two-step analysis method took one year in my dissertation. A great deal of complexity exists in this approach and this was the most time consuming yet most important step of the dissertation.

The strength of the study shows that caregivers need to support persons with disabilities rhetorically, reveal where that support is found, and how the support can be replicated. Therefore, the academic conversation is off to a solid start because this study blends the disability description narratives of caregivers and persons with disabilities in a strong two-part grounded theory and dramatisitic pentad analysis. This study evaluates a significant problem at the source and producing a helpful theory informing a critical resource that will be featured in the chapter six as one of the essential goals of this study is realized.

Disability description theory offers a pathway for caregivers to move beyond the lack of support and/or need to describe persons with disability in medical or simple terms. The development of the theory is supported in the narratives and carefully evaluated. The themes in *Disability description theory* frame how the disability description problem unfolds, and the stages outline a legitimate guide for caregivers. The narratives of how caregivers and persons with disabilities describe disability whether it is individually described or cocreated is analyzed with reliable qualitative data in lieu of assumptions made by researchers not utilizing interviews to describe the shared experiences of disability description between caregivers and persons with disabilities.

Recommendations

A recommendation based on the results, findings, and limitations of the study is to examine more qualitative research between caregivers and persons with disabilities. These relationships as exhibited in the narratives are critical to the identity of persons with disabilities

taking place over the course of years. My suggestion for future research is the narrow the focus evaluating different traditions, cultures, genders, disability situations, and caregiver responsibilities. The phenomenon of gender pronouns came up frequently in this study as caregivers and persons with disabilities consider the commonality of identity significance in gender pronouns with disability descriptions. This is an excellent consideration for future research.

Such research is an introduction into the phenomenon of disability description with a focus on where resources can be found, or what steps can be taken to help caregivers provide rhetorical support. Future scholarship should frame and shape resources that caregivers frequently mentioned in the interviews such as *making a plan* to describe disability descriptions. *Disability description theory* must be thoroughly examined to develop and evolve caregiver and persons with disabilities resources. My goal in conducting this study was to produce an applicable, and evolving resource for caregivers to provide persons with disabilities the rhetorical power and freedom to compose their own narratives, transform their identities, and enhance their lives as outlined in previous chapters. For that comprehensive goal to be accomplished the research needs to be nurtured to grow, and *disability description theory* to be evaluated, utilized, revised, and evolved.

CHAPTER SIX

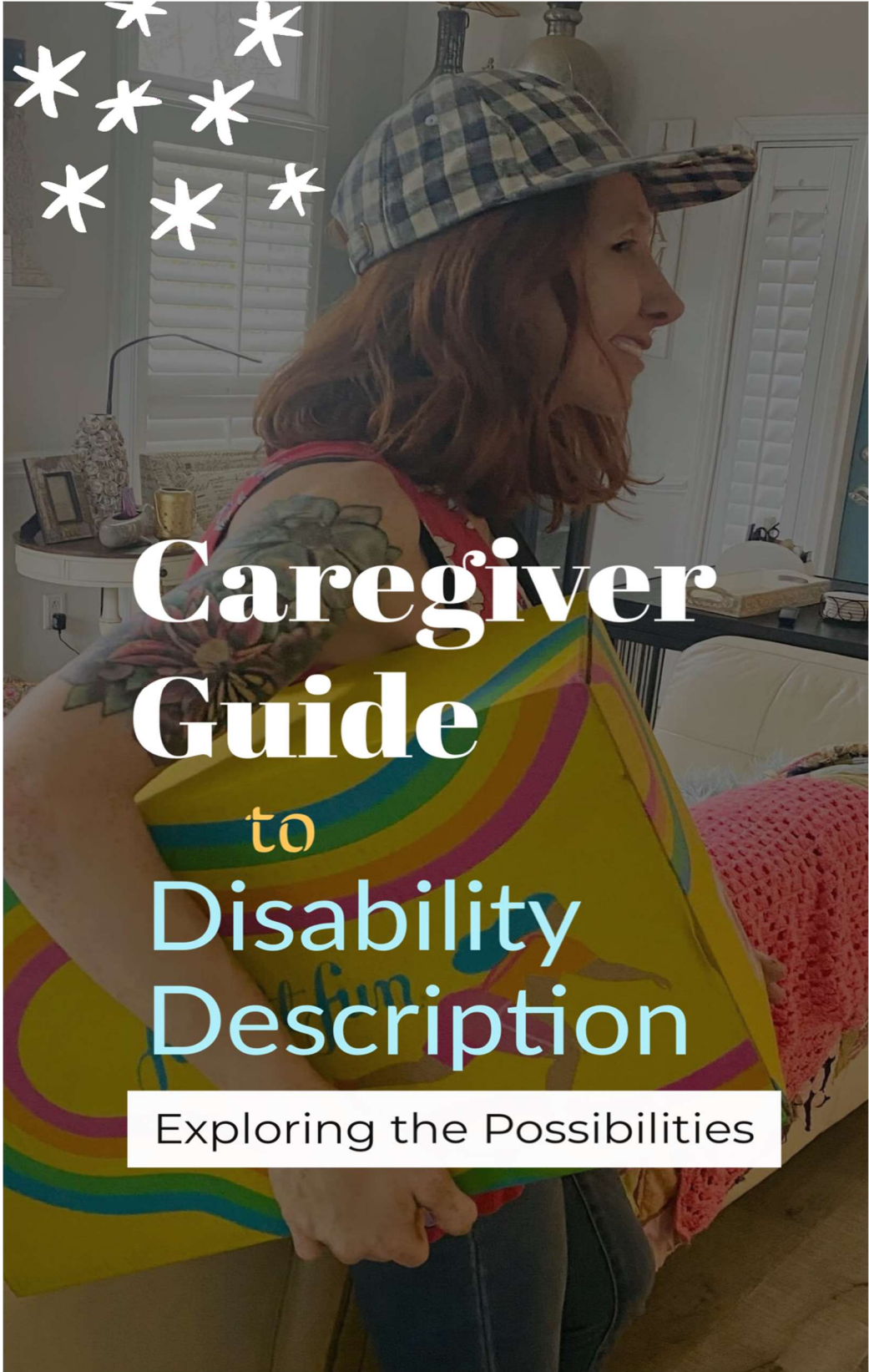
DISABILITY DESCRIPTION GUIDE FOR CAREGIVERS

Disability is a broad, ambiguous category that humans are placed in and described by. Like all other descriptions based on categories, we can revise, and evolve our understanding of the many layers of human complexity with a focused eye on creating opportunities. *Disability description theory* developed in this study exhibits how caregivers and person with disabilities have scalable choices that can go beyond definition or diagnosis with a disability description that be collaborated on, revised, and made actionable with rhetorical guidance. The data analyzed in Chapter 4 accurately portrays that an opportunity of disability description revision exists through the richest shared experience of the caregiver and person with disabilities by providing nuances to disability description that tell a more curated and authentic story instead of simply defining the challenges. In fact, this topic of a curated disability description dominated the results of these narratives.

The lack of resources that assist and guide the experience of disability description with caregivers and persons with disabilities presents one of the emergent problems to be addressed in an introductory guide. As a long-time experienced caregiver, some of the surprises featured in the interviews such as the concept of collaboratively revising a disability description between a caregiver and person with disabilities was an aha moment for me. If I had known this thirty years ago, it would have had a positive influence on my daughter's life.

As Thomson and White (2019) suggest, the caregiver is challenged in time, education, and resources. When creating a guide, my goal was to create a resource that acknowledged the limited time of a caregiver. The Caregiver Guide for Disability Description presents a simple, easy to understand guide explaining disability description based off the existing scholarship

informing the research conducted in this study. Designed to assist caregivers in identifying a disability description styles for those who they provide care, this introductory guidance offers a framework for discussing, revising, and applying the disability description to develop and act on a positive disability identity. According to Harter et al. (2006), Social change usually emerges as a contest between an entrenched vocabulary and orientation that is no longer useful, and a half-formed new vocabulary that holds promise of great things” (p. 6). The stages, and themes of *disability description theory* developed in this study glean new choices by challenging an ableist entrenched vocabulary that is not useful for caregivers within the important stages of the disability description outlined in Chapters 4 and 5. Designed to be useful and compelling the *Caregiver Guide to Disability Description* is graphically engaging with simple definitions, suggestions, and examples.



