

TURNING DISABILITY INTO A DREAM: A NARRATIVE INQUIRY OF ONE
MOTHER'S ENDURANCE

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TURNING DISABILITY INTO A DREAM: A NARRATIVE INQUIRY OF ONE
MOTHER'S ENDURANCE

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Abstract: Research has indicated that, as of 2017, 18.7 percent of individuals who had a disability held employment, as opposed to 65.7 percent without a disability (U.S. Bureau of Labor Statistics, 2018). Despite the passage of the Americans with Disability Act of 1990, this indicates that possible discrimination of individuals with disabilities still exists. This anomaly could be the result of misunderstandings of those who are nondisabled of actual limitations of individuals with disabilities and of their capacity to contribute to society and to the workforce. It is difficult for individuals to perceive the potential of individuals with socially defined disabilities (Marchioro, 2000).

There are nondisabled people that can inspire and motivate potential in those individuals to accomplish goals and attempt tasks beyond what was perceived as impossible. Critical Disability (CDT) and Authentic Leadership (AL) Theories are theoretical frameworks utilized in this qualitative narrative inquiry to tell the story of a mother's (Jane) journey of raising two children with disabilities. Through the examination of her critical life events, this study seeks to provide an understanding of how she inspired individuals with disabilities to reach potential beyond the limitations they experience because of their disability.

Due to their disabilities, barriers in school placement and expectations that underestimated their capacity and potential (Goodley, Hughes, & Davis, 2012) were experienced. Jane also experienced barriers from the hearing impaired community including non-acceptance of cochlear implants and resistance to involvement of hearing abled individuals in the deaf community. She developed into a strong advocate for hearing impaired individuals and developed an educational platform to advance their opportunities. Her approach to the hearing impaired community stands in stark contrast to typical societal perceptions of the disabled. CDT has limitations in explaining the development of Jane as an advocate for hearing impaired individuals. Therefore, AL provides a lens to understand her leadership role that evolved. Further, AL explains Jane's unique characteristics and positionality to lead individuals in the deaf community toward growth and development. Among the findings of this study were that Jane earned credibility as a leader and disability advocate.

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CHAPTER I

“Disability is a matter of perception. If you can do just one thing well, you're needed by someone” (Martina Navratilova Quotes, n. d., para. 1).

Background of the Problem

Important steps have been taken in the United States to provide enhanced opportunities and access for individuals with disabilities to participate in public life. For example, the Americans with Disabilities Act of 1990 (ADA) was passed to protect the disabled community by prohibiting any form of discrimination against people with disabilities in areas of employment, transportation, public accommodation, communications, and governmental activities; also providing protections for telecommunications relay services (Equal Employment Opportunities Commission, 2017). This legislation is especially important because it provides important groundwork for increasing access to an enhanced quality of life, including employment access for individuals with disabilities, to a group that has faced substantial barriers to gainful employment and obtaining an education (Cooper, 1991) in the past. The intent of the legislation was to promote equity for individuals with disabilities so that these individuals can contribute to society, despite the challenges that they face; however, while legislation has been valuable and necessary, 28 years after its passage, many disabled

individuals still experience unequal treatment regarding employment opportunities.

A fact that remains obvious is that, while the ADA encourages improvement in workplace accessibility for individuals with disabilities, it falls short in resolving the problem that there are less chances for people with disabilities regarding advancement (Blahovec, 2016). In fact, evidence suggested that few individuals in this minority sect actually enter the workforce (Burns, Barton, & Kerby, 2012; Southeast ADA Center, 2015), and even fewer hold leadership positions (Pederson, 1997). According to the Southeast ADA Center (2015) those disabled represented 19.8 percent; whereas their counterparts represented 68.2; in the same year, the unemployment rate of those with disabilities was 11.2 percent, as opposed to those without a disability, which was 5.6 percent.

Evidence has shown that people with disabilities, in relation to their counterparts without a disability, are viewed as being more unfavorable in the labor market, even though they may be capable of performing the same work (Cook & Burke, 2002). Data has shown that 70% of the disabled and 89% of those with severe disabilities were out of the labor force, as opposed to their working-age counterparts without a disability, at a paltry 18% (U. S. Census Bureau, 2001). Additionally, Yin, Shaewitz, Orevton and Smith (2018) of the American Institutes of Research approximated that of 64 million (1 in 5) individuals having a disability, 22 million or 35%, ages 16-64 with a minimum of one disability, are at their optimal working condition. The current underrepresentation of individuals with disabilities in the workforce is reflected in the above percentages and deserves additional consideration, given the fact that, directly after the passage of the ADA, Fortune 500 businesses immediately took steps to address and prevent discriminations by integrating the disabled into company work environments (McFarlin, Song, & Sonntag, 1991). Blahovec (2016)

moved forward with understandings concerning the hiring of the disabled and found that many Fortune 1000 companies that are high on the Disability Equality Index (DEI), such as Starbucks, Northrop Grumman, AT&T and Ernst & Young, are understood as viewing disabilities through a business model built on established inclusive hiring, retention and promotion practices, rather than an advocacy model. This is significant due to more of a focus on organizational policy that addresses the need for inclusive hiring practices, which is shifting from the traditional hiring process based on the fear of federal legislation like the ADA. This model represents the inching toward valuing the employee with a disability.

Statement of the Problem

The ADA of 1990 prohibited employment injustices of individuals on the basis of disability (Equal Employment Opportunities Commission, 2017). Furthermore, it protected individuals with disabilities and requires employers to provide reasonable accommodations to promote their accessibility to the workforce. Although the ADA has been in existence in the United States for over 28 years, a large percentage of individuals with disabilities remain outside of the work force. Further data evidenced that in 2011, there were 27,382,000 individuals who have a legal definition of disability, which as Section 504 of the Rehabilitation Act of 1973 outlines: “a physical or mental impairment that substantially limits one or more major life activities ... major life activities include walking, seeing, hearing, speaking, breathing, learning, working, caring for oneself, and performing manual tasks” (Henderson, 1995, p.4); however, while many of these individuals possess talents and skills that can contribute positively to the workforce, in 2012, only 5,722,000 of these individuals were counted in the labor force (Burns et al., 2012). That figure decreased to 5.35 million in 2021 (Statistica Research Department, 2021). This discrepancy suggests that

despite the ADA and efforts to promote social awareness to protect individuals with disabilities, American society is not responding fully to efforts to promote opportunities for these individuals; therefore, it is likely that discrimination of individuals with a disability still exists.

Therefore, it is plausible that there is a social perception of individuals with disabilities that makes them even more vulnerable to the assumptions that the disabled operate from the position of deficit. In fact, it is quite rare for individuals without a legal definition of disability to actually perceive the potential of disabled individuals with a Section 504 qualification of disability (Marchioro, 2000). One potential explanation of this deficit lens can be the result of misunderstandings, on the part of those in society who are not disabled, of actual potential and limitations of individuals with disabilities and of their capacity to contribute positively to society and to the workforce. However, an anomaly exists when individuals “see past” the perceptions of limitation of individuals due to their disabilities to actually perceive potential for growth beyond common understandings.

One individual who is enriching the lives of many individuals with disabilities is an educator living in the central part of the United States who has developed a sign language educational platform for hearing impaired children. This platform is an idea born from her experiences and personal challenges with her two children born with disabilities. Her younger daughter suffers from Chiari Malformation and spina bifida while the older daughter is deaf. Sign language became the prominent form of communication between the two girls, serving as the catalyst for this particular educational platform. What seems apparent, because of her life devotion to enriching educational opportunities for individuals with disabilities, is that Jane’s (pseudonym to protect her anonymity) perception of disability stands in stark

contrast to common understandings in the larger societal context, which is a notion that cabins and interweaves itself in and throughout Critical Disability Theory (CDT) (Hosking, 2008). Additionally, understanding Jane's story helps to expose her perceptions that eliminate certain barriers that exist for those individuals. Her story helps to provide understandings of how nondisabled people can inspire, encourage, and identify latent potential in those individuals with disabilities to accomplish goals and attempt tasks beyond the perception of traditional workforce paradigms.

Purpose Statement

This narrative inquiry seeks to tell the story of an educator and co-founder of an educational program that teaches children to use sign language as a valuable form of communication. This person has influenced the lives of many individuals with disabilities by creating opportunities for education beyond what was available to them before her intervention. The overall goal is to provide an understanding of how she is inspiring individuals with disabilities to reach potential beyond the limitations imposed by their disability. For the purposes of this study, an individual with a disability is defined as one who qualifies under Section 504 of the Rehabilitation Act. As mentioned, Section 504 defines disability as: "a physical or mental impairment that substantially limits one or more major life activities ... major life activities include walking, seeing, hearing, speaking, breathing, learning, working, caring for oneself, and performing manual tasks" (Henderson, 1995, p. 4).

Research Questions

Overarching Questions

1. How does Jane influence individuals with disabilities, their caregivers, and families to exceed expectations placed upon these individuals because of their disability?

2. How does Jane influence these individuals to achieve positions in the workforce beyond what was expected of them?

Sub-Questions

- A. How does Jane perceive individuals with disabilities and how does she communicate this perception?
- B. What factors influence Jane's perception of individuals with disabilities?
- C. How does Jane's influence guide disabled individuals to realize their potential to overcome real and socially constructed limitations?

Methodology

Narrative inquiry scholars have worked within the construct that people's lives are replete with successful achievements and challenged journeys that serve as the natural ups and downs, respectively; importantly, they hold discourse with others, discussing their lived experiences and exploits, leaving narrative researchers the ability to provide thick and rich descriptions of these lives, to develop a collective record of their stories and offer written narratives of particular experiences (Connelly & Clandinin, 1990). This narrative inquiry outlines the storied experiences of Jane, who, as mentioned heretofore, due to her daughters' disabilities, had to fight to overcome discriminations in effort for them to pursue an education in the public-school system.

The study incorporates semi-structured interviews, observations, as well as an analysis of a variety of artifacts and documents that relate to Jane, her staff, parents impacted by the educational platform, friends and co-workers. Within thematic narrative analysis, the collection of data is open coded and themes are identified (Riessman, 2008). The emerging themes provide a chronological story of her critical life events (Woods, 1993; Bohl, 1995;

Webster & Mertova, 2007) that establishes a learning construct derived from the meaning obtained from her narrative experiences. I used purposeful sampling to choose Jane as my primary interviewee and snowball sampling to find a least three staff members and seven parents who have children that Jane's educational platform is serving – all to be interviewed individually. To further understand others' perceptions of Jane's leadership, I asked interview participants who have worked with Jane and have been impacted by her leadership style to rate Jane utilizing the Authentic Leadership Questionnaire (ALQ); an instrument that has been tested for use in research (Walumbwa, Avolio, Gardner, Wernsing & Peterson, 2008).

Additional details concerning content validity and reliability are provided in Chapter III. The scale is designed so that I calculated means for each of the four major components of authentic leadership to gain a better understanding of others' perception of Jane's leadership.

In an effort to understand Jane's perception of her own ability to motivate those within the disability community, I asked Jane to rate herself on the Authentic Leadership Self-Assessment Questionnaire (ALQ) that was developed by Avolio, Gardner, and Walumbwa (2007). This ALQ is a version controlled by MinGarden, Inc., but is a tested instrument, unlike the version of the ALQ reported by Northouse (2016). The ALQ has utility to add a further layer of understanding of Jane's perception of her own leadership and ability to motivate those whom she serves (Avolio et al. 2007) and was utilized for triangulation purposes in this research study.

Epistemology

Epistemology refers to the idea that knowledge is found in specified theoretical perspectives; in turn, being cabined in the methodology of a research study (Crotty, 1998).

The research design of this study is qualitative in nature, using a narrative inquiry design, aligning with the constructivist epistemology (Crotty, 1998). Constructivism (Patton, 2002) is often paired or aligned with interpretivism, where “qualitative research focuses on meaning making as a reflexive, complex, and continuous process” (Manning & Kunkel, 2014, p. 435). Of note, both constructivists and constructionists center on the process of making meaning and recognize that different people construct meaning in differing ways, even for the same problems (Creswell, 2014; Crotty, 1998).

Social constructivism deals with processing meaning exclusively within the realm of the world in which they live (Creswell, 2014). According to Creswell (2014), qualitative researchers enmesh themselves in to participant’s setting to gather personal information to help discover deeper understandings of particular contexts. Constructivism is an important epistemology for this study because meaning is socially constructed (Crotty, 1998). It is the viewpoint of the participants that constructs meaning (Creswell, 2014). Caine, Estefan and Clandinin (2013) persuasively elucidated that it is the experiences within the inquiry framework that define the epistemological position. While this framework does encapsulate the mutual experiences of both the subject and the object, this study highlights mutual experiences while primarily focusing on the Jane’s experiences to derive meaning.

Theoretical Frameworks

Critical Disability Theory

Critical Disability Theory (CDT) has provided a perspective of disability that represents a social construction. The composition of social aspects consists of the “physical, institutional and attitudinal” settings that fail individuals with disabilities due to the implication that there is a certain degree of normality that everyone must attain. CDT has

analyzed social contexts occurring in social institutions, within which, individuals function while showing certain processes and behaviors (Creswell, 2014) within their environments, contributing to the mentality of people with no disability, illustrating how those with disabilities “fail” to meet the “social expectation of normalcy” (Hosking, 2008, p. 7). The social aspects encompass environmental and institutional settings that possess inherent challenges, creating insurmountable disadvantages that link failure to the disabled; furthermore, CDT has outlined that: 1) disability is a social construction; it is not an inevitable consequence of impairment; 2) disability is a "complex interrelationship between impairment, individual response to impairment, and the social environment" and 3) any social disadvantage of disabled people is brought on by "the physical, institutional and attitudinal environment which fails to meet the needs of people who do not match the social expectation of 'normalcy'" (Hosking, 2008, p. 7).

CDT has utility for understanding Jane’s influence on the disabled because she has devoted her professional life to providing opportunities to enhance the education and potential of individuals with disabilities. Her approach stands in stark contrast to societal expectations of “normalcy,” and it explains ways to support individuals with disabilities to maximize their potential. Her approach highlights institutionalized attitudes which fail many individuals with disabilities who seek to enter the workforce, and it provides perspectives for those who work with the disabled in educational environments. Moreover, while Jane’s approach positively impacts the attitudinal aspect of disability, efforts to pair it with policy considerations must be made, since focusing on changing minds is solely inadequate (Russell & Malhorta, 2002; Yeo & Moore, 2003).

Authentic Leadership

Authentic leadership (AL) is a concept that was born out of corporate corruption and governmental malpractice, leading to a pervasive moral and ethical bankruptcy that riddled a variety of bureaucratic organizational structures. This climate left many global leadership authors and scholars to weigh considerations that led to AL that is a leadership behavior that has values as the basis – in short, authentic (Gardner, Cogliser, Davis & Dickens, 2011). Northouse (2016) viewed AL from the intrapersonal and interpersonal perspectives, with one emphasizing the internal leader and the other being viewed as relational, respectively; going further to bring attention to authentic leadership as being viewed through the theoretical approach – rooted in the results of social sciences; the practical approach – based in the real-life experience.

Leadership literature has shown that many scholars feel it is difficult to define authentic leadership and go as far as to express concern in an attempt at the task (Cooper, Scandura, & Schriesheim 2005; Shamir & Eilam, 2005; Sparrowe, 2005). According to Northouse (2018) while “there is no single accepted definition of authentic leadership, it can be conceptualized intrapersonally, developmentally, and interpersonally” (p. 222). However, researchers have narrowed the scope of AL to a practical understanding, analyzing it through a social sciences perspective (Avolio & Luthans, 2003), taking the positive psychological perspective that enhances the sense of an individual’s balanced processing, internalized moral perspective, relational transparency, and self-awareness (Gardner et al., 2011; Northouse, 2016, 2018). Walumbwa, Avolio, Gardner, Wernsing and Peterson (2008) similarly defined authentic leadership as forms of behavioral leadership that “draws upon and promotes both positive psychological capacities and a positive ethical climate, to foster greater self-awareness, an internalized moral perspective, balanced processing of

information, and relational transparency on the part of leaders working with followers, fostering positive self-development” (p. 94).

Significance of Study

Establishing and maintaining equal access is critical and it is in the best interest of school districts to desire and protect differences that make people unique while offering those educators needing accommodations the support and flexibility to help overcome challenges that benefit the school and educator (Coombs, 1994). The concept of equal access is important because it seeks to provide an understanding of institutional limitations, or social constructions, that are indirectly created for specific school demographics such as individuals with disabilities. This article helps to inform policy makers and educators as they seek to encourage equity for individuals with disabilities. Understanding the perspective of an individual who is working to promote the success of persons with disabilities informs educational leaders and policy makers about the barriers to advancement these individuals may be experiencing despite legislation to protect them from discrimination. In spite of current legislation and policy, implementation measures remain insufficient unless there is an establishment of important understandings between non-disabled individuals, employers and educational leaders capable of providing opportunities for the vast numbers of individuals with disabilities that remain outside of the workforce.

Definition of Terms

Individual With a Disability

For the purposes of this study, an individual with a disability who identifies as an individual who qualifies under Section 504 of the Rehabilitation Act of 1973. Section 504 defines disability as: “a physical or mental impairment that substantially limits one or more

major life activities ... major life activities include walking, seeing, hearing, speaking, breathing, learning, working, caring for oneself, and performing manual tasks” (Henderson, 1995, p. 4).

Verisimilitude

In narrative inquiry, verisimilitude is the notion of “producing results that have an appearance of truth or reality” (Webster & Mertova, 2007, p. 10).

Narrative

A basic tenet in narrative inquiry is that people live storied lives. “Narrative is a way of characterizing the phenomena of the human experience and its study which is appropriate to many social science fields” (Connelly & Clandinin, 1990, p. 2).

Limitations

Being an individual with a disability and possessing the duties and responsibilities of a researcher, I have continuously remained aware to protect the data collection process to preserve Jane’s story, so that her experiences evolve in accordance to the foundational principals of narrative inquiry (Bochner & Riggs, 2014; Caine, Estefan & Clandinin, 2013; Clandinin, 2006; Connelly & Clandinin, 1990; Dewey, 1981; Mertova & Webster, 2012), free from my lived experiences. In the absence of safeguarding against limitations that arise from my disability, my personal lived experiences have potentially introduced a degree of bias (Creswell, 2014), and also may have impacted the observation process in a variety of ways that are unknown (Patton, 2002).

Patton (2002) continued to explain that one researcher limitation remained in understanding only the observation or the “external behaviors” that narrow the ability to grasp the inner working of participants. It was critical to safeguard against allowing my

circumstance to alter the natural perception currently residing within Jane's domain or context. Outside of observations, there were other potential limitations in the data collection process that took place when performing interview(s) and analyzing document(s) and record(s). I was cautious and vigilant in recognizing issues with personal bias, recall error, self-serving responses and/or incompleteness or inaccuracy in documentation(s) (Patton, 1999, 2002).

Summary

Chapter one of this narrative inquiry commenced with a background of the problem that provided the context of the existing research phenomenon. The proceeding sections constructed a narrative inquiry design and laid the foundation for understanding how Jane influenced the lives of individuals with disability. There were two overarching questions guiding this narrative inquiry, which included: 1) how does Jane influence individuals with disabilities, their caregivers, and families to exceed expectations placed upon these individuals because of their disability and 2) how does Jane influence these individuals to achieve positions in the workforce beyond what was expected of them? Additionally, there were three sub questions: A) how does Jane perceive individuals with disabilities and how does she communicate this perception, B) what factors influence Jane's perception of individuals with disabilities and C) how does Jane's influence guide disabled individuals to realize their potential to overcome real and socially constructed limitations?

Chapter two is a comprehensive literature review that begins by including a historic perspective of individuals with disabilities in the United States. This section opens the door of history to inform the reader of the civil rights struggles as well as the factors leading to the disability movement (Scotch, 1989). The following sections offer a review of the history of

legislation for people with disabilities in the United States before broaching literature topics regarding demographics of the disabled and the idea of leveling the playing field: education and opportunity for people with disabilities. Moving forward, Critical Disability Theory and Authentic Leadership are introduced as theoretical frameworks that illustrate linkage between the literature review and the purpose of the study.

Chapter three outlines this study's methodology. Connelly and Clandinin (1990) exclaim that "people by nature lead storied lives and tell stories of those lives, whereas narrative researchers describe such lives, collect and tell stories of them, and write narratives of experiences" (p. 2). This narrative inquiry details the storied experiences of Jane, the co-founder of an educational program targeted at enhancing the lives of individuals with hearing impairment, who, due to her daughter's disabilities, had to fight to overcome discriminations in effort for them to pursue an education. Further, the chapter includes a discussion of semi-structured interviews, observations, as well as an analysis of a variety of artifacts and documents that relate to Jane, her family, friends, parents impacted by the educational platform and co-workers. The incorporation of emergent themes is used to "restory" (Ollerenshaw & Creswell, 2002) Jane's critical life events (Woods, 1993; Bohl, 1995; Webster & Mertova, 2007) to resurrect meaning from her challenges that inform the study and provide answers to the research questions.

Chapter four describes Jane's story and includes the presentation of the study's findings. It starts with a very short summary overview of the problem, purpose, research questions and methodological design. The study's initial finding describe the participants in the narrative inquiry and commence with an explanation of the data analysis and findings component. Finally, the findings offer answers to the study's research questions.

Chapter five outlines Critical Disability Theory (CDT) and Authentic Leadership (AL) to serve as lenses to explain the findings. The themes that surface enrich and strengthen this narrative inquiry study. More specifically, the application of these particular lenses help view the challenges that Jane encounters to gain a deeper understanding of the qualities and traits she exemplified and any leadership and motivation techniques that help people with disabilities reach their potential, in effort to find meaningful explanations to address the research questions. A discussion of implications for practice, research and theory follow. Limitations discovered in the data collection process, as well as the strategies to minimize or control for them and their potential influence on my findings are discussed. Following the discussion, I include suggestions for further research.

Chapter six presents a discussion and the study's implications and findings.

CHAPTER II

LITERATURE REVIEW

History of Legislation for People with Disabilities

The historical past of the United States is replete with documented events that detail specific discriminations where minorities endure and overcome, fighting for civil rights to afford them equal protection under the law to enjoy equal participation in society (Karger & Rose, 2010). In more recent times, there have been many scholars in the humanities that have devoted a great deal of study on identity-based inequalities such as ethnicity, gender, race, etc. while challenging any logical explanation for them (Baynton, 2013). In particular, for the disabled, decades of social injustices piled up and forced action by those advocates within the disabled community to challenge unequal treatment. This action grew into the disability rights movement, where strategies and methods effectively revealed the injustices experienced by people with disabilities, bringing a greater awareness to Americans, including the politicians who possessed the authority to create and pass policy to help reverse the misfortunes.

As early as the nineteenth and early twentieth centuries, those with disabilities were overtly discriminated against, making it difficult for those in this minority group

who wanted to utilize their skills in the workforce to make a livable wage or even hold a position in society. In fact, those with disabilities were considered to be an aesthetic eyesore, which spurred on the creation of the “ugly laws” that made it illegal for those with deformities and various mutilations to pander for money on the streets (Schweik, 2009). In a review of Schweik’s work, *The Ugly Laws: Disability in Public*, Gerber (2010) added that “a number of American municipalities and states passed ‘unsightly beggar’ laws, the point of which was to clear the streets of diseased, maimed, and disfigured individuals who attempted to earn money by calling attention to their bodies” (p. 273).

Civil Rights Act of 1964

There have been major shifts in paradigms of thought as it relates to disability. Cook and Burke (2002) described these shifts as a sea change “in public attitudes, legislation, and political power at the end of the 20th century in the United States (that) has helped set the stage in the early 21st century” (p. 541). In large part, the ADA gained passage because of the ardent work of advocates from a multitude of physical and mental disabilities who created coalitions, which employed the same model of civil rights that worked well for African-Americans in their movement in the 1960s (Baldwin & Johnson, 1998). One of those advocates and a chief architect for the Americans with Disabilities Act of 1990, Lex Frieden, is no stranger to discriminating journeys. After suffering paralysis from a car accident, he encountered numerous challenges due to his disability. Like many disabled Americans during the 70s, his perspective stems from experiencing myriad discriminations, which, collectively, contributed to the rise of social movements to help overcome certain institutional policies and legal practices that either directly or

indirectly frustrated and made life considerably more difficult (Turner & Killian, 1987).

Lex Frieden made the argument that the disability movement shares responsibility in the carrying the mantle of other famous movements to resist disenfranchisement of civil rights. According to Frieden (2014), it was the other 1960 social revolution movements, including the anti-war movement, the women's movement, and Ralph Nader's consumerism movement that resulted in the formation of the disability movement. With poignant historical events dominating the international and domestic front, a generation of youth rose up in vociferous protest against establishment and disenfranchisement of rights, which ultimately provided much of the push for social change through legislative policy. Hall (2005) described the resistance, stating that "the country is beset by the Vietnam War, urban riots, and reaction against the excesses of the late 1960s and the 1970s, understood variously as student rebellion, black militancy, feminism, busing, affirmative action, or an overweening welfare state" (p. 1234).

Coming off of a time where the black community experienced immeasurable harm, numerous grievances, and the loss of this specific minority's iconic figure with the assassination of Dr. Martin Luther King, Jr., America was in tumult. To counter these injustices, the black community acted, and the civil rights movement began to push for equality and change. Events occurred such as the "freedom rides, riots and the intervention of federal troops at 'Ole Miss,' murders of both black and white civil rights activists, the historic March on Washington, the bombing of Birmingham's Sixteenth St. Baptist Church, and freedom riders martyred" (Rains, 1992, p. 186). Though it was contested vigorously, Congress and the Federal Government realized that it was crucial to establish policy that would look to reverse the discriminations influencing African

Americans. One such policy was the enactment of the Civil Rights Act of 1964 (CRA), which was noted as a landmark or historic article of social legislation in the modern era (Rodriguez & Weingast, 2003; Weatherford, 2015) signed into law by President Lyndon B. Johnson. This law was a recognition of historical inequity seeking to reverse a longstanding history of injustices. These circumstances represented a prevalent struggle for notions of freedom, justice, and equality; thusly, by the 1960s, a national discourse about discrimination took place where an agreement for remedies to address this moral issue (Eskridge Jr., 1991).

While this federal policy did not address the disabled community, it provided the opportunity for activists within the disabled community to establish their voice and led to the root of historical social movement such as the disability movement (Frieden, 2014). Mayerson (1992) wrote that just as the African Americans protested in the civil rights movements prior, individuals possessing disabilities “sat in federal buildings, obstructed the movement of inaccessible buses, and marched through the streets to protest injustice ... the disability rights movement sought justice in the courts and in the halls of Congress” (p. 1).

Legally speaking, the winds of change blew and legislative efforts like Section 504 of the Rehabilitation Act of 1973 and The Fair Housing Amendments Act of 1988 realized passage, representing historic momentum in the disability movement and ushering in exposure to actual discriminations that were being perpetrated. Several years later, those living with disabilities witnessed another huge legislative victory when the Americans with Disabilities Act of 1990 (ADA) passed, seeking to go further than

exposing discriminations, but seeking to prevent discriminatory practices and transition those with disabilities into society on a greater scale.

Section 504 of the Rehabilitation Act of 1973

In its time, Section 504 of the Rehabilitation Act of 1973 was widely considered to be the centerpiece of newly drafted antidiscrimination legislation. Because it required all institutions receiving federal assistance to adhere to its application (Katsiyannis & Conderman, 1994), this was a major public policy shift in the United States for the handicapped. This particular act provided more legal authority in civil rights for the disabled, affectionately known as the Civil Rights Act of the Handicapped (DeJong & Lifchez, 1983). Congress intended the act to prevent discrimination for those qualified persons with disabilities based only on a person's handicap. The federal legislation included language that prohibits any exclusion from or denied any benefits, or experience any form of discrimination in any program that is the recipient of federal monies from the Department of Housing and Urban Development (Act, 2003).

The Fair Housing Act of 1968 and the Fair Housing Amendments Act of 1988

Shortly following the Civil Rights Act of 1964, in order to prevent discrimination in taking place in the housing industry, Congress passed the Fair Housing Act of 1968 (FHA); specifically looking to stop the "corrosive effects of racial zoning, race-restrictive covenants, and the refusal of many property owners and their agents to serve people who are seen as different from the White majority" (Yinger, 1999, p. 93). Congress and the Supreme Court made it illegal for there to be any discriminatory actions using characteristics like national origin, race, religion, color as grounds for either renting, selling or obtaining loans and/or grants for dwellings that are associated with the federal

government of housing (Dubofsky, 1968). Preceding the FHA's passage in 1968, another of the last two legislative provisions furthered the anti-discrimination scope of the law by adding sex as a protected class passed in 1974 (Stanton, 2002).

Finally, in 1988, Congress, again, expanded protections in the FHA when it passed the Fair Housing Amendments Act (FHAA), which prohibited discrimination against a family's handicap status related to obtaining housing (Stanton, 2002). The FHAA addressed the failure of government at all levels, local, state and national, to "fund innovative quality housing adequately and (to) have succumbed to the prejudices and fears of potential neighbors by enacting and enforcing exclusionary zoning ordinances and restrictive covenants" (Kanter, 1993, p. 932). Essentially, the FHAA protected two additional categorical groups, deeming it an illegality to allow discrimination against those family units who have children with either a physical or mental disability. Additionally, it sought to ensure that housing builders took measures to create accessibility in the construction of housing units and held landlords and condominium associations responsible for making reasonable accommodations for their disabled tenants (Shill & Friedman, 1999).

The Americans with Disabilities Act of 1990

The Americans with Disabilities Act of 1990 (ADA) was a fairly modern piece of legislation in the fight for disability rights. Prior to the ADA, the federal government drafted the Act of June 10, 1948, which helped those veterans who became disabled during the Second World War. It sought to prevent employment discrimination in the United States Civil Service. Another act that followed was the Architectural Barriers Act of 1968 that required all federally assisted buildings to be financed, built or refurbished

so that people with disabilities could navigate the architecture (Weicker, 1991). The ADA was federal legislation that intended to prohibit discrimination against those persons with disabilities in many facets of society (Hurley, 2011). This particular federal legislation was signed into law by President George H. Bush on July 26, 1990, becoming a monumental achievement for those with disabilities (Mayerson, 1991); so much so that the ADA has been coined the “Emancipation Proclamation” for those living with disabilities (Rains, 1992).

The ADA has been transforming American culture, making society more diverse in talent and intellect and more inclusive for individuals with disabilities (Hums, Schmidt, Novak & Wolff, 2016); however, this legislative model has had far reaching effects in its impact, globally, motivating the worldwide establishment and sustainment of the disability rights movement (Mayerson & Yee, 2001). The ADA has effectively created international partnerships and created policy forums for discussion, and many activists from around the world have come to America to discuss issues surrounding disability; likewise, many American activists have taken their message about disability, internationally (Mayerson & Yee, 2001). Not only was it a significant milestone for disability rights in America, it was the model for other nations around the world, increasing global activism regarding disability rights groups, particularly those English-speaking countries like Australia, Canada and the United Kingdom (McColl, Jaiswal, Jones, Roberts & Murphy, 2017; Prince, 2010). Unlike the United States, Canada does not have a unified national disability law, but advocates are pushing for a disability policy that reflects the ADA with the focus on reducing barriers in areas like

employment, public services, transportation and telecommunications (Burns & Gordon, 2010).