Caregiver Guide

to

Disability Description

Exploring the Possibilities

Purpose

THE PURPOSE OF THE CAREGIVER GUIDE FOR DISABILITY DESCRIPTION

TO SHOW HOW CAREGIVERS CAN PROVIDE
PERSONS WITH DISABILITIES
THE RHETORICAL POWER AND FREEDOM TO
COMPOSE THEIR OWN
NARRATIVES, TRANSFORM THEIR IDENTITIES,
AND ENHANCE THEIR LIVES!



**What
is a
disability
description?**

DEFINITION

**HOW DO YOU
DESCRIBE
THE PERSON
YOU PROVIDE
CARE FOR?
WHAT ARE THE
DETAILS YOU SHARE?**

**A DISABILITY DESCRIPTION
PERTAINS TO HOW PEOPLE WITH
DISABILITIES DESCRIBE
THEMSELVES AND HOW
CAREGIVERS DESCRIBE
THE PEOPLE WITH
DISABILITIES THEY CARE FOR.**

**Does your disability description
build a positive disability identity?**

What is your disability description style?



This disability description can have challenges and opportunities within the same description.

EXAMPLE

“My father is vibrant and active, however, recently he was diagnosed with Alzheimer’s.”



This disability description offers no alternative details describing the individual beyond the diagnosis.

EXAMPLE

“My husband is courageous having battled many medical difficulties from his heart attack and head injury from the fall.”

In this disability description, the caregiver has opted not to include any details about diagnosis or impairment. While the diagnoses can be a big part of the person with a disability’s life, there are other details can be shared.



EXAMPLE

“Alex is a good kid. He makes good grades and he is a wrestler in high school.”

A close-up photograph of a person with long, reddish-brown hair looking through a magnifying glass. The magnifying glass is held over their eye, and the lens is focused on a document. The background is slightly blurred, showing what appears to be a white door or wall. The overall tone is professional and focused.

EXAMINE THE DISABILITY DESCRIPTION
YOU PROVIDE TO
DESCRIBE THE PERSON
YOU PROVIDE CARE FOR TO
DISCOVER YOUR DISABILITY
DESCRIPTION STYLE.

Is the disability
description, complete,
and clear? Compare
your disability
description with the
person you are
providing care for. Is this
an accurate disability
description? What
details would the person
you care for add?

Do you collaborate and revise the disability description with the person you provide care for?



When you describe the person that you provide care for, do you only provide details about how that person is stuck in or with the challenges of disability ?

EXAMPLE

“He has lost limbs to Diabetes...for a long time he was stuck.”



Do you acknowledge the possibility of a more fulfilling life when you are describing the person you care for?

EXAMPLE

“I know that we are going to have to find a different way of thinking about this disability.”

Have you identified the possibility of what is next in life for the person you care for within the disability description?



EXAMPLE

“Over the last 11 years I have learned that despite all of the medical issues he has faced, he is an intelligent, funny, and more often than not, a happy young man that has found his own way.”

CONSIDER ADDING EXAMPLES FROM YOUR OWN DESCRIPTION BEYOND CAREGIVING.

People with disabilities have the same, if not more complexity to their lives and their identity descriptions than those that are considered abled. Compare your descriptions! Do you have details that you share beyond the disability?



Practice and apply a disability description step-by-step with examples

Consider collaborating and practicing the disability description with the person you care for. Encourage them the individual to envision and apply the disability description in their own words.



Example

Consider the possibility that having open conversations about disability description can be the guidance needed for the person in your care.

"Some professional guidance to accompany all the medical care I have received would make the most difference in my life besides surviving."



Example

Talk through the details of disability description. Consider how you can co-create a narrative of hope and opportunity within the disability and description. Make a plan.

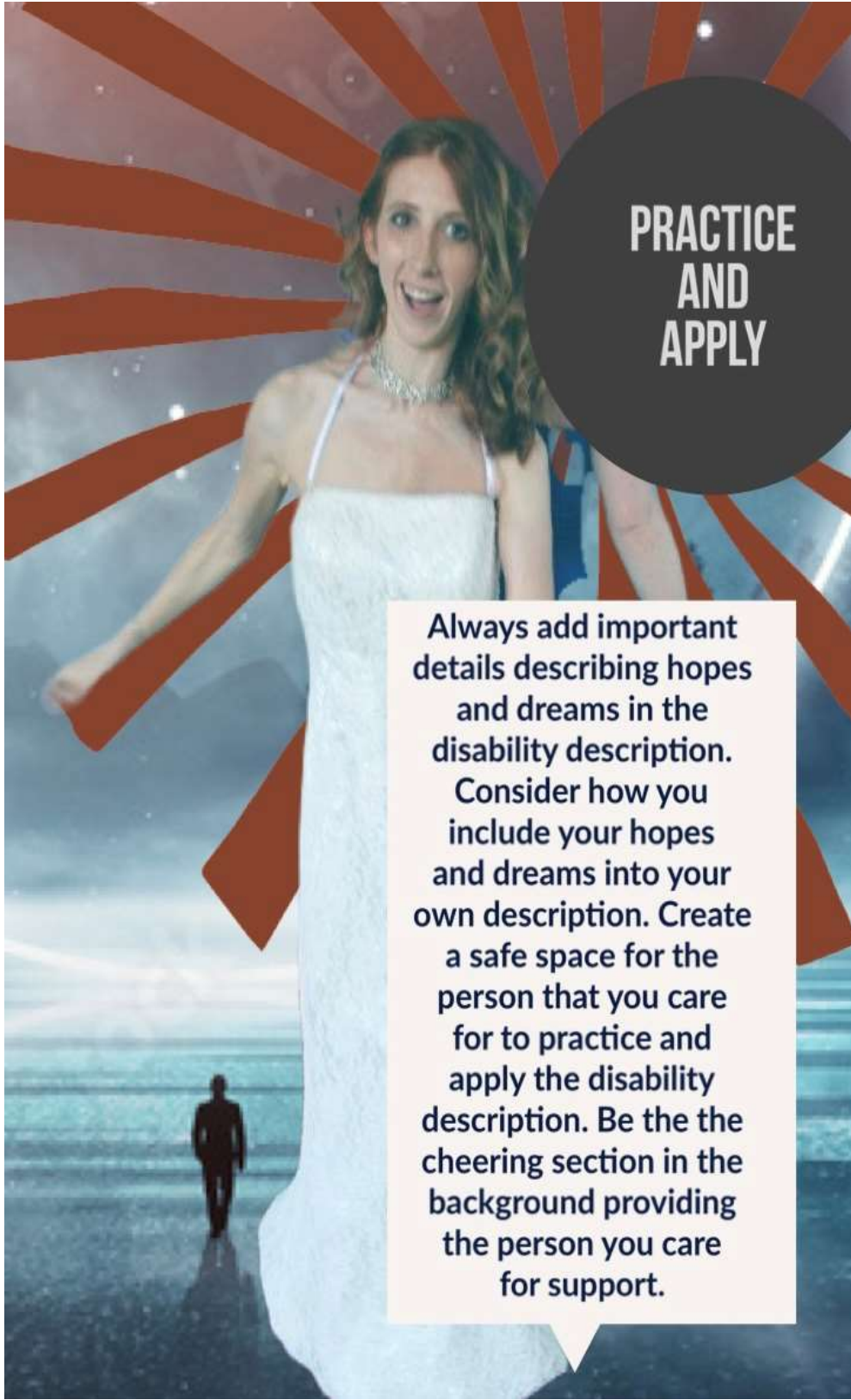
"My caregiver began to ask me what I want to do, what I dream about, and she brainstormed with me on how we might accomplish that."

Co-create a disability description that is actionable. The disability description can outline what the person you care for has the opportunity to accomplish. Make sure to include interests, goals, and a safe space to apply and practice the disability description.



Example

"I wanted to learn to cook for myself. My grandmother was an expert cook. She began to include me in preparing meals. Instead of describing what I could not do, she began to describe our cooking together instead."



**PRACTICE
AND
APPLY**

Always add important details describing hopes and dreams in the disability description. Consider how you include your hopes and dreams into your own description. Create a safe space for the person that you care for to practice and apply the disability description. Be the cheering section in the background providing the person you care for support.