The Strengths and Weaknesses of the Americans with Disabilities Act of 1990. Although the current state of employment for people with disabilities remains in flux, and despite the efforts of federal legislation such as the Americans with Disabilities Act of 1990 (ADA), the ADA has been and will continue to be a critical legal standard for the safeguarding of the civil rights of the disabled. As is the case with all legislative efforts, there is a continuous evolution in the law, so abandoning or eliminating efforts such as the ADA could lead to a dangerous vacuum filled by corruption and persons in opposition to ideas like civil rights, social justice and equal protections have the potential to reverse the course or progress (Karger & Rose, 2010).

In looking at employability of the disabled in connection to employers' perceptions, Bricout and Brentley (2000) characterized employability as negatively consistent, in general. National Organization on Disability/Louis Harris and Associates survey of Americans with disabilities, Louis Harris & Associates (1994) reported that approximately 29 percent of the disabled population had work while an overwhelmingly contrasted 79 percent of the nondisabled held gainful employment. For people ages 21 to 64 who are severely disabled, employment and business ownership remained at 26.1 percent, as opposed to the nondisabled who enjoyed a rate of 76.9% (Stoddard, Jans, Ripple & Kraus, 1998). Moving through time several years, the United States Department of Labor (2019) statistics indicated that, when comparing disabled (8.0%) to non-disabled populations (3.9%), the unemployment rate was nearly twice the rate between the two groups; further, 9.2% of the civilian non-institutional disabled community over the age of

16 had the likelihood of being unemployed at a rate that was approximately twice the amount of their civilian non-institutionalized nondisabled peers, age 16 and over, which accounted for (4.2%) of this particular population.

A major emphasis of the ADA was to prevent discriminations that work to inhibit individuals with disabilities from gainful employment (Mayerson, 1991; Mayerson & Yee, 2001). As of 2012, in America, there are 27,382,000 individuals who have a disability, with only 5,722,000 of these individuals that count in the labor force (Burns et al., 2012). Three years later, the Southeast ADA Center (2015) confirmed this problem and reported that “[i]n February 2015, the percentage of people with disabilities in the labor force was 19.8. By comparison, the percentage of persons with no disability in the labor force was 68.2”. However; the same statistical analysis found that, in the same month and year, “the unemployment rate for those with disabilities was 11.2 percent, compared with 5.6 percent for persons with no disability, not seasonally adjusted” (Southeast ADA Center, 2015, para. 1 & 2). This is important because it illustrates a trend between the years of 2012 to 2015 which implied an exposure of gaps in the ADA and showed a disturbing negative relationship that existed between those with disabilities and past, present and future unemployment rates. In their exploratory study, Bricout and Brentley (2000) confirmed this employment trend and found that their research went against other research that suggested the employment picture for the disabled is positive.

Despite the fact that legislation was created and passed to provide opportunity for people with disabilities, many institutions, including law schools, themselves, failed to fully adhere to the ADA regarding membership equality and diversity in the matriculation process. One of the more noteworthy weaknesses of the ADA was the lack of

advancement opportunities for the disabled community (Blahovec, 2016) and the application and impact this legislation has upon certain employment occupations. Although my study focused on the K-12 educational context, it was a somewhat unfruitful journey in the literature when seeking to capture data that speaks to education and the influence of the ADA. When looking at policies established to enhance inclusion, coupled with the idea that it is a necessity for school administrators to possess an understanding of how to bring about positive outcomes for their disabled study body, whether through educational and policy training or programs focused on instruction that increase equity and meet state standards, the hiring of those with disabilities was a beneficial correlate (Kraft, 2016). What is not known is why so few individuals with disabilities enter the field of education, and, for those that do, why so few are promoted to leadership positions; however, much can be learned from the paths of other groups that experience marginalization in the educational hierarchy. However, there remains circumstantial evidence that this law does show gaps with respect to other occupations and secondary educational institutions. The legal arena, itself, is a notable suspect. Legal scholars argued that law schools themselves stop short of utilizing the ADA in preventing equality and diversity in membership.

According to Long (2014), the American Association of Law Schools (AALS) continued in failing to practice inclusion of disability, stating that “when it comes to the duty of member schools to seek to have a diverse student body, faculty, and staff, diversity is defined solely in terms of race, color, and sex” (p. 117) when the spirit of the ADA clearly requires an equal opportunity that does not segregate based on other human factors that include disability. He went on to undergird his point, providing that there are

approximately 54 million, about 19% Americans who are noninstitutionalized, classified as disabled; however, research has shown that within the legal arena there are less than 4% who have a disability (Long, 2014). As an attorney, Long's conclusion was that the ADA had no positive impact on the employment of those with disabilities; finding that the unemployment statistics remained depressing (Long, 2014).

Demographics of the Disabled

Drawing upon the results from Worthington's 1994 study, Hinton (2003) explained that while subjects viewed the ADA as having been effective, overall, they felt it was not adequately resourced throughout all levels of government to be effectively and efficiently implemented and enforced. fact that remains obvious is that, while the ADA has encouraged improvements in workplace accessibility for individuals with disabilities, evidence suggested that few individuals with disabilities actually enter the workforce (U.S. Department of Labor Statistics, 2019), and even fewer hold leadership positions. As reported in 2012, in the American labor force, there are 27,382,000 individuals who have a disability, with only 5,722,000 of these individuals that count in the labor force (Burns, et al., 2012). Moving forward, the Statistical Research Department (2021) reported a decrease of those with a disability in the workforce to 5.35 million.

Directly after the passage of the ADA, Fortune 500 businesses immediately took steps to address and prevent discriminations by integrating the disabled into company work environments (McFarlin et al., 1991). The steps that Fortune 500 corporations took included accommodating the work environment, which allowed for increased work performance. In fact, these companies indicated positive attitudes regarding the hiring of people with a variety of intellectual and other significant disabilities, while suggesting

that the company and employee both benefit from this job situation and held positive views on the job performance of the disabled (Kaye, Jans, & Jones, 2011). Literature has indicated that people with disabilities are a valuable source of potential labor who can help address shortages that exist in certain economic industry sectors that find it difficult to hire and keep quality employees (Cook & Burke, 2002); yet, the literature has also shown that the degree in which the disabled experience gainful employment depends upon the industry chosen, as some fields are more accommodating than others (Yelin, 2001). An example is the field of education. What is not known is why so few individuals with disabilities enter the educational field, and, for those that do, why so few are promoted to leadership positions.

Deficit Lens: Misunderstandings and/or Actual Limitations

In an effort to overcome perceptions attached to the disabled, Hutcheon and Wolbring (2012) focused on language that promoted awareness through an initiative that created spaces for those with and without disabilities to participate in discourse, contributing to the notion of “ableism.” Ableism is defined as a “concept (that) describes, and is reflected in, individual and group perceptions of certain abilities as essential ... treated as both a *hegemony* which promotes ability preference and as *an analytical tool* used to understand these preferences and their impact” (Hutcheon & Wolbring, p. 40). The ADA brought about great social awareness of issues that challenge the disabled community when attempting to normalize their lifestyles in society; however, this federal legislation, designed to facilitate full participation in many aspects of society for those individuals with disabilities, also carried with it an evolution of stereotypes that have continued to exist, since its inception, and reconceptualize inaccurate perceptions about

those with disabilities and their competencies to work (Baldwin & Johnson, 1998). These stereotypes effectively lead to a deficit lens perspective among those without disabilities, contributing to the misunderstanding of abilities relating to the disabled.

When closely viewing perception, a lack of social awareness promotion (Kaye et al., 2011) and its importance is a silent aspect. This lack of awareness has influence in both societal and workforce spheres for those with disabilities. Meekosha and Shuttleworth (2009) spoke to the rise and importance of disability awareness, describing the genesis of new modes of humanities and social science literature that has allowed the formation of new paradigm shifts away from long standing practices of institutionalism that were driven by the antiquated adherence to understanding disability through the limitations of the medical model. The rise in new paradigms geared toward understanding disability stemmed from a focus both on curricula within the higher educational system, which spurred on a burgeoning body of academic work that established its own niche as disability studies (Meekosha & Shuttleworth, 2009).

They further explained that the “rise of the contemporary disability movement in the latter decades of the 20th century, and the vocal demand for relevant curricula by disabled people and their allies, lent weight to the legitimacy of the new discipline” (Meekosha & Shuttleworth, 2009, p. 48). Research practices became an extension of the disability movement that continually bring about renewed awareness of the evolution of issues that revolve around those with disabilities; especially, those issues that focus on employment. The New Paradigm (Cook & Burke, 2002) was one theory that is associated with “community inclusion, accommodation, and protection of civil rights ... can be applied in concert with rigorous behavioral science methodologies to shed light on the

outcomes of recent federal policy changes regarding the labor force participation of people with disabilities” (p. 541).

In fact, Tremain (2015) argued for a move away from understanding disability through the lens of the disability movement, solely, explaining there is a need to focus on disability through a set of new paradigms. Moreover, scholars in the field of Disability Studies have clarified the term “impairment.” They sought to explain how those who have limiting impairments have been fighting a contradiction regarding inclusion, when society develops a cultural mindset that sees those who are disabled as being imbued with rights to enjoy social lifestyles in specific contexts and time periods; yet, experience exclusion in those enjoyments of independent lifestyles in specific contexts that take place in certain time periods (Tremain, 2001). Older forms of thought view disability as an impairment or an economic cost/burden to society; however, The New Paradigm effectively spun the conversation of disability away from the medical model of limitation to opening the conversation to an understanding of disability as functioning with appropriate accommodations (U.S. Department of Education, 2000).

Leadership Roles for the Disabled

It is commonly understood that, in order to change opportunities for individuals with disabilities, establishing a workplace climate where diversity is valued and respected (England, 2003) is required. In addition, leadership is needed to expand accurate perceptions that promote equity in opportunity (Marchorio, 2000). The expression of external perception is an integral aspect in the leadership role, and its implications for helping to overcome and challenge the prevalent external, or “attitudinal,” perceptions that form stereotypes concerning individuals with disability is a central focus. These

perceptions are a possible explanation for barriers in employment, and concerns include such factors as accommodation or legal and financial concerns (Kaye et al., 2011). In looking at public policy concerning the disabled, in the not so distant past, DeJong and Lifchez (1983) pointed out that “the ultimate and most pervasive of environmental barriers are the attitudinal ones, particularly the view that disabled people are helpless, pathetic victims deserving of charitable intervention” (p. 49). In the past, and still today, there remains a sentiment throughout societal culture that is pervasive and perceives the disabled as being physically defective, roguish, and even viewed to be without value (Hosking, 2008).

The history of leadership probes has always had a genesis in questions about leadership, such as whether leaders are born or made. The nature versus nurture mindset argument had roots in scientific research that sought to identify certain traits that are requisite in strong leaders (Johnson, Vernon, McCarthy, Molson, Harris & Jang, 1998). Moreover, contained in their work was an analysis of Stogdill’s work in 1948 that attempted to understand characteristics that distinguished individuals as “leaders.” He performed a voluminous literature review and pointed to originality, popularity, sociability, judgment, aggressiveness, desire to excel, humor, cooperativeness, liveliness, and athletic ability (Johnson et al., 1998) as commonly perceived leadership characteristics.

While Stogdill’s work provided important insight into characteristics that are commonly perceived as necessary for leadership, it did place limitations on potential for development or enhancement of those characteristics. The conversation concerning whether leaders are born or are made, continues to exist (Pentilla, 2021); yet, Marques

(2010) suggested that the question is difficult to answer, and the increasing demand for a globalized framework regarding the skills and traits necessary to navigate the demands of leadership requires a constant evolution in just how to define leadership. Irrespective of the definition, research has evidenced that there are core traits such as drive, leadership motivation, honesty/integrity, self-confidence, cognitive ability, knowledge of business (Kirkpatrick & Locke, 1991) that are common among those in leadership positions. However, these scholars reminded their audience that traits are not the singularity that makes leaders successful, but that those possessing leadership traits increase the likelihood that measures will be made and are likely to be successful (Kirkpatrick & Locke, 1991).

The idea that perceptions of a particular person's leadership style equates to performance (Dirks, 2000) either being a successful or failed leader, was a major theme in the literature. In their work, *Leadership and Information Processing: Linking Perceptions and Performance*, Lord and Maher (1991) addressed the perception component to leadership, prudently distinguishing between leadership and merely managing, claiming that leadership is a concept that stems from a social-perceptual lens; in other words, leadership is essentially based on the perception of others. One implication of their work was that it is human nature to view leaders and visually judge their competencies. But, this paradigm has the potential to negatively impact the disabled. Whether directly or indirectly, our thoughts about leadership styles influence how we view leaders in our environment (Gentry, Deal, Stawiski & Ruderman, 2012).

Within any work environment, leaders always become bound by both patent and latent values that create a leader-follower contract based on subjectivity and individual

interpretations that shape perceptions about leaders and their behaviors (Caldwell, Bischoff, & Karri, 2002; Caldwell & Hayes, 2007). When exploring perceptions of leadership, the natural evolution of this study would be to extend the conversation into how external perceptions impact the disabled as leaders. Noting that the literature on this specific point is scant, there are only a few dissertations that have addressed this particular frame of thought. One work of interest has attempted to bring light as to how the glass ceiling (Bain & Cummings, 2000; Maume Jr, 2004; Morrison, White, & Van Velsor, 1992) impacts women and other minority groups, specifically those with disabilities, in high level positions of power that exist in organizations (Marchorio, 2000).

A study by Marchorio (2000) examined the perceptions attached to their leadership ability those individuals with physical disabilities. The focus of the study was to understand how “attitudinal” perceptions are formed and projected onto the physically disabled. Fifty-six males and 89 females from a psychology class participated in two studies. The first study found that when “compared to the nondisabled applicant, the applicant with a disability received lower ratings of supervisory job performance, was perceived as less able to work in a fast-paced work environment and travel overnight on business trips, and received fewer offers of employment” (Marchorio, 2000, p.154). Marchorio’s findings further confirmed Heilman’s lack of fit framework where people with disabilities have such negative perceptions as being leaders due to the fact that people feel they are not capable of being competent in performing their job duties (Heilman, 1983; Marchorio, 2000).

Additionally, the second study he reported countered his prediction that supervisors who were not disabled would always receive higher ratings. Marchorio

(2000) found that disabled supervisors that showed leadership behaviors were higher rated on their performance, overall, as opposed to their counterparts; moreover, the study further reported the nondisabled targets who exhibited behaviors antithetical to the resemblance of leadership either were similar to the nondisabled supervisors or were scaled lower. These findings from these two studies corroborated the study by Baldwin and Johnson (1998) whose work confronted workplace myths related to the disabled, highlighting the fact they hold reservations about individuals with disabilities because their conditions stymie their competence, limiting their ability to engage in specific tasks; however, a majority still are able to perform, adequately, and in some cases, may be as productive or more so than their non-disabled peers in certain jobs. A National Organization on Disability survey reported that 72% of those unemployed and with disabilities have a desire to work (1998); however; one of the most common impediments is the employer's inability to view those persons with disabilities as being capable of doing a good job (Hinton, 2003). The following section addresses understandings in the literature concerning workplace advancement for individuals with disabilities.

Glass Ceiling Effect: Limitations on Individual Advancement

Despite gainful employment, the literature has shown that for a variety of reasons, such as spatial inaccessibility in the workplace, for instance, a “glass ceiling” exists for the disabled, and they are less likely to receive promotions (England, 2003). According to Cotter, Hermsen, Ovadia, and Vanneman, (2001), the disadvantages from the “glass ceiling effect” usually are more prominent at the top levels of institutions, rather than the lower levels, and grow worse, in effect, at the later stages of a person's career. Aligning with Sir Bob Geldof's thoughts on antiquated organizational structures, Coyne (2016)

echoed the fact that many institutions and leaders are still operating in a 20th century mindset. When applying this statement to the educational setting, this regressive mindset is an inferred assumption that is a logical reason for the lack of educational administrators with disabilities in the K-12 American educational system.

Impact of Legislation on Opportunities in the Workforce

According to Shuttleworth (2007), sometimes unapproachable debates are necessary in addressing a variety of issues that have affected many minority groups, including the disabled, to begin moving forward in policy development in many differing work industries. In their work, *Reasons for Not Hiring or Retaining Workers with Disabilities*, Kaye, Jans and Jones (2011) provided a questionnaire that looked at policy strategies and reported their respondents' comments were overwhelmingly grounded in the notion that education was necessary to reshaping employer perception of those with disabilities, including workplace exposure where both parties collaborate together to gain first-hand knowledge. Extending this idea to the K-12 administrative educational context is a vital step in positively moving perceptions in a direction where barriers are minimized and policies of inclusion can be enhanced and improved.

In the literature pertaining to inclusion policies and the need for school administrators to help understand how to achieve positive outcomes for students with disabilities, be it via educational and/or policy training, instructional programs designed to achieve state standards and the concomitant strategies to increase equity, there was a beneficial corollary to hiring the disabled as leaders (Kraft, 2016). Those in charge of creating policy needed to focus on making successes on behalf of those students with disabilities a celebration and ensure that students have the best practices related to

instruction in effort to facilitate achievement and better prepare them (Schultz, 2011). Research has illustrated that student populations of a particular cultural background are more receptive to school leaders that reflect the sameness in ethnicity and diversity (Bush, Glover, & Sood, 2006; Coleman, 2012); therefore, the implication is that reflecting the sameness in diversity should be reflected in the administrative and teaching bodies also.

Leveling the Playing Field: Education and Opportunity for the Disabled

Many experts have agreed that, while the intent of the ADA is inherently good and has afforded many people with disabilities opportunities they otherwise have not realized prior to its passage, frivolous lawsuits and the interpretation of the spirit of the law has disenfranchised and stymied those within the disabled community, whom it was intended to protect (Burns & Gordon, 2010). Outside of individual experience with the failures that plague the ADA, governmental agencies wrestled with the results of this law. The Department of Justice (DOJ) and other advocates expressed concerns about the effectiveness of the ADA and indicated that this federal legislation is not being adequately used by those with true disabilities. As West (1994) explained, the ADA is being trivialized, and according to the DOJ, is failing those people who are currently employed and making it more arduous for those individuals with higher degrees of disability to find work.

The argument that this particular legislation is unintentionally impacting those with the disabilities it was intended to protect is echoed by Karger and Rose (2010) who mention that because of the vague language in the ADA, there are certain minority groups who protest vulnerability and claim protected status, when, in reality, this is

egregious classification and is a trivialization of the law and its intent. Arguing that the ADA is intended to transition the disabled into society and ensure equal participation, they pointed out that when the disabled undergo such classification of protections, actually, “they are being further isolated from mainstream American society. Social policy legislation should not further balkanize American society; instead it should create conditions that allow all people to participate as equal citizens with equal protections under the law” (Karger & Rose, 2010, p. 83).

Social policy formation that sets to achieve equal protections to those with disabilities is a scope that begins with a reorienting of mental constructs that create negative perceptions. In fact, much of the literature suggested that attitudes concerning those with a disability remain a workplace continue concern (Cubero, 2006; Kennedy, 1993); especially, those attitudes described as negative and fearful that remain as barriers to employment (Siperstein, Romano, Mohler, & Parker, 2006). A potential barrier for those people disabilities desiring to enter the workforce that Millington, Szymanski and Hanley-Maxwell (1994) point to is the organizational or employee selection process when hiring, which is impacted by deficit and negative perceptions, making it a crucial aspect to the level of employability of the disabled (Unger, 2002). Further, in looking at employment attitudes and perceptions of the hiring the disabled, some of the top concerns include the severity of the disability, the employers’ lack of previous experience of working with those with disabilities, extra training and supervision dependability, quality of work, cost of accommodation, misconceptions in work potential, etc. (Blanck, 1998; Olson, Cioffi, Yovanoff, & Mank, 2000; Unger, 2002). Additionally, the literature revealed mobility, educational level, sex, geographic location, age and number of

dependents as factors that contribute to unemployment for the disabled; adding Supplemental Social Security (SSI) and Social Security Disability Insurance (SSDI) to the list as elements that serve to stymie the motivation to work (Kennedy, 1993; Poole, 1987).

Leveling the playing field in order to create an environment where people with disabilities witness their employability increase has and will continue to remain a large task. Although, organizations who use anti-bias and diversity training programs to training personnel about their specific behavioral attitudes and biases will help positively influence how they view people with disabilities, which will help to establish and maintain equal footings for all employed in the organizational structure (Leasher, Miller & Gooden, 2009). Johnston and Macrae's (1994) research on stereotyping has found that when information is fully processed by subjects, the stereotypical evaluations of minority groups did reduce.

However, change for the sake of change is not sufficient. Regarding employer efforts to affect changes in an institution's culture of behavior, the commitment to train personnel must be a focus, and there needs to be evidence of subsequent organizational outcomes, such as enhancing practices that improve the willingness to recruit, hire and retain a diverse labor force (De Meuse, Hostager, & O'Neill, 2007). Positive changes in perceptions and attitudes towards those with disabilities have surfaced with the appropriate and necessary educational instruction and programs that are specifically developed to establish and promote contact between those with disabilities and those without disabilities (Corrigan et al., 2001). De Meuse, Hostager, and O'Neill (2007) agreed that the time and money spent on diversity training are worthwhile investments if

an organization desires to enhance the attitudes of the participants attending the workshop.

The workforce has much to benefit from the inclusion of people with disabilities. This is a rich pool that provides employers with “unique abilities to enhance labor force diversity, improve productivity, and inspire innovation ... there has been a recent rise in interest from businesses to engage the talents of this population to meet their labor supply shortages” (Yin, Shaewitz, Overton, & Smith, 2018, p. 2), and of great value, their hiring works to increase the public’s perception of both parties. One study estimated that approximately 92 percent of the study’s participants held favorable attitudes concerning businesses that hired disabled individuals and were more willing to use their services, as a result of this hiring practice (Siperstein et al., 2006); yet, in spite of the utilization of these favorable hiring practices, declining employment rates continue and bad policies remain in place (Burkhauser & Stapleton, 2004).

Combining anti-bias and diversity training programs with strong self-advocacy skills and the need to create new institutional policies that help ensure opportunity are a few other valuable steps in leveling the playing field; however, drafting the most effective organizational policies is a delicate balance between championing employment and instituting undue hardships on employers, which can act as a catalyst for the development of protective measures that further discriminations in the hiring process for the disabled. There is a body of literature and many disability advocates who have suggested that previous U.S. disability policymakers created policies that fall short of serving the population they were intended for, creating an environment where economic benefits for the disabled, as facilitated by the ADA, raised the disability benefit rolls and

decreased employment (Burkhauser & Daly, 2002). Zola (2005) argued for a shift in policy to represent the universal notion that society, overall, is not immune from the impact of disability.

Developing leadership through self-advocacy, by arming the disability community, is an important skill in promoting self-sufficiency and helping these individuals find a voice to inform employers in guiding policy making (Pederson, 1997). Breaking away from drafting policies through the lens of the medical model approach towards a self-sufficiency is a modernization of perspective; specifically, in the way disability is framed and viewed, allowing for innovative ways to incorporate technologies the help ameliorate the degree of a person's disability to increase productivity (Stapleton, O'day, Livermore, & Imparato, 2006). It was their contention that policy creation must stop focusing on "piecemeal changes to programs that are already too complex, we need systemwide reforms that fundamentally change support policies by replacing today's outdated policies with economic self-sufficiency policies" (Stapleton, et al., 2006, p. 716). Stapleton, et al. (2006) claimed that such a deftly designed policy will be incredibly beneficial in undercutting the welfare programs that frustrate disability employment, and that the point of contention is not if there is a move to a policy that promotes economic policy with self-sufficiency, but how rapidly we will progress in achieving the goal of lifting the standard of living for the disabled.

Theoretical Frameworks

Critical Disability Theory (CDT) and Authentic Leadership (AL) were two particular theoretical lenses that served to inform this study and address the research questions. CDT has suggested that disability is a perspective that views the condition as a

social construction that creates disadvantageous social circumstances that comprise of the “physical, institutional and attitudinal” settings that often fail individuals with disabilities because of the implied sense of a “social expectation of normalcy” (Hosking, 2008, p. 7). Additionally, AL has served as a catalyst for the development of positive mental faculties and high moral atmosphere driven by an individual’s ability to navigate the four core components germane to AL, which include “self-awareness, balanced processing, relational transparency, and an internalized moral perspective” (Gardner et al., 2011, p. 1123). George, Sims, McLean, and Mayer (2007) described AL in the context of a life journey that illuminates one’s personal life experiences, and it is through these critical moments of time that an individual yields their greatest influence to impact others in a substantial manner.

Critical Disability Theory

The literature review outlined societal constructs that limit opportunities for individuals with disabilities. According to Critical Disability Theory (CDT) (Hosking, 2008); however, another underlying message that should be revealed is the potential for those with disabilities to collaborate with the non-disabled community to dialogue and combine respective understandings of the factors that potentially provide barriers for the disabled. Identifying the barriers which hinder them from working in certain settings can potentially bridge the miscommunications that perpetuate the furtherance of social stigmas. One theory that has helped facilitate this process is CDT.

CDT is a theory that traditionally falls under the umbrella of feminist theory. Although many scholars have apprehensions concerning disability studies and its application with academia practice (Garland-Thomson, 2002) its use is gaining steam and

is beginning to blossom within the world of literature - finding a niche of its own. Moreover, the utilization of CDT continues to gain recognition from contemporary scholars because of the symbiotic relationship that helps to inform both the feminists and disability fields of study. Garland-Thomson (2002) argued for the expansion of disability studies, believing that disability and feminist studies share a usually beneficial relationship leading to examination of disability and how to better destigmatize and integrate people with disabilities into society.

Not too long in the past, disability carried with it a cold connotation: a definition that encompassed a notion that imported a restricted explanation that the disabled community are to be viewed as a medical issue or colored them as institutionalized subjects (Tremain, 2005). In a review of Canadian policy on disability, Jongbloed (2003) noted that the last century has seen a great deal of change with respect to the health of the disabled; pointing out that during the eighteenth century, the Canadian view swung from a medical issue to that of an economic deficit, finally resting in the minds as a sociopolitical problem. Hahn (1993) distinguished between these three paradigms, which show the progression of disability conceptualizations, writing that the limitations on major life activities are measured through the medical model; the economics are measured by the specification or type of work that can be undertaken; socio-politically speaking, it is the focus on the individual and environmental interactions.

Years following the era of civil rights, which brought about societal change for many groups of American people, many scholars that focus on the disability movement and disability studies continued to define the conversation as an association between disability and the physical environment; however, the experience of the disabled includes

the interplay of social institutions and human perceptions that require a great deal of conformity to function in their surroundings. These institutions have a responsibility to accommodate to promote access and equity for those with disabilities (Asch, 2017). The prescribed notions of leadership, as they are attached to those with a disability, are normally rooted in negative stereotypes that build barriers for individuals with disabilities (Marchioro, 2000; Unger, 2002). While the sociopolitical definition has spurred on social progress, the stereotypical attitudes that viewed those with a disability as biological inferior or charitable causes, remains impactful, still today (Jongbloed, 2003).

Additionally, the CDT model has addressed the perceptions and practices of viewing disability as a weakness (McRuer, 2003); in so doing, indirectly, it further removes the shackles of the long-standing idea of seeing disability in terms of a medical model and confirms the need to view it as a social model (Tremain, 2005), as CDT provides a perspective of disability that represents a social construction. As detailed, the composition of social aspects consists of the “physical, institutional and attitudinal” settings that fail individuals with disabilities due to the implication that there is a certain degree of normality that everyone must attain. It focuses on social contexts occurring in the societal institutions where individuals function, while showing particular patterns of behavior (Creswell, 2014) within their environments that shape how people without a disability view how those with disabilities are unsuccessful in meeting society’s definition of what is normal (Hosking, 2008). This perspective can help to uncover the “attitudinal” perceptions that influence opportunities for individuals with disabilities in leadership positions.

The model's first principle defines disability as a social construct where meaning is not defined by impairment, but rather, as shown in principle two, the existing dynamic relationship between impairment, participants' responses to the impairment, and the social environment the actor is bound (Hosking, 2008,). Principle three takes into consideration the social disadvantage that is lived by the disabled, inherently brought about by the "physical, institutional and attitudinal (together, the 'social') environment" which does not meet the needs of people who do not match the "social expectation of 'normalcy'" (Hosking, 2008, p. 7). A 2005-2006 qualitative study looked at factors that influenced employment of 56 disabled people and reported that the evidenced suggested that external perceptions of disability held a correlation with their ability to maintain and locate employment, rather than the accommodation factor (Shier, Graham & Jones, 2009). It is important to understand that CDT is not presenting disability as a rightful entitlement. Instead, it is soliciting ownership in constructing mental schemas that are conducive to building mutual relationships between the disabled and non-disabled in effort to curb workforce barriers. As Hosking (2008) concluded CDT "provides a conceptual framework to understand the relationship between impairment, disability and society and to inject disability interests into all policy arenas" (p. 17).

CDT and Jane's Story. This study sought to tell the story of Jane, the co-founder of a television educational program that teaches children to use sign language as a valuable form of communication. The overall goal was to provide an understanding of how she is inspiring individuals with disabilities to reach potential beyond the limitations because of their disability. For the purposes of this study, an individual with a disability is one who qualifies under Section 504 of the Rehabilitation Act, which defines disability

as: “a physical or mental impairment that substantially limits one or more major life activities ... major life activities include walking, seeing, hearing, speaking, breathing, learning, working, caring for oneself, and performing manual tasks” (Henderson, 1995, p. 4).

CDT is a useful theory that can help explain the findings from this study. The social aspects encompass environmental and institutional settings that possess inherent challenges, creating insurmountable disadvantages that link failure to the disabled; furthermore, CDT outlines that: 1) disability is a social construction; it is not an inevitable consequence of impairment; 2) disability is a "complex interrelationship between impairment, individual response to impairment, and the social environment" and 3) any social disadvantage of disabled people is brought on by "the physical, institutional and attitudinal environment which fails to meet the needs of people who do not match the social expectation of 'normalcy'" (Hosking, 2008, p. 7). The principles contained in CDT (see Table 1 for details) guide the development of a more complete understanding of disability. More specifically how the person’s physical, social and workplace environments interact with the disability, shaping outsider perceptions that create more challenges and barriers. More importantly, it accounts for how the impairment is viewed as a social framework and can be utilized to provide explanations for how obstacles in specific environments are considered to be disadvantageous to the person with a disability. A breakdown of CDT and its principles based on the social model of disability are shown directly below.

Table 1

Hoskins (2008) Critical Disability Theory

Critical disability theory (CDT)	CDT “is an emerging theoretical framework for the study and analysis of disability issues”	(Hosking, p. 1, 2008)
Critical disability theory (CDT)	“(c)ritical disability theory adopts a version of the social model based on the principles,” shown directly below”	(Hosking, p. 1, 2008)
Social Model of Disability: Principal One	“(d)isability is a social construct, not the inevitable consequence of impairment”	(Hosking, p. 7, 2008)
Social Model of Disability: Principal Two	“(d)isability is best characterised as a complex interrelationship between impairment, individual response to impairment, and the social environment”	(Hosking, p. 7, 2008)
Social Model of Disability: Principal Three	“(t)he social disadvantage experienced by disabled people is caused by the physical, institutional and attitudinal (together, the ‘social’) environment which fails to meet the needs of people who do not match the social expectation of ‘normalcy”	(Hosking, p. 7, 2008)

Note. Adapted from Hosking, D. L. (2008). Critical Disability Theory. A paper presented at the 4th Biennial Disability Studies Conference at Lancaster University, UK, Sept. 2-4, 2008.

Authentic Leadership

Authentic leadership is a model built on broad, measurable principles that is based on the need for trustworthiness and includes a moral component concerned with values and allows for leadership development over time; antithetically, one of the greatest criticisms includes the need for more empirical research to substantiate the practical approach and explore the moral complexity (Northouse, 2018). Additionally, Cooper,

Scandura, and Schriesheim (2005) addressed the need for further developing validity in measuring authentic leadership, stating that it “will eventually be necessary to have a valid measure of authentic leadership in order to be able to evaluate any training interventions” (p. 477). Since that time, work has been done to develop a survey instrument that is both valid and reliable (Walumbwa et al., 2008). This instrument operationalizes authentic leadership around four constructs: self-awareness, relational transparency, internalized moral perspective, and balanced processing (see Figure 1 below). These four constructs, together, form the “higher-order” latent condition of authentic leadership. (Gardner et al., 2011; Walumbwa et al., 2008). While initial concerns about developing an instrument to measure authentic leadership centered around an inability to discriminate between authentic leadership and other normative leadership conditions (e.g. ethical leadership and transformational leadership, their “results suggest that it is possible to discriminate the authentic leadership measure from other related leadership orientations (e.g., ethical leadership and transformational leadership)” (Walumbwa et al., 2008, p. 118). Findings suggested that the Authentic Leadership Questionnaire (ALQ) is, indeed, a reliable and valid instrument to assess authentic leadership characteristics (Gardner et al., 2011; Walumbwa et al., 2008).

The literature also contains critical analysis of the authentic leadership, purporting that within the context of this model, it is impossible to rely on the authenticity of a leader due to the fact that authentic leadership approach fails to account for a person’s imperfections (Ford & Harding, 2011). Moreover, although they did find some validity in understanding the self in relation to the influence a person has upon an organization, they provided two potential weaknesses with the authentic leadership model, highlighting that

it utilizes a positive psychology perspective that fails to account for the fact that individuals are contradictory and that those who both lead and follow are so closely tied to the organization that they abdicate any personal identity and the ability to remain subjective (Ford & Harding, 2011).

Falling under the umbrella of the practical approach, George (2010) put forth the notion of the “True North,” which he explains through a values-based lens where leaders have “a clear idea of who they are, where they are going, and what the right things is to do” (Northouse, 2016, p. 198-199). Authentic leaders hone their skills, using natural ability to overcome challenges and adversity that helps them identify their weaknesses to become an even better at leading with “purpose, meaning and values” (George, 2003, p. 12). At the core of authentic leaders are characteristics that include remaining *passionate* in purpose, adhering to values, remaining connected in relationships, staying consistent in self-discipline, and keeping a compassionate heart (George, 2003).

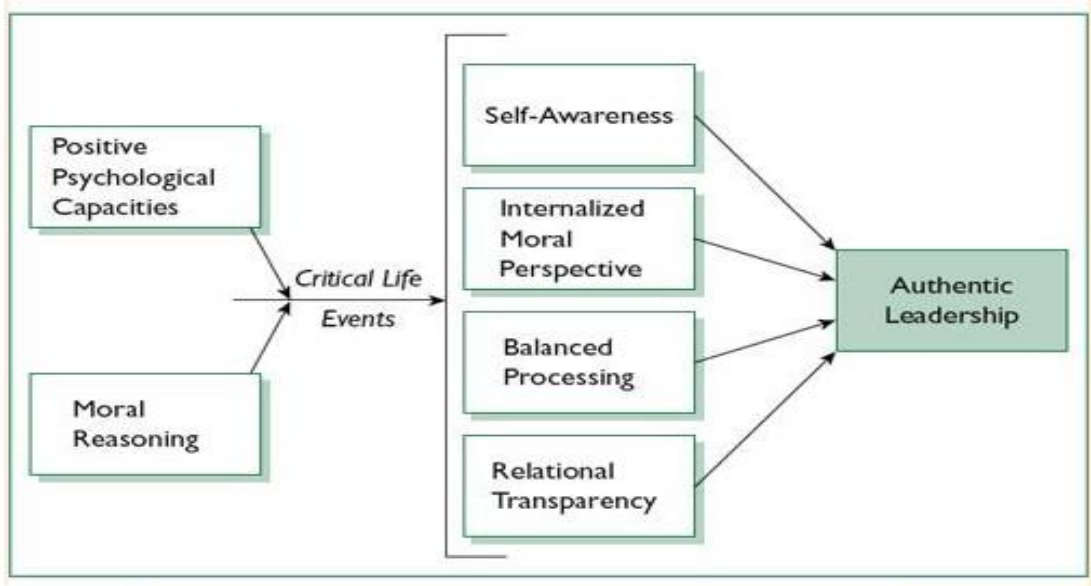
A person’s leadership style surfaces from one’s life story (George, Sims, McLean, & Mayer, 2007). Much like narrative inquiry, the notions of individual reflection, the self and critical life events all intertwine to become a pivotal point of the framework that promotes positive progress and crafting authentic leaders (Connelly & Clandinin, 1990; Murphy, 2012; Sparrowe, 2005; Webster & Mertova, 2007). Shamir and Eilam (2005) elucidated on how accounts of leader’s stories and lived experiences proffer meaningful understandings that are established and barnacle themselves to a person, helping to construct platforms of self-transparency imbued with degrees of self-knowledge and concept clarity that serve to help followers judge leader authenticity. These critical life events are powerful tools in harnessing and instilling maturity that is foundational for

strong leadership (Avolio & Luthans, 2003). Northouse (2018) told that “critical life events are major events that shape people’s lives, and therefore also shape an individual’s development as an authentic leader” (p. 206).

Turning from a focus on the organizational scope as it pertains to authentic leadership, a theme that carries through and grows apparent in authentic leadership is the important premise as to how the self and life experiences play a primary role in becoming genuine and guide this particular leadership development process at the individual level (Shamir, & Eilam, 2005). Much like narrative inquiry, as it relates to the personal level, the experiences gained through lived or critical life events are valuable in creating the story of the individual. George et al. (2007) discussed authentic leadership in terms of it being of an odyssey that “begins with understanding the story of your life. Your life story provides the context for your experiences, and through it, you can find the inspiration to make an impact in the world” (p. 2). This study sought to understand Jane’s story and her leadership abilities are able to reach and motivate those with disabilities to overcome life and educational challenges.

Figure 1

Authentic Leadership



Note. Four Elements of Authentic Leadership (Northouse, 2016, p. 202).

CHAPTER III

METHODOLOGY

Summary of the Problem and Purpose

This study tells the story of a woman, who shall remain anonymously known as Jane, who is involved with an educational program that teaches children to use sign language as a valuable form of communication. The overall goal was to provide an understanding of how she inspired individuals with disabilities to reach potential beyond the limitations they have experienced because of their disability. For the purposes of this study, an individual with a disability is one who qualifies under Section 504 of the Rehabilitation Act, which defined disability as: “a physical or mental impairment that substantially limits one or more major life activities ... major life activities include walking, seeing, hearing, speaking, breathing, learning, working, caring for oneself, and performing manual tasks” (Henderson, 1995, p. 4). The problem identified for this study was that even though the Americans with Disability Act (ADA) was established in 1990 to promote equity and prohibit employment injustices for individuals based upon disability, (Equal Employment Opportunities Commission, 2017) many individuals still experience discrimination and lack opportunity in the workforce.

The ADA protects individuals with disabilities and requires reasonable accommodations that promote accessibility in the workforce. In 2012, America had

27,382,000 individuals with a disability, but only 5,722,000 of those individuals counted in the labor force (Burns et al., 2012). In 2015, 19.8% of those with disabilities were counted in the labor force and held an 11.2% unemployment rate, while the non-disabled demographic comprised 68.2% of the labor force with an unemployment rate of 5.6% (Southeast ADA Center, 2015, para. 1 & 2). Although the COVID-19 pandemic contributed to the unemployment rates, in 2020, there were 5.35 million people with a disability who represented either full or part-time workers (Statistica Research Department, 2021).

Furthermore, as of February 2020, those with a disability and without a disability in the labor force were 17.9% and 61.8%, respectively, which equated to an unemployment rate of 12.6% for those who were disabled and 7.9% for those without a disability (U. S. Bureau of Labor Statistics, 2021). According to the U. S. Bureau of Labor Statistics (2021), 8 in 10 of the disabled were not in the labor force, while 3 in 10 of those with no disability worked, concluding that those within the disabled community experienced higher levels of unemployment than individuals outside of the disabled community. Although these numbers indicate that discrimination of individuals with disabilities is a potential factor, there are a minority of individuals with disabilities who enjoy gainful employment and successfully utilize their talents to sustain that employment.

One potential explanation of this anomaly could be the result of misunderstandings by those in society who do not have a disability or possess actual limitations that challenge their capacity to contribute to society and to the workforce. In fact, it is quite rare (Marchioro, 2000) for individuals without a disability to understand

what it is like to have a disability. This is not to say that such a perspective is an impossibility. There are nondisabled people who inspire, encourage and stir the potential in those individuals to accomplish goals and attempt tasks beyond the perceptions of the medical and/or educational professionals. The purpose of this study is to tell the story of Jane, a woman who inspires individuals with disabilities to reach their potential beyond the limitations placed upon them by societal expectation, which resulted because of their disabilities. The research questions for this study included:

Research Questions

Overarching Questions

1. How does Jane influence individuals with disabilities, their caregivers, and families to exceed expectations placed upon these individuals because of their disability?
2. How does Jane influence these individuals to achieve positions in the workforce beyond what was expected of them?

Sub-Questions

- A. How does Jane perceive individuals with disabilities and how does she communicate this perception?
- B. What factors influence Jane's perception of individuals with disabilities?
- C. How does Jane's influence guide disabled individuals to realize their potential to overcome real and socially constructed limitations?

Qualitative Paradigm

According to Crotty (1998), epistemology refers to “the theory of knowledge embedded in the theoretical perspective and thereby in the methodology” (p. 3) of a

research study. The research design of this study was qualitative in nature, using a narrative inquiry design, which aligns with the constructivist epistemology (Crotty, 1998). Constructivism (Patton, 2002) is often combined with interpretivism, where “qualitative research focuses on meaning making as a reflexive, complex, and continuous process” (Manning & Kunkel, 2014, p. 435). Constructivists analyze the multiple realities and the following implications that stem from how people’s lives are constructed through human interactions within their experiences; whereas, constructionism analyzes the knowledge about reality, instead of the reality, in and of itself (Patton, 2002). With respect to constructivism, Creswell (2014) purported that the “goal of this [qualitative] research is to rely as much as possible on the participants’ views of the situation being studied” (p. 8).

Constructivism was an important epistemology for this study because meaning is socially constructed (Crotty, 1998) and it is the viewpoint of the participants that constructed meaning (Creswell, 2014). Caine et al. (2013) explained that it is the experiences within the inquiry construct that clarifies the epistemological consideration. Qualitative researchers have interpreted findings in light of their own mutual experiences (Creswell, 2014); however, this study highlights mutual events of the researcher and participants and focuses on the participant’s experiences that derive meaning.

Methods

Qualitative research methods are increasingly becoming more common place across a wide variety of research disciplines, and having a growing footprint, internationally (Zitomer & Goodwin; 2014; Easterby-Smith, Golden-Biddle, & Locke, 2008; Elliott, Fischer, & Rennie, 1999; Pitney, 2004; Temple, 1998; Whitemore, Chase,

& Mandle, 2001). Connelly and Clandinin (2006) have defined narrative inquiry (as cited in Clandinin, Pushor & Orr, 2007) as “a methodology [that] entails a view of the phenomenon ... adopts a particular narrative view of experience as phenomena under study” (p. 22). This study utilized a qualitative narrative inquiry design and has established an understanding of the experiences of Jane, who is the co-founder of an educational program that meets the needs of individuals who experience a variety of disabilities. Her journey has given her the platform to help those with disabilities since she had to fight challenges and discriminations that she encountered due to her daughters’ disabilities.

The inherent nature of narrative inquiry heavily relies upon the notion of experience, which captures a deeper and richer meaning and understanding of a phenomenon under study (Bochner & Riggs, 2014; Clandinin, 2006; Mertova & Webster, 2012). This particular qualitative methodology is valuable and facilitates the process whereby the “human experience” expresses itself (Connelly & Clandinin, 1990). Connelly and Clandinin (1990) eloquently posited that narrative inquiry has become a prevalent methodology, both inside and outside the field of educational studies because human beings are complex, interactive, and lead storied lives in an evolving state; therefore, there must be a mechanism that captures the way we all experience the world by fragmenting these personal lived experiences in our own individual journey, but also those who interact with us and each other (Connelly & Clandinin, 1990).

Outside of the participant’s experiential viewpoint, a “[r]esearchers’ own personal training and experiences also influence their choice of approach” (Creswell, 2014, p. 20). The narrative inquiry paradigm is deeply relational, so it is vital that the researcher

recognize the importance of being objective. It is also necessary that the researcher understand that the more the connections continually deepen between both parties, the more they learn of one another, and the more the dynamics between both of them change (Pinnegar & Daynes, 2007). Research has further addressed this issue and clarified that “[a] narrative ontology precedes the emergence of research puzzles and calls forth obligations and commitments. A narrative ontology implies that experiences are continuously interactive, resulting in changes in both people and the contexts in which they interact” (Caine et al., 2013; Dewey, 1981).

A participant’s story permits an authentic examination or interpretation of compelling occurrences or problems that people experience (Caine et al., 2013). As this study naturally evolved through time, I established a foundational understanding of Jane’s journey and the challenges that shaped her critical life events (Miller, 2000). Jane has a very important story that needs exploration, and narrative inquiry is the ideal methodology for this qualitative study because it allows for a thorough navigation of Jane’s personal journey, “organically.” The term “organic” is appropriate since this study’s structural research design and epistemology helped to explain the information from the participant’s perspective. Such a perspective rendered useful data found from an examination of critical events in Jane’s life (Bohl, 1995; Webster & Mertova, 2007). Critical events as they relate to the human experience, teaching and learning is not a new mechanism (Woods, 1993). Bohl (1995) explained their significance in that critical events become impactful in the very notion that they are poignant to the storyteller, which makes them extremely influential. The expression of events as stories help guide understandings of varying worldviews and take on a critical nature by being attractive

and traumatic, contain risk, and possess powerful consequences (Webster & Mertova, 2007).

It is important that these challenges are understood because they open avenues of discussion that are necessary for exploring meaningful explanations that have application to others' personal and parallel life experiences. Clandinin and Connelly (1990) explained that the essence of living storied lives involves telling stories that stem from living in an evolving context where reflections about people and their lives are expressive to others. Riessman (2008) added that the process of telling stories captures the attention of the audience and highlights the experiences of the narrator. "Importantly, the act of narration that structures and projects our sense of selfhood and identity over time, along with the tellability of personal stories, is an embodied process" (Smith & Sparkes, 2008, p. 7).

Narrative inquiry uses story as a method in which participants convey critical events that stem from their lived experiences (Barrett & Stauffer, 2009; Clandinin, 2006; Clandinin & Huber, 2002; Clandinin & Rosiek, 2007; Connelly & Clandinin, 1990; Costello, 2015; Huber, Murphy, & Clandinin, 2011; Miller, 2000; Webster & Mertova, 2007). Although stories are valuable sources for understanding, narrative inquiry scholars have agreed that there must be a "visible" distinction between methodology and phenomenon with respect to stories and narrative (Connelly & Clandinin, 1990). According to Caine et al. (2013) a responsible researcher employs narrative inquiry and protects the integrity of such a distinction, stating: "we distinguish our commitments from research practices that use stories as data; view narrative and story as representational form, as content analysis, and as structure; or treat stories as the

phenomena under study” (p.2).

Within the narrative inquiry construct, it is the story in which we reside (Okri, 1997). As Caine et al. (2013) reminded us, “[s]tories as they are lived, told, retold, and relived circulate in and fill spaces between people. They offer us insights into experiences and resonate in ways that help us to learn and form connections with others” (p. 583). Central to narrative inquiry is the focus on experiences, which is based in the pragmatic works of John Dewey in relation experience to educational inquiry (Clandinin, 2006; Dewey, 1938, 1958 & 1904). More specifically, Clandinin and Connelly (2000) developed a narrative viewpoint with a basis on Dewey’s (1938 & 1958) principles of experience with interaction and continuity as the two criteria. Interaction is the first criterion and it explains that we understand individuals as complex and dynamic (Clandinin & Connelly, 2000). The second criterion, continuity, has basis in the notion that experiences beget experiences and create a cyclic experiential evolution of experiences, and “[w]herever one positions oneself in that continuum - the imagined now, some imagined past, or some imagined future – each point has a past experiential base and leads to an experiential future” (Clandinin & Connelly, 2000, p. 2).

Context is another noteworthy and a critical aspect of narrative inquiry. When it represents the form of human interaction, Goodwin (2000) explained that context contains complexities and is a “dynamic, temporally unfolding process accomplished through the ongoing rearrangement of structures in the talk, participants’ bodies, relevant artifacts, spaces, and features of the material surround that are the focus of the participants’ scrutiny” (p. 1519). The integrity of this particular narrative inquiry is maintained as the participant’s personal and social conditions are considered (Clandinin

et al., 2007). It is an all-encompassing process. Ollerenshaw and Creswell (2002) explained that contextual enmeshment in the participant's environment allows the researcher to gain "rich detail about the setting or context of the participant's experiences. This setting in narrative research may be friends, family, workplace, home, social organization, or school—the place in which a story physically occurs" (p. 332).

Ollerenshaw and Creswell (2002) indicated that within the educational research context, there is a growing legitimacy in the use of the stories and life experiences that individuals tell. The emergence of gathering stories is growing and has become a popular method of interpretive or qualitative research (Gudmundsdottir, 1997). Narrative inquiry is a valuable framework that is conducive to telling Jane's story that is replete with critical life events that have shaped who she is both personally and professionally. Her critical life events, like having two daughters with disabilities, shed light on her lived experiences. When viewing these experiences through the lenses of Critical Disability Theory and Authentic Leadership, it helps inform the study in understanding how Jane has been able to motivate those with disabilities to achieve beyond their potential.

Data Sources

In this study, Jane was the main source of data. I wanted a greater understanding of Jane's story that brought clarity to this qualitative study; therefore, the three employees and seven parents helped provide the study with a rich depth and differing points of view to Jane's life story. The study design employed purposeful and snowball sampling that identified interview participants who were sources of rich data (Patton, 2002). Suri (2011) differentiated between the two sampling strategies and explains that purposeful sampling requires identifying particular individuals or groups of people that yield access

to the necessary avenues of information in a given context. On the other hand, snowball sampling is a “method of sampling in qualitative research ... through which informants are accessed, or as an auxiliary mean, which assists researchers in enriching sampling clusters, and accessing new participants and social groups ... (Noy, 2008, p. 330). For purposes of this study, Jane was purposefully sampled; whereas, the three employees and seven parents were identified through snowball sampling.

Data Collection

Caine et al. (2013) suggested that full enmeshment in the lives of the participants is important for narrative inquirers no matter how arduous or challenging. The Institutional Review Board (IRB) protocol process was met with satisfaction and the hurdle of obtaining permission to interview subjects was cleared. I underwent the interview process, which followed semi-structured interview protocols. Semi-structured interviews were suitable for this study because they provided the ability to be flexible and prepared, (Cohen & Crabtree, 2006; Drever, 1995). I took the same considerations into account for the observation and document analysis process. I carefully approached the collection of data with respect for the subjects and the concomitant data. The logistics of the data collection process were developed and coordinated with Jane and the other interview subjects. This process included the creation of a convenient schedule that allotted for the appropriate dates and times for all of the subjects to interview.

Interviews

There were 11 interviews in total, which included Jane, three employees, and seven parents. Because of her experiences working with individuals with disabilities, she possessed intimate knowledge and skills related to the disabled, I chose Jane as the

primary interviewee. The other interview subjects were chosen because Jane had served them through her educational platform, so they had both a direct and indirect association with her. These participants provided a perspective of Jane's influence on individuals with disabilities and those in relation to them. The interviews took place until her circle created redundancy of data (Creswell, 2014; Crotty, 1998; Patton, 2002).

In terms of interview protocol, every interviewee was asked to sign an adult consent form (see Appendix A) before the interview started. This narrative inquiry employed semi-structured interviews that guided data collection (Patton, 2002). Three separate 16 question interview protocols (see Appendix B) were created to be utilized during the interview process. The first 16 question set was created for Jane's interview. The second and third 16 question sets were designed for the three employees and seven parents, respectively, and distributed prior to the interview, accordingly. An audio device recorded the individual question and answer interview sessions. The open-ended questions were designed to facilitate a deeper discussion that examined "people's experiences, perceptions, opinions, feelings, and knowledge" and provided the study with even more depth and rich context (Patton, 2003). The interview protocol helped to facilitate a smooth and efficient process; in turn, to capture the organic evolution of the information that surfaced during the interviews, which provided me the opportunity to ask follow-up questions to probe for more data.

Authentic Leadership Assessment Questionnaire (ALQ). The MindGarden, Inc. ALQ's (Appendices C & D) were distributed after each interview, and the interviewees were asked to complete their respective ALQ surveys on a volunteer basis. There were two different ALQ surveys provided to the interview stakeholders. The

Avolio et al. (2007) Authentic Leadership Self-Assessment Questionnaire (ALQ) (see Appendix C) was administered to Jane; whereas, the three employees and seven parents were given rater version of the ALQ (Avolio et al., 2007) (see Appendix D). More specifically, Jane was asked to rate herself on this leadership scale while the other interviewees who have worked either directly or indirectly were asked to rate her leadership abilities.

The ALQs were printed beforehand and given to the interview participants, individually, to be completed. The ALQ and pencil were both provided. I explained the purpose of the ALQs and entertained all of the questions the participants had both before and while they worked to finish the questionnaires. If they felt they did not have an answer, I instructed them to place a “Not Applicable” (NA) next to the specific question. I ensured all interviewees that the questionnaires were kept confidential and their names were not going to be disclosed in the study. There were a select few interviewees who used the NA descriptor on a few questions and while Parent Four volunteered, she elected to apply NA to all of the questions. Each completed ALQ was gathered and labeled as employee one, parent one, parent three etc. and placed in a folder I kept in my bag.

The license for the ALQs is controlled by MindGarden, Inc. (Avolio et al., 2007). It is a global tool that is accessed in 40 languages (Morton, 2012). I emailed MindGarden, Inc. and applied for permission to use the ALQ and was given confirmation. I utilized these questionnaires to interpret others’ perceptions of Jane’s leadership and then compared their ratings to her own self-rating. The completed report provided mean scores for each subscale of the ALQ. These ALQs were tested for validity and reliability with acceptable internal consistency reliability for each ALQ measure (self-awareness, .73;

relational transparency, .77; internalized moral perspective, .73; and balanced processing, .70) (Walumba et al., 2008). An overall model fit was performed through confirmatory factor analysis (CFI = .97, REMSEA = .06) (Walumbwa et al., 2008) and the model indicated that the higher order ALQ fit the (four factor) model well.

Self-Assessment ALQ. Once I interviewed Jane, I distributed a paper copy of the Authentic Leadership Self-Assessment Questionnaire (Avolio et al., 2007). This ALQ Self-Assessment was a 16-item survey that utilized a five-point Likert type response set with 0, which indicated “Not at all” and 4, which indicated “Frequently, if not always” response set. Sample items included, “say exactly what I mean” (transparency) and “make decisions based on my core values” (moral/ethical). Although this ALQ Self-Assessment was tested for validity and reliability, for purpose in this study, it provided an additional source of data about Jane’s perception of herself as a leader (Avolio et al., 2007) This self-assessment ALQ was used to compare Jane’s perceptions against those perceptions held by her three staff members and seven parents.

Rater ALQ. I asked others who worked with Jane and served under her leadership to assess Jane on the rater version of the Authentic Leadership Questionnaire (Avolio et al. (2007), which was a tested instrument, also. Walumbwa et al. (2008) explained that the ALQ “offer[s] a theory-driven higher order authentic leadership measure providing future researchers with one method for assessing authentic leadership” (p.118). This particular ALQ was a 16-item survey utilizing a five-point Likert type response set with 0, which indicated “Not at all” and 4, which indicated “Frequently, if not always” (Avolio et al., 2007). Sample items included, “admits mistakes when they are made” (transparency) and “asks you to take positions that support your core values”

(moral/ethical). Again, the stakeholder responses from this ALQ were compared with Jane's responses on the self-assessment ALQ.

Observations

A rich collection of data depended upon recording and analyzing all field texts (Clandinin, 2013) that related to the participants. Creswell (2014) explained that the qualitative approach tends to find those researchers who enjoy literary writing, conducting personal interviews, or making observations in close proximity. In addition to my personal interviews, I undertook up-close observations in a myriad of pertinent contexts, and ensured that I recorded any informal and formal interactions that provided a multitude of perspectives to the study.

The first of my observations took place on day one around 8:30 a.m. I arrived at the studio prior to any of the employees or Jane, but the first person I met was the administrative assistant, Employee One. We had a cordial introduction with a bit of humor about arriving so early before she showed me around the studio and explained the rooms and their purpose. While she stepped upstairs to place her personal effects, I found myself at the back entrance. There were stairs to the left, which led to the main office where Employee One and Employee Three worked. I took pictures of the artifacts that covered the walls of the hallway below the office that led straight into the open production area that was full of hanging lights that filled the room with soft lighting. I have included an entry taken from my initial observations on day one:

Building has stairs to access office and no elevator. I'm able to freely move about the screen room and front lobby where the interviews take place. The room is chilly, unlike the rest of the building. YouTube awards, a Women's Magazine

article with a smiling Jane and her daughters, a Utah Business and a Salt Lake Tribune newspaper articles about [Jane's educational platform], and many other artifacts are plugged and decorate the walls, which show Jane's and her company's success. (personal observation, October, 2019)

Several minutes passed before Employee One came downstairs to show me the rest of the building, which the front room that was designated solely for the interviews for the next few days, as well as the production and film editing rooms. For about forty-five minutes we toured and talked generally about me visiting and how long she had worked in the company, her role, and the day's agenda. She made certain I felt welcomed and had everything I needed. She informed me that Jane was on her way. She needed to get back upstairs, so I roamed about the building and reconnoitered and recorded notes about the physical setting.

From the colorful animation screen to the purple and green colored misshaped door that is used in the signing videos, the colors all around made the setting delightful and unique against the black walls that were dotted with sound material. I felt comfortable and noticed a warmth. I felt like I was dropped into a Dr. Seuss book. As I became acquainted with the environment, I saw other employees trickle inside and settle into their offices. Three of the film editors noticed me and greeted me with smiles. They graciously asked if I needed anything or if I had an appointment, but I kindly introduced myself and told them my purpose. Employee Three walked through room at a brisk pace. Before he entered the back hallway, upstairs, he glanced my way and gave me a head nod to indicate hello as he continued.

I visited the front room where the interviews were to take place that day to place

my pack. Once I located a spot for my wheelchair I continued to oscillate and recorded more notes about how I felt and my observations. Jane showed around 10:00 a.m. and her bright spirit set a positive tone for the whole day. Making her way to me, she greeted a few employees with a big smile. We greeted each other with smiles and laughter about the trip. We talked for several minutes before she continued to show me around the studio and introduced me to the film editors and the rest of the office team. She excused herself to go to the office and to call and make sure her youngest daughter was heading to the studio. Having a few minutes alone, I recorded the following observation:

All of the staff, the film editors and office staff feel very comfortable interacting with Jane. She is such a people person, naturally, so I'm not surprised she is the face of [the company]. Her personality is infectious and caring, which is driven by the family, I believe, since several family members work here. This is a very relaxed and family-oriented environment. Everyone who passes me asks if they can help me or get me anything. She is such a people person who works out of the office, a majority of the time, but her staff adore her. This is evident by their lighthearted and jocular behaviors when interacting. She has a very joyful nature and her smile comes with lots of laughter that creates a great and informal rapport. All of the staff feel very comfortable interacting with her. Her personality is so warm. There are people coming in and out, freely, and it seems that everyone knows their responsibility and role. The environment is not overly micromanaged and the employees are given freedom to speak their opinions. Even when employees are focusing on tasks, and Jane steps aside to field phone calls, they

are happily singing to themselves, laughing with another, or whistling. (Sean, observation, October, 2019)

The production studio was a fun and relaxed environment, which was a direct reflection of the staff. Jane returned from the upstairs office with Employee One by her side. I observed Jane and Employee One for approximately three minutes. It was both a pleasant and perfunctory exchange, as they chatted about the day's agenda and some other matters dealing with communications and other daily business. Jane smiled a lot and nodded her head while Employee One talked to her. She was expressive and engaging while Employee One spoke softly to her. Employee One was equally receptive and while she did not smile as much as Jane, she held a positive disposition, but I could tell she was anxiously thinking about her work day.

Shortly after my first observation, Jane's youngest daughter arrived through the back entrance. I was able to watch them interact with one another, briefly, before Jane introduced me. I was several feet away in the open gym area, so I could not hear any audible conversation, other than watching Jane throw open her arms and hearing her belt out, "hey" to her youngest child. Jane is very animated and did not hesitate to quip about her daughter's wheels compared to mine. This made her daughter smile and forget the early morning routine of getting ready for the day and traveling to the studio. After our short introduction, the three of us made our way outside and around the block to the go to an early lunch of soup and sandwiches. All of us immediately clicked and felt comfortable enough to inquire about Jane's family, her youngest daughter's future plans, her disability and how it influences their family; in turn, I answered questions about myself, my research, my accident and the challenges that come with paralysis. It was a

great lunch and the perfect way to continue learning about each other. After a few hours, the three of us strolled back to the studio and my interview with Jane commenced. I was heartened by Jane's invitation to come stay with them sometime and move to the area. It was an informative starting conversation.