CAREGIVER GUIDE FOR DISABILITY DESCRIPTION RECAP:

**1. EXPLORE
AND IDENTIFY
YOUR DISABILITY
DESCRIPTION
STYLE.**

2. Remove the roadblocks by making a disability description plan. Seek guidance from the person you care for about how the individual wants to be described.

3. Create a safe space for the person you care for to practice and apply alternative disability descriptions.



AUTHORSHIP
AND CREDIT

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Dr. Clare Mullaney
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Dr. Cynthia Pury

APPENDICES

Appendix A

IRB Exempt Review Application Board Application



IRB Exempt Review Application

Office use only	Protocol Number: <input type="text"/>
Approval Date: <input type="text"/>	
Exempt Category: D <input type="text"/>	

1. Principal Investigator (PI): <u>The PI must be a Clemson faculty or staff, per the PI assignment policy.</u> Graduate students may not be the PI if they are conducting the research for their thesis or dissertation. The PI must have valid human research protections training .	
Name: <u>David Blakesley</u>	E-mail: <u>dblakes@clemson.edu</u>
Department: <u>English</u>	Phone: <u>765-469-2649</u>
Campus address: <u>616 Strode Tower, Clemson, SC 29654</u>	
<input checked="" type="checkbox"/> Faculty <input type="checkbox"/> Staff <input type="checkbox"/> Other: <input type="text"/>	CITI expiration date: <u>02-Feb-2021</u> (provide copy of CITI completion certificate)

2. **Enter Project Title:** Circumventing Ableism: A Grounded Theory Study Exploring Rhetorical Caregiver Strategies to Promote a Positive Disability Identity
 - a. Enter title on informed consent form **if different** from project title:
3. **Research Personnel:** Will other individuals assist with recruiting, obtaining informed consent, data collection or data analysis?
 - No
 - Yes IF YES, complete and attach the [Additional Research Team Members Form](#). [CITI completion certificate required for all team members.](#)**
4. **Study Purpose:** Describe the purpose and goals of the research using plain language (avoid technical terms, acronyms or jargon, unless explained).

Description: The purpose of this study is to show how caregivers can provide persons with disabilities the rhetorical power and freedom to compose their own narratives, transform their identities, and enhance their lives. Specifically, I will explore the following:

 - How does the rhetoric of disability and the rhetoric of ableism define identity for persons with disabilities, and how do caregivers and the support system navigate this identity?
 - How do caregivers make rhetorical choices when supporting persons with disabilities, and do these choices foster the desired effect? What are these rhetorical strategies' outcomes?
 - When and how do caregivers access and distribute rhetorical resources for persons with disabilities?
5. **Sharing of Results:** Describe how research results will be shared (e.g., academic publication, evaluation report to funder, conference presentation)?

Description: The lack of research on the phenomenon of providing rhetorical strategies or scenarios to persons with disabilities indicates a significant gap. This is crucial not only to persons with disabilities, but also to the U.S. population overall because disabled persons comprise the country's largest minority (CDC, 2018). Facilitating these individuals' ability to thrive is emergent because it affects all Americans culturally and economically. This research can potentially produce theories that inform quick guides containing effective rhetorical strategies or scenarios for persons with disabilities to move past the roadblocks of ableism. Such information can help caregivers shorten the learning curve to provide more effective and expeditious assistance.

6. **Research Timeline:** Anticipated start date: 10/30/2020 Anticipated completion date: 01/01/2021

7. **Funding:** Is the research funded (external, internal) or are you offering monetary incentives?

- No
 Yes **IF YES**, answer 7a-b

a. Enter funding source (Do not use acronyms):

b. **If the research is externally or internally funded:**

Was the award processed through InfoEd?

- No
 Yes, **enter ten-digit InfoEd** proposal number (PPN):

Did the IRB office issue a developmental (temporary) approval for this research?

- No
 Yes, enter the IRB protocol number:

8. **Research Site(s):** Check all that may apply.

- online
 Clemson campus - enter site location(s):
 non-Clemson site (within U.S.)-enter site location(s):
 international (outside of the U.S.)-enter site location(s):

Non-Clemson site(s): Off-campus site permission required. Contact appropriate office/department and keep site/support letter or e-mail approval on file with your research records. If collecting data at another institution that has an IRB, you may need permission from each participating institution's IRB office. See [Guidance on the Submission of Research Site/Permission Letters](#) for more information.

International projects: Additional approval may be required. See [FAQs](#) and [OHRP International Compilation of Human Research Standards](#).

9. **Exempt Review Categories:** Select **one or more of the categories** below that applies to your research **AND** provide the information requested for each category selected.

Category 1: Research, conducted in established or commonly accepted educational settings, that specifically involves normal educational practices that are not likely to adversely impact students' opportunity to learn required educational content or the assessment of educators who provide instruction. This includes most research on regular and special education instructional strategies, and research on the effectiveness of or the comparison among instructional techniques, curricula, or classroom management methods.

Category 1 may be applied to research involving minors.

- a. Are the research activities a part of the normal class activities?
 No-describe how the activities will not adversely impact students' opportunity to learn required educational content:
 Yes
- b. Does the project involve a team member who is responsible for evaluating the performance of the instructor(s)?
 No
 Yes-describe how the activities will not adversely impact the assessment of the instructor(s) providing instruction:

- e. Will the class instructor(s) be evaluated on the performance of the research activities?
- No
- Yes-describe how the activities will not adversely impact the assessment of the instructor(s) providing instruction: _____

Category 2: Research that **only includes** interactions involving educational tests (cognitive, diagnostic, aptitude, achievement), survey procedures, interview procedures, or observation of public behavior (including visual or auditory recording) if at least one of the criteria below is met.

Observation of public behavior criteria: observation occurring in public settings where there are no expectations of privacy (i.e., public park, concert) and researchers do not interact with participants.

Category 2 MAY NOT include interventions. See [Guidance on Interventions in Research Studies](#).

Check at least one criterion below. Note: Identifiers include names, student ID numbers accessible through Canvas, audio/video recordings or photographs, demographic data that could identify a participant based on small sample size, master log with names and ID numbers.

The information obtained is recorded in such a manner that the **identity of the human subjects cannot readily be ascertained**, directly or through identifiers linked to the subjects. **(Criterion may be applied to research involving minors.)** **Criterion 1 applies if NO identifiers will be linked to the research data. Criterion 1 NOT applicable if you check criterion 3.**

Any disclosure of the human subjects' responses outside the research **would not reasonably place the subjects at risk of criminal or civil liability or be damaging to the subjects' financial standing, employability, educational advancement, or reputation.** **(Criterion may be applied to research involving minors.)**

The information obtained is recorded in a manner that the **identity of the human subjects can readily be ascertained**, directly or through identifiers linked to the subjects. **(Criterion may NOT be applied to research involving minors.)** **Criterion 3 applies if you WILL HAVE identifiers linked to the research data (refer to note above for examples of identifiers). Criterion 3 NOT applicable if you check criterion 1.**

Category 3: Research involving **benign behavioral interventions** in conjunction with the collection of information from an **adult subject** through verbal or written responses (including data entry) or audiovisual recording if the **subject prospectively agrees to the intervention** and information collection.

Definition: For the purpose of this provision, benign behavioral interventions are brief in duration, harmless, painless, not physically invasive, not likely to have a significant adverse lasting impact on the subjects, and the investigator has no reason to think the subjects will find the interventions offensive or embarrassing.

Provided all such criteria are met, **examples of such benign behavioral interventions** would include:

- having the subjects play an online game;
- having them solve puzzles under various noise conditions; or
- having them decide how to allocate a nominal amount of received cash between themselves and someone else.

If the research involves **deceiving the subjects** of the nature or purposes of the research, this **exemption is not applicable unless the subject authorizes the deception** through a prospective agreement to participate in research in circumstances in which the subject is informed that he or she will be unaware of or misled regarding the nature or purposes of the research.

Category 3 may NOT be applied to research involving minors.