When we returned to the studio after lunch, I said goodbye to her daughter and prepared to interview Jane. As we settled into the front room of the studio to start, Employee Three apologetically popped inside to speak with Jane for half a minute. Jane calmly resolved the issue without budging from the chair, and Employee Three hurriedly left, gently shutting the door behind him as he spoke the last of his thought. The rapport between the two of them was casual. Everything about Jane's interactions with the staff was casual. She had a talent of telegraphing through her facial and body language that the issue would be managed to a successful outcome.

The next few informal observations I witnessed came when Jane saw Parent One. I had just learned in our interview that these two have known each other for a number of years, so it was more of a reunion for them. It took place shortly after I finished interviewing Parent One, and she opened the door to make her way to the back entrance when Jane happened to be heading to the front room. There was a little boisterous conversation with some laughter and a hug. Their meeting did not last more than a minute before they both approached me and Jane began telling how important Parent One was to the company. I could tell that Jane genuinely valued her. Parent One expressed appreciation and that she enjoyed being a part of the company's mission. My next observation happened when Employees Two and Three crossed paths in the large stage production area. It was the briefest of all of the informal observations. These employees

share an office space upstairs, and the interaction that occurred was very business-like in nature. There were no smiles or laughter, but from afar, I could tell there were a few words shared followed by his nodding of his head. The whole time I observed, it was apparent that these employees carried a load of responsibilities within the company, and there was a professional respect for one another.

I also observed two film editors communicating and working together. There were only two of them in a room that mirrored the other film editing area that was separated by a hallway that connected the front entrance of the studio to the big production area. They both were equipped with sliding glass doors, so I was able to view them from where I positioned myself for the interviews. Both of the women were at their computers, clearly joking around while they worked. The youngest lady leaned over a few times and pointed out something on the screen of the other lady's computer. I did not leer for more than a minute, but from my perspective, they had close working relationship and were friendly. I later learned that the older lady was related to Jane and the youngest girl doubled as a film editor and made appearances in the signing videos, as well.

Lastly, my dinner with Jane and her youngest daughter was the last of my informal conversations. The three of us went for sushi at a place just across the street from my hotel. We had fun and held a conversation that was full of sarcastic humor, but was also serious, at times. Daughter Two spoke a bit more this time, and was a bit freer with her laughter. It was a great way to end a busy and informative trip to Utah. There were a few questions pertaining to my research and if I was able to get all of the interviews, but we also discussed more about her family. One of the more interesting Jane mentioned was that her uncle was the voice over for He-Man, from the cartoon. We all

chuckled about how actors ran in the family. She disclosed more about how she dealt with the challenges of having disabled children, and further discussed some very personal problems that she faced as a young adult, but was able to resolve years later. I appreciated the candid conversation and how Jane was authentically genuine and was not afraid to admit her past mistakes and talk about the wisdom gained from them. Daughter Two was equally as open, and I liked that she was not scared to offer her opinion. She definitely had a lot of her mother's strength.

Document Analysis

Documentations such as pictures, journal entries, archival pieces, or those “memory box artifacts” (Clandinin, 2013) were included in document analysis. During the data collection process in Utah, the collected data dominantly included 11 formal audio recorded interviews. Additionally, I recorded notes of the informal conversations and observations that took place between the actors in the setting, which were Jane, Daughter Two, employees, and parents. I also captured photographs both inside and outside of the studio. Among those photos taken were magazine and newspaper articles, and awards hanging on the studio walls. Further, I located and listened to prior interviews Jane had given on YouTube that detailed her story and involvement with the co-founding of the educational platform (Hanson, Balmer, & Giardino, 2011).

Various field notes that captured the mood of the climate and descriptions of the physical environmental context were also written. The majority of the data collection process occurred at the central production studio. Many pictures and field notes were taken outside of the building to create the “richness, nuance, and the intricacy of the lived stories and the landscape” captured in narrative inquiry (Clandinin & Connelly, 2000, p.

80). As a qualitative researcher it helped me to further enmesh myself into the complete environment (Patton, 2002). I spent a majority of the time inside the studio, but I was able to completely make my way around the outside of the studio to capture photographs and write about the environmental context and climate. The actual setting of the interviews was a location in front of the studio. It was a very bright and naturally well-lit area surrounded by windows and one wall that abutted the production rooms.

Gathering field records in a pragmatic setting via empirical observation of the subjects was a valuable tool in narrative inquiry (Connelly & Clandinin, 1990). The field notes I collected included observations of the environment and the informal behavioral interactions that I observed between the actors within the setting, which were recorded outside of the primary and secondary interviews. The field notes were written, and I actively worked to capture the mood of the studio; however, during the interview, the communications were recorded with an audio device. Ollernshaw and Creswell (2002) state that the “holistic-content analysis of field texts (e.g., transcripts, documents, and observational field notes) include[d] more than description and thematic development as found in many qualitative studies” (p. 330). I was attentive and prudent in working with sensitive information pertaining to an individual’s personal life story. I wanted to respect the information rather than a simple treatment as raw data. All of the necessary documents and pertinent information are located in the appendix portion of this study.

Data Analysis

Thematic Narrative Analysis

To guide the data analysis, I utilized Riessman’s (1993) thematic narrative analysis, which was an approach that allowed me to be concerned with the content of

Jane's story. Riessman (2008) explained that "narrative inquiry is, of course, concerned with content – "what" is said, written, or visually shown – but in thematic analysis, content [was] the exclusive focus" (p. 53). During the interview process, I focused upon the aspect of "what" data was being shared rather than "how" the data was represented (Riessman, 1993). Ultimately, my goal was directed at understanding how Jane motivates those in the disabled community to reach beyond their potential. Thematic narrative analysis was useful in providing an emphasis on the content of the data that allowed for richer findings. After the fact, I utilized critical disability theory and authentic leadership frameworks as lenses to synthesis the findings.

This data analysis was not coded by software, it was largely coded via written and typed notes. I recognized that Jane had her own voice and storied experiences that intersected with mine, experientially. The narrative inquirer and the informant possess their own separate stories and voices, which, at times, overlap in the narrative process (Connelly and Clandinin, 1990). I negotiated the required balance to honor her voice while I maintained distance during the data collection process, remaining aware to remove any potential personal bias on my part.

In this study, the interview questions were designed to render data from narratives that centered around how Jane motivates disabled individuals. "The thematic approach is useful for theorizing across a number of cases – finding common thematic elements across research participants and the events they report" (Riessman, 2005, p. 3). I employed several techniques to ensure the veracity of information that came from the interview participants. I engaged in active listening, used repetition of specific aspects of the narratives for clarity, cross-referenced interviewee information, and utilized follow-

up and open-ended questions that probed for additional information. These interview methods, along with sharing stories with the interviewees as they shared theirs, allowed me to become somewhat of an active participant in the interview process.

In attending to the details of the informant's narratives, I employed open-ended questions and followed-up their stories with probing questions. When I was uncertain of certain points of their narratives, it helped to ask the interview participants to repeat the information. While being attentive to their experiences, I highlighted and inquired about specific elements of their narrative for further clarification. This provided a more accurate understanding of their narrative as they repeated certain aspects of the story. These methods served to increase the level of interaction and communication, which helped me gather more data and facilitate the interviewer-interviewee relationship. I echoed pieces of information among all interview participants to ensure that information was all in the best possible alignment. I focused on interview participants' mannerisms and that brought more animation to the interview process. It was important and beneficial to bring color to all of the narratives. I made sure to follow-up with Jane to cross-reference the particular details that were discussed in the other interviews to gain further clarification and/or confirmation of the details within the narratives. While I cross-referencing their information, I was able to gauge their recollections and reactions, and found value in asking more probing questions. I was mindful of Jane's and the other informants' lived experiences, ensuring that I was able to capture her successes and challenges that related to those critical life events within her narrative.

All of the data were read and analyzed. While sorting through the stories, I categorized successes and challenges, separately, and looked for any themes that

reoccurred. I journaled reflections about the data and made note of the certain themes that came about during the interviews. Mentally, I could see how these themes would continue to surface during the transcription process. From this point, I began the transcription process. Jane was my first interview and the transcription process began immediately upon my transcribing her interview on the first day. This step proved to be helpful because I was able to review her narrative and further follow-up with her to clarify specific points; whereupon, I also discussed other shared stories and experiences from other interviews, which further helped in understanding the development of the intersectionality of relationships. It confirmed and tightened up timelines and brought more clarity to certain elements of her professional platform, as well. I continued the transcription process and informally coded the narratives captured by the 16 open-ended questions on the interview questionnaires (Marsland, Wilson, Abeyasekera, & Kleih, 2001). The informational data that was rendered from the three employees and seven parents was juxtaposed to the informational data that surfaced from Jane's interview. I took rudimentary notes while I transcribed the interviews, as I continued to discover redundancies in word patterns that sparkled in the data.

The analysis of data was an ongoing process (Rossman & Rallis, 2012; Taylor, Bogdan, & DeVault, 2015). Even as I transcribed the information, I was critically thinking about most pertinent portions of information required for the study and making notes about the reoccurring themes. I recorded copious amounts of data and used inductively analysis and aggregated the data to continually generate categories of themes (Creswell, 2014). Patton (2002) further notes that inductive analysis began with the "(i)mmersion in the details and specifics of the data to discover important patterns,

themes, and interrelationships” (p. 41). The transcription process provided the opportunity to immerse myself into the data for a more detailed discovery. I sequentially arranged the data to facilitate the interpretation of meaning in a chronological and poignant way (Ollerenshaw & Creswell, 2002; Riessman, 2008). Once the transcribing was completed, I reviewed each interview, again, and located and made note of the information that supported Jane’s storied narrative.

I open coded the data with the idea that the spirit of the data drove the determination of the themes, not any preconceived ideas that I had about the findings. I created a Word document with sections that were titled Jane, employee one, parent one, and so forth. Then I chunked portions of their narratives and placed them with their respective interview. This gave me the opportunity to dig into that specific data as I pulled out those words patterns and sentence segments from the separated sample. Using axial coding, I further examined these disparate chunks of data and established linkages between the data. This coding process captured the relevant themes that both aligned with and supported information that arose from Jane’s stories, vignettes, and various anecdotal data. I consolidated any duplication found within the chunked pieces of data and matched them with a particular theme, which helped reduce the number of themes. Ultimately, the process of coding rendered three major themes and two sub-themes that contributed to the development of a sequential and meaningful narrative of Jane’s life events (Woods, 1993; Bohl, 1995; Webster & Mertova, 2007). The three major themes that surfaced were voice, advocacy, and institutional practices. Moreover, determination (fight) and resourcefulness were identified as two sub-themes that related to Jane’s leadership capabilities.

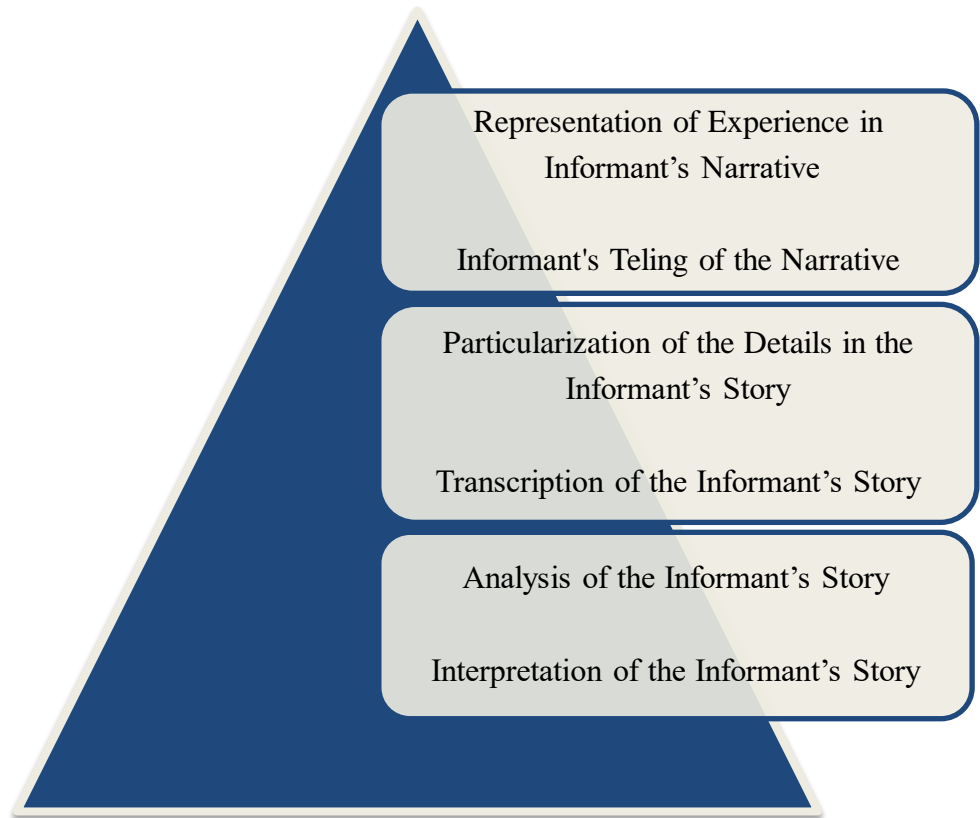


Figure 2. Thematic Narrative Analysis (Reissman, 1993).

Researcher's Role and Position in the Study

Due to the fact that I am physically disabled, I was aware of the potential bias that I could inject into the study (Creswell, 2014). Narrative inquiry provides a balance for the researcher to have a voice in the process; however, my voice and story did not alter or interfere with Jane's voice and story. Connelly and Clandinin (1990) have confirmed that the researcher and the participants have their own voices in the narrative process. Many qualitative scholars have discussed the delicate responsibility of maintaining balance between the researcher-practitioner voices in narrative inquiry and press the importance of muted subjectivity for the preservation of the emic voice of the native (Peshkin, 1988, 2001). Being the researcher, I was the primary data collection instrument (Creswell, 2014) in the study. I listened first to the practitioner's story, and then they provided the

appropriate freedoms, in context, that brought authenticity and legitimacy to their stories. This instilled and ensured integrity in the research (Connelly & Clandinin, 1990); therefore, I recognized the power of subjectivity (Peshkin, 1988) and understood that researchers largely played a role in the determination of “values, attitudes, preferences, and experiences—all lenses of a sort—through which they apprehend the world around them” (Peshkin, 2001, p. 242). I positioned myself in this study as a mutual storyteller (Connelly & Clandinin, 1990) and gave Jane the necessary time and space where Jane told and validated her story.

My interest in this study began with events both in high school and during my teaching career. My teaching experience started in a private school setting in Stillwater, OK; however, it was a major life event several years prior to my professional career that was the primary reason driving this particular narrative. At the age of 16, paralysis resulted from a zip line accident that left me unable to feel from my chest downward or walk, permanently. This journey led to a shift in my perspective. I found myself a servant leader and motivating figure (Claar, Jackson & Tenhaken, 2016; Feldman, 2014; Greenleaf, 1977; Reinke, 2004; Sendjaya & Sarros; 2002). After teaching for seven years, I endeavored to become an administrator, but quickly encountered a new challenge.

I held numerous informal conversations with principals and superintendents I personally knew, and the overwhelming majority indicated that my disability prevented me from being competent in my work performance as a potential administrator. From what I have learned in all of my experience, as a person with a disability, it was not uncommon for disabled individuals to be perceived as incompetent because of their physical condition, which became an extreme employment barrier in the public school

administrative arena (Coffey, Coufopoulos, & Kinghorn, 2014; Krause & Pickelsimer, 2008; Kitchin, Shirlow & Shuttleworth, 1998; Loprest & Maag, 2001; Shier et al., 2009; Sykes, 2007).

While some current administrators disagreed with this position, the reasoning had basis in their perception of my ability to be competent in a multitude of tasks that administrators performed. Their perceptions motivated me. I took them as a personal challenge and fervently accepted this new journey and searched for potential leadership positions. My condition forced me into a position where I developed and relied upon life skills such as self-awareness, resourcefulness, integrity, and self- advocacy that sustained my independence. Also, I had to be my own advocate and gradually constructed motivational techniques and practiced them at a high level, which sharpened my ability to problem solve. I grew as a reflective thinker that led to wisdom, humility, and patience. All of these attributes helped me and sustained my autonomous lifestyle and greatly aided me in my teaching and professional career.

My leadership potential continued to be a catalyst that drove and motivated me. I found great interest in and developed and honed certain skill sets that established a richer understanding of how individuals without disabilities and employers (Unger, 2002) perceived people with disabilities' leadership capabilities (Marchioro, 2000). My specific interest was in how those perceptions contributed to employment barriers – specifically, in the educational administration arena. One step in the achievement of this goal was education, so I sought a Ph.D. The educational leadership program offered me the opportunity to research, so I gathered data and learned about the employment climate for people with disabilities. In little time, I realized the existing limitations in research

(Barnes & Mercer, 1997) and found that an adequate sample population to make a discovery of the employment barriers that other disabled individuals potentially experienced was improbable. Despite this challenge, I felt as if there were important stories to be told, so I needed an avenue where I expressed my personal challenges that resulted from my physical impairment. Narrative inquiry was the avenue that captured the personal stories of participants and constructed meaning that could be an explanation to this personal and human reality that individuals with disabilities often experience (Bochner & Riggs, 2014; Caine et al., 2013; Clandinin, 2006; Connelly & Clandinin, 1990; Dewey, 1981; Mertova & Webster, 2007, 2012).

Verification

Narrative inquiry represents an alternate paradigm from traditional research formats. It deviates and establishes its own research paradigm, which Lincoln & Guba (1985) have aptly explained that “[w]e stress the fact that other techniques and methods are not excluded ... but that certain methods are more congenial to each paradigm ...” (p. 11). With this particular research methodology, it brings different criterion that measure the reliability and validity (Golafshani, 2003; Lincoln & Guba, 1985, 1988 & 1994). Clandinin and Connelly (2000) posited that narrative inquirers are “wakeful” and recognize the necessity to remain alert and aware of the contexts where our work takes place.

Trustworthiness (Tuckett, 2005) is a valuable criterion that relates to internal validity (Guba & Lincoln, 1994) and grows in prevalence in qualitative studies. Furthermore, central to the point of “trustworthiness and/or goodness” (Lincoln & Guba, 1988, p. 9) is how important it is that a multiplicity of realities be recognized by the

researchers (Lincoln & Guba, 1985; Webster & Mertova, 2007). According to Guba (1981), truth value, applicability, consistency, and neutrality are four different elements that trustworthiness addresses. Moreover, Webster and Mertova, (2007) have corroborated a list of interrogatives that serve as a checklist available to the researcher that assesses trustworthiness. Lincoln and Guba’s (1985) trustworthiness criterion and techniques (see Table 2) supported the study’s findings and establish quality and rigor (Loh, 2013), which surpass mere “thoughtful” approaches (Clandinin & Connelly, 2000).

Table 2

Trustworthiness Criteria and Establishing Techniques

Criteria	Techniques	Example
Credibility (internal validity)	1) Prolonged engagement 2) Persistent observation 3) Triangulation (sources, methods, investigators) 4) Peer debriefing 5) Negative case analysis 6) Referential adequacy (archiving of data) 7) Member Checks	3) Data was balanced the 11 interviews, informal and formal observations and an analysis of a variety of documents
Transferability (external validity)	8) Thick Description	8) Provided detail and description of the setting, introduced the characters, and exposed lived experiences of the participants
Dependability (reliability)	9) Overlap methods (triangulation of method) 10) Dependability audit – examining the process of the inquiry (how data was collected; how data was kept; accuracy of data)	

Confirmability (objectivity)	11) Confirmability audit – examining the product to attest that the findings, interpretations and recommendations are supported by data)	
All 4 criteria	12) Reflective journal (about self and method)	

Note. Adapted from Inquiry into issues of trustworthiness and quality in narrative studies:

A perspective, by Loh, J., 2013, p. 5.

Triangulation is a method that researchers use to promote trustworthiness (Golafshani, 2003). I was attentive to historical veracity of Jane’s story that gained verification and was supported by a variety of documents (Hanninen, 2004; Miller, 2000). A triangulation of data balanced the interviews, observations, and document analyses. This process minimized the weaknesses and preserved the strengths of data, but also served as a checks and balances system and ensured accountability (Creswell & Miller, 2000; Creswell, 2014; Patton, 2002). Although vast amounts of data, the duration of time, and researcher bias are several shortcomings for triangulation, it has several benefits that include “increase confidence in research data, creating innovative ways of understanding a phenomenon, reveal unique findings, challenge or integrate theories, and provide a clearer understanding of the problem” (Thurmond, 2001, p. 254).

The data collection process took measures to protect and preserve verisimilitude – the appearance of being true or real (Creswell & Miller, 2000; Loh, 2013; Webster & Mertova, 2007). Verisimilitude (Webster & Mertova, 2007) is another measure of reliability and validity specific to narrative inquiry; yet, there are numerous narrative studies that employed verisimilitude as criteria for quality, even though many scholars have argued that it does not adequately address the measure of quality or rigor. This view

was set forth by Jason Loh (2013) and has roots in a critique of quality or authenticity; however, he recommended Lincoln and Guba's trustworthiness techniques as a means to provide the necessary reliability and validity to satisfy the following criteria: "prolonged engagement, persistent observation, triangulation (sources, methods, investigators), peer debriefing, negative case analysis, referential adequacy (archiving of data), [and] member checks" (p. 7).

Ethical Considerations

The notion of "wakefulness" (Clandinin & Connelly, 2000; Clandinin, 2013) was no more relevant than when it has application to matters involving ethics. Narrative inquiry is a very personal and relational process (Clandinin & Connelly, 2000), so I worked from an ethical framework, of what Noddings (1984, 1986, & 1992) explained as a relationship bound by fidelity. Fidelity carries with it the implication of responsibilities the inquirer possesses via negotiations with the researcher and participant throughout the inquiry process (Clandinin & Connelly, 1988, 2000; Clandinin, 2013). An important note about negotiation, specific to narrative inquiry, is the timing of getting the ethical approval; with the researcher's imagination and creativity, as well as the willingness of both sides who utilize all field texts that relate to the inquiry, solutions surface (Clandinin, 2013).

How I started and finished the process of narrative inquiry research, as well as maintained the integrity of the experience, was recognized and bound by fidelity (Noddings, 1984, 1986, & 1992; Caine et al., 2013). A critical driver within this methodology was the essential element of the relationships that develop and create a mutual partnership in the inquiry that render more in-depth experiences. "Narrative

inquirers cannot bracket themselves out of the inquiry but rather need to find ways to inquire into participants' experiences, their own experiences as well as the co-constructed experiences developed through the relational inquiry process" (Connelly, 2006, p. 4). I addressed my personal bias and motivations that I carried into this study, and while the inquiry was a co-construction (Connelly, 2006; Riessman, 2008), the promotion of ethical vigilance upheld Jane's storied experiences. My personal experiences ran unchallenged to hers; rather I played the role as a catalyst for the development of mutual respect.

As Riessman (2008) remarked, "[s]tudents will have to make the arguments for the trustworthiness of their work from within their situated perspectives that ... inform the ethical parameters of the inquiry" (p. 185). Webster and Mertova (2007) listed informed consent, harm, risk, honesty, trust, privacy, confidentiality, anonymity, intervention and advocacy as potential ethical concerns. Transparency in my research approach guided the formation of ethical standards that I brought into my study. I also approached ethical considerations with wisdom in their application and consequence. In order to make certain to expressly practice ethical values that facilitated a positive and fruitful relationship with Jane, and the other subjects, I prudently negotiated the process of inquiry with Jane and obtained substantive data while I exposed her critical life experiences.

Plan for Narrative

This qualitative study includes a thick and rich description (Patton, 2002) of the setting where the data collection took place, and the participants who were interviewed. Moreover, each individual theme was included, followed by an in-depth thematic discussion of the emergence of the themes that surfaced during the coding phase. The

“restorying” of the subject’s story derived meaning of their lived experiences (Ollerenshaw & Creswell, 2002), and flowed in a sequential and chronological fashion (Ollerenshaw & Creswell, 2002; Riessman, 2008). The process of retelling (Clandinin, 2013; Clandinin & Connelly, 2000; Ollerenshaw & Creswell, 2002) Jane’s story unveiled several important revelations, which provided rich data that concerned her professional and personal life. She had the unique challenge of educating her two daughters and other individuals with disabilities who overcame challenging barriers. These challenges essentially made her an educator/advocate with relevant knowledge and experience worth studying. Educator stories and lived experiential narratives were both introspective reflections of the individual that provided meaningful historical information and rich social fabric records of the contexts in which they lived (Clandinin & Huber, 2002).

Finally, the results either offered support for or against existing theoretical constructs in the literature. There was confidence that the themes that surfaced enriched and strengthened this narrative inquiry study. Chapter four outlines and provides a detailed discussion of the themes. In chapter five, I used Critical Disability Theory (CDT) and Authentic Leadership (AL) (Walumba, et al., 2008) to explain my findings. More specifically, these particular lenses provided a lens through which to view the challenges that Jane encountered to gain a deeper understanding of the qualities and traits she exemplified. It explained any leadership and motivation techniques that helped people with disabilities, and identified meaningful explanations that addressed the research questions. A discussion of implications for practice, research and theory followed. Additionally, there was a discussion of the limitations in the data collection process, as well as strategies that minimized the findings. The final component included suggestions

for further research.

Summary

Chapter III outlined this narrative inquiry's methodology. It started with a brief overview of the problem, purpose, and research questions. It outlined the storied experiences of Jane, the co-founder of an educational program, who, due to her daughters' disabilities, had to fight and overcame specific challenges in their pursuit of compulsory education. It is important that participants understand the world in which they live (Creswell, 2014), so the epistemological perspective was constructivism (Patton, 2002). During the data collection process, a triangulation of data approach minimized the weaknesses and preserved the strengths of the data sources, which included semi-structured interviews, observations, as well as an analysis of a variety of artifacts and documents that related to Jane, her family, friends, co-workers, and parents impacted by the educational platform.

When I analyzed the data, I utilized thematic narrative analysis (Riessman, 2008) on the content of the story. The incorporation of emergent themes was used to "re-story" (Ollerenshaw & Creswell, 2002) Jane's critical life events (Woods, 1993; Bohl, 1995; Webster & Mertova, 2007) and resurrected meaning from her challenges that informed the study and provided answers to the research questions. Chapter three also addressed the researcher's role in the study. Because I had a physical disability, I was aware of the bias that I inserted into the study (Creswell, 2014). Trustworthiness was a verification issue, and this study used Lincoln & Guba's (1988) trustworthiness table that illustrated how validity was secured. The chapter concluded with the topic of ethics; particularly on the negotiation of the timing and aspects of the process of narrative inquiry that were

both key components (Caine et al., 2013; Clandinin, 2013).

CHAPTER IV

THEMES

When beginning this research endeavor, I never thought that collecting data for this narrative inquiry would take me to another state. As I boarded the plane for Utah, an old familiar feeling surfaced. It was akin to the experience of being in the hospital and rehabilitation after my accident. Staring outside the window and flying over the mountains and salt flats, I recalled meeting some very interesting and inspiring people during this trying period of my life. It never dawned on me that I was about to interview a woman who held an attitude of determination that rivaled and even surpassed mine. Her personality is “bigger than life” and infectious. I understood I wanted to do my best to reveal her story and those challenges that she overcome with her two disabled daughters, but I found so much more. I was both motivated and inspired. In addition to gathering information from her storied life, a friendship was forged. I was astonished with her spirit of determination. The challenges that she and her family faced required tenacity, wisdom and humility. As a researcher, it is my hope that this narrative inquiry successfully brings Jane’s incredible story to the fore, so the audience will be informed to draw their own conclusions about Jane. More importantly, it is my goal to help the reader re-live her journey, feel her unbridled spirit, witness her determination, and to become inspired.

Problem Statement

In spite of the fact that there have been steps taken to advance the workforce participation rates for those with disabilities, a deficit in these rates of employment for the disabled still remains a challenging reality (Burns et al., 2012; Statistica Research Department, 2021). One of the most widely known measures was the Americans with Disability Act (ADA) of 1990 that secured workforce and societal accommodations, removed barriers of discrimination, and allowed those with a legally defined disability to gain and enjoy employment with a more level playing field in the workforce (Equal Employment Opportunities Commission, 2017). Section 504 of the Rehabilitation Act addressed what constituted a legal definition of disability and qualified it as mental and physical that created limitation in activities like walking, breathing, hearing, etc. (Henderson, 1995).

Given the efforts to decrease rate of unemployment for the disabled, statistics continually illustrated that more progress was necessary. Burns et al., (2012) explained that in the United States there are approximately 27,000,000 individuals with a disability, while less than 6,000,000 of these individuals are counted in the labor force. In fact, in 2020 there were 5.35 million people with a disability who represented either full or part-time workers (Statistica Research Department, 2021). Indubitably, the unemployment rate for the disabled fell due to the impact of the COVID-19 pandemic, but the decrease of employment follows historical trends. This evidenced that people with disabilities continued to experience discriminations that limited opportunities that led to increased unemployment figures; however, even though the data indicated that discrimination still is an issue for individuals with disabilities, conversely, it indicated that there are a smaller

minority of disabled people who are gainfully employed and have been able to remain in the workforce.

Perceptions of the disabled as leaders are established by a combination of characterizations of the individual with the disability and how the non-disabled or “perceivers” mental schemas (Marchioro, 2000). He explained, that “perceptual processes may work to the disadvantage of individuals who are disabled, if, as a group, they are not perceived as possessing characteristics commonly associated with leadership such as being dominant, extroverted, intelligent, and ambitious” (Marchioro, 2000, p 14). One anomaly that explained the formation of perceptions of those who are disabled included the notion that those without disabilities are limited by viewing individuals with a disability through a deficit lens; as such, perceptions of limitation are hoisted upon those who are disabled due to the fact that the non-disabled cannot actually understand what it is like to be challenged by limited ability in society and the workforce.

Research Questions

Overarching Questions

1. How does Jane influence individuals with disabilities, their caregivers, and families to exceed expectations placed upon these individuals because of their disability?
2. How does Jane influence these individuals to achieve positions in the workforce beyond what was expected of them?

Sub-Questions

- A. How does Jane perceive individuals with disabilities and how has she communicated this perception?

- B. What factors influence Jane’s perception of individuals with disabilities?
- C. How does Jane’s influence guide disabled individuals to realize their potential to overcome real and socially constructed limitations?

Presentation of Data

“For Narrative Inquirers both the stories and the humans are continuously visible in the study” (Pinnegar & Dyanes, 2007, p. 7). Jane was the primary source of data for this study. Before meeting her, we had spent time talking, telephonically, and got familiar with each other. The bulk of the data collection took place in a beautiful Utah city nestled in a valley and surrounded by steep mountains. My hotel was less than a block from the central production location of Jane’s educational platform. Since Jane was the primary data source, in addition to the semi-structured interview, I spent a great deal of time with her and gathered data while speaking with her in casual or informal conversation. I also observed her in her work environment and recorded many of the interactions she had with employees and a variety of other people that included parents and members of her family, both inside and outside of the workplace.

I woke early and was welcomed to the cold that had been created by the mountains blocking the morning sun. I made my way to the central production location and captured photos before entering the building. Once inside, I was met by Jane’s administrative assistant. She informed me that Jane and her daughter were on their way. I took the time to take more pictures and record notes about the environment as I wandered the premises. Once they arrived, I spent time with them at lunch. It was very informal meeting where we were all able to get acquainted before the interviews begun. This

informal chatting was a valuable way to hear their stories, and I was able to ask open ended questions and ask follow-up questions. I gained a greater understanding about their life and how her educational platform originated.

Jane, three employees, and seven parents were rich sources of data (Patton, 2002) who provided a contextual depth that served to deepen the understandings of the study, which balanced Jane's narrative (Patton, 2003). These interviewees were chosen by a few sampling methodologies. Purposeful sampling (Suri, 2011) was used to identify Jane. The employees and parents were located through snowball sampling (Noy, 2008). Additionally, as a complement to the interviews, I examined several other artifacts (Clandinin, 2013) that added to the collection of data and were used to undergird the findings that surfaced during the interview process. Such artifacts included photographs, newspaper articles, awards, prior interviews Jane had given, informal observations, and field notes (Hanson, Balmer, & Giardino, 2011; Riesmann, 2008).

Participants

Each of the participants have their own relationship with Jane. One of the employees was her brother, and the remaining two have worked for Jane's educational platform for a number of years. Moreover, two of the seven parents knew her, personally, while other five had only worked with her a short time, either directly or indirectly, or just know her strictly through her work with the educational platform. Specific to the seven parents, all were women, and several brought their children with them to interview sessions. While this presented a bit of a challenge, the children filled the interviews with laughter, crying, and made their situations even more real. One participant brought her autistic child and used sign language to communicate with him throughout her interview.

Additionally, several of the interviewees swelled with emotion and cried when talking about Jane and her work. They were filled with tears and expressed gratefulness about how sign language has given them the ability to communicate with their children, especially when they talked about communicating with their children for the first time. The women whom I interviewed ranged from the role of stay at home mothers to working professionals who are very career driven. Each interviewee relaxed in a comfortable lounge chair with a table small table near for placement of personal items.

A further description of these participants, with pseudonyms, is provided below.

Jane. Jane is between the ages of 45 and 50, and she is a co-founder of an educational platform that teaches sign language. As this study attests, she is an extremely driven, spirited, and determined individual. As a mother of two daughters with disabilities, she had to learn to overcome societal challenges and fight outdated institutional practices in order to navigate and propel her daughters through the compulsory educational system. Her older daughter is deaf, and the youngest daughter is confined to a wheelchair due to being born with spina bifida and the development of cerebral palsy at the age of nine. The following story shows how Jane's character evolved and highlights how she embraced it and used it as motivation for positive change:

Oh, well, (deep breath), I think everyone we come into contact changes. I think my whole family's changed. I have eight siblings. They've changed. Their spouses, their children, I've got like 36 nieces and nephews. Everyone has a deeper understanding of human beings, of disabilities. I have a nephew, he was probably eight; he's like, "there's this girl in school, and she gets bullied in school because she's different." And like, they stand up for people who are different.

They have a voice on behalf of kids who have disabilities. Maybe those kids don't have a voice yet, or their teachers or their peers don't. But, my family, our community, my friends; like my friends that I have are people who were fans of [the signing platform] and then became friends. It is a very deep-rooted network of compassionate, compassionate people. (Jane, personal communication, October, 2019)

This story is an important piece of her narrative that spoke directly to Jane's character and offers a glimpse of her as a leader. It shows the caring nature that brews under Jane's powerful personality marked by a loud confidence fueled by a spirited and intensely driven personality. It was patently obvious that she is an extremely determined individual; however, as mentioned, Jane holds a quiet determination that is motivated by a passion that smolders. She ardently wants to be a source of strength and beckon of knowledge for others who have children with a disability. The manner in which she handled her own critical life events have impacted and influenced her immediate family, who became more aware of those with disabilities and understood empathy on a deeper and more personal level.

As an interviewee, Jane was very spirited in her responses and never shied from eye contact. She primarily stayed calm, gestured softly with her hands, quipped "you know," a lot and held a smooth tone whenever she conveyed her story; however, at times she would drastically motion with her hands, quickly moving her body. Her tone modulated up and down when she became more serious with her points, so I could tell these were the moments in her narrative that carried great meaning. Additionally, as I watched her interact with employees and parents, it was patently obvious that she

possessed an uncanny ability to capture her audience with her charisma. During the interview, many times, she began her answers and stories with a deep breath or with laughter or a big smile. Jane's facial expressions, animated voice and laughter, and genuine eyes were the most indelible qualities. Her self-confidence and assured nature were impressionable. They carried an authenticity and her presence demanded attention to her lived experiences. She draws people into her life and motivates them while visiting with them. The narrative directly below provided more of a glimpse into her personality and qualities:

I would say that is very true. Even as a teen and as a kid, I did not feel like I could make a difference though. I didn't feel like, oh, I'm here to make a difference. I was very shy. I was very quiet. And I didn't have my own, I didn't have a powerful voice for myself. I think I gained that on behalf of my children. By having children with disabilities, oh my gosh, I was like [Daughter One] was deaf. I was like nooo, I'm gonna have to sit in front of people and use sign language and people are gonna look at me. Like, I just didn't want people to look at me. But I also knew that I would do it because it's my kid. And so, it pushed me to be something I might not have been. (Jane, personal communication, October, 2019)

Jane's character showed more depth as she told her stories. In particular, she had shown substantial growth, personally, after the birth of her first child, who is deaf. As she noted in her last sentence of the personal communication, directly above, she overcame a variety of feelings about having a deaf child and found the resolve to mature as a parent and leader. She was very raw and transparent in how she dealt with having children with disabilities and just how shocking it was, overall. Importantly, the growth she gained

from her determination in these challenges, strengthened her commitment to those families who had children with disabilities. Even though her professional career introduced her to an array of people with differing backgrounds, her personable and caring nature treated all people as friends and family. Jane's dedication to relationships and her commitment to use her journey to help were paramount.

Employee One. Employee One is between the ages 45 and 55 years of age. She is a tall, affable, and extremely welcoming lady who is very soft spoken with a clam presence. She is a long-term administrative assistant that has been with Jane and the educational platform for approximately 14 years. As one of the more senior ranking employees, she plays an integral part in the management of the office. Employee One knows Jane through her non-disabled daughter, who was hired by Jane's sister to work in customer service and accounting. Jane's sister eventually hired Employee One, as well.

Employee Two. Employee Two is one of the younger adults on the film editing staff, between the ages of 25 and 35. He is a very cautious, quiet, and observant person who became involved with Jane's company in 2014 while searching for a stable work situation. Through a connection of his, he learned that Jane and the company were in search of a film editor. Upon request, he submitted some work samples, and was eventually hired through Jane's brother after a film editor on staff left. Once he was hired, he began to develop a working relationship with Jane, and he has been with the educational platform the past seven years.

Employee Three. Employee Three is Jane's brother and is between the ages of 20 and 30, and he is very high energy, as he constantly moved about from room to room, working busily and talking to other staff members and Jane. Aside from having an

immediate family relationship with Jane, he, also, is one of the more senior ranking members on the staff. Although his children are not disabled, he used the educational platform with his children to teach them to sign. He serves in a CEO-CFO position, sharing in a multitude of roles that include the facilitation of finance, daily operations, and marketing. He carries a great amount of responsibility, so his demeanor is somewhat stoic and serious while carrying out business.

Parent One. Parent One is between the ages of 30 and 40. She became familiar with Jane and her work around 2004 when a daycare where she worked was gifted with Jane's educational videos and CD's. Through work, she grew familiar with Jane's sign language platform, and she used them when her daughter was born in 2016. Subsequently, she and her husband had a second child born with Down Syndrome, so Jane's platform was utilized to help her children communicate through sign language. In May of 2019, she met Jane in person, a few times at Knighted Angles and Walk for Angels, which are events that Jane is heavily involved with.

Parent Two. Parent Two is between the ages of 25 and 35, and like many of the parents associated with Jane's platform, she had a child with a disability and was given signing educational videos as a resource. From that point, she searched for more online resources and started watching Jane's interviews. After some time passed, she, her spouse, and children were at a grocery store when a woman came to their hearing-impaired child and started talking to her. They asked if it was who they thought it was, and, in her words:

... she's like "Yes!" And then she, like, started-practically broke out in a song, singing to my daughter, who was a baby, at the time. And so then, um, she's like,

“you need to come to my house,” oh, and she gave me her email and told me to email her, and then I did. She’s like, you guys need to come over, and, um, she kind of, we came over to her house and she talked to us. And kind of, it was just nice to talk to another parent of a deaf child because we hadn’t really, hardly met any, at that point, so. (Parent Two, personal communication, October, 2019)

Parent Three. Like many of the parents of children with a disability I interviewed, Parent Three was gifted with Jane’s videos by a member of her family. In fact, she was the recipient of Jane’s very first video production for her disabled daughter to learn to communicate through signing language. Initially, she joined a Yahoo group with Jane and another co-founding member of the company, and Jane asked for her testimonial. She gave her testimonial in a 2002 interview and followed by getting more involved in the Yahoo groups, where she met Jane in person during a play group that was organized. Shortly after this meeting, she started helping Jane and the company sell their educational videos. Parent Three is between the ages of 35 and 45.

Parent Four. Parent Four is between the ages of 30 and 40, and she has never met Jane in person, but she is familiar with her work and sign language resources. She stumbled upon Jane when watching Netflix, and because of her interest in ASL (American Sign Language), she started watching Jane’s educational productions. Ironically, several years later, she became pregnant, and the child was diagnosed with Down Syndrome. As a result, she continued watching Jane’s DVD’s and reading Jane’s books that explain sign language.

Parent Five. Parent Five found Jane through her daughter’s speech therapist. Her daughter has a brain injury, so they started using Jane’s educational resources to teach her

to identify colors. Her daughter could never verbalize the correct color, but could identify colors by signing. This practice led to her and her husband teaching more signs, which led to the family being able to communicate more frequently. Parent Five is between the ages of 29 and 36.

Parent Six. Parent Six is between the ages of 35 and 45, and she has a child who is disabled. She was given Jane's videos as a baby shower gift soon after her child was born, and she started using the videos to teach her daughter sign language to communicate. She actually met Jane when she joined Jane's fan club and began chatting with Jane during weekly chat sessions. In her words:

So, we kinda got to know each other a little bit on that, just online. Um, and then, I actually met her in person when, um, I went to one of her performances at local zoo. And um, we stood in line so that my daughter could meet her and Hopkins, and-and get the photo. Um, and then [Jane and company] had seen my daughter and thought she was darling and could be potentially a good model for some of their needs, and so I started to talk to [them], things went from there, um, and ended up meeting Jane that way. (Parent Six, personal communication, October, 2019)

Parent Seven. Parent Seven is fluent in sign language and came across Jane on YouTube. She wanted to teach her daughter sign language and found that watching Jane's DVD and YouTube videos, together, helped. She pursued becoming an ASL (American Sign Language) teacher, which led her to a working relationship with Jane. Her three-year-old took part in a nursery rhymes video production with Jane, and the

relationship with Jane started and still continues. Parent Seven is between the ages of 30 and 40.

Themes

The purpose of this study was to tell the story of Jane and her educational program that teaches children to learn to communicate using sign language. Ultimately, the goal was to provide an understanding of how she has inspired individuals with disabilities to reach potential beyond the limitations imposed on them by their disability. Change was a monumental thread that wove throughout Jane's story and was supported by and aligned with the other interviewees' stories. This particular concept became very prevalent throughout the interviews, and it undergirded many of the themes that were identified. Upon an analysis of the data, it grew evident that voice, advocacy, and antiquated institutional practices were the three major themes that proved themselves to be most redundant. Additionally, determination (fight) and resourcefulness were the two subthemes that originated from Jane's critical life events that contributed to the development of strong leadership capabilities. The educational platform is described below followed by an explanation of each theme that emerged.

Jane's Educational Platform

Jane co-founded an educational platform in 2002 in collaboration with her sister to meet the needs of hearing impaired children. The purpose of the platform is to provide a "multisensory approach to learning through three senses: visual, auditory, and kinesthetic" to encourage interaction/communication through sign language, speaking and movement (Educational Platform Website, 2021). The mantra on the website states,

“Every child is extraordinary; all children are here to shine! We are here to help every child reach their potential” (Educational Platform Website, 2021).

The history of the educational platform emerged from the experiences that Jane encountered with her daughters. Jane described the development of the platform as “one mother’s journey from adversity to opportunity” (Educational Platform Website, 2021). In May of 2002, the first video was completed and the production side was born. The business model started from humble beginnings with only volunteer help to distribute DVD’s from the trunk of their vehicles. However, today, the platform has increased to have a substantial online and digital footprint, with millions of views on YouTube and Netflix. Over time, their resources have expanded to offer sign language techniques for babies and children. The platform includes resources for special needs children and a curriculum for homeschoolers and teachers, and it addresses a variety of areas that are specific to age. For example, Jane’s platform uses ASL to teach topics that range from science and reading to educating small children on how to “potty.” Notably, Jane’s educational platform won the Association for Library Service to Children award in the “Notable Children’s Videos” category in 2004, the 2007 Parents’ Choice Award, and was nominated in 2008 for a Daytime Emmy Award (Education Platform Website, 2021). Success of the educational platform is further evidenced by the fact that it has been featured on Nick Jr., NPR, the New York Times, the Today Show, and Parents Magazine (Educational Platform Website, 2021). Through this platform, Jane has impacted the lives of countless individuals with disabilities and their families motivating and equipping those in the disabled community to move beyond their perceived potential.

Voice

Voice was the most prevalent theme that surfaced during the interview process. Jane and many of the parents mentioned it when talking about the educational platform and how it influenced theirs and other children with a wide array of disabilities. It was very poignant for those parents who touched upon the subject. For many parents, including Jane, sign language provided them opportunity to communicate with their children after several years of silence, in most cases. In the following, Jane talked about voice, in terms of how sign language opened a new world for her and her daughter who has cerebral palsy and spina bifida. She discussed how Daughter Two did not have a voice for several years, but eventually was able to work through many bodily challenges to finally learn to communicate with modification of signs. Jane explained:

Sign language actually gave [Daughter Two] a voice that she wouldn't have until she was over three years old, she couldn't talk until she was three years old.

There's so much that comes together. Breathing and coordination and muscles and everything it takes to make a sound, let alone a word. And, that was so difficulty with [Daughter Two's] set of disabilities, but, we, fine motor skills developed first and so [Daughter Two] was able to communicate with modified signs. (Jane, personal communication, October, 2019)

On a more passionate level, going from an attitude of detailing the benefits of finding a voice by way of sign language, Jane visibly began getting emotional in further highlighting the impact of sign language. She revealed that by helping children with disabilities find their voice, they were not only learning to communicate a few signs to their families, but they were able to participate as active learners in subject content areas. She was excited about the sense of normalization that the children experienced as a result

of her educational platform for a number of years. She masw note of the fact that they are children from the spectrum of disability who were given the ability to speak their “wants and needs” and have them satisfied. Of interest, Jane mentioned the importance between sign language and the connection between the linear effect in signing to the visualization of objects that led children to speak words. She recalled:

They’re spelling words they learned from [our signing platform] so they’re not just signing. They are not only communicating with sign language, but they are reading, and we wouldn’t know that without the signs. We wouldn’t know that without this program ... there is something that connects, so, they sign ball, and they’ve never said that word, but when they have that concrete or that visual image in front of them, there’s something about the physicality that they say the word ... we’re signing with children (sigh) with all kinds of medical procedures that wouldn’t have been able to communicate what they needed because they were too young, but they were able to sign their needs, their wants and have those fulfilled. It was, it’s been, 19 very inspiring years of hearing how we have impacted families and impacted children, and given a voice to so many (pause) children who wouldn’t have had one, otherwise. (Jane, personal communication, October, 2019)

One of the threads that was central throughout the experiences of all the parents and Jane was just how appreciative these families were to be positively impacted by Jane’s educational platform. To the point, how parents were able to discover their own voices through helping their children find their voices. After a deep breath, Jane sat back and contemplated a minute and turned more inward about how she discovered her own

voice during her journey, as had the parents who participated in this study. Also, she disclosed her concern for how society viewed her daughters' capabilities and the best practices in on how to teach and treat her daughters, during that time. Specifically, she talked about an encounter with certain medical and teaching practices, and how she had to have the courage to avoid and move forward with what she described as being best for her daughters. According to Jane:

It helped me find a voice I didn't know I had, and it helped me give a voice to generations of children that their parents may have never known that they had ... I saw more in [Daughter Two] than the doctors saw in [Daughter Two]. But what's really scary is, what if I had believed them? (Long pause) where would we be, you know? ... but I can absolutely, like [Daughter Two] not speaking in preschool, her teacher didn't even know she could talk 'til I told her. That's terrifying. That was terrifying to me. Let's get her out of her, you know. (Jane, personal communication, October, 2019)

She went on further and provided a bit of information of how she was as a child and compared herself to her life now. The birth of her two disabled daughters were critical life events that moved her outside of her comfort zone, eventually into the spotlight. Jane attributed this metamorphosis to having children with disabilities, which motivated and pushed her to become more of an advocate for her and her family. Jane reflected:

Even as a teen and as a kid. I did not feel like I could make a difference though. I didn't feel like I'm here to make a difference. I was very shy. I was very quiet ... I didn't have a powerful voice for myself. I think I gained that on behalf of my

children. By having children with disabilities ... it pushed me to be something I might not have been. (Jane, personal communication, October, 2019)

Parent One followed and added to the importance of Jane's work with the signing language platform:

Giving them a voice (deep breath). I think that is the biggest, what I would see, as a parent. And, someone who's, you know, has a special needs child, you're giving a child that may not be able to communicate. (Parent One personal communication, October, 2019)

Parent Three echoed parent four and their sentiment's about Jane and the influence of her work through the educational platform:

(Crying) she gives them a voice. (Long pause and crying) ... I have met some of my best friends, to this day that have children with cerebral palsy, down syndrome, autism; families that didn't think their child would get to do much. Their child began to thrive and begin to have a voice. [O]ne of my friends, she has shared an article, and I can send it to you, that talks about how signing gave her son a voice. (Parent Three, personal communication, October, 2019)

During the interview process, it became evident that Jane and educational platform were instrumental in providing children the chance to learn sign language and communicate with their parents, which strengthened the bonds within the family. Going further into previous comments that parents made concerning the impact of Jane's work, her platform also helped parents discover their own voices within their own journeys that served them in overcoming challenges they confronted by society and outdated approaches to disability and other institutional practices. Parent Three was grateful for Jane's

willingness to go beyond teaching sign language and to share Jane's testimony, which helped many new parents dealing with their child with a disability. She expressed:

I think for too many they don't have voice. And, I think as [Jane] shares her experiences and [Daughter Two] and [Daughter One] share their experiences, it gives people hope and a place to start. (Parent Three, personal communication, October, 2019)

Parent Four discussed Jane's work, which undergirds the other interview participants' thoughts:

[T]hey need a voice and she's been able to give these little kids and adults a voice. [I]t's opened up a piece of my heart that I did even know was there. I feel very, very grateful for [Jane's platform]. It-it actually overwhelms my heart (starts crying). I know it's a children's show, but it is, it has allowed him, again, to have a voice. To have a voice, together ... [a]nd so, I feel extremely deeply, deeply grateful for her work. For her willingness to share her talents. And to put herself out there. To show us little [Daughter One]. He says [Daughter One]. (Parent Four, personal communication, October, 2019)

Parent Seven highlighted how Jane's educational platform enhanced the relational bond and helped decrease tension between families and their disabled child:

[I]t's sweet to see how people, like, "it's [Jane], you've helped me so much." You know, so, it's cool [be]cause her product is communication. [A]nd so a lot of these families who have a disability, have that communication delay. For some reason or another, the sign language gives them the opportunity to-to express themselves. And to have that communication, where before it was complete

frustration of not being able to know that your kid is hungry, or it tired or whatever, the sign language helps them be able to express those things and to have that communication, increase bonding, and all those things. (Parent Seven, personal communication, October, 2019)

Additionally, Parent Seven provided an illustrative example of how powerful Jane's work is on young children with disabilities. Parent Seven added:

I worked with one who had autistic, had completely non-verbal and be able to start to communicate through sign language because of watching Jane's work. And, he knew his ABC's and his numbers and all these things, it was really cool, just from watching her. But, now he's able to verbally express himself because he learned how to communicate with sign language through [the educational platform] and now he can say things. Like, "oh, communication is cool." (Parent Seven, personal communication, October, 2019)

Advocacy

Advocacy was the next primary theme, second only to voice. While it was not surprising, advocacy was an element that Jane touched upon as it related to growing into the role of an advocate because she had to become the voice for her daughters throughout their life journey that included certain challenges such as schooling, for example. This particular theme was supported by the employees and parents that knew her both personally and professionally. Not surprisingly, helping parents who had children who are disabled became a big motivator for Jane, and helped drive the creation of her educational platform. The parental interview participants mentioned advocacy in terms of a valuable lesson that they took from Jane's personal experience of having daughters with

a disability. This theme was supported by the employee participants, as well. In the words of Parent Seven:

I like what she does with her two daughters; that she's always had to go and support and get up the means ... she teaches self-advocacy and just go be successful people ... when you have the opportunity to work with them and show [them] you have full potential and then helping them self-advocate and remove those barriers by saying, "oh, I can do this." (Parent Seven, personal communication, October, 2019)

Advocacy is something Jane internalized. It became evident that she had learned to become her own advocate from through her critical life events. She had become adept at motivating those with disabilities to reach beyond their potential Jane explained the power of advocacy and how she views it:

I think there's different kinds of advocates. There are political advocates, and changing legislation or there are social media advocates. There are non-profits or groups. I don't even know that it's about disabilities. It's like I am the voice of the underdog. I am an advocate for anyone who is seen as less than. Whether that's LGBTQ or whether that's disabilities ... I have a special view that I hold for people with disabilities ... [w]e may have physical limitations. (Jane, personal communication, October, 2019)

Employee Two offered his point of view about Jane as an advocate for people with disabilities. He corroborated other interviewees' thoughts about how eager and competent Jane is in helping those within the disabled community. Succinctly, he said:

I would say she's a very strong advocate because she understands that people with disabilities are people just like anyone else. [S]he knows how to treat them with respect, accordingly. I'd say she's a great advocate for people with disabilities.

(Employee Two, personal communication, October, 2019)

Parent Two summarily followed with:

She's a huge advocate for people (Parent Two, personal communication, October, 2019).

Parent Two added:

[S]he's been through that, and so, she's a huge advocate. And, it empowers, I think, parents to know they can do it too (Parent Three, personal communication, October, 2019).

Parent Four was also very succinct in her point when she spoke only one sentence with respect to Jane's work:

I think [she's] a strong advocate (Parent Four, personal communication, October, 2019).

Antiquated Institutional Practices

In the interviews with Jane and several of the parents, there was mention of certain views regarding institutional practices they expressed as being antiquated. Families expressed disappointment at the low learning expectations that educational and medical professionals had for their disabled children when it came to teaching their disabled children. These stakeholders believed these professionals were too eager in accepting limiting viewpoints of their children's' capabilities in the classroom.

Ultimately, this led Jane and her co-founder to create videos to teach American Sign Language (ASL) to facilitate increased communication and learning capacity.

[W]e didn't, my sister and [co-founder] and I didn't mean to start a business. We just wanted to make a video. [Daughter One] was 4 years old and was on the soccer field, every other kid on her team, they could hear. [Daughter One] was the only deaf kid, and I'm out there signing. They're running drills and this little boy gets teamed up with [Daughter One], and he says I don't want to be with [Daughter One] because she can't talk or understand me. (Jane, personal communication, October, 2019)

Reliving the moment in her mind, Jane sat in the chair with a perplexed gaze. She recounted and continued the story and how it became the driving force behind the business:

And, I stood there on the field and thought, "what can I do to change his perspective? Is there something I can do that will make a difference for this little boy, about how he feels about my deaf kid?" And that is my everything approach. Is what can I do? Is there something I can do? Can I interrupt how this is going? And, is there something I can do to alter this? So, I volunteered to teach sign language at his preschool. I – he went to a different school than [Daughter One], but I called and said hi, can I do sign language with your kids? And they said, "totally". They hired me to come teach some sign language and we did full stories. And, within a couple of weeks, we were on the soccer field and he runs up straight to [Daughter One] and signs, "friend, play ball". And, instead of, "I don't want to be with her", she doesn't understand me, three signs built a bridge. And, I

didn't think, from that, I just looked at, alright, what can I do? Can I contribute? Can I alter the trajectory? And, and, that's what I look for. How do I do that? And I do that, you know, as a leader. I do that as a mother. I do that as an advocate. I thought I should just go teach sign language at every preschool in the area, and that week my sister, [co-founder], called me and said, "hey, do you wanna make a video for kids?" I said, sure. And she said, "let's teach them all about music and rhythm". And I said no. I'm not doing music. We need to do sign language. And she said, "you're right." And we created [the educational platform]. Again, we didn't mean to make a business. We didn't want to. We did not want to be stay at home moms, and I just, we thought ... I thought let's make a 100 of these videos and let's give them away to people we know and love [Daughter One] and they'll have the-those few signs to build a bridge. And, [co-founder] said, "let's buy [educationaplatforml].com". And (gestures) the rest is history. (Jane, personal communication, October, 2019)

Outdated practices also acted as a catalyst for her and other parents to overcome many challenges they faced in surpassing the older institutional methods that had potentially left so many children with disabilities behind in the classroom. One of those challenges was highlighted by Jane when she talked about the how she had to inform Daughter Two's teacher that she could talk. When Daughter Two was 4 years of age, she had been in a Special Education school for a few years with other children who could not talk because the school did not know that she could speak. Upon learning that the teacher was not aware that Daughter Two could speak, Jane found another school for Daughter Two, so she could continue to learn to speak with children in her age group. In the

following paragraph, Jane reflects about her motivation for creating her educational platform, which was a platform where she would teach ASL and eventually create a children's and baby's curriculum. Her explanation illustrates the degree of determination to take ownership of her own daughters' futures and push forward to shape it the way she saw fit, rather than listening to the professionals within the educational and medical systems. She explained:

[W]ith [Daughter Two] we were told that she'll never walk; she'll never talk; she'll never roll over; she'll never crawl. I didn't believe that either ... I just believed that in school, it was Special Ed. Preschool, and they wanted her to stay in Special Ed. all through her schooling. I know [Daughter Two] does better with typical kids. In [Daughter Two's] second year of Special Ed. Preschool, it was December, so she'd been there August, September, October, November, December, there was a Christmas party. I go in and I ask the teacher, I said "are you learning the months of the year?" And she goes, "yeah." [Daughter Two] has been singing the January, February, March, April, song. The teacher looked at me stunned and she said: "[Daughter Two] can talk?" This is in December and I was like, we have got to get her out of here. None of the other kids can talk, so [Daughter Two] wasn't going to talk. She totally matched her peer group, and so we knew we had to get her out of there, and we did in kindergarten and it was a very tough transition. Even all the way through high school was (tears up) really, really hard for [Daughter Two] to be mainstreamed. That was the best option and opportunity for her ... she graduated with a regular diploma and that was because

we said she could do this – we believed in her. (Employee Two, personal communication, October, 2019)

The short story Jane shared, directly above, provided a look at the evolution of Jane’s thought process she was forced to navigate. Understanding disability differently was a natural progression that resulted from having shared in her daughters’ life experiences that were shaped and lived through a disabled perspective. Rather than understanding disability from afar, her understanding about disabilities was felt on a more personal manner. Jane further commented about directly challenging the medical and educational systems in how they approached teaching her daughters, stating:

So, as far as leadership (pause), I don’t have an MBA. I don’t have a college degree, at all. I went for a couple of semesters and dropped out to be a musician. But, (laughter), my life’s course has led me to be in a position of influence and leadership and a mentor, and, I think just questioning. Just not taking a diagnosis at face value. Not taking, “oh, here’s what we can do in 18 years”. You go well, let’s see what I can do in 18 years. A lot can happen to a human being in 18 years, in their education. Why would you, why would you accept a limiting belief?
(Jane, personal communication, October, 2019)

Parent Three kept on this particular theme in overcoming the medical and educational community practices. She detailed the following:

Well, the way that [Jane] taught American Sign Language; it’s vocabulary, she’s not teaching the complete language – it’s the vocabulary. But, because some of these children are deaf, [the professionals in the medical and school communities] don’t think they need ASL as part of their IEP’s or 504’s. When, if that’s what

they need to be able to communicate their needs, that should be included. It shouldn't be the educator's place or the medical's place to decide what your child needs. Or, what the person needs. And, that's one of the hurdles that I think, I've watched her help people navigate just, you are the advocate for your child. And, you keep fighting. (Parent Three, personal communication, October, 2019)

Parent Two gave her opinion about institutional practices; more specifically, she addressed the public-school system's approach to teaching children with disabilities that were assessed as having the ability to only attain a third-grade level education:

It just blows my mind that all those families that settled, "like ok, third-grade reading level." You know, but I guess people weren't as educated back in the day (laughing). You know what I mean. Like, they thought if you can't hear, you can't learn ... (Parent Two, personal communication, October, 2019)

Determination (fight)

Another theme that emerged from data analysis was Jane's determination, her fight. This theme was one of the more obvious qualities about her. She possessed an outcome determinative spirit. Jane, the employees, and the parents all spoke to how driven she was in her pursuit to help families. Parent Three explained:

She's a fighter. I mean, clearly, there was no resources for [Daughter One]. And, she fought. And, she fights for [Daughter Two] and the resources that [Daughter Two] needs. And at various times when I was going through 504 and IEP for my daughter, she gave me advice. (Parent Three, personal communication, October, 2019)

Employee One explained:

“Yeah. She’s very determined to not let people fall through the cracks”

(Employee One, personal communication, October, 2019).