- a. Does the research involve benign behavioral intervention(s) as described below?
- No-your project **does not** meet the criteria for Exempt review under category 3. Complete the [Expedited application](#).
- Yes-describe intervention(s): _____
- b. Does the research involve deceiving the participants of the nature or purposes of the research?
- No
- Yes-see guidance on [Research Involving Deception or Concealment](#) **AND** attach the [debriefing form](#) for review.
- c. Will you **notify the participants in the informed consent document** that the research involves an intervention and/or deception of the nature or purposes of the research (you do not have to describe the details of the intervention or deception, just that the research involves an intervention and/or deception of the nature or purposes of the research)?
- No-your project **does not** meet the criteria for Exempt review under category 3. Complete the [Expedited application](#).
- Yes

Check at least one criterion below. Note: Identifiers include names, student ID numbers accessible through Canvas, audio/video recordings or photographs, demographic data that could identify a participant based on small sample size, master log with names and ID numbers.

The information obtained is recorded by the investigator in such a manner that the **identity of the human subjects cannot readily be ascertained**, directly or through identifiers linked to the subjects. **Criterion 1 applies if NO identifiers will be linked to the research data. Criterion 1 NOT applicable if you check criterion 3.**

Any disclosure of the human subjects' responses outside the research **would not reasonably place the subjects at risk** of criminal or civil liability or be damaging to the subjects' financial standing, employability, educational advancement, or reputation.

The information obtained is recorded by the investigator in such a manner that the **identity of the human subjects can readily be ascertained**, directly or through identifiers linked to the subjects. **Criterion 3 applies if you WILL HAVE identifiers linked to the research data (refer to note above for examples of identifiers). Criterion 3 NOT applicable if you check criterion 1.**

Category 4: Secondary research for which consent is not required: Secondary research uses of identifiable private information or identifiable biospecimens.

Category 4 may:

- be applied to identifiable private information or identifiable biospecimens collected from minors;
- involve future collection of identifiable private information or identifiable biospecimens if the data or biospecimens are not being collected specifically for your proposed research study.

Data Use Agreement or Material Transfer Agreement may be required to share the data and/or biospecimens with other researchers.

An [Institutional Biosafety Committee \(IBC\)](#) protocol may be required for secondary research use of biospecimens.

- a. Was the data or biospecimens **initially** collected for non-research purposes or from other research studies that did not require the participants' informed consent?
- No-your project **does not** meet the criteria for Exempt review under category 4. Go to category 8.
- Yes
- b. **Check at least one criterion below. Note:** Identifiers include names, ID numbers, audio/video recordings or photographs.
- The identifiable private information or identifiable biospecimens are **publicly available** (either by paying a fee, submitting a request, or available without restrictions).
- Information, which may include information about biospecimens, is recorded by the investigator in such a manner that the **identity of the human subjects cannot readily be ascertained** directly or through identifiers linked to the subjects, the investigator does not contact the subjects, and the investigator will not re-identify subjects.
- The research involves only information collection and analysis involving the investigator's use of **identifiable health information** when that use is regulated under HIPAA (45 CFR parts 160 and 164, subparts A and E), for the purposes of "health care operations" or "research" as those terms are defined at 45 CFR 164.501 or for "public health activities and purposes" as described under 45 CFR 164.512(b).
Criterion 3 ONLY applies if identifiable health information is being shared between two HIPAA covered entities (i.e., two health facilities sharing data). Criterion 3 DOES NOT APPLY if identifiable information is being shared from a health facility to an academic institution.
- The research is conducted by, or on behalf of, a **Federal department or agency** using government-generated or government-collected information obtained for nonresearch activities, if the research generates identifiable private information that is or will be maintained on information technology that is subject to and in compliance with section 208(b) of the E-Government Act of 2002, 44 U.S.C. 3501 note, if all of the identifiable private information collected, used, or generated as part of the activity will be maintained in systems of records subject to the Privacy Act of 1974, 5 U.S.C. 552a, and, if applicable, the information used in the research was collected subject to the Paperwork Reduction Act of 1995, 44 U.S.C. 3501 et seq.
- c. List the data fields/variable and/or describe the biospecimens that will be used:
- d. Identify the data holder and/or source of the biospecimens:
- e. Is a Data Use Agreement and/or Material Transfer Agreement required for you to access the data and/or biospecimens?
- No
- Yes— provide copy of agreement
- f. Describe, **in details**, your data management plan for storing and securing the data and/or specimens, including protecting the privacy of participants and maintaining confidentiality of data:

If requesting Exempt review under Category 4 ONLY, then go to question 15.

Category 5 (Contact IRB office if you believe your study falls under this category): Research and demonstration projects that are conducted or supported by a **Federal department or agency**, or otherwise subject to the approval of department or agency heads (or the approval of the heads of bureaus or other subordinate agencies that have been delegated authority to conduct the research and demonstration projects), **and that are designed to study, evaluate, improve, or otherwise examine public benefit or service programs**, including procedures for obtaining benefits or services under those programs, possible changes in or alternatives to those programs or procedures, or possible changes in methods or levels of payment for benefits or

services under those programs. **Such projects include**, but are not limited to internal studies by Federal employees, and studies under contracts or consulting arrangements, cooperative agreements, or grants.

Category 5 may be applied to research involving minors.

Category 6: Taste and food quality evaluation and consumer acceptance studies:

Check at least one criterion below:

- Wholesome foods without additives are consumed.
- Food is consumed that contains a food ingredient at or below the level and for a use found to be safe, or agricultural chemical or environmental contaminant at or below the level found to be safe, by the Food and Drug Administration or approved by the Environmental Protection Agency or the Food Safety and Inspection Service of the U.S. Department of Agriculture.

Category 6 may be applied to research involving minors.

Category 7 (Contact IRB office if you believe your study falls under this category): Storage or maintenance for secondary research for which **broad consent is required:**

Data Use Agreement or Material Transfer Agreement may be required to share the data and/or biospecimens with other researchers.

Category 7 may be applied to identifiable private information or identifiable biospecimens collected from minors.

An [Institutional Biosafety Committee \(IBC\)](#) protocol may be required for secondary research use of biospecimens.

a. **Check all that apply. Note:** Identifiers include names, ID numbers, audio/video recordings or photographs.

- Storage or maintenance of identifiable private information for secondary research.
- Storage or maintenance of identifiable biospecimens for secondary research.

b. Was broad consent for storage, maintenance, and secondary research use of identifiable private information or identifiable biospecimens **obtained from participants?**

- No-your project **does not** meet the criteria for Exempt Category 7.
- Yes

c. Was broad consent obtained in writing or did an IRB waive the documentation for written informed consent?

- No-your project **does not** meet the criteria for Exempt Category 7.
- Yes-describe the informed consent process: _____

d. Describe your management plan for storing and securing the data and/or specimens, including protecting the privacy of participants and maintaining confidentiality of data: _____

If requesting Exempt review under Category 7 or under Categories 7 and 8 ONLY, then go to question 15.

Category 8 (Contact IRB office if you believe your study falls under this category): Secondary research for which **broad consent is required:** Research involving the use of identifiable private information or identifiable biospecimens for secondary research use.

a. **ALL of the following criteria MUST apply. Note:** Identifiers include names, ID numbers, audio/video recordings or photographs.

- Broad consent for the storage, maintenance, and secondary research use of the identifiable private information or identifiable biospecimens was obtained;
- Documentation of informed consent or waiver of documentation of consent was obtained;
- The research to be conducted is within the scope of the broad consent; AND
- The investigator does not include returning individual research results to subjects as part of the study plan. This provision does not prevent an investigator from abiding by any legal requirements to return individual research results.

- a. List the data fields/variables and/or describe the biospecimens that will be used: _____
- b. Identify the data holder and/or source of the biospecimens: _____
- c. Is a Data Use Agreement and/or Material Transfer Agreement required for you to access the data and/or biospecimens?
 - No
 - Yes— provide copy of agreement
- d. Describe your management plan for storing and securing the data and/or specimens, including protecting the privacy of participants and maintaining confidentiality of data: _____

Category 8 may be applied to identifiable private information or identifiable biospecimens collected from minors.

An [Institutional Biosafety Committee \(IBC\)](#) protocol may be required for secondary research use of biospecimens.

If requesting Exempt review under Category 8 or under Categories 7 and 8 ONLY, then go to question 15.

10. Study Population

- a. Enter **projected number** of participants that will be enrolled in the study: 50
- b. Identify the group(s) **specifically targeted** for the study (**check all** that may apply).