Employee Three provided a deeper glimpse into Jane’s thoughtful approach in looking for avenues to help those children and families in the disabled community to overcome challenges with a resilient and “whatever it takes” attitude: He stated:

I think somewhere on one of our websites she’d come up with the vision statement of ... empowering children regardless of ability to communicate. I think that just kind of sums it up ... regardless of ability, it’s, you know, “disability, great, how can we help you have a happy fulfilled life?” (Employee Three, personal communication, October, 2019)

Resourcefulness

Jane had been able to harness and apply the lessons she learned from her own experiences, and she was successful in her ability to develop strategies that lead to solutions. Parent Three touched upon and highlighted one key strategy that Jane utilized to move her educational platform from the local and national levels to the international sphere by efficiently creating and accessing her professional network:

The [educational platform] is our educational leg of the business. Jane can’t be everywhere, so she’s trained other people to teach her curriculum. It is the [children’s educational platform] curriculum and the [baby educational platform] curriculum. They are using ASL vocabulary to teach early communication. So, we have an instructor in Canada whose son is deaf. And, she is advocating for her son and the laws and stuff up there. And, she has followed some of [Jane’s] example, and I know thinks very highly of [Jane]. So, that’s up in Canada. You know, I

know there's instructors in China. There are instructors in Japan that are using ASL and the curriculum that [Jane] and [co-founder] created to teach English as a second language ... I know she has a global impact. I think she speaks as a keynote speaker. I think she customizes it for whichever group she's speaking to, but I think that also empowers them, just shows that they are able to do anything.

(Parent Three, personal communication, October, 2019)

Parent Three aptly described Jane's ability to overcome challenges by being resourceful in finding services to ensure accessibility and equality. Importantly, she mentioned how Jane helped and showed parents the lessons she had learned in pursuing resources and services for her daughters. She indicated that was beneficial for families to learn and explained:

[G]etting adequate services. I think that's one of the biggest hurdles. I think accessibility ... to the same experiences that we all have, or should have. [Jane] models for those families how to help their child. Get the resources they need.

(Parent Three, personal communication, October, 2019)

Parent Four further commented and expounded upon the comments and sentiments that Parent Three made. She echoed how Jane directly and indirectly motivates families to become proactive in learning to be resourceful in the ideas that Jane provides them.

Parent Four offered the following:

[S]he's put her story out there. She's allowed for some vulnerability. I think, her talents, using her resources to help families, children ... [Jane] has good ideas

(Parent Four, personal communication, October, 2019).

ALQ Data Analysis

In data analysis, I also compiled, organized, and read through the completed authentic leadership questionnaires (ALQ). The ALQ tabulation was performed using excel. Of note, all of the questions on the rater ALQ were addressed by the employers; however, parents one and two used NA (not applicable) when answering question two: “admits mistakes when they are made.” Additionally, parent seven indicated NA for questions 11 and 13, which read: “analyzes relevant data before coming to a decision” and “seeks feedback to improve interactions with others,” respectively. The overall mean for the stakeholder ALQ was 3.66 on a 5-point scale. The lowest tabulated mean was 3.25 for “analyzes relevant data before coming to a decision,” with the highest being reported at 5.00 for “makes decisions based on his or her core values” (see Table 3 for details). Ultimately, the means ranged from 3.25 to 5.00, which indicates that the stakeholders hold the perception that she presents herself as an authentic leader (Walumbwa et al., 2008).

Table 3

Stakeholder Item Response

Survey		
Item	(N)	Mean
1. Says exactly what he or she means	9	3.78
2. Admits mistakes when they are made	7	3.57
3. Encourages everyone to speak their mind	9	3.78
4. Tells you the hard truth	9	3.67
5. Displays emotions exactly in line with feelings	9	3.67
6. Demonstrates beliefs that are consistent with actions	9	3.89

7. Makes decisions based on his or her core values	9	4.00
8. Asks you to take positions that support your core values	9	3.78
9. Makes difficult decisions based on high standards of ethical conduct	9	3.78
10. Solicits views that challenge his or her deeply held positions	9	3.56
11. Analyzes relevant data before coming to a decision	8	3.25
12. Listens carefully to different points of view before coming to conclusions	9	3.56
13. Seeks feedback to improve interactions with others	8	3.50
14. Accurately describes how others view his or her capabilities	9	3.67
15. Knows when it is time to reevaluate his or her position on important issues	9	3.44
16. Shows he or she understands how specific actions impact others	9	3.67

Note. (Version 1.0 Rater) Authentic Leadership Questionnaire by Mindgarden, Inc. (2007).

Additionally, the mean scores were tabulated for each of the four factors of the ALQ: transparency, moral/ethical, balanced processing, and self-awareness (see Table 4 below). The self-awareness component related to a leader's ability to possess a complex understanding of how they created meaning of the world and developed a view of themselves by analyzing their strengths and weaknesses in relation to their interaction, with others over period of time, and how they affect other people (Walumbwa et al., 2008). Relational transparency was the presentation of the authentic self (Walumbwa et al., 2008). Balanced processing referred to the ability of a leader to be objective in their decision-making, being careful in the analysis of any and all data to inform their

decisions (Walumbwa et al., 2008). Finally, the moral/ethical component evidenced an internalized regulation of oneself (Walumbwa et al., 2008).

Once tabulated, the mean scores from the stakeholder ALQ and Jane’s ALQ were compared across all four sub-areas of the questionnaire. The mean calculation for both the rater and self-rater questionnaires called for questions 1, 2, 3, 4, and 5 to be calculated to find the mean of transparency; questions 6, 7, 8 and 9 related to the calculation of the moral/ethical component, while the balanced processing mean aligned with questions 10, 11, and 12. Finally, the calculations for questions 13, 14, 15, and 16 were associated with the mean tabulation for self-awareness. As indicated by the table below, Jane’s overall mean score (3.31) compared favorably to the overall stakeholder mean (3.66). Interestingly, for Jane, the data showed self-awareness as the lowest mean with the moral/ethical factor the highest rated mean; however, the stakeholder mean reported balanced processing as the lower mean with transparency rated the highest. It is noteworthy that Jane rated herself lower than her peers and employees. Given the nature of the numbers, both Jane and the stakeholders both showed strong agreement in all four factors.

Table 4

Stakeholder and Jane ALQ Factors

Categories	Jane (Mean)	Stakeholders (Mean)
Transparency (1, 2, 3, 4, and 5)	3.20	3.69
Moral/Ethical (6, 7, 8, and 9)	3.50	3.86

Balanced Processing		
(10, 11, and 12)	3.30	3.46
Self-Awareness		
(13, 14, 15, and 16)	3.25	3.57
Overall Mean	3.31	3.66

Note. (Versions 1.0 & 2.0 Rater) Authentic Leadership Questionnaire by Mindgarden, Inc. (2007).

CHAPTER V

NARRATIVE

In an era when the United States was dealing with the impact of the Cold War and fighting Communism, Jane was born in Los Angeles, California, as an October baby in the early 1970s. Coming out of 1960s, L.A. still had a historical stain left by many iconic religious and cultic figures such as the Manson Family, Jim Jones, and the People's Temple, the Sources Family with Father Yod, the Children of God and the Church of Scientology to name a few; however, the 70s ushered in shag carpet, tie-dye and lava lamps. Culturally speaking, L.A. was embracing the hippie movement that brought with it messages of peace and love, but with it came the promise of a more futuristic economy that would eventually become the home of many technology giants like Google and Facebook.

Jane was born on October 9, 1974, and comes from a large family. She was the fifth child of nine children; she has five sisters and three brothers. Her grandmother was a member of a big band era vocal group in the 1960s. Following in the footsteps of her grandmother, Jane's father is musically gifted and made a name as an American Mormon composer who is known for his film scores. Surprisingly, according to Jane, she was a

quiet and shy middle child, which is ironic given her current status and role with the educational platform. She remarked that:

(E)ven as a teen and as a kid. I did not feel like I could make a difference though.

I didn't feel like, "oh, I'm here to make a difference." I was very shy. I was very quiet. And I didn't have my own; I didn't have a powerful voice for myself."

(Jane, personal communication, October, 2019)

In the Summer of 1985, her family moved from Los Angeles to Salt Lake City where she started 7th grade as an 11-year-old. Moving into her teenage years, she attended and graduated from high school in 1992 and later spent one year at the local community college. As a teenager, Jane remained a quiet-natured and shy girl; however, she started to suffer from anxiety and depression. It was in this moment in her life when Jane was 17, she encountered one of her critical life events that both altered and inspired Jane's life journey. Being so young and filled with a multiplicity of emotions, she was faced with and settled on a tough and remarkable decision that she mentioned was in her best interest. In order to cope with the painful ordeal, find a sense of normality in her teenage years, and deal with the fact that very few people, outside of her immediate family, knew of her challenge, Jane turned to music as a safe way to find expression and mentally process her experience (Jane's blog, n. d.). Years after the tough circumstance, Jane revealed that "this unexpected [life event] was the reason I started writing songs ..."

(Jane's blog, n. d.).

It did not take long for Jane to realize her musical talent, which was similar to the talent displayed by her father and grandmother. After discovering her newfound talent, Jane continued in her aspiration of becoming a singer/songwriter/performer. With support

from her family, she set out on her journey by borrowing a guitar from her oldest sister. While teaching herself to play this newfound instrument, Jane continued writing more and more songs, honing her passion. She would enlist her friends as her audience and play her music in their living rooms. These performances were a start in developing her craft; they served as ideal venues to begin elevating her status as a musician. It did not take long for her to find herself playing in front of crowds at local coffee houses.

Jane continued to pursue music, and between the years of 1994-1997, Jane performed with a band while residing in Utah. Even though music was a primary focus in her life, she met her husband in September 1995 at a wedding in California. Jane was a maid of honor when she recalled a man telling her “You look like you are from Utah!” (Jane’s blog, n. d.). Being perplexed at this statement, and given Jane’s personality, she later found the man and asked what he meant, exactly. Still today, Jane admitted that she does not know what he meant. Whatever his intention was in that statement, the following year, the man who asked the question eventually became Jane’s husband. Jane and her husband married July 30, 1996, and have been married for 25 years. The young couple remained at their then current residence while he studied at the nearby university. Jane had joined a band and continued to play venues and write music.

Shortly after their marriage, the newlywed couple had their first child, Daughter One. Jane and her husband immediately began enjoying their beautiful newborn baby and the life that was before them; however, they both suspected that something was odd with Daughter One. Jane and her husband were nerved that no sounds other than a high shriek sounds were coming from Daughter One. Jane has mentioned in many interviews and disclosed the story on her blog about how her mother played a pivotal role in helping

Jane to discover that Daughter One was having trouble hearing. She relayed that after spending hours with the band, Jane went to pick-up Daughter One from her mother's house. Once she arrived, her mother told Jane: "(d)on't let (Daughter One) see you. Stand behind her and call her name." (Jane's blog, n. d.). Jane did just as her mother asked. She called out Daughter One's name out from behind her. There was no response from her baby. Standing there, absorbing the new information, Jane knew that their life had instantly changed. This young family was presented a challenge that changed their lives permanently. Curiously, she wondered how her mother discovered the hearing impairment her daughter faced. Earlier in the day, her mother indicated that they accidentally turned on the radio and the volume was up full blast, and everybody jumped and reacted except Jane's newborn daughter.

Jane and her family were left with many questions. Chief among them included: how could the hospital not identify this condition? They eventually found out that the hospital had performed newborn hearing screenings; however, Daughter One was born in December of 1996, during a period of time when the hospital briefly halted the hearing screenings while they compiled the collected data relate to the hearing screenings. The hospital performed those screenings from July to November of 1996. When Daughter One was 14 months old, they received the official diagnosis that she had a "severe to profound hearing impairment," and they were devastated and mourned (Jane's blog, n. d.). Jane wrote that they were certain there was a mistake. They just couldn't believe that she was deaf. Jane expressed that she felt angry and embarrassed that she had been around her for a little over a year, and this disability had escaped her. In spite of all of their emotions, Jane remarked that she found happiness in her daughter's smile. To her,

nothing was different or had altered her world; therefore, Jane and her husband made the decision to accept their daughter's attitude "... that nothing was wrong. It was just the way it had always been ... and I knew that we needed to learn something new. We needed to learn how to communicate with our child" (Jane's blog, n. d.).

Not long after receiving the stunning diagnosis that her daughter was deaf, in 1997, Jane made the decision to quit the band. This critical life event was too big, and Jane, along with her husband, dedicated themselves to understanding how to communicate with their baby girl. Her life focus had shifted, and she was now learning American Sign Language (ASL). Amidst everything, on one hand, they wanted to have another child; on the other hand, they wanted to prudently choose an approach that benefited Daughter One. Jane sought advice from professionals and those within the deaf community. She read everything and sought early intervention. All of their efforts helped them learn about their daughter. Perhaps one of the more sobering and unacceptable ideas they learned dealt with expert opinions about how far their deaf daughter would advance in high school. Jane addressed her reaction in that moment when she entertained the state about Daughter One's education:

... they said: "well, (Jane) statistically, (Daughter One) is going to graduate high school with a third-grade reading level". And this is a 14-month baby, a toddler. And I am thinking, you're telling me, you know, I give her to you and you promise me that in 18 years, by the time she graduates she can read like an 8-year-old. Forget it! (Jane, personal communication, October, 2019)

In 1998, Jane and her family moved from the city where they lived to another state. She needed a change of venue and an escape from her current environment. Jane

was trying to keep pace with her deaf child in learning ASL. Her fear was that she would fall behind her daughter in learning this new communication technique that was essential and allowed her to speak with her daughter. The situation only kept getting more challenging for Jane. She witnessed a shrinking community of friends who were able to communicate with her daughter. In Jane's mind, a move mitigated hearing apologies about how those in her circle couldn't talk with Daughter One and would open the door for more resources; yet, this was not the case. Jane recalled that it "... felt like we were fighting the system every day for things we took for granted back home" (Jane's blog, n. d.).

The learning curve for raising a deaf child came fast and furious for Jane. One of the many epiphany's she had as Daughter One grew older was how her daughter was learning. More specifically, Jane never thought about it, but her daughter was not privy to all of the indirect information that comes from a variety of different external inputs. Daughter One was not benefiting from hearing the television, radio, or conversations that took place in her surroundings. Jane had come to the realization that everything her daughter knew either came from her or her husband. Jane accepted this responsibility and was determined to provide her child with the tools to freely interpret, assimilate, and learn the information that was in her world. Jane knew that literacy was going to play a critical role in her daughter's intellectual and emotional development. Her little girl was going to have to learn to read.

Jane continued to be a spectator of her daughter's struggle in communicating with those outside of the deaf community. Although Daughter One tried her best understanding and tried hard to be understood, Jane knew that the few signs that people

could use to communicate would not be suffice. Jane increased her efforts to widen her daughter's circle of friends. For Jane, this would be accomplished by teaching others how to sign, so she started volunteering at the local pre-schools. Every week she would teach a signing story class. In a graduated fashion, Jane began seeing Daughter One's communication with others growing. Jane later mentioned that "(t)hese were the seeds that grew to become "[her educational platform]!" (Jane's blog, n. d.).

By the time Daughter One was three years old and had a strong communication strategy to guide her choices, Jane knew it was time to have another child. She had been thinking about another child and already had a name chosen for her next child. Mentally, Jane's feelings were that there would be no more mourning, crying, and she expressed that she felt very prepared for the eventuality that this baby should be born with a disability, too. With Daughter One set to begin pre-school, Jane just knew this was an ideal time for her pregnancy. She kept believing this time would be much easier for her.

After a few months, Jane had her 18- week ultrasound, which revealed that Daughter Two had hydrocephalus – a buildup of excessive fluid deep within the ventricles of her brain. This condition turned out to be the least of the bad news, unfortunately. The doctors were not able to see her cerebellum because it rested atop her spinal column. Daughter Two was diagnosed with Chiari Malformation. To make matters worse, Jane was told that her baby's spinal column was not closing as it should, which indicated that she also had spina bifida that carried forms of paralysis. Jane was devastated, once again. She admitted that she did cry and was concerned that any wrong movement could further exasperate the damage that already existed.

Jane was stunned and in disbelief. She was back in a similar position when she experienced the emotions of the raw reality of a severe medical diagnosis of Daughter One's profound deafness. While Daughter Two's medical conditions opened old wounds, Jane captured the same spirit and developed perspective that "Daughter Two was fine and nothing was wrong" (Jane, personal communication, October, 2019). Jane just needed to diligently research the new medical conditions and educate herself about what kind of life her daughter could potentially live. Jane immediately reached out to Vanderbilt University Medical Center and inquired about the work a pair of fetal surgeons were performing. They were providing groundbreaking operations for spina bifida. At 22-24 weeks gestation, Jane and her unborn baby underwent surgery to repair the spine. After multiple weeks of bedrest, Jane had Daughter Two, who arrived eight weeks early in 2000.

The surgery successfully reversed the Chiari Malformation, which meant that there was no need for a shunt at age three. This was a needed win that brought a sense of relief and comfort for Jane; however, it was short lived as Daughter Two was diagnosed with cerebral palsy at 9 months. On one hand, the doctor indicated that her cerebral palsy would not grow worse, nor would it get any better. Although this news was bittersweet, Jane was relieved. On the other hand, the neurologist relayed to her that Daughter Two would be mentally retarded. According to the doctor, her baby would never be able to communicate, either verbally or through signing.

Jane remained positive and was determined to show that the doctors were going to be proven wrong. It was during Daughter Two's very early childhood when Jane began laying the groundwork for her educational platform. In a remarkable turn of events,

Daughter Two started to learn basic signs. Given her experience with Daughter One, Jane was ecstatic because she understood how crucial increased communication would be for her daughter. The ability to communicate would be important for her learning and socialization. Importantly, Jane was now able to talk with her daughter and signing would help communication and undergird the development of fine motor skills. According to many medical professionals this outcome was thought to be an impossibility because of the cerebral palsy. Jane doggedly continued to work with her young daughter, and eventually her ability to use sign language enabled her to develop speech patterns. Her voice was finally being heard.

The Educational Platform Starts

Jane's sister was the third born child and four years older than Jane. Jane always looked up to her and appreciated her entrepreneurial spirit. They were best of friends and both had an affinity for the camera and created and directed their own impromptu and childhood productions. Both of their talents were instrumental and put to use much later in life, as Jane and her sister established their educational platform in May of 2002. Her sister quickly started a career in the voice-over industry at the age of 12 while Jane followed her father's footsteps in the music industry. Ironically, Jane and her sister did not intentionally mean to begin the educational platform.

There were several events that stuck with Jane, which resulted from her daughters' condition. One of those took place when Daughter One was four and played soccer. Being the only deaf child on the field, Jane always ran around and followed her daughter, signing to her directions when running drills. She was teamed up with a little boy, but since he did not understand her and she did not speak, he did not want to be

paired with her daughter. Jane just stood there and wondered if there was anything she could do to create a change in perspective in how this boy and any others felt about the deaf. This experience motivated Jane, and she quickly volunteered her time to teach sign language at local pre-schools, and was eventually hired to teach sign language at his preschool. Jane made it a fun and enjoyable experience for students, as she taught basic sign language through storytelling. Jane recollected on the past experience and claimed:

... within a couple of weeks, we were on the soccer field, and he runs up straight to Leah and signs, “friend, play ball.” And, instead of, “I don’t want to be with her, she doesn’t understand me,” three signs built a bridge ... from that, I just looked at ... what can I do? Can I contribute? Can I alter the trajectory? (Jane, personal communication, October, 2019)

This modicum of success led Jane to think about calling every preschool in the locality to teach basic sign language to students; however, her sister phoned Jane about creating a video for children. Originally, her sister wanted to make the video all about music and rhythm, but Jane interjected and insisted that they make sign language the focus. This idea aligned perfectly with the spirit that Jane had tried to accomplish in the preschools. She wanted to build bridges between the deaf and nondeaf communities, and the video built a communication bridge by teaching non-deaf children a few signs to communicate with deaf children. They made a large amount of these videos and distributed them for free to people within their circle, and included those people who followed from afar and loved the stories about Daughters One and Two. Her sister agreed with the sign language angle and they quickly purchased the educational platform’s internet web address.

In what seemed to be accidental on their part, Jane's educational platform was born, and as with any new business, she worked tirelessly towards its success. The educational platform was unique in that it was developed to target members both inside and outside of the deaf community. Fortunately for Jane, research that concerned the benefits of sign language for children without hearing deficits began to become more widely reported and recognized. Parents outside of the deaf community learned that ASL for hearing infants showed elevated IQ levels and reading levels; led to better social adjustment and parents recognized that this form of early communication decreased temper tantrums that made the "terrible twos" not so terrible (Jane, n. d.).

Jane had always expressed that sign language was an excellent tool for all children of all abilities. She sought families who had children without hearing impairments and noticed they were interested in teaching their children to sign. As a co-creator, Jane distributed videos to as many people who were interested in learning sign language with their children, as possible. She sought after parents that had children either with or without deafness, equally. She thoughtfully strategized ways to access parents. Initially, she, established a parental group who met online and in person. Many of the parents who became acquainted with the educational platform knew Jane from her work in the pre-schools, but several other mothers joined the Yahoo group that Jane created.

Parent Four joined Jane's Yahoo group in its early inception. She described her experience as she learned about Jane, her educational platform, and how she became more involved. She provided some insight when she exclaimed:

I joined the Yahoo group just to have other parents who were also signing with their children ... I hadn't been really exposed to sign language before that ...

[t]hat's how we started. They asked ... in her first year, in the group ... for testimonials. I sent mine in and they interviewed me ... (Parent Four, personal communication, October, 2019)

Jane and the educational platform were able to harness parent testimonials as a valuable tool that effectively increased the visibility of the business' overall goals and mission. The interviewed parents provided their testimonials and the platform continued to grow. The result was that people became more interested and offered their time and energy to help Jane. Parent Four became even more active in the Yahoo group. She finally met Jane, in person, at a playgroup. Parent Four recalled:

... I met Jane in that way for the first time, in person. I had been sharing my success quite a bit with everybody, and I said, I should sell these [videos] for you. And, [Jane's sister] said, 'okay'! So, I started selling them from the back of my car. (Parent Four, personal communication, October, 2019)

Not everybody shared Parent Four and others' excitement and enthusiastic spirit. Jane became the face of the platform, as she was the personality that everyone viewed on the videos. While her ingenuity and creative nature in how she taught signs to children was an effective measure, it did not rest well with certain members of the deaf community. Many in the deaf community voiced their concern that Jane potentially aimed to change the culture of sign language. This was a big challenge for Jane and the new platform. It even reached the point where she was verbally attacked. Employee One noted:

... they see it as their community and their language and she's intruding ... I hear that, now and then, as this is our language and you're trying to change it ... [l]ike

... the tape on her fingers. She uses different colored tape so that the children, as they're watching her, can distinguish the different fingers that she's doing. And it's been very helpful for them. And we've had negative comments from some in the deaf community that ... think that it should be a certain way. [P]eople who are signing should just be in black clothes ... not have any colors ... (Employee One, personal communication, October, 2019)

Another Day - Another Challenge

After Daughter Two was born and Jane was learning much about her new baby and her condition, Daughter One turned two years old and started her educational journey as a preschooler. Jane encountered a new set of demanding and laborious issues when it came to her daughters' Pre-school-12 educational experience. Pre-school represented a whole new challenge for Jane and her family. Each daughter had her own separate disability that presented a variety of physical, emotional, and mental challenges that Jane had to overcome. Throughout these critical events, Jane had adopted a determined attitude in dealing with her children's disabilities. She held the perspective they were just typical children, but, admittedly, the last thing Jane wanted was pity from people outside of the disabled community.

When her daughters were born, Jane assiduously studied and learned about their disabilities, which guided her decisions in their care. Jane took the same approach as she diligently educated herself of the available resources, appropriate connections, laws and policies, and avenues for proceeding with action. This information helped her to navigate the insurance and educational systems to find any and all of the advantages she could for

her girls. When asked about Daughter One and her disability, Jane provided insight into her immediate thought process when she stated:

... let's learn what we need to learn ... you know to give her all the advantages that she deserves ... (Jane, personal communication, October, 2019).

This advice served her well and led to great success in educating her children through the compulsory education system; however, there were definite obstacles Jane encountered along the way. She grew very adept and overcame institutional issues that challenged people with disabilities. As it pertained to her daughters, she learned and navigated section 504 of the Rehabilitation Act of 1973. Jane had gained the knowledge of working through Individualized Education Plans (IEP's). She quickly identified, located, and culled all of the resources she could for her daughters to move forward with the expansion of their lives and their educational pursuits, and allocated resources as efficiently as possible. In fact, later in her parental and professional careers, Jane became an advocate for many parents who faced similar circumstances with their disabled children. Parent Three corroborated Jane's actions during the interview process when she stated:

... she models for those families how to help their child. Get the resources they need. I mean there [were] no resources for [Daughter One] ... she fights for [Daughter Two] and the resources that [she] needs ... she's a huge advocate [and great at] getting adequate services [like] medical care. (Parent Three, personal communication, October, 2019)

Jane's outspoken role as an advocate expanded after a series of unforeseen circumstances in the sphere of the educational realm that shaped Jane's opinion about

how she wanted her children to be educated. More specifically, these experiences informed her thought process, and it evolved toward the need to mainstream her daughters into regular classroom settings. Jane grew to understand that they benefitted as they interacted with differently abled students, which eventually undergirded the development of their potential and helped them overcome their limitations. It became apparent to Jane that if her daughters were always with students of similar abilities, that is all they would ever achieve. She believed that it was prudent for her to further her efforts to advocate for her children.

As a few birthdays passed, her daughters were getting older and advanced into higher grades in school. Jane understood her daughters' talents and natural abilities, and she persisted in her focus of ensuring that their educational experience enhanced and facilitated growth. One of the decisions Jane made for Daughter One was getting a cochlear implant. Up this point, Daughter One gathered no indirect information that everyone else takes for granted; conversations her mind failed to input as external stimuli. She only inputted the information that was gathered through reading lip movements. Very early on in Daughter One's educational career, Jane tried to offset any learning deficit by enrolling her daughter into Kindergarten one year early, which put her ahead of her peer age, in essence.

Because of the cochlear implant, Jane mainstreamed her daughter into a regular third-grade classroom setting, as she was able to intake informational cues as a regular hearing individual. Jane's persistently advocated for her daughter to be mainstreamed and the implant was a positive step forward in her daughter's intellectual and emotional growth. She learned to process increased amounts of external stimulus and quickly

learned English. In her view, her daughter would greatly benefit from being able to interpret the world around her and her insistence was rewarded. Daughter One effectively socialized with her peers. Jane decided to have her daughter to repeat third-grade so that she would be among peers of similar age.

However, despite the new opportunities that the cochlear implant afforded Daughter One, given her status and involvement in her educational platform, Jane's decision inflamed specific members within the deaf community. Jane understood how volatile this certain community was, but there were others within this community that understood her perspective. This experience taught her that the deaf culture is comprised of people who communicated and were bonded through a common language (ASL) and valued their shared history, skills, traditions, and value systems. Jane learned that members of the deaf community were concerned about cochlear implants because it was seen as an attempt to change the deaf culture or abandon its membership. Although she respected the sentiments of deaf culture, Jane happily decided to put her daughter's needs above any threat of judgement. For Jane and Daughter One, this new technology increased her hearing ability and provided more accessibility to the world. In the face of the newest criticism, Jane stood by their decision and remained resolute in her decision.

With Daughter Two now in school, Jane would be faced with the challenges with Daughter Two getting an education. However, because she had faced similar challenges with Daughter One, she was better able to be prepared. As expected, the first issue she addressed was to counter the idea that her disabled daughter would only attain a third-grade educational level, which Jane understood to be an antiquated notion. This perception of her daughter's ability would be an issue that would always bother her. To

Jane's consternation, this belief was echoed by expert professionals far after her daughters graduated high school. She lamented:

[t]hey still tell parents, "oh your kid's deaf, they're [going] to graduate from high school with a third-grade reading level." There still are deaf children, [and] most ... show up at kindergarten, and they don't have their basic preschool skills.

They're still not ready for kindergarten. And this has been the case for 23 years.

(Jane, personal communication, October, 2019)

In spite of the many professional opinions Jane encountered when it came to her daughters' abilities and how they equated to success in their schooling, she always remained mentally and emotionally steadfast in her positions with respect to mainstreaming her daughters into traditional classrooms. One particular incident that really shocked Jane took place at a Christmas party that she attended in Daughter Two's class. Daughter Two was four years old and in her second year of Special Education Pres-School. Jane met with her teacher and asked if they were learning months of the year. The teacher turned and gave Jane a confused look. She inquired: "how'd you know that?" With a bewildered demeanor, Jane responded: "because she has been singing the song - January, February, March, April, etc. She would lay on the bed and sing this song." The stunned teacher gazed at Jane and replied, "she can talk?" Jane immediately knew that she had to remove Daughter Two from the Special Education program in favor of the traditional classroom environment, just as she had done with Daughter One. Jane understood that it wouldn't be the easiest path, but it would push her beyond the limits that she was being pushed in a classroom where her teacher did not even know that her daughter could speak.

Culminating Journeys

For years, Jane labored selflessly to prepare her daughters for each day of school. She diligently worked and showered, dressed, fed, and transported both of her children to and from school. Given that one of her daughters had a severe disability that inhibited mobility, this was a task that required much effort and planning. Only when her children were cared for did she take time for her own needs. As they encountered the world around them, Jane watched as her daughters struggled to become assimilated into their peer groups. This caused mental anguish for her, but she understood there was maturity in how they worked their way through the challenges they faced with their forms of communication. Eventually, she was rewarded, as Jane witnessed the graduation of both of her daughters. Daughter One graduated high school with honors while Daughter Two received her diploma that was earned in a regular classroom setting.

Amidst the successes that her daughters experienced, Jane continued in her role with the educational platform. As the organization expanded, so did her confidence, as she continually gained notoriety as an advocate for more families and peoples from a variety of communities. Jane discussed her growing role as an advocate:

... I think there's different kinds of advocates. It's like I am the voice of the underdog. I am an advocate for anyone who is seen as less than ...[w]hether that's LGBTQ or whether that's disabilities (Jane, personal communication, October, 2019).

Jane embraced being the “voice of the underdog,” which, in turn, built bridges of communication and provided avenues for people to discover their own voices – adults and children alike. A few of the testimonials given from mothers who used Jane’s

platform included pieces entitled: “Using [educational platform] Helped Me Get to Know My Autistic Son” and “I Got My Baby Back Because of Sign Language.” These types of successes became more prevalent, and, with time, Jane found herself becoming more than a well-known local figure. In 2003, Jane’s story was featured in a prominent women’s journal, as well as a local business magazine. In that same year, there was a write-up about Jane and her work with sign language in a local magazine. A few years later, Jane and both of her daughters were the focus of a story in another popular women’s magazine. Additionally, her sign language productions were recognized by a national magazine (2007) and the local newspaper in 2014. For her achievement of surpassing one million subscribers, YouTube has presented several plaques to the educational platform for many of their video productions and programs that teach sign language to a variety of differently aged children.

The educational platform’s multitude of productions continually gained recognition. Jane’s innovative mind and diligent work ethic helped her company reinvent the delivery of its messaging that accommodated and taught children from many different demographics, characteristic categories, and families. While success opened more doors and brought more opportunities for Jane, admittedly, her tireless efforts inevitably led to moments where she felt tired and entertained the notion of succumbing to her feelings of giving in to the mental toll. However, her mission for helping others grow was a strong source of strength. As she explained:

... I always find that doing something for someone else pulls me out of it. [Y]ou know, I’m just done, then I get a call: “hey we’ve got a make a wish,” and ... I’m

not done ... even just talking to another parent, sharing our story. (Jane, personal communication, October, 2019)

In addition to her work domestically, Jane became heavily involved in traveling internationally to help people. This opportunity motivated Jane, so she expanded her mission to teach sign language globally. An element of her platform contained an educational component where Jane trained people on the platform's curriculum. She has taught instructors who used this curriculum in countries such as Canada, Japan, and China, who are currently teaching American Sign Language vocabulary and early communication.

Jane enjoyed presenting keynote speeches to a variety of groups all over the globe. This opportunity allowed her to meet these communities who were influenced by her educational platform's work. She also participated in events where she worked with The United Angels Foundation (UAF). This is a non-profit parental support group between parents that supports parents and families of children who have special needs. She and her frog mascot held concerts and walk in buddy walks in support of families within the disabled and special needs communities. Parent Three described one of these concerts in the following manner:

... [I]t's overwhelming when you're at ... one of these shows is like. It's like, she's the rock star. But, not just that she's the rock star, she takes the time to acknowledge [families] (Parent Three, personal communication, October, 2019).

Undoubtedly, Jane's far reaching dedication positively impacted the lives of many families. Throughout the span of her career, her work with her platform successfully either built or enhanced patterns of communication and unlocked trapped voices of many

children. However, later on in her professional career, Jane participated in a few roles where she continued to make an even larger impact. She quickly found herself drawn into the lives of children at a level that even Jane never realized was possible whenever she became involved with the Make-A-Wish Foundation. In this role, she happily fulfilled a children's wishes to meet her. On more than a few occasions, she visited them in the hospital.

Next, Jane accepted an Executive Director position with a 53-year old non-profit organization, the American Society for Deaf Children. This particular non-profit was created by parents, as a parental support organization, for families with deaf children. In this position she was able to harness her first-hand experience as a parent with a deaf child and addressed some of the issues she had encountered while her daughters were in school. One of her areas of focus was emphasizing to parents the importance of ensuring their kids were equipped with the basic preschool skill sets, which would help the transition into kindergarten. Furthermore, she encouraged parents not to be dismayed or disappointed when faced with policies that suggested that their children would likely graduate from high school with a third-grade reading level merely because they were deaf. Jane's journey had culminated. The life events that had brought so many trials and times of joy had led her to a zenith of influence. An even more empowered Jane had reached another platform where she continued her determined fight through advocacy.

CHAPTER VI

DISCUSSION

Theoretical Application

Historically, the perceptions of individuals with disabilities, by the non-disabled community, have often been characterized by limited expectations regarding their ability to contribute significantly to society. Specifically, even though individuals with disabilities have vastly varying skills and abilities, and vastly differing limitations caused by their disability, the social construction of “disabled” often meant that their abilities were perceived through a deficit lens, with a stronger focus on their limitations rather than their actual abilities. As a result of this perspective, the disabled have experienced limited opportunity to actively participate in their local economies and have been underrepresented as leaders in social institutions.

In addition, societal perceptions have, historically, negatively impacted the quality of life for those with disabilities, as low expectations pushed this group to the fringes of employment opportunities where they were often forced to depend on government assistance to make a sustainable wage (Gerber, 2010). The progression of marginalization continued for decades; whereupon, unsightly laws were passed that made it illegal for individuals with disabilities to remain on the streets to even pander for money (Schweik, 2009). The societal perspective of disability gradually started to reverse as the world

evolved; yet, the traditional standards of practice and societal attitudes related to the disabled have continued to influence a majority of current-day modes of practice that still have dismissive repercussions for this group (Munyi, 2012).

Given the immense adversity that the disabled community encountered, there were civil rights groups and disability activists and advocates who navigated the cultural, political, and legal arenas and fought for equal rights and accommodations that successfully changed the arc of history for the disabled (Karger & Rose, 2010).

Throughout time, society evolved to a point where people with disabilities gradually have been welcomed to participate as active and valued members within their communities. Accommodations for the disabled slowly progressed, which made the environmental and institutional landscapes more accessible for people who had a variety of disabilities. These changes are important because, as Baffoe (2013) noted, when barriers in the physical setting, architectural institutions, and areas of transportation are acceptable in communities, the lack of alterations perpetuated oppression and created more social disadvantages. Such progress was due to the passage of laws like the Americans with Disability Act of 1990. However, despite this progress, there remained barriers for people with disabilities in areas of gainful employment. These opportunities were often limited due to perspectives towards the disabled related to their abilities as perceived by those without disabilities, which limited access to “opportunities, privileges, and resources in society” (Baffoe, 2013, p. 188).

Findings Explained Through Critical Disability Theory

Critical Disability Theory (CDT) had utility to explain the findings from this study. It was utilized because the core tenets provide understanding of factors that

influenced educational opportunities for Jane's daughters and her tenacity and dedication as she fought to overcome the challenging critical life events that she and her children experienced (Northouse, 2018; Ollerenshaw & Creswell, 2002). The core tenets of CDT that had utility for explaining Jane's story included the following: 1) disability as a social construct; 2) collaborative complexities experienced within a disability or impairment interact with each other to yield a response from the interplay between the person's condition and their social environmental setting; 3) social disadvantages experienced by those disabled individuals that primarily arise out of "the physical, institutional and attitudinal environment which fails to meet the needs of people who do not match the social expectation of 'normalcy'" (Hosking, 2008, p. 7).

These outlined CDT tenets provided a framework for understanding societal roadblocks that Jane and her daughters experienced, and though not generalizable, CDT helped to illuminate these situations as limitations placed on these two daughters as they sought to engage and even participate in society. Furthermore, CDT explained how Jane dared to combat the challenges that she and her daughters encountered due to their medical disabilities. Courageously, she pushed back against the circumstances that she faced, particularly as related to expectations (or limitations) placed upon them in their educational settings.

Tenet One. CDT views disability as a socially constructed framework rather than a result of the individual's impairment (Culham & Lind, 2003; Hosking, 2008). Findings from this study were explained through this CDT tenet, in that, throughout history, people with disabilities have faced perceptual barriers that associated disability with weakness. Negative perceptions have contributed to the social construct that have informed many

models of disability. Specific models include the moral and medical model frameworks which interpreted disability as a functional limitation that started with the individual (James, Bustamante, Lamons, & Chini, 2018). On the other hand, CDT promotes the removal of barriers and suggests that individuals with physical or cognitive challenges should not be defined based upon impairment (Goodley, Hughes, & Davis, 2012). Examples from this study that were explained through this understanding included the experiences that Jane encountered when the state and the public school administration at her daughters' school viewed her children as being incapable of communication or academic potential beyond a third-grade reading level. This social construct was foreign to Jane. In her thought process, she held the expectation that the state and the school system would provide the necessary support for her daughters' education similar to supporting other non-disabled students in their academic pursuits. Jane's remarks regarding the inability for the experts to see her daughters' potential support this explanation:

I look at both of my kids and what the likely result would have been in their education, and in their life, had we not just been like, "that can't be true, we don't agree, we don't believe it." [Daughter One] would've graduated and been reading on a third-grade level. [Daughter Two] maybe would have never spoken, never communicated and would've been relegated to a Special Ed. classroom ... (Jane, personal communication, October, 2019)

More specifically, this theory was utilized to expose the deficit perspectives held by the school district in an effort to empower Jane's daughters. At an individual level, CDT provided a lens to view disabled individuals through the lens of strength, capability,

and production based on unique skill sets, characteristics, and talents (Hosking, 2008). Findings from this study suggest that Jane's focus on her daughters' strengths instead of their limitations stands in stark contrast to typical societal perceptions of individuals with disabilities. Along the line of findings in this study, Jane saw her daughters as unique individuals with potential, including being capable of reading at higher levels and even mainstreaming into the general student population. She was surprised, although not deterred, by the school administration's attempt to categorize her children in a way that limited their potential for academic growth.

Viewing the findings from this study through the lens of CDT was important because the prevailing perception of disability stemmed from the deficit approach that emphasized "deficiency and intrinsic flaws" within the individual and focused on what they "*cannot do*" (D'Amato, Crepeau-Hobson, Huang, & Geil, 2005, p. 98). Further, CDT addresses imbalances of power involved with overcoming the broad categorization of groups of people. Typically, in a situation involving a parent and school officials, the parent's voice may be marginalized as "experts" in the district explain academic potential. Jane's situation was an anomaly to the expected norm of limitations. Jane did not perceive people's potential based upon inability. Instead, she developed and continually valued those with disabilities based on their individual strengths and capabilities. Employee One's explanation of Jane's perception, "Everybody has certain abilities they need to learn and overcome ... Everybody is equal," supports this understanding regarding how Jane perceived people with disabilities. Through her active participation in the life of her daughters, Jane became very aware of the barriers that they experienced and fought for opportunities for her daughters to express their gifts.

Tenet Two. CDT considers the balance of an impairment with societal standards, and it views disability as a complex experience that results from the interplay between the person's condition and their response to their social environmental setting (Hosking, 2008). Disability activists have asserted there are no impairments that result from a disability, "only the failure of society to accommodate difference" (Hosking, 2008, p. 7). The failure to accommodate often results in limited options in life for the disabled. Importantly, it speaks towards tenet two of CDT because this failure creates an imbalance between impairment and standards set forth by societal institutions.

As outlined in tenet two, there were contexts in many areas of society where the stigma of disability existed for Jane's daughters. Specifically, looking at Daughter Two's schooling was another example that illustrated the balance between the confluence of Daughter Two's impairment, her response to impairment, and the social context (Hosking, 2008). At Daughter Two's school Christmas party, Jane held a conversation with the teacher and discovered that the instructor was not aware that her child could speak. Jane was struck with amazement at the teacher's lack of awareness. Especially significant was the fact that the teacher had been working with Daughter Two for a full semester. As was the case in Daughter One's schooling, Jane was, again, forced to advocate for a way where she could have her daughter placed in a better educational setting that did not put Daughter Two at an educational disadvantage. She knew her daughter deserved to be in a classroom where more attention was provided and her skills could be cultivated. Jane made the difficult decision to place her in a traditional classroom setting. Jane admitted that it was "really, really hard for [Daughter Two] to be mainstreamed ... [t]hat was the best option and opportunity for her."

Jane's mindset ran counter to societal perceptions that her daughter was best served in placement in a Special Needs classroom. This placement represented categorization of the disabled based upon a deficit lens that further maximized limitations and minimized potential. Jane quickly recognized that Daughter Two was initially in an environment that failed to meet her educational needs due to an unclear understating of her disability and, more importantly, her abilities. Jane's instinctive response to fight to have her child mainstreamed into a general school classroom enhanced Daughter Two's chances for skill development and moved her toward independence for the next step after high school. Moreover, understanding the challenges the move presented for her daughter, Jane put her in an environment that pushed her child and rewarded her talents. She recognized the failure of the teacher to view Daughter Two as a more capable student. Jane immediately moved to have Daughter Two's classroom setting changed to an environment that did not allow her disability to dictate a limited educational outcome. Instead, Daughter Two was eventually included among students without disabilities, and she experienced success in this placement.

Further insight that CDT offered into these findings is that Culham and Nind (2003) contended that changes at the institutional levels are all too often "piecemeal or add-on rather than the fundamental and pervasive change" necessary for increased participation (p. 74). As can be seen from the examples provided above, Jane's frustration was highlighted when it came to the intersection of both of her daughters' disabilities and her desire to have her children accommodated and mainstreamed into a regular classroom setting. The institution's "default position" to keep her daughters in their respective classes showed how their failure to accommodate collided with Jane's expectations and

created imbalance and complexity between their disabilities and social environmental settings. As a result, Jane began to advocate for them to be included in regular classrooms and voiced her unfavorable position regarding this recommendation; however, although the state and school listened to Jane's position, they did not entertain the idea of reviewing their recommendation and continued to inform parents that "your kid's deaf, they're going to graduate from high school with a third-grade reading level."

Jane responded with strength to the challenges that she experienced in trying to find sound educational experiences for both of her daughters. The development of her educational platform was how Jane responded to limitations placed on her daughters. She quickly realized that institutional limitations influenced not only her daughters, but also other children she had met with hearing impairments. These limitations motivated Jane, and those whom she influenced, to become more comfortable and establish a greater depth of familiarity with disability. Jane noted that parents with disabled children often experience an avalanche of emotions that are brought on by their learning of the disability and how the health condition impacts the lives of the family unit and their individual members. Jane recanted the enormity of the moment and the multiplicity of feelings she felt as she was told that Daughter One was profoundly deaf:

You know how there are times in your life that are lines of demarcation? Once you cross it, things are never the same. Well this was one of the moments ... we mourned. We cried. We felt silly. We couldn't believe it. We thought there was a mistake. We hoped it would go away. We felt all of that and more at once! (Jane's blog, n. d.)

Because of lessons she had learned through experiences with her daughters, Jane was determined to bridge the communication gap between the deaf and nondeaf communities by equipping children from the deaf and hearing-impaired cultures with sign language skills. She disliked the idea that her children had peers that could not communicate with them. Jane was motivated to inform parents that they do not “have to settle” for limited expectations for their children. For her, personally, she was dissatisfied with the implication that her disabled children would graduate high school with a “third-grade reading level,” and she was compelled to advocate for other disabled children as well. Jane established her sign language platform to provide important resources to hearing impaired children and their families. In providing these resources, she was also able to embolden other parents to search for answers regarding how to respond to attitudes and policies that their children would likely face in institutional settings. Also, her organization was designed to provide the tools to empower individuals who are disabled with a form of communication that helps facilitate a degree of independence. The ability to communicate expands their voice to create self-advocating individuals (Pederson, 1997) with an increased self-esteem (Kernis, 2003). In speaking toward what was the catalyst for her platform’s goals, Jane reached back in her memory and contemplated about her initial approach:

I’m always looking for, I can’t help it, how do we solve the [unsolvable]? So, how do we, how do we solve the stuff that people just sort of [have] thrown their hands up and said, “well, we can’t really solve that.” I think it’s solvable, but you can’t look at things as unsolvable or you wouldn’t even try. So, that’s something I

[think] what do we have that can make life easier for them and their children.

(Jane, personal communication, October, 2019)

The complexity of disability was a theme that heavily impacted Jane's story. She was handed incredibly arduous circumstances when she became a mother of two children, each of them having unique disabilities that required specific attention. These circumstances necessitated an assessment of her own attitude, as well as her physical and social environments, regarding how they interacted to impact her girls and their conditions. Prudently, she pondered considerably the challenges and opportunities when it came to raising disabled children. This was important thought process because there were a multitude of factors that interfaced and created a web of considerations for Jane. She carefully contemplated upon the intersection of these environments and how her surrounding milieu would influence her daughters' responses based on their ability to participate in many facets of everyday life that, in turn, impacted Jane and their family also. For example, she had to be assiduous and mindful to ensure that Daughter Two's wheelchair could access certain buildings and physical landscapes. Similarly, she needed to make sure that Daughter One had interpreters at a variety of events, so she could interact and be an active participant within those contexts. There was complexity brought on by inaccessibility that were barriers that Jane had to consistently account for.

Jane's quote directly above illustrates the gravity of her complex circumstance by emphasizing the mental and emotional growth that Jane showed as she encountered her first personal and impactful experience with disability upon learning about each of her daughters' diagnoses. Her instinctive response was to seek ways to support the development of her daughters, regardless of the environmental setting. Because she was

willing to approach challenges with a determined spirit, Jane found ways to motivate her daughters to overcome barriers, which allowed them to discover their unique personalities and build confidence along the way. Furthermore, her perspective of disability clearly shifted from a position of sadness and gloom to a mindset that avoided the association of disability with weakness, an overall theme in CDT.

Tenet Three. In tenet three, CDT focuses on “the physical, institutional and attitudinal environment which fails to meet the needs of people who do not match the social expectation of 'normalcy'" (Hosking, 2008, p. 7). These contexts are important in understanding how the disabled often fall outside of the expectational standard of normality as defined by society (Hosking, 2008). These failed expectations often limit those with cognitive or physical challenges from participation in their communities (Baffoe, 2013; Culham & Nind, 2003). Also, the concept of normalcy, an underpinning of CDT (Hosking, 2008), provides further understanding of how society defines disability within terms of what is “normal.” More specifically, “normalcy” explains how disability converges within a variety of social environmental settings that create barriers for people with disabilities. Academic scholars such as Davis (1997) shifted attention away from deconstructing the concept of disability and conceptualized the normal body in effort to raise an awareness of the disabled body. Davis further explained that the “problem is not the person with disabilities; the problem is the way that ‘normalcy’ is constructed to create the ‘problem’ of the disabled person” (p. 3). An example that highlighted conceptualization of disability came from the establishment of Jane’s educational platform, which is an extension of Jane’s perspective of disability. Her organization’s approach of working with disability came from a position of strength and potential when

it comes to the disabled meeting expectations of normalcy. Essentially, Jane and her platform provided a space for hearing impaired individuals to find “community.” In doing so, the perception of normalcy within this space was redefined. Additionally, Jane was able to provide resources and connections that shifted perspectives away from the “problem” of hearing loss to the “solution” of developing language skills (Davis, 1997).

Normalcy, understood in this context, implied a sense of uniformity among communities of people in society; thus, those within the disabled community shared lived experiences that resulted from the interactions between their medical conditions and their surrounding physical, institutional, and attitudinal environments (Hosking, 2008). As evidenced by the previously discussed examples, Jane’s daughters encountered such an interaction in their social environments. Their school experiences showed how the school system’s expectation of normalcy represented a problem that could have stymied their academic progression. The ideas that the non-disabled consider “normal” create expectations that remain pervasive in the physical, institutional, and attitudinal environments that make it harder for the potential of the disabled to be realized. In Jane’s story, these perceptions enhanced limitations that these girls experienced because of their impairments. This finding can be explained through CDT in that social norms often develop around perceptions of the non-disabled regarding normalcy that add to social hinderances for disabled individuals.

In each of the daughters’ cases, they were operating within a setting where their full potential was stymied. This was evidenced with respect to Daughter Two where the school administration followed prescribed guidelines that would have kept Jane’s child in Special Education class if Jane had not stayed aware of her needs and advocated for them

strongly. In both of the girls' cases, the school's understanding of disability led to static thinking in how to best address educational accommodations. The effort to provide accommodations to help the girls overcome their perceived inabilities fell short; whereas, Jane believed that her girls were capable of much higher educational achievement, and wanted their talents cultivated by attending classes with the general population of students. Jane was confident that her girls, and other people with disabilities, could move forward when motivated properly and when provided with opportunities for growth. For her children, she understood that Daughter One and Daughter Two would be pushed to a greater degree by being among students outside of the disabled community. This placement would take them outside of their "comfort zone" to help them surpass the third-grade reading level that was ascribed to them in their educational experience. In this example, the school system reflected a deficit-minded framework regarding disability.

This study's findings suggest that Jane held a positive perception of her daughters' abilities. Jane also valued others' abilities through a positive lens by perceiving their capabilities and potential rather than their limitations. Jane's story was explained through CDT because this particular theoretical framework explains disability as a social construction rather than a consequence of impairment. Further, CDT explains that disabilities are a "complex interrelationship between impairment, individual response to impairment, and the social environment". Lastly, "the physical, institutional and attitudinal environment which fails to meet the needs of people who do not match the social expectation of 'normalcy'" contributed to the formation of social disadvantages the disabled experienced (Hosking, 2008, p. 7).

Jane's approach to working with her daughters and others in the disabled community provides evidence that she values individuals for their individual strengths. CDT exposes the barriers for persons with disabilities that diminish individualistic character traits of those individuals with a disability; specifically, the individual assets and contributions that these individuals can make to society. Moreover, Jane recognized and cultivated a variety of skills and abilities of her daughters and those with whom she works in her educational platform. She did not default to the categorization of individuals based upon disability; instead, her work with the disabled through her educational platform exhibits a mental construction that the disabled are capable of great achievement when certain barriers are acknowledged and removed to promote participation among all peoples in their communities.

One finding that this story revealed was that although CDT has utility as a lens that explains existing oppression, it cannot explain Jane's approach to serving as an advocate for her daughters or her extension of that advocacy to the hearing-impaired community. Specifically, while CDT does have utility to explain the structural, cultural and societal barriers that could have, potentially, limited the growth and development of her daughters, it does not have utility to explain Jane's strength and advocacy. Therefore, CDT as a theoretical framework is limited in explaining one of the study's important findings: the development of Jane's leadership platform and her leadership role in the deaf community that emerged as a result. Her advocacy allowed her to break cultural barriers of raising her deaf daughter with a cochlear implant, something that is not widely accepted by the deaf community. This penetration of the deaf community allowed Jane to expand the deaf community's understandings of how to potentially meet the needs of the

hearing-impaired through medical advancements that enhanced hearing ability. Jane's approach to working with the deaf community to provide resources and support for their growth requires a framework to explain her strength that developed her into a powerful leader for the deaf community. As such, CDT has limitations for explaining the findings of this study because it cannot explain benevolent actions, those that are not based on interest convergence, that counter societal norms and expectations.

Authentic Leadership (AL) does have utility to explain this finding because Jane had innate leadership qualities that, combined with her authentic goodwill in wanting to help those beyond her personal orbit, immersed herself into the deaf community and culture to effectively reconfigure certain boundaries of acceptance. Jane's voice raised an awareness on behalf of the deaf who were often excluded in the deaf culture because of their choice to have cochlear implants. Jane's unique experience gave her a credible message and put a spotlight on the fact that the deaf community's position against cochlear technology limited the inclusion of a selected body of deaf individuals. This cultural practice further marginalized those individuals because it rendered them isolated from the deaf community. For this reason, AL was selected as a second theoretical framework for this study. AL was utilized to explain Jane's unique characteristics and positionality to lead individuals in the deaf community toward growth and development.

Findings Explained Through Authentic Leadership Theory

Authentic leadership (AL) was developed, primarily, to explain leadership in morally bankrupt organizations; it prevailed as a behavioral prescription for organizations because it injected a sense of authenticity into ethically deficient settings (Gardner et al., 2011). Walumbwa, et al. (2008) viewed authentic leadership as behavioral leadership that

focused upon successful mental capacities, in addition to a positive ethical climate, where a “greater self-awareness, an internalized moral perspective, balanced processing of information, and relational transparency on the part of leaders working with followers, foster positive self-development” (p. 94). Additionally, AL has practical applications, in that, it can be accommodated and tied to real-life experiences (Northouse, 2016). AL is a lens that captured the essence of Jane’s narrative that is filled with life experiences that contributed to her leadership style and her sense of credibility.

Findings from Jane’s story can be explained through AL. It is notable that the means of the rater and self-rater ALQ’s (Table 4) suggested that although Jane rated herself below the perceptions of stakeholders, the means were not disparate. In fact, the reported means indicated an alignment between Jane’s perceptions and stakeholders’ perceptions in relation to all four AL components. These findings are explained more fully below.

Self-Awareness. Within the AL framework, self-awareness is a key component that has utility in explaining how leaders make meaning in leadership situations. Further, self-awareness explains how a leader’s self-conceptualization is dynamically constructed through environmental exchanges between themselves and the individuals surrounding them. Kernis (2003) posited that this particular component involves a realized “trust in one’s motives, feelings, desires, and self-relevant cognitions” that is not exclusionary to the “strengths and weaknesses, trait characteristics, and emotions” of oneself (p. 13). Jane had many circumstances in her life that required self-reflection and an analysis of her emotional self. The development of Jane’s self-awareness was best illustrated as she

progressed from a mother raising two disabled children to becoming a bold and determined advocate for those people with disabilities and their families.

Jane's propensity for authentic leadership was discovered through adversity, a common phenomenon mentioned in literature regarding authentic leaders (George et al., 2007). Of her initial challenges, the births of her two daughters introduced dramatic life altering events in Jane's life. Ironically, as she used her direct experience with disability to help others discover their voices, she began developing a powerful message that, as Jane attested, "helped me find a voice I didn't know I had." Eventually, she co-founded a successful educational sign language organization that provided Jane a platform to advocate for those impacted by disability.

One of the specific examples of adversity that has been previously alluded to is the birth of her two daughters. Jane was emotional as she learned of Daughter One's diagnosis; however, her response to this challenging situation serves as evidence that she could overcome a multitude of barriers and frustrating circumstances, a characteristic of authentic leadership (George, 2003; Roop, 2022). The knowledge and wisdom gained from the birth of Daughter One carried Jane through the birth of Daughter Two, who was diagnosed with spina bifida. Without question, Jane was able to internalize these two events and understand herself in relation to the circumstance and how they influenced her as an emotional and thoughtful person. She better understood her strength and honed her motives for the future. Jane applied these difficultly learned lessons that helped her become a powerful advocate for hearing-impaired individuals. Her trials and learned lessons made her a stronger leader, which were valuable skills necessary to persevere

through the criticism she received from the deaf community regarding Daughter One's cochlear implant and the creation of Jane's educational platform.

Findings from this study revealed that the deaf culture that Jane experienced was a tightly-woven group that worked hard to maintain their customs, ideas, and cultural practices. Although Jane worked within her capacity to provide resources to the deaf community to enhance their ability to communicate with a hearing world, the deaf community's cultural norms that she experienced challenged Jane's "interference" in providing resources to enhance their communication skills. The perceived intrusion on this community's norms was displayed in the outrage that members of this deaf community expressed when her oldest daughter received a cochlear implant. Additional criticism was voiced towards Jane's ASL teaching methods. A bewildered Jane stated: "I try not to stomp all over someone's culture and experience." Moreover, these individuals in the deaf community opposed Jane's efforts by arguing that only those who were deaf should be teaching sign language. This finding is evidenced by the statement made by Employee One: "there are some in the deaf community that don't really like what she's doing." However, Jane challenged this opposition by persisting in her efforts, focusing on the needs of her daughters, and expanding her influence to support needs in the deaf community through her online platform. Jane recalled the sentiments the deaf culture expressed about her educational platform and the cochlear implant technology they decided upon for her daughter:

[W]e created [the educational platform] and made it available, publicly ... we started to receive criticism from the deaf community that was you shouldn't be doing this ... there's so many slices of the world of deafness. When [Daughter

One] got the cochlear implant, same thing. That just inflamed certain sections of people ... ‘how dare you’ or ‘we’re never gonna refer anyone to your products again’ ... (Jane, personal communication, October, 2019)

As mentioned by Jane, the criticisms from within deaf circles were particularly loud when it came to Daughter Two having the cochlear implant operation. As Daughter One continued to progress in the public-school system, Jane noticed that her daughter was not able to read and interpret environmental contexts and cues in school at the same pace as her hearing abled peers. In effort to avoid placing her daughter in a position to fail, she believed strongly that Daughter One should receive a “controversial” cochlear implant. After her daughter successfully received the implant, Jane continued to receive a great deal of criticism from within the deaf community about their decision, which was a difficult choice and required much research and contemplation. Jane’s decision to move forward with the procedure was her understanding that, in order for her daughter to succeed in life, she would need to develop a sound educational foundation to support further opportunities for success. The cochlear implant seemed to be the obvious choice to provide the educational support that Daughter One needed.

It became evident to Jane that, if she had not quickly acted to help, her deaf daughter would have been impacted by institutional expectations that would have limited her potential in learning to read at higher grade levels. Academically, Jane believed that Daughter One was capable of staying “on course” with her peer group. Her inclination was to seek a solution to propel her child past the current expectation that she would only attain a third-grade reading level based on her disability. She quickly identified the need for Daughter One to attend classes with the general student population, which required

Daughter One to receive a cochlear implant. The implant enhanced input so that she could interpret “new information and learn how to listen ... and understand English” (Personal Interview, 2019).

As explained through AL, Jane’s experiences and decisions related to those experiences allowed Jane to gain greater self-awareness. Additionally, she has been able to sharpen her leadership skills utilizing her “natural ability to overcome challenges and adversity,” allowing her to confront her weaknesses to become an even more burgeoning leader with great determination and fight (George, 2003, p. 12). Thus, although it was tough and tiresome, the births and schooling of two disabled daughters helped define Jane’s journey in positive ways. First, by virtue of the experience she gained just by being a mother of disabled children, Jane developed as a leader. Secondly, her lived experience marked the starting point of character development that gave her the necessary ability to embrace arduous circumstances while she remained steadfast and determined to advocate for others.

Balanced Processing. Balanced processing occurs when leaders review information with objectivity, prior to making decisions, and actively seek countering viewpoints that challenge their own (Datta, 2015; Gardner et al., 2005; Walumba et al., 2008). Jane’s rise to the status of a leader was a grass roots process that evolved from a series of events that included becoming a parent of two children with disabilities, making the decision in favor of a cochlear implant for Daughter One, and co-founding her educational platform. These events required informed decision-making and the ability to be evaluative of herself for growth purposes. Jane illustrated balanced processing in how she approached these impactful life events with thoughtfulness. Her initial diligence can

be seen in how she thoroughly researched both of her daughters' disabilities and developed a plan for how to best make decisions for her children. Further, prior to Daughter One receiving a cochlear implant, Jane was not impetuous as she gathered all of the available research data and information related to the device and the implant process. Moreover, because receiving a cochlear implant was a controversial issue within the deaf community, she entertained countervailing opinions, which helped her gain a cultural perspective about cochlear implants. Jane was sympathetic to the deaf culture's point of view and understood that "within the deaf community, there's a lot of hurt ... many people have had the experience of being oppressed ... [t]reated as second-class citizens" (Personal Interview, 2019).

The primary purpose of leadership is to create movement, facilitate change, and influence people to achieve desired outcomes using agreed upon objectives (Northouse, 2013). Specifically, authentic leadership is viewed as a genuine and highly interactive relationship between the leader and follower (Gardner et al., 2005; Walumba et al., 2008). With a joyous chuckle, Jane recalled her early business endeavors: "we didn't mean to make a business." Her educational platform was established out of her volunteer work where she taught children sign language at area preschools. She then went from selling educational sign language videos from the trunk of her car to co-founding her company. Consistent with AL, Jane effectively worked and earned the trust of parents who became loyal followers of her story and platform. Unbeknown to Jane, she had started a movement that would influence individuals and communities for a number of years throughout her professional career. With the addition of an online presence on YouTube and Netflix, Jane's platform has been viewed by millions of people.

Once her sign language organization gained momentum, Jane and her sister became more balanced in processing their business decisions (Walumba et al., 2008). She made her story available for public consumption, and she quickly discovered that her experience resonated with many parents who had disabled children. With an identified target audience, Jane's platform incorporated the use of technology as a useful tool in the dissemination of her message. As Jane's support started to evolve and grow, she entertained weekly chat sessions where she and parents, such as Parent Six, "got to know each other a little bit ... online." Parent Six responded positively to Jane's organizational mission and enjoyed her uniquely messaged encouragement that was delivered with an upbeat energy that became a source of strength for families impacted by disability.