<input type="checkbox"/> Clemson students	<input type="checkbox"/> Clemson faculty/staff
<input checked="" type="checkbox"/> Adults not affiliated with Clemson	<input type="checkbox"/> Minors, including wards of the state, or any other agency, institution, or entity: describe age group _____
<input type="checkbox"/> Non-English speaking individuals specifically targeted	<input type="checkbox"/> Individuals with intellectual disabilities specifically targeted
<input type="checkbox"/> Individuals with impaired decision-making capacity specifically targeted	<input type="checkbox"/> Individuals economically or educationally disadvantaged specifically targeted
<input type="checkbox"/> DoD personnel (includes civilian employees)	<input type="checkbox"/> Pregnant women specifically targeted
<input type="checkbox"/> Prisoners (requires Full Board Review Application)	<input type="checkbox"/> Human Fetuses and/or Neonates
<input type="checkbox"/> Other-describe: _____	

11. Recruitment Procedures

- a. Describe how potential participants will be identified and how you will obtain contact information: 30 participants. I will use a snowball sampling method via Facebook disability sites, social media web pages, and for both the 15 persons with disabilities and the 15 caregivers. According to Browne (2014), Snowball sampling is often used because the population under investigation is "hidden" either due to low numbers of potential participants or the sensitivity of the topic, such as, for example, research with women who do not fit within the hegemonic heterosexual norm. (p. 47) Therefore, this method is ideal for the sampling that needs to be done in the disability and caregiving community. The subjects will be selected at random but must fall within the criteria.
- b. Are there any inclusion or exclusion criteria for participation?
 No
 Yes-describe criteria and screening process to determine eligibility (provide copy of screening tool) and briefly explain why the inclusion or exclusion criteria is necessary for your research:The participants will comprise individuals with at least 1 identified disability and individuals identified as caregivers for persons with disabilities. In total, 15 participants will be people with disabilities ages of 19-69, and 15 will be caregivers for persons with disabilities ages 19-69.
- c. **Check all** recruitment methods below **AND attach** copy of recruitment documents for review. See [Guidance for Recruitment Materials](#) for more information on what is required on the documents. Participants may not be contacted prior to IRB review.
- | | |
|--|---|
| <input type="checkbox"/> Flyers/Advertisements | <input type="checkbox"/> E-mail notice |
| <input type="checkbox"/> In-person-describe: <input type="text"/> | <input checked="" type="checkbox"/> Internet-describe: <u>Social media platforms including Facebook, Twitter, and Instagram utilizing snowball sampling</u> |
| <input type="checkbox"/> Dept. subject pool-describe: <input type="text"/> | <input type="checkbox"/> Letter mailed to individuals |
| <input type="checkbox"/> Other-describe: <input type="text"/> | |

12. Participant Incentives

- a. Will participants receive any incentive or compensation for participating in the study?
 No
 Yes-answer 12b-c.
- b. Are there any conditions for receiving incentives (i.e., have to complete all research activities, answer attention check questions correctly)?
 No
 Yes-describe:
- c. **Check all** that apply and provide requested information for each incentive checked (all incentives must be listed on informed consent document):

- Course/extra credit for students (an equivalent alternative to research participation must be provided and described on informed consent document): Indicate number of credits that will be offered **and** if partial credits will be offered:
- Gift(s) - describe gift(s) [include value and when gift(s) will be given]:
- Monetary incentive(s): Indicate value of incentive, when incentive will be given and if partial payment will be offered:

13. Research Methods and Procedures

- a. What data will you collect? **Check all** that may apply **AND attach** copy of data collection instruments/tools for review (i.e., surveys, interview questions).
- Surveys/Questionnaires Individual interview
 - Focus group Observation
 - Student educational records ([FERPA](#) may apply) Protected Health Information ([HIPAA](#) may apply)
 - Digital data (i.e., computer, cell phone, other equipment/devices)- describe data that will be collected:
 - Other-describe:

- b. Will you audio/video record or photograph participants?
- No
 - Yes-check all that may apply: Audio Video Photographs and will you use audio, video, or photographs in presentations, publications, and/or training materials?
 - No
 - Yes-a media release form is required

See [Guidance on the Use of Audio/Video Recording and Photographs](#) for more information on what is required on the informed consent document.

- c. Will you use concealment (incomplete disclosure) or deception in this study? **(If you are requesting Exempt review under Category 3 AND your research only involves deception of the nature or purposes of the research, then check "N/A.")**
- N/A
 - No
 - Yes-describe concealment or deception and provide rationale:

See guidance on [Research Involving Deception or Concealment](#) **AND** attach the [debriefing form](#) for review.

- d. Does your study involve in-person interactions with participants?
- No
 - Yes-describe your COVID-19 safety procedures for maintaining social distancing and disinfecting surfaces, equipment/devices, computer or any other items the participants or study personnel will touch. Review the IRB [COVID-19 guidance](#) for additional requirements and information.

Description: In consideration of COVID 19, all interviews with research participants will be conducted over the phone.

- e. Describe the informed consent process, include who will obtain consent from all participants, when, and how this will be done. If participants are not competent to consent for themselves, then describe procedures for obtaining consent from legally authorized representative. Attach all [informed consent document\(s\)](#) for review: information letter, online script, and/or oral script.

Description: Participants will be provided the informed consent form in advance of the interview and will read and sign the informed consent form (see attached). I will also read the form during the interview to confirm understanding and participants will be given a copy of the consent form.

- f. Describe, **in detail**, your data collection methods and procedures. Describe how data will be collected, what information will be collected from participants and what sessions will be audio/video recorded and/or photographed. **Describe data collection procedures for all instruments checked in question 13a.** Provide a timeline or schedule of events, if applicable.

Description: The student will utilize in-depth face-to-face semi-structured recorded interviews with approximately 30 people who meet the inclusion criteria as listed above. First, participants will read and sign the consent form (see attachment). Second, participants will be given a copy of the consent form. Third, participants will be instructed to complete a demographic questionnaire (see attachment). Finally, I will interview participants with the interview guide (see attachment for caregiver and person with a disability). In order to protect the identity of interview subjects, I will, (1) create pseudonyms for interview participants and (2) store materials relating to the study on a password protected computer. (3) I will delete all files relating to any identifiable information relating to any of the interviewees. Confidentiality will be guaranteed by changing the names of each of the participants, including any references to organizations that might identify an individual, or organization. Interviews will be conducted by telephone as a measure for COVID-19 safety. The informed consent, demographic forms, and interview guide will be provided ahead of time, and all signatures will be obtained before the interview.

Schedule

Gathering of Principal Data	10/30/2020
Research on Subject/Interviews	11/30/2020
Research on Method/Analysis	1/01/2020

- g. What is the total time (hours, minutes, days) that each participant will spend **completing the research activities**, include follow-up sessions?

Description: 45 minute semistructured qualitative interviews (See attached interview guides) .

14. Data Management Plan

- a. Will you collect identifiable information (i.e., **names, student ID numbers accessible through Canvas, audio/video recordings or photographs, demographic data that could identify a participant based on small sample size, master log with names and ID numbers**) during the study that **could DIRECTLY link the participants** to the research data being collected?

- No-go to question 15.
 Yes-answer 14b-d.

- b. Describe, **in details**, your data management plan for storing and securing the **identifiable data**, protecting the privacy of participants and maintaining confidentiality of data.

Description: All interviews will be recorded. After pseudonyms have been assigned to the file, and audio recordings have been transcribed, the audio files will be deleted. To protect the identity of the interviewee, I will, (1) create pseudonyms for interview participants and (2) store materials relating to the

study on a password protected computer. (3) delete all files relating to any identifiable information relating to any of the interviewees. Confidentiality will be guaranteed by changing the names of each of the participants, including any references to organizations that might identify an individual, or organization. Anonymity will be protected through the use of pseudonyms on all transcripts and writeups. The list of willing participants will be stored (under password protection) separately from all de-identified data. Data analysis will use open coding and axial coding in a modified version of Corbin and Strauss's constant comparative technique of analysis, focusing on identifying and analyzing recurring themes in the interviewees responses.

- e. How long will you retain **identifiable data** (i.e., names, audio/video recordings, photographs, digitized data, codes or links to identifiers)?