Conversely, even parents with children without disabilities sought to teach their children to sign. Her authenticity continued to shape itself as her role as a leader within her professional platform and her work with advocacy grew more influential. As her professional career advanced, Jane operated within the balanced processing construct as an authentic leader. She became more informed and intentional with decisions in accordance with the mission of her organization. Her story and stature flourished while the company continued to serve the domestic sphere; however, Jane desired to extend her ASL curriculum internationally. Prudently, another well planned strategy, installed by Jane and her co-founder, was the creation of an educational curriculum and training component that expanded their business model. They understood that Jane's story and platform were powerful, but they also recognized that the scope of her reach was limited. In an effort to move the platform beyond its current boundaries, instructional training of the ASL curriculum, designated as programs for children and babies, was offered to teach

early communication techniques. To date, Jane's platform has trained people to teach the ASL curriculum in several countries including Canada, China, and Japan. This training has been a resource to influence change. Instructors have utilized the curriculum to teach ESL student populations, and it has motivated them to become disability advocates as well. Parent Three proclaimed:

[W]e have an instructor in Canada whose son is deaf. And, she is advocating for her son and the laws and stuff up there. And, she has followed some of [Jane's] example, and I know thinks very highly of [Jane]. (Parent Three, personal communication, October, 2019)

Relational Transparency. The third tenet of AL, relational transparency in leadership, involves being authentic in the presentation of one's self (Kernis, 2003). This component of AL stems from the self-awareness component because trust is a key element for authenticity. When truly authentic leaders are appropriately transparent with "information and expressions of one's true thoughts and feelings," they establish trusting relationships with open environments characterized by positive channels of communicational exchanges (Walumba et al., 2008, p. 95). Findings of this study indicate that Jane carried credibility as a leader and disability advocate. Jane's ability to convey her reality to others commanded trust. Relational trust resulted in the cultivation in a myriad of long-lasting personal and professional relationships that were symbiotic for her and those she impacted.

AL's relational transparency component can help to explain Jane's leadership style. She harnessed lessons from specific critical life events that forged her spirit of determination. This determination removed fears that might deflate her propensity to

fight through tough situations for herself and others. From as early as her childhood, she never expected to be as impactful as she has become. Jane proclaimed that she never had “a powerful voice for myself ... I think I gained that on behalf of my children.” Over time, life circumstances placed her into a situation where she took advantage of her experiences and expanded her influence beyond her immediate family through the establishment of her educational platform. Her persistence in raising and seeking the best outcome for her daughters lent her credibility in her role as an advocate and leader.

Empowering people through advocacy, such as Jane’s advocacy for her daughters and the hearing-impaired community, requires a level of authenticity to build trust. Experiential knowledge also empowers an authentic leader to lead. Disability advocacy become a reoccurring theme throughout Jane’s story. Jane’s advocacy is an important factor for influencing individuals with disabilities. Trevisan (2016) explained that disability advocacy is instrumental in the empowerment of those with disabilities because it provides opportunities for increased participation that offer opportunities for more independence. Jane’s lived experiences afforded her the credibility that she needed to serve as an advocate. Her personality traits further her effectiveness as an authentic leader because she is a genuine personality who effectively relays her experiences with compassion.

The component of AL, relational transparency, further emphasizes the necessity for leaders to construct trustful relationships. Northouse (2018) exclaimed that AL “can be conceptualized intra-personally, developmentally, and inter-personally” (p. 222). Jane’s critical life experiences, coupled with her introspective nature, consistently contributed to the further development of her leadership capabilities. She remained

proactive in her own self-learning process. Jane knew that her influence was important and sought by others, making her an influential change agent in her local community and beyond. Her first-hand knowledge of disability helped her educational platform gain notoriety. Despite this notoriety and success, she thoughtfully stayed in-tune with her motives and desires, as espoused in the AL framework. As a result, her voice was seen as an authentically credible – not disingenuous or “fake” (Kernis, 2003).

Further evidence of Jane’s influence as an authentic leader was demonstrated in the changes in her followers as they moved from deficit thinking to acting to improve their individual situations. By virtue of raising daughters with disabilities, Jane personally encountered societal prejudices, consistent with findings in the literature, that explain how attitudinal impediments often inhibit individuals with disabilities’ opportunities for growth (Baffoe, 2013; Culham & Nind, 2003). The followers that looked to Jane for leadership also encountered the same prejudices. As a result of Jane’s leadership, however, Jane was able to accomplish the goal of educating against such stereotypes and prejudices of disability. Specifically, as Jane navigated the challenges that her daughters faced and as she promoted the success of other hearing-impaired individuals through her educational platform, Jane motivated many other individuals to overcome adverse perspectives that formerly recognized boundaries and limitations concerning the disabled, to perspectives that recognized strengths and opportunity.

Her mission of “building bridges” of communication through sign language led Jane to discover her own leadership identity. Jane perceived herself as someone who could make a positive difference in the lives of others. The perception was initiated as Jane witnessed Daughter One’s adversity, and she personally came to understand the

variety of challenges that hearing-impaired individuals face. An example of one such adversity for Daughter One was not being able to communicate with a soccer teammate due to the fact that she was the only deaf child on the team. According to Jane, the team was doing drills “and this little boy gets teamed up with [Daughter One], and he says I don’t want to be with [Daughter One] because she can’t talk or understand me.” This circumstance stirred Jane, and she began her volunteer work, teaching children at the pre-school levels sign language. Her primary goal was to teach as many preschool kids ASL as possible to expand Daughter One’s friendship circle. She disliked that other kids her daughters age could not communicate with her on the soccer field or invite her to a birthday party. The event, also, acted as a catalyst for the development of her educational platform.

Another example of Jane’s authentic leadership was evidenced in how Jane internalized adversity and turned adversity into momentum for change. For example, Jane became frustrated by the fact that Daughter Two could actually communicate, yet her communication skills were rarely recognized by others. Jane navigated those very personal challenges by helping others to understand Daughter Two’s capabilities rather than her limitations. In keeping with AL’s relational transparency component, Jane became skilled in sublimating her emotions, learning from her experiences to best understand her motives to effectuate positive achievements. Importantly, she stayed mindful and transparent with her own thoughts and feelings, and she was able to effectively interpret those of others. This relational ability allowed her to build and sustain fruitful personal relationships and professional connections.

Internalized Moral Perspective. This particular AL element refers to a form of self-regulation and integration (Ryan & Deci, 2003) driven by a set of internalized moral standards and values that produce behavior. Further, it supports a decision-making process immune from external sources and adheres to moral and value systems (Avolio & Gardner, 2005; Gardner, Avolio, Luthans, May, & Walumbwa, 2005; Walumbwa et al., 2008). Jane's internalized moral perspective remained a source of strength and passion that guides her decisions and serves as a solace of satisfaction in her work and life. Jane demonstrated authentic leadership in that AL places value upon being *passionate* in purpose while being mindful in a strong adherence to value that informs a moral system. AL also includes maintaining connectivity in relationships, sustaining a consistency in self-discipline, and cultivating a compassionate heart (George, 2003). These characteristics were clearly evident in Jane's advocacy work as her passion for advocating for those with disabilities was primarily based upon having the personal knowledge of what life was like raising and sharing lived experiences with children who possess disabilities. As the culmination of her advocacy work, Jane's children's journey inspired her to help those with disabilities to find their voice and motivate them beyond their potential. This inspiration was a primary factor in leading her to establish her educational platform to serve the needs of those families both inside and outside of the disabled communities. One of Jane's most passionate endeavors that exhibited her penchant towards human connectivity was being a part of the Make-A-Wish Foundation. Employee Two touchingly recalled:

I know there's been a couple cases where the last wish of the kid was to meet [Jane] And ... there's been a couple of times where she's gone out and met kids in

hospitals, and had a positive impact on them that way. Where she was able to meet them and kind of grant their last dying wish to help bring happiness to them in the last days of their life. I think that's really touching. (Employee Two, personal communication, October, 2019)

Jane's message of help and hope, along with her organization's sign language products, climbed in popularity. The advocacy, educational services, and encouragement she has offered have been embraced by parents and others within the hearing-impaired community. This evidence suggests that the value system that guided Jane was based upon a passion for equity and expanding the "voice" of hearing-impaired individuals (George, 2003; Northouse, 2018). Her passion for equity expanded to teaching parents with disabled children how to obtain educational and medical services for their children. Parent Four expressed that "getting adequate services" is one of the primary obstacles for parents who have disabled children. This part of her work was important because she knew how difficult it was to fight to prevent her disabled daughters from being neglected by social service providers such as the hospital, dentist, or school system. (O'Connell, O'Halloran, & Doody, 2013).

With years of leadership in sustaining her production company, family studio, and pursuing her advocacy work, Jane's work somewhat culminated when she accepted a position as Director of the American Society for Deaf Children, a non-profit organization that supports parents of deaf children. Chief among her goals was to utilize her experience in raising a deaf child and confront "issues that have still yet to be addressed." This finding aligns with George's (2010) explanation that within the AL context, leaders reach their "True North" where their work is guided by an internal compass centered

upon “what is most important to you, your most cherished values, your passions and motivations, the sources of satisfaction in your life” (p. xxiii) Jane’s “internal compass” guided her to expanded opportunities for leadership and has crescendoed over the span of her life experiences as a parent and advocate. Her passion pulled her towards her purpose of enriching the lives of others (George, 2003 & 2010).

Further describing her internalized moral perspective, Jane is an extremely caring, charismatic, and trusted leader who has become a beckon of knowledge and source of motivation to people around the world. An illustration of Jane’s passionate humility and natural charisma came from Parent Two. Smiling, Parent Two conveyed the sentiment of how she thought of Jane as a genuine personality:

I was at the grocery store and this lady started talking to my baby who had hearing aids. My husband’s like, “wait, are you?” And she’s like “Yes!” And then she practically broke out in a song, singing to my daughter ... And she’s like, “you need to come to my house,” and she gave me her email ... She’s like, you guys need to come over, and we came over to her house and she talked to us. And it was just nice to talk to another parent of a deaf child because we hadn’t really, hardly met any, at that point. (Jane, personal communication, October, 2019)

This example of Jane’s behavior aligns with AL’s explanation of internalized moral perspective in that, throughout the journey, she remained sensitive to the overall well-being of many families with disabilities and open to mentoring those newly developed relationships over extended periods of time (Daly, 2012; Seymour, Wood, Giallo, & Jellett, 2013). Jane’s charisma, combined with her life experiences and honed talents, transcended her setbacks as she became a powerful advocate for the disabled;

further, she prudently channeled her learned lessons as a parent with disabled children and greatly encouraged and supported families of people with disabilities to share their experiences (Maxwell & Barr, 2003). Parent Three graciously emphasized: “I think for too many, they don’t have voice. And, they don’t know where to start. I think as Jane shares her experiences ... it gives people hope and a place to start.”

In accordance with the study’s findings, Jane’s initial inclination was to see the positive potential that her girls possessed. This attitude that viewed the disabled as limited compared to able-bodied individuals (James et al., 2018) drove how she developed her work as an advocate and leader within the disabled communities. Jane’s personal experience with the disabled communities fed her credibility that propelled her educational work with children who have disabilities; thus, it provided Jane with the necessary knowledge and an experiential base that benefitted those children and families in similar situations.

The difficult circumstances that came upon her in waves instilled a maturation in perspective of how Jane viewed disability. Despite the arduous work of being a life-long mother and caregiver to daughters with disabilities, her daughters’ situations revealed to her that the disabled are capable of great achievements. Once Jane accepted the challenges that lay ahead of her, she experienced a pleasant side of disability that Jane embraced and applied to her life moving forward. Humbly, she reflected upon her life and professional career:

... as far as leadership, I don’t have an MBA. I don’t have a college degree, at all.

I went for a couple of semesters and dropped out to be a musician. But, my life’s

course has led me to be in a position of influence and leadership and a mentor ...

(Jane, personal communication, October, 2019)

Findings from this study suggest that many others, both within and outside of the deaf community, agree with Jane's assessment.

Conclusions

Jane's story highlights many of the challenges in society that the disabled community face. These challenges include institutional and cultural barriers that limit growth opportunities for individuals with disabilities. Additionally, because the barriers that Jane's daughters faced were institutionalized, they were difficult barriers to overcome. For example, low expectations at school could have prevented the academic growth of Jane's daughters. Findings from this study highlight the essentiality of advocacy for individuals who cannot advocate for themselves. For example, only when Jane advocated for her daughters and revealed the capacity that each daughter held for higher levels of academic achievement did the school district seriously consider less limiting accommodations in their educational placement. This finding is important because, even though the "least restrictive environment" is codified in federal law (Underwood, 2018), advocacy was a necessary component in Jane's journey to finding the best educational environment for her daughters.

Findings from this study further suggest that without Jane's advocacy, institutional barriers would likely have limited the academic progress of each daughter. In addition to institutional barriers, Jane's daughters also experienced unexpected cultural barriers in the deaf community. Cultural norms such as rejection of advancements, such as cochlear implants for example, seemed to facilitate isolation through enhanced

separation between the deaf community and hearing abled individuals. Transcending the barrier constructed by the deaf community was a challenge for Jane. This task was accomplished through persistence, embedding herself within the deaf community through her daughters, and developing relational ties that led to shared understandings.

Jane's story further reveals how she was able to turn "adversity into opportunity" (Educational Platform Website, 2021). Jane's character and capacity, as an authentic leader, resulted from experiencing unexpected challenges in parenting and culminated in expansion of opportunities as she acted on behalf of individuals within the deaf community. Jane's narrative revealed that she was able to grow through the challenges she faced, and, as a result of that growth, she grew into a leader who was able to motivate others with disabilities to reach beyond their potential. Moreover, she served as a change agent and difference maker because she had the tenacity to open opportunities through her educational platform. This platform emerged because of Jane's compassion and desire to provide enhanced opportunities for the deaf community. Specifically, Jane's immersion into the deaf community where she was able to effectively challenge some of the deaf culture's norms that were exclusionary practices, was an authentic experience and foundation for leadership. Her compassion and passion to help others is clearly evidenced throughout her story. Through the waves of critique and the efforts of addressing the needs of Daughter One, Jane transitioned from a parent facing adversity to becoming a powerful advocate for others within the deaf community.

Implications

The following section includes implications in theory, practice, and research. This study is valuable because of its potential significance to each of these particular areas that follow.

Theory

Critical Disability Theory (CDT) addresses the insider and outsider perceptions associated with disability (Hosking, 2008, p. 7), and points to discriminations that stem from deficit perceptions, at the societal level, of those with disabilities. CDT, therefore, was utilized to explain the social circumstances/limitations experienced by Jane's daughters, as members of the deaf community, that could have impeded their growth. However, despite its ability to explain social constructions that limit the capacity and growth of hearing impaired individuals, CDT could not explain Jane's benevolent actions. For this study, therefore, Jane's actions could not be explained through a lens that addresses power dynamics between social groups. Findings from this study suggest that Jane's individual actions were motivated by benevolence and passion to enhance opportunities for disabled individuals. Therefore, the additional lens of Authentic Leadership was utilized to explain Jane's story. Combining CDT with AL provided lenses to explain both the challenges that Jane's daughters experienced as a result of societal norms as well as the individual characteristics that Jane exhibited as a leader as her advocacy grew. Utilization of two theories, one to explain limitations at the societal level and the other to explain acts of benevolence at the individual level, provided a more nuanced explanation to Jane's story.

Practice

Findings from this study have important implications for practice. These findings highlight the importance of Jane's advocacy for hearing impaired individuals. Further, Jane's story explains barriers, both internal and external to the deaf community, that limited opportunities for her daughters. One interesting finding of an internal barrier was that the deaf community, itself, had cultural norms that further isolated it from the hearing abled community. Jane was able to transcend those barriers through relationship building and transparency in her advocacy work. Further, findings from this study suggest that even though federal law mandates that individuals with disabilities are to be educated in the "least restrictive environment" (Underwood, 2018), cultural and societal misunderstandings may cause those working with hearing impaired individuals to misunderstand appropriate placement. Though not generalizable, this study's finding has practical implications for educators as they work with hearing impaired individuals because Jane uncovered unexpected abilities of her two daughters. This perspective of accurately understanding the unique skills and abilities of individuals with disabilities can help inform educators. Further, Jane's story reveals her perspective of disability as an "opportunity" for empowerment. Through her advocacy work, Jane utilized adversity to open up avenues for advancement and achievement for this particular community.

Research

Findings from this study have important implications for research. This study provides insight into the specific skills that two individuals with disabilities possessed that were not recognized by those who were responsible for educating them. Further research is needed to explore if a more nuanced perspective of the disabled as "individuals" rather than members of a disability category can provide a more informed

understanding of the potential that each individual holds. This study also adds to understandings of leadership development. Jane's authenticity developed through lived experiences. Findings from this study suggest that drawing upon leaders' individual experiences may be an important factor in leadership development. Specifically, these findings suggest that learning may not always be facilitated only within cognitive realms, but Jane's story shows that there are circumstances in life that drive and mold leadership characteristics. Jane's critical life events and work with the disabled endowed her with a wealth of authenticity and credibility in her leadership and message, respectively, that had the potential to transform the notion of disability within her immediate deaf community. Importantly, Jane was able to frustrate many of the prejudices that non-disabled and disabled individuals possessed. Jane was able to transcend perceptions of both the disabled and non-disabled community to promote growth for her daughters and hearing impaired individuals around the globe.

Limitations

In terms of generalizability, it is worth mentioning that this study is limited, in scope. Rousseau, Manning, & Denyer (2008) offered that "[a]ll studies have limits" (p. 506). There are many individuals who work with people with disabilities, but Jane accounts for only one person working to teach American Sign Language (ASL) and serve as a disability advocate. In terms of behavioral research, outliers are powerful influencers and uniquely positioned outside of the norm, deviating from the general populations (Osborne & Overbay, 2004). Jane possesses unique skills and abilities that have been molded by several unique life events over an extended period of time; therefore, her story is not generalizable to larger populations within her niche. The identification of outliers

helps researchers gain key aspects of knowledge that helps supports better decision making, given insightful information (Wang, Bah & Hammad, 2019). Jane's distinctive story and abilities were the impetuses for undertaking this study.

Another limitation to this study is the fact that I was participating as the researcher and a person with a disability who has had critical lived experiences of my own. To ensure that objectivity during the data collection process was maintained, I actively recognized the importance of being cautious to separate Jane's lived experiences from my potential bias in effort to preserve her narrative (Creswell, 2014). It was a priority to safeguard against the interjection of my voice during the interviews and observations, so that Jane's story naturally unfolded according to the tenets of narrative inquiry design (Bochner & Riggs, 2014; Caine, Estefan & Clandinin, 2013; Clandinin, 2006; Connelly & Clandinin, 1990; Dewey, 1981; Mertova & Webster, 2012).

Additionally, while it is valued for its capacity for capturing the complexity of how life is lived, narrative inquiry does have limitations and critiques (McMullen & Braithwaite, 2013). According to Atkinson and Delmont (2006) "[n]arratives are collected and celebrated in uncritical and analyzed fashion" (p. 166). This narrative inquiry's sole purpose is to highlight and tell Jane's story. There was no intentional critical examination of countervailing opinions. The primary goal was to harness the complexity of her lived experiences to gain insights from her unique abilities and skills.

Lastly, to protect anonymity, this study utilized pseudonyms to ensure that all names, locations, and organizations were not identifiable. Moreover, since data collection for this study, Daughter One has reconsidered her gender identity. This transition implies

a sense of independence; however, implications from this change are not included in the findings of the study because it took place after data collection was completed.

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APPENDICES

Appendix A

Adult Consent Form

Oklahoma State University

PROJECT TITLE: Turning Disability Into A Dream: A Narrative Inquiry Of One Mother's Endurance

INVESTIGATORS: Sean Kinder, Doctoral Student, Graduate College of Educational Leadership

PURPOSE: The purpose of this study is to gain insight into the lived experiences of a mother with two disabled daughters. An analysis of her journey through life, and the critical events she faced, will provide understandings of the societal and structural barriers that exist for people with disabilities and how people like the main subject can motivate disabled individuals to exceed their potential. The main subject and those she worked with, directly and indirectly, will be asked to participate in this study. I want to explore the critical life events that have helped her establish a pathway in life and afforded her the chance to build a successful educational platform and career through working and advocating for those people and families of the disabled. A contribution this study made to research is how leadership is conceptualized. Further, her story could be insightful for policy makers at the institutional level. This is especially true when viewing the disabled as leaders in the public-school context.

To understand others' perceptions of Jane's leadership, I will ask interview participants who have worked with Jane and have been impacted by her leadership style to rate Jane utilizing the Authentic Leadership Questionnaire (ALQ), which is an instrument that has been tested for use in research. This scale is designed so that I can calculate means for each of the four major components of authentic leadership to gain a better understanding of others' perception of Jane's leadership. Additionally, in an effort to understand Jane's perception of her own ability to motivate those within the disability community, I will ask Jane to rate herself on the Authentic Leadership Self-Assessment Questionnaire. The Authentic Leadership Self-Questionnaire is an adaptation of the ALQ that has not been tested. Even though the Self-Assessment has not been tested, it has utility to add a further layer of understanding of Jane's perception of her own leadership and ability to motivate those whom she serves.

Appendix B

Interview Questions for Main Subject, Colleagues and Co-Workers, and Parents

Interview Questions for Jane

1. How did you become involved in working with individuals with disabilities?
2. What motivates you to continue that work?
3. What are your goals in the work that you do with individuals with disabilities?
4. How have your goals changed over time?
5. How do you perceive individuals with disabilities?
6. How would you describe yourself as an advocate for individuals with disabilities?
7. You run an organization that has a direct influence on individuals with disabilities. How would you best describe your leadership approach?
8. What challenges have you experienced in your work with individuals with disabilities?
9. How do you address these challenges?
10. How do you motivate those with disabilities to reach their potential?
11. What do you think are the most difficult aspects in guiding the disabled to overcome their hurdles to realize their potential?
12. What are some factors that have shaped your perception of the disabled?

13. Can you provide some examples of the greatest challenges the disabled experience?
14. How have you changed as a result of this work?
15. How have others around you changed?
16. Is there anything else you would like to add?

Interview Questions for Colleagues and Co-Workers

1. How did you become involved with Jane?
2. What is your perception about what motivates Jane to continue the work that she does?
3. What kind of influence does Jane have on individuals with disabilities?
4. How has that influence changed from when Jane first became involved with her work at signing time?
5. What kind of influence does she have on families, caregivers and other important others in the lives of these individuals?
6. How does Jane perceive individuals with disabilities?
7. How would you describe Jane as an advocate for individuals with disabilities?
8. She runs an organization that has influence on many people. How would you best describe Jane as a leader?
9. What challenges has Jane experienced in her work with individuals with disabilities?
10. How does Jane motivate those with disabilities to reach their potential?

11. What do you think is the most difficult aspect in guiding the disabled to overcome their hurdles to realize their potential?
12. What is your perception about factors that have shaped Jane's perception of the disabled?
13. Can you provide some examples of the greatest challenges the disabled experience?
14. How has Jane changed as a result of this work?
15. How have others around her changed?
16. Is there anything else you would like to add?

Interview Questions for Colleagues and Co-Workers

1. How did you become involved with Jane?
2. What is your perception about what motivates Jane to continue the work that she does?
3. What kind of influence does Jane have on individuals with disabilities?
4. How has that influence changed from when Jane first became involved with her work at signing time?
5. What kind of influence does she have on families, caregivers and other important others in the lives of these individuals?
6. How does Jane perceive individuals with disabilities?
7. How would you describe Jane as an advocate for individuals with disabilities?
8. She runs an organization that has influence on many people. How would you best describe Jane as a leader?

9. What challenges has Jane experienced in her work with individuals with disabilities?
10. How does Jane motivate those with disabilities to reach their potential?
11. What do you think is the most difficult aspect in guiding the disabled to overcome their hurdles to realize their potential?
12. What is your perception about factors that have shaped Jane's perception of the disabled?
13. Can you provide some examples of the greatest challenges the disabled experience?
14. How has Jane changed as a result of this work?
15. How have others around her changed?
16. Is there anything else you would like to add?

Interview Questions for Parents

1. How did you come to know Jane?
2. Please describe her work with your child.
3. What kind of influence does she have on those with disabilities?
4. What kind of influence does she have on families of those with disabilities?
5. What motivates Jane to continue the work that she does?
6. How long has your child been influenced by Jane? Why do you continue in that relationship?
7. How does Jane perceive individuals with disabilities?
8. How would you describe her as an advocate for individuals with disabilities?

9. Jane runs an organization that has influence on many people. Please describe Jane as a leader.
10. What challenges has Jane experienced in her work with individuals with disabilities?
11. How does Jane motivate those with disabilities to reach their potential?
12. What do you think is the most difficult aspect in guiding the disabled to overcome their hurdles to realize their potential?
13. What are some factors that have shaped Jane's perception of the disabled?
14. Can you provide some examples of the greatest challenges the disabled experience?
15. How have you or your child changed as a result of your relationship with Jane?
16. Is there anything else you would like to add?

Appendix C

Authentic Leadership Self-Assessment Questionnaire

Authentic Leadership Self-Assessment Questionnaire

Instructions: This questionnaire contains items about different dimensions of authentic leadership. There are no right or wrong responses, so please answer honestly. Use the following scale when responding to each statement by circling the number that best corresponds with your perception.

Key: 1 = Strongly 2 = Disagree 3 = Neutral disagree 4 = Agree 5 = Strongly agree

- | | | | | | |
|---|---|---|---|---|---|
| 1. I can list my three greatest weaknesses. | 1 | 2 | 3 | 4 | 5 |
| 2. My actions reflect my core values. | | | | | |
| 3. I seek others' opinions before making up my own mind. | 1 | 2 | 3 | 4 | 5 |
| 4. I openly share my feelings with others. | 1 | 2 | 3 | 4 | 5 |
| 5. I can list my three greatest strengths. | 1 | 2 | 3 | 4 | 5 |
| 6. I do <i>not</i> allow group pressure to control me. | 1 | 2 | 3 | 4 | 5 |
| 7. I listen closely to the ideas of those who disagree with me. | 1 | 2 | 3 | 4 | 5 |
| 8. I let others know who I truly am as a person. | 1 | 2 | 3 | 4 | 5 |
| 9. I seek feedback as a way of understanding who I really am as a person. | 1 | 2 | 3 | 4 | 5 |
| 10. Other people know where I stand on controversial issues. | 1 | 2 | 3 | 4 | 5 |
| 11. I do not emphasize my own point of view at the expense of others. | 1 | 2 | 3 | 4 | 5 |
| 12. I rarely present a "false" front to others. | 1 | 2 | 3 | 4 | 5 |
| 13. I accept the feelings I have about myself. | 1 | 2 | 3 | 4 | 5 |
| 14. My morals guide what I do as a leader. | 1 | 2 | 3 | 4 | 5 |
| 15. I listen very carefully to the ideas of others before making decisions. | 1 | 2 | 3 | 4 | 5 |
| 16. I admit my mistakes to others. | 1 | 2 | 3 | 4 | 5 |

Total Scores

Self-Awareness: _____

Internalized Moral Perspective: _____

Balanced Processing: _____

Relational Transparency: _____

Appendix D

Authentic Leadership Rater Assessment Questionnaire

Authentic Leadership Questionnaire (ALQ Version 1.0 Rater)

Bruce J. Avolio, Ph.D.

Name: _____ Date: _____

Organization ID #: _____ Person ID #: _____

Instructions: The following survey items refer to your leader's style, as you perceive it. **Judge how frequently each statement fits his or her leadership style using the following scale:**

Not at all Once in a while Sometimes Fairly often Frequently, if not always
0 1 2 3 4

My Leader:

- | | | | | | |
|---|---|---|---|---|---|
| 1. says exactly what he or she means | 0 | 1 | 2 | 3 | 4 |
| 2. admits mistakes when they are made | 0 | 1 | 2 | 3 | 4 |
| 3. encourages everyone to speak their mind | 0 | 1 | 2 | 3 | 4 |
| 4. tells you the hard truth | 0 | 1 | 2 | 3 | 4 |
| 5. displays emotions exactly in line with feelings | 0 | 1 | 2 | 3 | 4 |
| 6. demonstrates beliefs that are consistent with actions | 0 | 1 | 2 | 3 | 4 |
| 7. makes decisions based on his or her core values | 0 | 1 | 2 | 3 | 4 |
| 8. asks you to take positions that support your core values | 0 | 1 | 2 | 3 | 4 |
| 9. makes difficult decisions based on high standards of ethical conduct | 0 | 1 | 2 | 3 | 4 |
| 10. solicits views that challenge his or her deeply held positions | 0 | 1 | 2 | 3 | 4 |
| 11. analyzes relevant data before coming to a decision | 0 | 1 | 2 | 3 | 4 |
| 12. listens carefully to different points of view before coming to conclusions | 0 | 1 | 2 | 3 | 4 |
| 13. seeks feedback to improve interactions with others | 0 | 1 | 2 | 3 | 4 |
| 14. accurately describes how others view his or her capabilities | 0 | 1 | 2 | 3 | 4 |
| 15. knows when it is time to reevaluate his or her position on important issues | 0 | 1 | 2 | 3 | 4 |
| 16. shows he or she understands how specific actions impact others | 0 | 1 | 2 | 3 | 4 |

Appendix C

Recruitment Script

“Hi, I am Sean Kinder. I am doing research for my dissertation at Oklahoma State University. The focus of my study is a narrative inquiry about the story of an educational leader/advocate who inspires others through her educational platform, specifically (Jane). I am also interested in her journey of advancing her two daughters through the K-12 public school system. I am calling to ask if you would be interested in volunteering to participate in this study. Your participation is entirely voluntary and would involve an interview. Each interview will take approximately 45 minutes to an hour to complete. We can schedule the interview at a location and at a time that is convenient for you. After the interview, I will ask if you will take a brief online survey, the Authentic Leadership Questionnaire Assessment, which I will send to you by email. All participant names will be kept strictly confidential and only aggregated results will be included in any written reports. You will have the opportunity to review the interview after it is transcribed and make any changes you wish to make.”

Would you be willing to participate in this study? If you would be willing to participate in this interview, we can schedule a time now or, if you can let me know what time works best for you, we can schedule it.”

If the participant is interested, the investigator will schedule the date and time and provide the subject with investigator’s contact information. “I have scheduled you for an interview on _____. Should you have any questions or concerns, I can be

reached at 918.779.5099 or sean.kinder@okstate.edu. I sincerely appreciate your help.”

Should the participants not be interested, the investigator will end the call: “I really appreciate you taking the time out of your day to speak with me.”

VITA

Sean Kinder

Candidate for the Degree of

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Thesis: TURNING DISABILITY INTO A DREAM: A NARRATIVE INQUIRY OF ONE MOTHER'S ENDURANCE

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Biographical:

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