Description: The audio files will be deleted immediately after the interviews have been transcribed and no later than 1/01/2021 to protect the anonymity of the research participants.

- d. Will you share **identifiable data** with other institutions, agencies, or companies?
 No
 Yes

Describe **data management plan on informed consent document(s)** and notify participants if data will be shared with other institutions, agencies, companies and/or used to support future studies.

15. Conflict of Interest Statement/Financial Disclosure:

Could the results of the study provide an actual or potential financial gain to you, a member of your family, or any of the co-investigators, or give the appearance of a potential conflict of interest (COI)? Refer to [Conflict of Interest policy](#) for more information.

- No
 Yes; indicate the status of the COI and/or financial disclosure: On file with COI office Will be submitted to COI office

16. PI Confirmation: Submission from the PI certifies that:

- The information in the IRB packet is accurate and complete.
- The PI is familiar with the [Federalwide Assurance for the Protection of Human Subjects](#) held by Clemson University and institutional guidelines regarding human subjects research, and agrees to abide by the provisions of the Assurance and the determination of the IRB.
- The PI is responsible for assuring that all team members listed on the protocol are properly trained and adverse events, research-related injuries, or unexpected problems affecting the rights or safety of research participants are reported promptly to the [Office of Research Compliance](#).
- The proposed research study is in compliance with the PI department's policies and procedures.
- The PI understands that failure to adhere to any of these guidelines may result in immediate suspension or termination of the research.

Principal Investigator: David Blakesley

Date: 10/20/2020

Submission Instructions:

The PI has to submit the IRB packet (application, recruitment materials, informed consent materials, and data collection instruments/tools) to IRB@clemson.edu.

International research – Review of international research may require additional time due to requirements in other countries, negotiation of Individual Investigator Agreements, arranging appropriate local context reviews, and geographical and communication constraints. **Submit IRB application at least three to six months before your**

anticipated start date. More information on local context reviews is available on our FAQ webpage, <http://www.clemson.edu/research/compliance/irb/faq.html>. The [International Compilation of Human Research Standards](#) is available on the Office of Human Research Protections (OHRP) webpage.

Current versions of the applications and templates are available on the [IRB forms webpage](#).

Appendix B

Additional Research Team Members Form



Additional Research Team Members

All research team members must have completed CITI [human research protections training](#). **Please send CITI completion certificates for all team members. Team members not affiliated with Clemson University need IRB review at their respective institution.**

Use this sheet as many times as necessary.

Name: June Blalock Furr		E-mail: jbfurr@clemson.edu	
Department: Rhetoric Communication and Information Design		CITI expiration date: 11-Aug-2024	
<input type="checkbox"/> Faculty	<input checked="" type="checkbox"/> Graduate student	<input type="checkbox"/> Other-specify: _____	
<input type="checkbox"/> Staff	<input type="checkbox"/> Undergraduate student		
Briefly describe research responsibilities: This research is part of my PhD Dissertation in the Rhetoric Communication And Information Design Program at Clemson. The Principal listed on this project is my Dissertation Chair, Dr. David Blakesley who will be supervising me as I perform the listed scope of this project in the main application.			
Do you want team member copied on e-mail communications? <input checked="" type="checkbox"/> No <input type="checkbox"/> Yes			
Name: _____		E-mail: _____	
Department: _____		CITI expiration date: _____	
<input type="checkbox"/> Faculty	<input type="checkbox"/> Graduate student	<input type="checkbox"/> Other-specify: _____	
<input type="checkbox"/> Staff	<input type="checkbox"/> Undergraduate student		
Briefly describe research responsibilities: _____			
Do you want team member copied on e-mail communications? <input type="checkbox"/> No <input type="checkbox"/> Yes			
Name: _____		E-mail: _____	
Department: _____		CITI expiration date: _____	
<input type="checkbox"/> Faculty	<input type="checkbox"/> Graduate student	<input type="checkbox"/> Other-specify: _____	
<input type="checkbox"/> Staff	<input type="checkbox"/> Undergraduate student		
Briefly describe research responsibilities: _____			
Do you want team member copied on e-mail communications? <input type="checkbox"/> No <input type="checkbox"/> Yes			
Name: _____		E-mail: _____	
Department: _____		CITI expiration date: _____	
<input type="checkbox"/> Faculty	<input type="checkbox"/> Graduate student	<input type="checkbox"/> Other-specify: _____	
<input type="checkbox"/> Staff	<input type="checkbox"/> Undergraduate student		
Briefly describe research responsibilities: _____			
Do you want team member copied on e-mail communications? <input type="checkbox"/> No <input type="checkbox"/> Yes			
Name: _____		E-mail: _____	
Department: _____		CITI expiration date: _____	
<input type="checkbox"/> Faculty	<input type="checkbox"/> Graduate student	<input type="checkbox"/> Other-specify: _____	
<input type="checkbox"/> Staff	<input type="checkbox"/> Undergraduate student		
Briefly describe research responsibilities: _____			

Appendix C

CITI Program Completion Report

COLLABORATIVE INSTITUTIONAL TRAINING INITIATIVE (CITI PROGRAM) COMPLETION REPORT - PART 1 OF 2 COURSEWORK REQUIREMENTS*

*NOTE: Scores on this Requirements Report reflect quiz completions at the time all requirements for the course were met. See list below for details. See separate Transcript/WADDF for more/different quiz scores, including those on optional (supplemental) course elements.

- **Name:** June Furr (ID: 9301915)
- **Institution Affiliation:** Clemson University (ID: 539)
- **Institution Email:** jfurr@clemson.edu
- **Curriculum Group:** Human Subjects Protections Course
- **Course Learner Group:** Group 1 - Investigators Conducting Social and Behavioral Science Research (SBR) at Clemson University
- **Stage:** Stage 1 - Basic Course
- **Record ID:** 57833583
- **Completion Date:** 12-Aug-2020
- **Expiration Date:** 12-Aug-2022
- **Minimum Passing:** 80
- **Reported Score:** 98

REQUIRED AND ELECTIVE MODULES ONLY

	DATE COMPLETED	SCORE
Unanticipated Problems and Reporting Requirements in Social and Behavioral Research (ID: 14628)	12-Aug-2020	5/5 (100%)
Populations in Research Requiring Additional Considerations and/or Protections (ID: 16680)	12-Aug-2020	5/5 (100%)
Conflicts of Interest in Human Subjects Research (ID: 17454)	12-Aug-2020	5/5 (100%)
History and Ethical Principles - SBE (ID: 490)	12-Aug-2020	5/5 (100%)
Defining Research with Human Subjects - SBE (ID: 491)	12-Aug-2020	5/5 (100%)
The Federal Regulations - SBE (ID: 502)	12-Aug-2020	5/5 (100%)
Assessing Risk - SBE (ID: 503)	12-Aug-2020	5/5 (100%)
Informed Consent - SBE (ID: 504)	12-Aug-2020	5/5 (100%)
Privacy and Confidentiality - SBE (ID: 505)	12-Aug-2020	5/5 (100%)
Clemson University (ID: 823)	12-Aug-2020	No Quiz
Students in Research (ID: 1321)	12-Aug-2020	5/5 (100%)
Internet-Based Research - SBE (ID: 510)	12-Aug-2020	5/5 (100%)
International Research - SBE (ID: 509)	12-Aug-2020	4/5 (80%)

For this Report to be valid, the learner identified above must have had a valid affiliation with the CITI Program subscribing Institution identified above or have been a paid Independent Learner.

Verify at: www.citiprogram.org/verify?userid=7020-5-31-4731-9&id=999&stid=955&_stid=11000

Collaborative Institutional Training Initiative (CITI Program)
Email: ajacobs@citiprogram.org
Phone: 866-520-5829
Web: <http://www.citiprogram.org>

Appendix D

Institutional Review Board Approval with Approved Demographic Form and Interview Guides



To: David E. Hinkley
Re: Clatsop IRB Number: IRB2021-0157
Exempt Category: D2
Determination Date: 16-Apr-2021
Funding Sponsor: N/A
Project Title: Characterizing Adults: A Grounded Theory Study Exploring Rheumatoid Arthritis Strategies to Promote a Positive Disability Identity

The Office of Research Compliance determined that the proposed activities involving human participants meet the criteria for exempt review under 45 CFR 46.104(d).

Principal Investigator (PI) Responsibilities: The PI assumes the responsibility for the protection of human subjects as outlined in the [Principal Investigator's Responsibilities](#) guidance.

Non-Clatsop Affiliated Collaborators: This determination only covers Clatsop affiliated researchers on the study. External collaborators will have to consult with their respective institution's IRB office to determine what is required for their role on the project. An IRB Authorization Agreement is required for Clatsop's IRB to be the IRB of record for the study.

Continuing Review: Exempt determinations do not have to be renewed.

Modifications: In general, investigators are not required to submit changes to the Clatsop University's IRB office once a research study is designated an exempt as long as those changes do not affect the exempt category or criteria for a exempt determination (changing from exempt status to expedited or full review, changing exempt category) or that may substantially change the focus of the research study such as a change in hypothesis or study design.

If you plan to make changes to your study, please submit the [modification request form](#) to the IRB office. All changes must be reviewed and approved prior to implementation.

New Funding: Notify the IRB office if new funding is received for an active study. IRB review of the new award must be completed before any funds can be spent on human research activities, as the new funding source may have additional or different requirements.

Reportable Events: Notify the IRB office immediately if there are any unanticipated problems involving risk to subjects, complications, adverse events and/or any complaints from research participants that may change the level of review from exempt to expedited or full board review. Additional information available at <https://www.clatsop.edu/research/compliance/ohrt.html>

Study Personnel Changes: Notify the IRB office if the PI of the study changes. The PI is not required to notify the IRB office of other study personnel changes for exempt determinations. The PI is responsible for maintaining records of personnel changes and appropriate training.

CTTI Training: All study personnel are required to complete the [CTTI human subjects training course](#).

Non-Clatsop Affiliated Sites: A site letter is required for off-campus sites. Refer to the [guidance on research site verification letters](#) for more information.

International Research: Clatsop's approval is based on U.S. human subjects protections regulations and [Clatsop University human subjects protection policies](#). Researchers should become familiar with all pertinent information about local human subjects protection regulations and requirements when conducting research in countries other than the United States. We encourage you to discuss with your local contacts any possible human subjects research requirements that are specific to your research site, to comply with those requirements and to inform Clatsop's IRB office of those requirements so we can better help other researchers prepare for [international research](#) in the future.

New IRB Application: A new application is required if the study remains open for more than 5 years after the initial determination.

Closure: Notify the IRB office when the study can be closed or if the PI leaves the university. Closure indicates that research activities with human subjects are no longer ongoing, have stopped and are complete. Human research activities are complete when investigators are no longer obtaining information or bi-specimens about a living person through interaction or intervention with the individual, obtaining identifiable personal information or identifiable bi-specimens about a living person, and/or using, analyzing, or generating identifiable private information or identifiable bi-specimens about a living person.

Contact Information: Please contact the IRB office at IRB@clatsop.edu or visit our [website](#) if you have questions.

Clatsop University's IRB is committed to facilitating ethical research and protecting the rights of human subjects. All research involving human participants must maintain an ethically appropriate standard, which serves to protect the rights and welfare of the participants. This involves obtaining informed consent and maintaining confidentiality of data.

Institutional Review Board
Office of Research Compliance

Appendix

Appendix I.

Information about Being in a Research Study Clemson University

Circumventing Ableism: A Grounded Theory Study Exploring Rhetorical Caregiver Strategies to Promote a Positive Disability Identity

KEY INFORMATION ABOUT THE RESEARCH STUDY

Dr. David Blakesley is inviting you to volunteer for a research study. Dr. Blakeley is a professor in the Rhetorics, Communication, and Information Design Program at Clemson University conducting the study with PhD student, June B. Farr at Clemson University.

Study Purpose: The purpose of this research study is to understand the connections between resources offered to assist persons with disabilities and the disability rhetoric attached to those resources. The results will be used for my Ph.D. Dissertation and/or provided to Clemson University.

You must be 18 or older to participate in this research.

Voluntary Consent: Participation is voluntary, and the only alternative is to not participate. You will not be punished in any way if you decide not to be in the study or to stop taking part in the study.

Activities and Procedures: Your part in the study will be to participate in a 30-45-minute semi-structured interview. You will be asked questions about your experience with a disability and/or your experience working with persons with disabilities.

Participation Time: It will take you about 30 to 45 minutes.

Risks and Discomforts: There is no anticipated discomfort for those contributing to this study, so risk to participants is minimal. Answering the questions may cause you to think about feelings that make you sad or upset. You will be informed of any new findings that may affect your decision to remain in the study.

Possible Benefits: Your participation in this study may help persons with disabilities work toward methods to develop healthier identities

EXCLUSION/INCLUSION REQUIREMENTS

The participants will comprise individuals with at least identified disability and individuals identified as caregivers for persons with disabilities. In total, 15 participants will be people with disabilities ages of 19-69, and 15 will be caregivers for persons with disabilities.

AUDIO/VIDEO RECORDING AND PHOTOGRAPHS

30-45-minute semi-structured interviews will be recorded then deleted after translated. The interviews will be recorded through a n iTunes app, voice pro on an iPad Pro, then moved and stored on a secure computer in a safe place until translated with all identifiable information deleted. The recording will then be erased for destroyed.

PROTECTION OF PRIVACY AND CONFIDENTIALITY

The results of this study may be published in scientific journals, professional publications, or educational presentations.

- Your records will be kept confidential and will not be released without your consent except as required by law.
- Your identity will be kept private. Pseudonyms will be used, and all identifiable information will be deleted.
- If the results of this study are written in a scientific journal or presented at a scientific meeting, your name will not be used.
- The data will be stored in a locked file cabinet or an encrypted file folder.
~~Your original consent form will be stored in a cabinet separate from the data.
The cabinet will be removed with any information that could identify you. The tape will then be erased for destroyed.~~
- Identifiable information collected during the study will be removed and the de-identified information could be used for future research studies or distributed to another investigator for future research studies without additional informed consent from the participants or legally authorized representative.

CONTACT INFORMATION

If you have any questions or concerns about your rights in this research study, please contact the Clemson University Office of Research Compliance (ORC) at 864-656-0636 or irb@clemson.edu. If you are outside of the Upstate South Carolina area, please use the ORC's toll-free number, 866-297-3071. The Clemson IRB will not be able to answer some study-specific questions. However, you may contact the Clemson IRB if the research staff cannot be reached or if you wish to speak with someone other than the research staff.

If you have any study related questions or if any problems arise, please contact Dr. David Blakesley at 765-409-2649 or dblakes@clemson.edu.

CONSENT

By participating in the study, you indicate that you have read the information written above, been allowed to ask any questions, and you are voluntarily choosing to take part in this research. You do not give up any legal rights by taking part in this research study.

- Your decision to take part in this research study is entirely voluntary.
- You may refuse to take part in, or you may withdraw from the study at any time without penalty or loss of benefits to which you are normally entitled.
- You may leave the study for any reason.

I have read the above description of this research study. I have been informed of the risks and benefits involved, and all my questions have been answered to my satisfaction. Furthermore, I have been assured that any future questions I may have will also be answered by a member of the research team. I voluntarily agree to take part in this study. I understand I will receive a copy of this consent form.

Print name: _____

Participant's signature: _____ Date: _____

Today's date: _____

Appendix 2

Disability and Caregiver Demographic Information Form

Instructions: Please provide a response for each of the following questions:

1. What is your age? _____
2. What is your gender identification? _____
3. What is your marital status?
Single Married Separated Divorced Widowed
3. What is your employment status?
Employed Full Time Employed Part Time Student Unemployed
SSI
4. What is your annual income (or combined annual income if you have a spouse)?
Less than \$60,000 \$60,001 to \$70,000 \$70,001 to \$80,000
\$80,001 to \$90,000 \$90,001 to \$100,000 Greater than \$100,000
5. With which racial or ethnic category do you identify?
African American Asian/Pacific Islander Caucasian Latino
Other: _____
6. With what denomination or faith tradition do you most closely identify?

7. What type of Disability do you have? _____
8. What is your current academic rank?

High School Diploma

Associate Degree

Undergraduate Degree

Graduate Degree

No degree

9. Did you use resources for Special Education or SSI? _____

10. Is there any additional information that you would like to share?

Appendix 3

Interview Guide – Disability Participant

1. I start by introducing myself and tell about the project.
 - a. Explain that the interview will be recorded and should last between 30-45 minutes
 - b. Say it is possible to withdraw at any time, no questions asked.
 - c. Refer to safety measures on consent form

Questions about Caregiver experiences

2. Can you say a little bit about yourself (Yes No
 - a. Can you tell me about your caregiver? (Yes No
 - b. How does your caregiver assist with building your identity? Can you share a personal experience that made an impact on you?
 - c. How does your caregiver describe you to other people? Can you provide an example?
 - d. Was there a time when the description limited you in any way? (Yes No
Can you provide an example?
 - e. Is there a time when the description empowered you? (Yes No
Can you provide an example?
 - f. Can you please describe an experience with learning to do something a different way that does not fall under disability?
 - g. Can you please describe any experiences where you might have felt able but not recognized for that ability? Did you use any strategies to overcome challenges? Did your caregiver provide any strategies or tactics to help? Can you provide an example?
 - h. What advice have you been given to help with building your identity? Were you offered any types of scenario that helped with your identity?
 - i. Have you ever attempted to rebrand or reclassify yourself according to your abilities? (Yes No
Can you elaborate? Did your caregiver provide guidance or any other support group? Can you provide an example?

Questions regarding the job/ community involvement

- Do you belong to any support clubs or communities? (Yes No
 - If yes, ask - Can you tell me a little bit about your community involvement?

- How do you and the person that cares you spend time together?
- Can you tell me about experiences in the work or community?
 - How do you make friends/peers/colleagues?
 - Have you ever received advice on building relationships?
- Can you share your experiences with being a part of a community?
- Do you feel a sense of involvement? (Yes No Did you have strategies for being included? (Yes No
 - Why?
 - Why not?
- Do you ever receive advice on how to succeed professionally from your caregiver? (Yes No Can you share an example?
- Can you share an experience where you felt successful in your community? (Yes No
 - An experience where you took a chance and failed? What were the steps?
 - An experience where you took a chance and succeeded? The steps?
 - Did you share these experiences with your caregiver? (Yes No)
 - Can you share the feedback from your caregiver?

Elaborate on the themes?

- Are there times where you felt sidelined? (Yes No Can you give an example?
- Are there times you felt you moved off the sidelines? (Yes No Can you give an example?
- When do you feel excluded? How do you handle that? What strategies are suggested by your caregiver?
- If you do not rely on your caregiver for strategies, how do you determine tactics?
- Do you have anyone that you go to for advice when you have a challenge with participating in your community? (Yes No Can you give an example? Do they have steps that are effective? (Yes No Can you give an example?
- Can you give me a scenario that has been successful? What did you say?
- How open were you about your own disability?
- Did you feel accepted? (Yes No Can you give an example?
- What do you feel is important for people with disability/wheelchair users to be successful? Can you give me an example?

Appendix 4

Interview Guide – Caregiver Participant

1. I start by introducing myself and tell about the project.
 - a. Explain that the interview will be recorded and should last between 30-45 minutes
 - b. Say it is possible to withdraw at any time, no questions asked.
 - c. Refer to safety measures on consent form.

Questions on Education

2. Can you say a little bit about yourself? (Yes No
 - a. Can you tell me about your experience as a caregiver?
 - b. Can you tell me about the individual you are caring for?
 - c. Can you describe the disability of the person you are caring for?
 - d. What was your experience when you first became a caregiver? Can you give an example?
 - e. How has the individual you care for handled his/her identity as a person with a disability? Do you have an example you can share?
 - f. Can you share a personal experience that made an impact on your caregiving?
 - g. How did you develop the way you describe the person you care for? Were you ever given resources to help him/her build identity?
 - h. Would you describe the person you care for as having a positive identity? If so/ or not, what do you believe led to that identity?
 - i. Did you use any strategies to help the person you care for to overcome challenges? Do you have an example?
 - j. Did you ever receive advice or were you given any types of scenario that helped with your identity?
 - k. Have you ever attempted to help the person you are caring for to rebound or reclassify themselves according to your abilities? Can you elaborate?
 - l. Can you share an experience where you felt the person you care for felt successful in his/her community?
 - An experience you gave advice to the person you care for to take chances and failed? What were the steps?

- An experience where you took a chance and he/she succeeded? The steps?
- Did you repeat the successful steps to the person you care for? (Yes No Can you give an example?

Elaborate on the themes?

- Are there times when you felt successful at creating opportunities for the person that you care for to move off the sidelines and take chances? (Yes No Can you give an example?
- Are there times when you felt that your advice moved the person you care for moved off the sidelines? (Yes No Can you give an example?
- Did you recognize your success at first? What was your reaction? What strategies have you suggested? Can you describe any feedback from the person you care for?
- Have you developed tactics and strategies to help with a positive identity? (Yes No Can you give an example?
- Do you have anyone that you go to for advice when you have a challenge with participating in your community? Do they have steps that are effective? (Yes No Can you give an example? What did you say?
- How open are you about the disability of the person you care for?
- Do you feel accepted as a caregiver? (Yes No Do you have examples of times you felt accepted as a caregiver?
- What do you feel is important for people with disabilities to be successful? Can you give me an example?

Appendix E

GS7D — Doctoral Dissertation Defense and Approval Form

CLEMSON

The GRADUATE SCHOOL TRANSFORMATION BEGINS HERE

GS7D — Doctoral Dissertation Defense and Approval Form

Date: 8 April 2023

To the Dean of the Graduate School:

This committee has given June B. Furr C40807570
Student's name Student's ID#

a final examination for the PHD degree with a major in Rhetorics, Communication, and Information
Degree (PhD, EdD, DMF, etc.) Major

and reports the results as follows:

PASSED oral defense, dissertation required, and the student's committee has approved the manuscript.

FAILED oral defense. Please indicate recommendation relative to a second oral defense, if any:

Examining Committee:
This form must be signed by all committee members. If signing electronically*, please sign, attach this PDF file to an email, and forward to the next member. Final signer may submit.

<p>Signature:</p> <p><u>David Blakesley</u> <small>Digitally signed by David Blakesley Date: 2023.04.08 12:58:58 -0400</small></p> <p><input checked="" type="checkbox"/> Advisor signature OR <input type="checkbox"/> Co-advisor signature</p> <p><u></u></p> <p><input type="checkbox"/> Co-advisor OR <input type="checkbox"/> Committee member signature</p> <p><u>Cynthia L. S. Pury</u> <small>Digitally signed by Cynthia L. S. Pury Date: 2023.04.08 12:58:58 -0400</small></p> <p><small>Committee member signature</small></p> <p><u>Kristen E. Okamoto</u> <small>Digitally signed by Kristen E. Okamoto Date: 2023.04.08 12:58:58 -0400</small></p> <p><small>Committee member signature</small></p> <p>_____</p> <p><small>Committee member signature</small></p>	<p>Printed name:</p> <p><u>David Blakesley</u></p> <p><input checked="" type="checkbox"/> Advisor name OR <input type="checkbox"/> Co-advisor name (Type or print)</p> <p><u>Claire Mulloney</u></p> <p><input type="checkbox"/> Co-advisor OR <input type="checkbox"/> Committee member name (Type or print)</p> <p><u>Cynthia Pury</u></p> <p><small>Committee member name (Type or print)</small></p> <p><u>Kristen Okamoto</u></p> <p><small>Committee member name (Type or print)</small></p> <p>_____</p> <p><small>Committee member name (Type or print)</small></p>
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*This form allows digital completion, e-signatures, and submission via email by clicking the submit button. To use these interactive features reliably, save this form to your device and open it in Acrobat Reader, rather than completing it with your browser's PDF extension. Alternately, you may submit a printed copy to Enrolled Student Services, 304D Sikes Hall, Clemson, SC 29634, in person or via regular mail.

SUBMIT

Clemson University Graduate School Form GS7D-1 | <http://www.clemson.edu/graduate/students/forms/7d> | GS7D - Final Exam and Thesis Approval - Rev 03/2022

CLEMSON UNIVERSITY GRADUATE SCHOOL | Enrolled Student Services | 304D Sikes Hall | Clemson, SC 29634 | 864.656.2174

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